Appendix K: Evidence tables

Risk of developmental problems

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Ref Id

412370

Full citation

Brown, H. K., Speechley, K. N., Macnab, J., Natale, R., Campbell, M. K., Mild prematurity, proximal social processes, and development, Pediatrics, 134, e814-24, 2014

Country/ies where the study was carried out

Canada.

Study type

Population based prospective cohort study.</td>
<td>Sample size

N = 15099 at 2-3 years

N = 12302 at 4-5 years

Absolute numbers of term/preterm infants were not reported.

Characteristics
<table>
<tr><th>Characteristic</th><th>Weighted % with characteristic at 2-3 years of age</th><th>Weighted % with characteristic at 4-5 years of age</th></tr>
<tr><td>Neonatal special care</td><td>8.5%</td><td>8.3%</td></tr>
<tr><td>Single parent family</td><td>8.9%</td><td>7.1%</td></tr>
<tr><td>Maternal education</td><td></td><td></td></tr>
<tr><td>Secondary or less</td><td>30.6%</td><td>32.0%</td></tr>
<tr><td>Some postsecondary</td><td>18.4%</td><td>14.8%</td></tr>
</table>
</td>
<td>Risk factors

Gestational age</td>
<td>Setting

National survey data.

Method(s) of measurement for risk factor(s)

Gestational age was determined by maternal report of the days or weeks before/after the due date that the child was born. To improve accuracy, children with implausible birth weight for gestational age (>4 SDs) were excluded. Children were classified as late preterm (34-36 weeks), early term (37-38 weeks) or full term (39-41 weeks).

Outcome(s) ascertainment/measures

Developmental delay was measured at 2-3 years using the Motor</td>
<td>Outcome(s) at age

<u>At 2-3 years</u>
Risk of developmental delay
39-41 weeks: Reference
34-36 weeks: RR 1.13 (0.90-1.42)

<u>At 4-5 years</u>
Risk of receptive vocabulary delay
39-41 weeks: Reference
34-36 weeks: RR 1.06 (0.79-1.43)

Adjusted for alcohol during pregnancy, smoking during pregnancy, placental ischaemia, delivery mode, other biological determinants (not described further), delivery mode, gestational age, partnership status, number of siblings, family income adequacy, maternal education, maternal age at birth of child, maternal health, maternal mental health, family functioning, parenting interactions, parenting effectiveness and parenting consistency.</td>
<td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: mod erate risk of bias
Gestational age was categorised according to maternal report and not verified with hospital records.
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and Reporting: low risk of bias.
Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Aim of the study To assess the role that gestational age plays in determining risks of poor developmental outcomes. **Study dates** 1994 to 2009. **Source of funding** Canadian Institutes of Health Doctoral Research Award.	<table><tr><td>College or university degree</td><td>51.0%</td><td>53.2%</td></tr><tr><td>Maternal age at birth of child</td><td></td><td></td></tr><tr><td><20 years</td><td>3.8%</td><td>3.8%</td></tr></table> **Inclusion criteria** Gestational age 34-41 weeks. **Exclusion criteria** Multiple pregnancy, respondent for questionnaires was not biological mother, children living in institutions or on reserves, children whose parents are members of the armed forces.		and Social Development Scale. The parent responds to 15 yes/no performance questions, and the "yes" responses are summed. Scores were standardised by 1-month age groups and children scoring ≥1 SD below the mean were classified as having a delay. Receptive vocabulary delay was measured at 4-5 years using the Peabody Picture Vocabulary Test-Revised (PPVT-R). A trained tester presents a series of pictures and states a word for which the child must choose the correct picture. The number of correct responses is computed and an age-standardised score is based on 1-month age groups. Children scoring ≥1 SD below the mean were classified as having a delay. **Statistical methods**		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			Adjusted relative risks were estimated using multivariable modified Poisson regression. Parsimonious models were built with blockwise entry of variables according to conceptual categories: perinatal variables, gestational age, family structure, family resources, family functioning, proximal social processes and other covariates. A p value of <0.20 was used to retain covariates at each step. **Length of follow-up** 2-3 years and 4-5 years. Adjusted ages are not reported, therefore it is assumed that chronological age was used.		
Ref Id 398250 **Full citation** Carlo, W. A., McDonald, S. A., Fanaroff, A. A.,	**Sample size** n=10,541 infants born between 1993-2009 at 22-25 gestational weeks with birth weight 401-1000 g n=5,691 infants born between 1993 and 2008 who survived up to follow-up at 18-22 months of corrected age	**Risk factors** Antenatal corticosteroid use.	**Setting** 23 National Institute of Child Health and Human Development Neonatal Research Network centers in the	**Outcome(s) at age** **Outcomes assessed at 18-22 months corrected age:** Logistic regression models adjusted for maternal variables (age, marital	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Vohr, B. R., Stoll, B. J., Ehrenkranz, R. A., Andrews, W. W., Wallace, D., Das, A., Bell, E. F., Walsh, M. C., Laptook, A. R., Shankaran, S., Poindexter, B. B., Hale, E. C., Newman, N. S., Davis, A. S., Schibler, K., Kennedy, K. A., Sanchez, P. J., Van Meurs, K. P., Goldberg, R. N., Watterberg, K. L., Faix, R. G., Frantz, I. D., 3rd, Higgins, R. D., Eunice Kennedy Shriver National Institute of Child, Health, Human Development Neonatal Research, Network, Association of antenatal corticosteroids with mortality and neurodevelopmental outcomes among infants born at 22 to 25</td>
<td>n=4,924 infants with neurodevelopmental assessments at 18-22 months of corrected age (follow-up rate 86.5% of the ones who survived up to 18-22 months corrected age)
n=3999 infants with exposure to antenatal corticosteroids
n=925 infants with no exposure to antenatal corticosteroids
Subgroups:
22-25 GA weeks n=4924 (total)
22 GA weeks n=72
23 GA weeks n=553
24 GA weeks n=1755
25 GA weeks n=2544

Characteristics

Characteristics for infants born 22-25 gestational weeks between 1993-2009, n=10541
<table>
<tr><td></td><td>Antenatal corticosteroids</td><td>No antenatal corticosteroids</td></tr>
<tr><td>Study population, n</td><td>7808</td><td>2733</td></tr>
<tr><td>Birth weight, g</td><td>680+-121</td><td>657 +-124</td></tr>
<tr><td>SGA, %</td><td>6.1</td><td>3.5</td></tr>
<tr><td>Race black, %</td><td>43.1</td><td>57.2</td></tr>
<tr><td>Race white, %</td><td>52.9</td><td>39.6</td></tr>
<tr><td>Race other, %</td><td>4.0</td><td>3.2</td></tr>
<tr><td>Male gender, %</td><td>52.5</td><td>53.9</td></tr>
</table>
</td>
<td></td>
<td>US between 1993 and 2009.

Method(s) of measurement for risk factor(s)

Infants were considered to be in the "antenatal corticosteroid" group if their mother received 1 or more doses of antenatal corticosteroids (dexamethasone or betamethasone).

Outcome(s) ascertainment/measures

Bayley II Psychomotor Development index (PDI) <70. Standardized comprehensive neurodevelopmental assessment was performed by certified examiners unaware of exposure to antenatal corticosteroids.

Statistical methods</td>
<td>status, race, diabetes, hypertension/preeclampsia, rupture of membranes >24h, antepartum haemorrhage, and delivery mode), multiple birth, gender, and center, unless otherwise stated.

<u>PDI <70</u>
<u>22 weeks GA:</u>
No antenatal corticosteroids: reference
Antenatal corticosteroids: 1.47 (0.48-4.50)*
*Only adjusted for gender due to convergence problems because of low outcome prevalence.
<u>23 weeks GA</u>:
No antenatal corticosteroids: reference
Antenatal corticosteroids: 0.93 (0.58-1.50)
<u>24 weeks GA:</u>
No antenatal corticosteroids: reference
Antenatal corticosteroids: 0.69 (0.49-0.95)
<u>25 weeks GA:</u>
No antenatal corticosteroids: reference
Antenatal corticosteroids: 0.82 (0.60-1.11)
<u>22-25 weeks GA:</u>
No antenatal corticosteroids: reference
Antenatal corticosteroids: 0.79 (0.65-0.96)</td>
<td>Participants: low risk of bias
Attrition: moderate risk of bias
Of the whole population of 10,541 infants, only 5,691 survived to follow-up (46% lost to follow-up there). Of the ones who survived to to 18-22 months of corrected age, 13.5% were lost to follow-up, whether they differed compared to the ones included in analysis not reported.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
However, the neurodevelopmental outcomes were measured differently for children born after 2005, but validated tools were used at both times and they accounted for that in the statistical models.
Confounding: low risk of bias</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>weeks' gestation, JAMA, 306, 2348-58, 2011

Country/ies where the study was carried out

United States

Study type

Cohort study

Aim of the study

To determine if antenatal corticosteroid exposure in infants born at each gestational week from 22 to 25 weeks is associated with improvement in important outcomes, including primary outcome of death or childhood neurodevelopmental impairment.</td>
<td>
<table>
<tr><td>CS, %</td><td>52.8</td><td>36.6</td></tr>
<tr><td>APGAR <+3 at 5min, %</td><td>15.1</td><td>30.5</td></tr>
<tr><td>Intubation, %</td><td>88.6</td><td>91.4</td></tr>
<tr><td>Resuscitation, %</td><td>97.5</td><td>99.1</td></tr>
<tr><td>Surfactant use, %</td><td>87.4</td><td>80.3</td></tr>
<tr><td>Maternal age <=19, %</td><td>14.2</td><td>19.2</td></tr>
<tr><td>Mother not married, %</td><td>53.3</td><td>64.7</td></tr>
<tr><td>Mother < high school graduate, %</td><td>26.1</td><td>38.2</td></tr>
<tr><td>Income $<32,000, %</td><td>43.6</td><td>57.9</td></tr>
<tr><td>Medicaid, %</td><td>63.1</td><td>69.3</td></tr>
<tr><td>Mother not English speaking, %</td><td>16.7</td><td>14.6</td></tr>
<tr><td>Follow-up rate, %</td><td>87.6</td><td>82.2</td></tr>
</table>
Inclusion criteria

Inclusion criteria for neurodevelopmental outcomes:
</td>
<td></td>
<td>Logistic regression models were to used to estimate the relationship between antenatal corticosteroid use and outcome.

Length of follow-up

18-22 months corrected age</td>
<td></td>
<td>Analysis and reporting: low risk of bias

Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study dates Infants born between 1993-2009, follow-up at 18-22 months corrected age. **Source of funding** Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network	Infants born at any of the 23 National Institute of Child Health and Human Development Neonatal Research Network centers between 1993* and 2008 (for analysis with death as outcome, infants born between 1993-2009 were included). Infants born at 22-25 weeks of gestation. Infants with birth weight of 401-1000 g. *In the text, there must be a typo because they report that only infants born between 2003 and 2008 are included but everywhere else they write about 1993 to 2008. **Exclusion criteria** Infants who died within 12 h after birth without receiving delivery room resuscitation. Children who died before follow-up at 18-22 months corrected age.				
Ref Id 410048 **Full citation** Chan, E., Quigley, M. A., School performance at age 7 years in late preterm and early term birth: a cohort study, Archives of Disease in Childhood Fetal & Neonatal	**Sample size** Sample recruited - N = 18818 Sample eligible for assessment - N = 13543 Sample analysed after exclusions - N = 6031 n=69 - Very preterm (<32 weeks) n=67 - Moderately preterm (32–33 weeks) n=360 - Late preterm (34–36 weeks) n=1258 - Early term (37–38 weeks) n=4277 - Full term (39–41 weeks) Reference **Characteristics** Gestational age: n=69 - Very preterm (<32 weeks) n=67 - Moderately preterm (32–33 weeks) n=360 - Late preterm (34–36 weeks) n=1258 - Early term (37–38 weeks)	**Risk factors** Gestational age	**Setting** The Millennium Cohort Study (MCS) is a UK nationally representative longitudinal study of 18 818 children born in 2000–2001. This study included MCS families who responded at 9 months and 7 years of age with known gestational age.	**Outcome(s) at age** **Outcome(s) at age 7 years** Specific learning difficulty - School performance at age 7 years. RRs for not achieving the expected level in: <u>Key Stage 1 (OVERALL) adjusted RR (95% CI):</u> <32 weeks: 1.78 (1.24 to 2.54) 32–33 weeks: 1.71 (1.15 to 2.54) 34–36 weeks: 1.36 (1.09 to 1.68)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants: low risk of bias** **Attrition:** moderate risk of bias (the attrition was higher in the cocaine-exposed cohort) **Prognostic factor measurement: low risk of bias**

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Edition, 99, F451-7, 2014 **Country/ies where the study was carried out** UK **Study type** Prospective Cohort Study **Aim of the study** To investigate the effect of gestational age, particularly late preterm birth (34–36 weeks gestation) and early term birth (37–38 weeks gestation) on school performance at age 7 years. **Study dates** 2000/2001: Period of data collection	n=4277 - Full term (39–41 weeks) **Inclusion criteria** Children and born and attending school in England, UK Families included in the Millennium Cohort Study (MSC) who responded at 9 months and 7 years of age with known gestational age **Exclusion criteria** Children were excluded if: the mother was not the main respondent, gestational age was unknown, implausible for birth weight or below 23 weeks or above 42 weeks		**Method(s) of measurement for risk factor(s)** Gestational age was derived from the mother's report of the expected due date in weeks taken at the 9-month survey, which has been shown to have high agreement with routine hospital records except for >42 weeks gestation. **Outcome(s) ascertainment/measures** School performance was investigated using the statutory Key Stage 1 (KS1) teacher assessments performed in the third school year in England. At KS1, children generally perform between level 1 (below expected level) to level 3 (considerably above the expected level), with adequate performance categorised as achieving level 2 or above.	37–38 weeks: 1.07 (0.94 to 1.23) 39–41 weeks: Reference. <u>Key stage 1 (READING) adjusted RR (95% CI):</u> <32 weeks: 1.84 (1.12 to 3.05) 32–33 weeks: 1.82 (1.12 to 2.98) 34–36 weeks: 1.55 (1.20 to 2.00) 37–38 weeks: 1.22 (1.04 to 1.44) 39–41 weeks: Reference. <u>KS1 (WRITING) adjusted RR (95% CI):</u> <32 weeks: 1.82 (1.24 to 2.68) 32–33 weeks: 1.69 (1.14 to 2.50) 34–36 weeks: 1.35 (1.07 to 1.71) 37–38 weeks: 1.03 (0.88 to 1.21) 39–41 weeks: Reference. <u>KS1 (SPEAKING & LISTENING) adjusted RR (95% CI):</u> <32 weeks: 2.48 (1.63 to 3.78) 32–33 weeks: 1.58 (0.79 to 3.17) 34–36 weeks: 1.36 (0.96 to 1.94) 37–38 weeks: 1.31 (1.08 to 1.60) 39–41 weeks: Reference.	**Outcome measurement: low risk of bias** **Confounding moderate risk of bias (No sufficient information about the measurement and the definition of confounders measured in the study)** **Analysis and Reporting:** high risk of bias (presentation of data in narrative way for some important outcomes. Potential risk of selective reporting) **Overall:** low quality

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
(patient enrolment) 7 years: follow-up assessment **Source of funding** No details given			KS1 results were obtained from the Department of Education's National Pupil Database. **Statistical methods** As study outcomes were common, risk ratios were estimated (rather than ORs) using modified Poisson regression to adjust for potential confounders. The child's sex and age within the school year were adjusted for in all models. Other variables likely to affect school performance were adjusted for if they were independently associated with the outcome ($p<0.05$): maternal age at delivery, maternal education, maternal socioeconomic status, marital status, multiple births, whether the child was firstborn, and smoking during pregnancy (all collected at 9 months). Six children had missing information on	<u>KS1 (MATHEMATICS) adjusted RR (95% CI):</u> <32 weeks: 1.89 (0.92 to 3.64) 32–33 weeks: 1.96 (0.97 to 3.99) 34–36 weeks: 1.03 (0.66 to 1.59) 37–38 weeks: 1.38 (1.11 to 1.72) 39–41 weeks: Reference. <u>KS1 (SCIENCE) adjusted RR (95% CI):</u> <32 weeks: 1.87 (0.93 to 3.74) 32–33 weeks: 2.25 (1.16 to 4.38) 34–36 weeks: 1.33 (0.91 to 1.94) 37–38 weeks: 1.28 (1.06 to 1.55) 39–41 weeks: Reference. Adjusted for child's sex, child's age in school year taking into account premature children who if born at full term would have been placed in the year below, multiple birth, firstborn status, mother's age, mother's education, mother's social class, marital status, smoking during pregnancy.	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>some confounding variables and were excluded from the final adjusted results.

Length of follow-up

7 years</td><td></td><td></td></tr>
<tr><td>Ref Id

410214

Full citation

de Jong, M., Verhoeven, M., Lasham, C. A., Meijssen, C. B., van Baar, A. L., Behaviour and development in 24-month-old moderately preterm toddlers, Archives of Disease in Childhood, 100, 548-53, 2015

Country/ies where the study was carried out

The Netherlands.

Study type</td><td>Sample size

Overall sample:
n = 123 moderately preterm children (32-36 weeks' gestation)
n = 103 term controls (>37 weeks')

Sample included in follow up:
n = 116 preterm children
n = 99 term children

Characteristics
<table><tr><td>Characteristic</td><td>Term controls GA 37-41 weeks n = 99</td><td>Preterm GA 32-36 weeks n = 116</td></tr><tr><td>GA in weeks, mean (SD)</td><td>39.45 (0.98)</td><td>34.66 (1.35)</td></tr><tr><td>Birth weight, g, mean (SD)</td><td>3575 (460)</td><td>2575 (508)</td></tr><tr><td>Age at follow up, months,</td><td>23.71 (0.52)</td><td>23.60 (0.63)</td></tr></table></td><td>Risk factors

Gestational age.</td><td>Setting

Multicentre prospective cohort study.

Method(s) of measurement for risk factor(s)

Neonatal characteristics were based upon discharge letters in the hospital files.

Outcome(s) ascertainment/measures

At 24 months of age, corrected for prematurity, a trained examiner performed the Dutch version of the Bayley III to assess the developmental level of the children. This</td><td>Outcome(s) at age

DEVELOPMENTAL OUTCOMES
<u>At 24 months corrected age</u>
Cognitive developmental delay
Term: Reference
Moderately preterm: OR 0.89 (0.19-4.15)
Fine motor developmental delay
Term: Reference
Moderately preterm: OR 0.48 (0.04-6.36)
Gross motor developmental delay
Term: Reference
Moderately preterm: OR 1.61 (0.69-3.73)
Receptive communication developmental delay
Term: Reference
Moderately preterm: OR 2.07 (0.37-11.56)
Expressive communication developmental delay
Term: Reference</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounding: mod erate risk of bias
Only adjusted for maternal education and maternal age, other potentially important confounding factors were not adjusted for.
Analysis and reporting: low risk of bias</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Multicentre prospective longitudinal cohort study.

Aim of the study

To investigate if cognitive and behavioural problems in moderately preterm children are present at the age of 2 years.

Study dates

March 2010 and April 2011.

Source of funding

Utrecht University.</td>
<td>
<table>
<tr><td>mean (SD)</td><td></td><td></td></tr>
<tr><td>Male gender</td><td>45.5%</td><td>57.8%</td></tr>
<tr><td>Maternal age at birth, years,

mean (SD)</td><td>32.52 (4.20)</td><td>31.04 (4.43)</td></tr>
<tr><td>Maternal educational level</td><td></td><td></td></tr>
<tr><td>Low (no education, elementary school, special education or lower general secondary education</td><td>3.0%</td><td>7.8%</td></tr>
<tr><td>Medium (high school or vocational education)</td><td>12.1%</td><td>35.3%</td></tr>
<tr><td>High (college, university or higher)</td><td>84.8%</td><td>56.9%</td></tr>
</table>
Inclusion criteria

Preterm group: born at 32-36 weeks
Term group: born at 37-41 weeks</td>
<td></td>
<td>consists of five subtests: cognition, fine motor, gross motor, receptive communication and expressive communication. Scaled scores based on Dutch norms were used which vary between 1 and 19 with a mean of 10 and a SD of 3. Scores of 7-13 are considered normal, a score below 7 indicates a mild developmental delay. Mothers completed the Dutch version of the Child Behaviour Checklist 1½-5 to assess behaviour problems. Seven subscales (emotional reactivity, anxious/depressed behaviour, somatic complaints, withdrawn behaviour, sleep problems, attention problems and aggressive behaviour) and two broadband scales (internalising and externalising behaviour) are generated. For total problems and the broadband scales scores below 60 are</td>
<td>Moderately preterm: OR 0.48 (0.13-1.75)

<u>At 24 months uncorrected age</u>
Cognitive developmental delay
Term: Reference
Moderately preterm: OR 2.19 (0.56-8.63)
Fine motor developmental delay
Term: Reference
Moderately preterm: OR 2.13 (0.40-11.44)
Gross motor developmental delay
Term: Reference
Moderately preterm: OR 2.30 (1.03-5.13)
Receptive communication developmental delay
Term: Reference
Moderately preterm: OR 3.52 (0.69-17.82)
Expressive communication developmental delay
Term: Reference
Moderately preterm: OR 1.03 (0.33-3.17)

BEHAVIOURAL OUTCOMES
<u>At 24 months corrected age</u>
Total problems
Term: Reference
Moderately preterm: OR 1.37 (0.31-6.02)
Internalising problems</td>
<td>Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
	Exclusion criteria Birth weight below the 10th centile according to Dutch reference curves, multiple birth, severe congenital malformations, antenatal alcohol or drug abuse by the mother and chronic antenatal use of psychiatric drugs by the mother. Children admitted to a tertiary neonatal intensive care unit were also excluded.		considered normal, between 60 and 64 is seen as borderline clinical, and 64 or higher as clinical scores. For the subscales, scores below 65 are considered normal, between 65 and 70 borderline clinical, and 70 or higher as clinical scores. Subclinical and clinical scores were considered as clinically relevant scores for this study. **Statistical methods** Group differences in clinically relevant scores were investigated with logistic regression analyses. Analyses were adjusted for background characteristics that differed between the groups. **Length of follow-up** 24 months corrected age. Analyses of development are	Term: Reference Moderately preterm: OR 3.70 (0.41-33.09) **Externalising problems** Term: Reference Moderately preterm: OR 1.88 (0.54-6.54) **Emotionally reactive** Term: Reference Moderately preterm: OR 3.70 (0.40-34.22) **Anxious/depressed** Not able to calculate as no events in either group **Somatic complaints** Term: Reference Moderately preterm: OR 2.26 (0.58-8.83) **Withdrawn** Term: Reference Moderately preterm: OR 0.76 (0.04-15.14) **Sleep problems** Term: Reference Moderately preterm: OR 0.53 (0.06-4.43) **Attention problems** Term: Reference Moderately preterm: OR 1.06 (0.28-4.04) **Aggressive behaviour** Not able to calculate as no events in either group Analyses are adjusted for maternal education and maternal age at birth.	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			presented separately for adjusted ages and chronological ages.		
Ref Id 410231 **Full citation** Delobel-Ayoub, M., Arnaud, C., White-Koning, M., Casper, C., Pierrat, V., Garel, M., Burguet, A., Roze, J. C., Matis, J., Picaud, J. C., Kaminski, M., Larroque, B., Behavioral problems and cognitive performance at 5 years of age after very preterm birth: The EPIPAGE study, Pediatrics, 123, 1485-1492, 2009 **Country/ies where the study was carried out** France	**Sample size** Full sample: n = 2276 preterm infants born at 22-32 weeks n = 557 term controls born at 39-40 weeks Sample included in the follow up: n = 1102 preterm children n = 375 term controls **Characteristics** Not reported in this article. **Inclusion criteria** Preterm infants: born at 22-32 weeks during the study dates. Term controls: born at 39-40 weeks during the study dates. **Exclusion criteria** Death before follow up. Declined follow up. Multiple births. Children with severe sensory impairment (blindness or deafness) or severe neuromotor deficiency. Children aged ≥6 years at the time of assessment.	**Risk factors** Gestational age Gender Maternal age Socioeconomic status Maternal mental health	**Setting** Population based cohort. **Method(s) of measurement for risk factor(s)** Gestational age was expressed in completed weeks of amenorrhoea. Cranial ultrasound scans were conducted in 98% of the very preterm infants and the results were classified into 4 categories: Major lesions - periventricular leucomalacia or periventricular parenchymal haemorrhagic involvement Moderate lesions - intraventricular haemorrhage with ventricular dilatation or isolated ventricular dilatation or	**Outcome(s) at age** <u>At age 5 years</u> <u>Abnormal total difficulties score</u> **Gestational age** Term: Reference Preterm: OR 1.8 (1.2-2.8)† †adjusted for cognitive performance, maternal age at birth, health of the child, development of the child (assessed by the parents) at 5 years of age, previous hospitalisations of the child between birth and 5 years of age and the mental wellbeing of the mother during the previous month. *Within the preterm group only* <u>Abnormal total difficulties score</u> **Gestational age** (24-26 weeks', 27-28 weeks', 29-30 weeks', 31-32 weeks') not significant on univariate analysis **Gender** not significant on multivariate analysis **Cerebral lesions**	**Limitations** Based on the NICE manual 2014 checklist for prognnostic studies and QUIPS **Participants:** low risk of bias **Attrition:** moderate risk of bias. More than 20% of participants did not complete the follow up questionnaire, and no information is reported regarding difference between these individual and those included in followup. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study type Population based prospective cohort study. **Aim of the study** To compare the frequency of behavioural problems in very preterm and term children at 5 years of age. **Study dates** 1997. **Source of funding** Institut National de la Santé et de la Recherche Médicale, Marck-Sharp, Dohme-Chibret, la Fondation de la Recherche Médicale and la Direction Générale de la Santé du			echodensity lasting >14 days. Minor lesions - intraventricular haemorrhage without ventricular dilatation or germinal matrix haemorrhage No lesion - none of the above. Social class was assessed by the parents' highest level of occupation, or the mother's if she lived alone. Mothers also completed questions that explored their physical and mental wellbeing during the previous month. **Outcome(s) ascertainment/measures** The French version of the Strengths and Difficulties Questionnaire was completed by one or both parents' (98%) or another caregiver (2%). Scores from the	not significant on univariate analysis **Socioeconomic status** not significant on multivariate analysis **Mental wellbeing of the mother during the previous month** *n/N for each category* Very well (62/393): Reference Fairly well (133/555): OR 1.8 (1.2-2.7)‡ Fairly or very poor (37/93): OR 3.4 (1.9-6.3)‡ **Maternal age at birth** *n/N for each category* 25-34 yrs (145/678): Reference <25 yrs (60/207): OR 1.6 (1.0-2.4)‡ ≥35 yrs (34/202): OR 0.6 (0.4-1.0)‡ ‡mutually adjusted for cognitive performance, maternal age at birth, development of the child (assessed by the parents), hospitalisations between birth and 5 years and mental wellbeing of the mother during the previous month.	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Ministère des Affaires Sociales, the Programme Hospitalier de Recherche Clinique.			four symptom scales (hyperactivity/inattention, conduct, emotional and peer problems) are summed to provide a "total difficulties" score, with higher scores indicating poorer mental health. Cut-offs were defined based on the 10th percentile of the observed scores in the control group. **Statistical methods** Factors associated with a high total difficulties score in the very preterm children were assessed using multivariable logistic regression analysis. Covariates were included in the initial model if they were associated at the 10% significance level in the univariate analysis. A backward procedure was used to remove variables (5% significance level). A weighted multivariable logistic regression analysis was used to compare the behavioural		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			problems in preterm and term children. **Length of follow-up** 5 years (assumed to be chronological age).		
Ref Id 412504 **Full citation** Delobel-Ayoub, M., Kaminski, M., Marret, S., Burguet, A., Marchand, L., N'Guyen, S., Matis, J., Thiriez, G., Fresson, J., Arnaud, C., Poher, M., Larroque, B., Behavioral outcome at 3 years of age in very preterm infants: The EPIPAGE study, Pediatrics, 117, 1996-2005, 2006 **Country/ies where the study was carried out** France.	**Sample size** Full sample at hospital discharge: n = 2276 preterm children n = 557 term controls Sample included in follow up: n = 1228 preterm children n = 447 term controls **Characteristics** Not reported in this article. **Inclusion criteria** Preterm children: all children born in nine regions of France during 1997 at 22-32 weeks gestation. Term controls: born at 39-40 weeks in the same regions of France. **Exclusion criteria** For this analysis, multiple births were excluded. Children with major disabilities (such as blindness, deafness or severe cerebral palsy at 3 years of age) were also excluded. 6 children from the preterm group were excluded as they were more than 4 years old at the time of completing the questionnaire.	**Risk factors** Gestational age Gender SGA status Maternal age Cerebral lesions Bronchopulmonary dysplasia (BPD)	**Setting** National cohort study in France - EPIPAGE **Method(s) of measurement for risk factor(s)** Data about pregnancy, delivery and medical care of infants were extracted from medical charts in maternity and neonatal units. Gestational age was calculated as the number of completed weeks of amenorrhoea and was the best obstetric estimate using the first prenatal ultrasound and the date of the last menstrual period. SGA was defined as a birth weight less than the 10th percentile for gender and gestational age.	**Outcome(s) at age** At 3 years of age Gestational age **Total difficulties score** Term: Reference Preterm: OR 1.9 (1.3-2.8)† **Hyperactivity** Term: Reference Preterm: OR 1.7 (1.2-2.5)† **Conduct problems** Term: Reference Preterm: OR 1.6 (1.1-2.3)† **Emotional symptoms** Term: Reference Preterm: OR 1.4 (1.0-2.1)† **Peer problems** Term: Reference Preterm: OR 1.5 (1.0-2.3)† †OR were adjusted for gender, maternal age at birth, birth order, maternal education, marital status of the mother, hospitalization during the last year, neurodevelopmental delay and the health of the child (assessed by the parents) at 3 years of age	**Limitations** Based on the NICE manual 2014 checklist for prognnostic studies and QUIPS **Participants:** low risk of bias **Attrition:** moderate risk of bias. More than 20% of participants did not complete the follow up questionnaire, and no information is reported regarding difference between these individual and those included in followup. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study type Population based prospective cohort study. **Aim of the study** To assess the risk of behavioural problems at 3 years of age in a cohort of preterm children, as compared to term children. **Study dates** 1997 **Source of funding** Institut National de la Santé et de la Recherche Médicale, Marck-Sharp, Dohme-Chibret, la Fondation de la Recherche			Cranial ultrasound scans were conducted in 98% of the very preterm infants and the results were classified into 4 categories: Major lesions - periventricular leucomalacia or periventricular parenchymal haemorrhagic involvement Moderate lesions - intraventricular haemorrhage with ventricular dilatation or isolated ventricular dilatation or echodensity lasting >14 days. Minor lesions - intraventricular haemorrhage without ventricular dilatation or germinal matrix haemorrhage No lesion - none of the above. BPD was defined as the need for supplemental oxygen	*Risk factors within the preterm group only:* Gestational age **Total difficulties score** 31-32 weeks: Reference 29-30 weeks: OR 0.9 (0.6-1.3)‡ 24-28 weeks: OR 1.4 (0.9-2.2)‡ <u>Gender</u> **Total difficulties score** Female: Reference Male: OR 1.3 (0.9-1.7)‡ <u>SGA status</u> Not a significant predictor on univariate analysis <u>Maternal age at birth</u> **Total difficulties score** 25-34 years: Reference <25 years: OR 2.5 (1.7-3.7)‡ ≥35 years: OR 0.9 (0.5-1.4)‡ <u>Cerebral lesions</u> **Total difficulties score** No lesion: Reference Minor lesion: OR 1.3 (0.9-2.0)‡ Moderate lesion: OR 0.9 (0.6-1.5)‡ Major lesions: OR 2.4 (1.1-5.2)‡ <u>BPD</u> Not a significant predictor on univariate analysis	**Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Médicale and la Direction Générale de la Santé du Ministère des Affaires Sociales, the Programme Hospitalier de Recherche Clinique.			at 36 weeks postmenstrual age. **Outcome(s) ascertainment/measures** The French version of the Strengths and Difficulties Questionnaire (SDQ) was completed by parents when the child was 3 years of age. This is a brief behavioural questionnaire which surveys 5 types of behaviour: hyperactivity-inattention, conduct problems, emotional symptoms, peer problems and prosocial behaviour. Cut-offs were defined so that 10% of children in the control group were considered as having a behavioural problem. **Statistical methods** Multivariate analyses were used to identify the major risk factors	‡OR were adjusted for gender, maternal age at birth, birth order, maternal education, marital status of the mother, gestational age, cerebral lesions, hospitalization in NICU ≥13 weeks, hospitalization during the last year, neurodevelopmental delay at 3 years, and the health of the child (assessed by the parents) at 3 years of age	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			for behavioural disorders in very preterm infants. Variables that were related to the total difficulties at p<0.2 were included in the multivariate model: gender, maternal age at birth, birth order, maternal level of education, marital status of the mother, gestational age, cerebral lesions, duration of neonatal hospitalisation, neurodevelopmental delay at 3 years, hospitalisation during the last year and health of the child (assessed by the parents) at the age of 3. Behavioural problems in term and preterm children were compared after controlling for potential confounders. Three models were used to identify which risk factors explained the difference between term and preterm children: model 1 included social characteristics, model 2 included the medical		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			and developmental status of the child, and model 3 included all of these factors. **Length of follow-up** 3 years (assumed chronological age)		
Ref Id 412575 **Full citation** Farooqi, A., Hagglof, B., Serenius, F., Behaviours related to executive functions and learning skills at 11 years of age after extremely preterm birth: A Swedish national prospective follow-up study, Acta Paediatrica, International Journal of Paediatrics, 102, 625-634, 2013 **Country/ies where the study was carried out**	**Sample size** Full sample: n = 89 surviving preterm infants n = 89 full term controls Sample included in follow up n = 83 preterm children n = 86 term controls **Characteristics** Article states that there were no significant differences between the preterm and control participants regarding family structure, maternal education, socioeconomic status or family function. At 11 years of age, 13 preterm (15%) and 2 control participants (2%) had one or more neurosensory impairments. 15% of preterm children were receiving special education, as compared to 5% of control participants. **Inclusion criteria** Preterm children: all preterm children born at <26 weeks gestation in the whole of Sweden during the study dates and surviving to follow up.	**Risk factors** Gestational age	**Setting** National cohort of preterm babies. **Method(s) of measurement for risk factor(s)** No information provided on estimation of gestational age. **Outcome(s) ascertainment/measures** Executive function and learning skills were assessed using the Five to Fifteen (FTF) questionnaire, completed by parents and teachers. Results of >2SD above the mean score were classified as problem scores.	**Outcome(s) at age** <u>At 11 years of age</u> Total population **Attention problems** Term: Reference Preterm: OR 2.8 (0.81-9.6)† Preterm: OR 4.2 (1.3-13.5)‡ **Hyperactivity/impulsivity problems** Term: Reference Preterm: OR 2.3 (0.72-7.2)† Preterm: OR 2.7 (0.7-10.9)‡ **Hypoactivity problems** Term: Reference Preterm: OR 1.5 (0.5-4.5)† Preterm: OR 3.8 (1.2-12.2)‡ **Planning/Organising problems** Term: Reference Preterm: OR 5.9 (2.1-16.9) † Preterm: OR 4.7 (1.6-13.4)‡ **Working memory problems** Term: Reference Preterm: OR 8.6 (1.8-39.7)† Preterm: OR 5.5 (2.1-14.5)‡	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: high

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Sweden. **Study type** National prospective cohort study. **Aim of the study** To examine the behaviours related to executive function and learning skills in a national cohort of 11 year old children born extremely preterm. **Study dates** April 1990 to March 1992. **Source of funding** The Svenjerringsfond Foundation.	Term controls: matched for hospital, gender and birth date (+/- 7 days) and recruited at the time of current assessment. **Exclusion criteria** Death before follow up or loss to follow up.		**Statistical methods** Multivariate logistic regression analyses were performed to examine the differences in dichotomous outcomes regarding executive functions between the groups. Social risk, family function and gender were entered as covariates. **Length of follow-up** 11 years (assumed to be chronological age)	Population after excluding those with neurosensory impairment **Attention problems** Term: Reference Preterm: OR 2.5 (0.6-11.2)† Preterm: OR 5.2 (1.4-19.7)‡ **Hyperactivity/impulsivity problems** Term: Reference Preterm: OR 1.8 (0.48-6.9)† Preterm: OR 2.0 (0.5-9.1)‡ **Hypoactivity problems** Term: Reference Preterm: OR 1.6 (0.47-5.3)† Preterm: OR 5.1 (1.3-19.1)‡ **Planning/Organising problems** Term: Reference Preterm: OR 5.03 (1.6-16.2) † Preterm: OR 5.9 (1.8-18.8)‡ **Working memory problems** Term: Reference Preterm: OR 14.2 (1.7-116.2)† Preterm: OR 6.6 (2.4-18.8)‡ † scores based on parental report ‡ scores based on teacher report All OR are adjusted for gender, social risk and family function.	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Ref Id

336410

Full citation

Guellec, I., Lapillonne, A., Renolleau, S., Charlaluk, M. L., Roze, J. C., Marret, S., Vieux, R., Monique, K., Ancel, P. Y., Epipage Study Group, Neurologic outcomes at school age in very preterm infants born with severe or mild growth restriction, Pediatrics, 127, e883-91, 2011

Country/ies where the study was carried out

France

Study type

Prospective population based cohort study.</td>
<td>Sample size

Original sample size
N = 2458 preterm infants discharged home alive.

Participants eligible for follow up
N = 2357

Participants included in follow up data:
n = 1677 with information on behavioural difficulties
n = 1535 with MPC data
n = 1439 with school questionnaire data

Characteristics
<table>
<tr><td></td><td colspan="2">24-28 week</td><td colspan="2">29-32 week</td></tr>
<tr><td>Characteristic</td><td>AGA ≥ 20th centile n (%)</td><td>SGA <10th centile n (%)</td><td>AGA ≥20th centile n (%)</td><td>SGA <10th centile n (%)</td></tr>
<tr><td>Male gender</td><td>349 (51.6)</td><td>37 (52.1)</td><td>887 (54.3)</td><td>104 (54.4)</td></tr>
<tr><td>Antenatal corticosteroids</td><td>443 (67.2)</td><td>53 (75.7)</td><td>1168 (73.6)</td><td>151 (83.9)</td></tr>
<tr><td>Multiple pregnancy</td><td>222 (32.8)</td><td>17 (23.9)</td><td>516 (31.6)</td><td>48 (25.1)</td></tr>
<tr><td>Maternal age <25 years</td><td>156 (23.2)</td><td>15 (21.7)</td><td>389 (24.0)</td><td>50 (26.5)</td></tr>
</table>
</td>
<td>Risk factors

Small for gestational age.</td>
<td>Setting

Population based cohort study in France.

Method(s) of measurement for risk factor(s)

Small for gestational age was defined as birth weight below the 10th centile for gestation.

Outcome(s) ascertainment/measures

Behavioural problems were assessed using the French version of the Strengths and Difficulties Questionnaire which was completed by the parents. 25 items from 5 rating scales are included (hyperactivity-inattention, conduct, emotional and peer problems and prosocial behaviour). Scores for the first four domains are summed up to a "total</td>
<td>Outcome(s) at age

<u>At age 5 years</u>
24-28 week preterm infants
Inattention-hyperactivity symptoms
AGA (n = 75/346): Reference
SGA (n = 4/21): OR 1.29 (0.37-4.46)‡

Total behavioural difficulties
AGA (n = 82/346): Reference
SGA (n = 7/21): OR 2.30 (0.82-6.48)‡

29-32 week preterm infants
Inattention-hyperactivity symptoms
AGA (n = 156/1041): Reference
SGA (n = 27/115): OR 1.78 (1.10-2.89)‡

Total behavioural difficulties
AGA (n = 201/1037): Reference
SGA (n = 22/115): OR 0.98 (0.59-1.63)‡

‡ adjusted for gestational age, gender, social class of the family, maternal age, parity, maternal nationality, type of pregnancy (single versus multiple) and antenatal corticosteroids.</td>
<td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS:
Participants: low risk of bias
Attrition: moderate risk of bias. >20% of participants were lost to follow up, and no information is presented regarding whether there are any difference between those individual who were, and were not, included in the follow up.
Prognostic factor measurement: low risk of bias
Outcome measurement: high risk of bias. School difficulties includes the outcome of "low grades" but this is not further described, and is based solely on parental report.
Confounding: low risk of bias
Analysis and reporting: low risk of bias</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Aim of the study To assess cognitive performance and school performance in preterm children according to growth restriction at birth. **Study dates** January 1st and December 31st 1997. **Source of funding** Not reported in this article.	<table><tr><td>Maternal age ≥35 years</td><td>102 (15.2)</td><td>15 (21.7)</td><td>243 (15.0)</td><td>37 (19.6)</td></tr><tr><td>Socioeconomic status</td><td></td><td></td><td></td><td></td></tr><tr><td>Professional</td><td>90 (15.1)</td><td>8 (14.5)</td><td>194 (12.6)</td><td>19 (10.9)</td></tr><tr><td>Intermediate</td><td>127 (21.2)</td><td>12 (21.8)</td><td>370 (24.0)</td><td>38 (21.7)</td></tr><tr><td>Administrative/public service/ self-employed/student</td><td>145 (24.2)</td><td>8 (14.5)</td><td>346 (22.5)</td><td>47 (26.9)</td></tr><tr><td>Shop assistant/service worker</td><td>100 (16.7)</td><td>8 (14.5)</td><td>241 (15.6)</td><td>28 (16.0)</td></tr><tr><td>Manual worker or unemployed</td><td>136 (22.7)</td><td>19 (34.5)</td><td>389 (25.3)</td><td>43 (24.6)</td></tr></table> **Inclusion criteria** Preterm children: born before 33 completed weeks in 9 regions of France during the study dates. Term controls: one in every four births at 39 or 40 weeks during one week of 1997. **Exclusion criteria** Death before discharge, or before the follow up period. Declined follow up (n = 106).		difficulties score" which indicates poorer mental health. Cut-offs were defined so that 10% of the term control group were considered to have a behavioural problem. School performance was assessed at 8 years of age by parental questionnaire. School difficulties were defined by special schooling (institution or special school, special class in mainstream school, mainstream class) or low grades (not further defined). **Statistical methods** Bivariate relationships between birth weight for gestational age and each outcome were assessed with X^2 or Fisher's exact test. Logistic regression models were used to study these associations after adjustment for potential confounders and gestational age. Covariates were	At age 8 years *24-28 week preterm infants* **School difficulties** AGA (n = 98/295): Reference SGA (n = 6/17): OR 1.39 (0.47-4.14)* *29-32 week preterm infants* **School difficulties** AGA (n = 163/887): Reference SGA (n = 30/107): OR 1.74 (1.07-2.82)* * Adjusted for gestational age, gender, social class of the family, maternal age and parity.	Overall quality: low

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>included in the model if they were known risk factors and found to be associated with the studied outcome at the 20% significance level in univariate analysis.

Length of follow-up

Behavioural outcomes were assessed at five years of age. School outcomes were assessed at 8 years of age.
Chronological age is assumed, but not stated by the authors.</td><td></td><td></td></tr>
<tr><td>Ref Id

410767

Full citation

Johnson, S., Evans, T. A., Draper, E. S., Field, D. J., Manktelow, B. N., Marlow, N., Matthews, R., Petrou, S., Seaton, S. E., Smith, L. K., Boyle, E. M., Neurodevelopmental outcomes following late</td><td>Sample size

Sample recruited - N = 2383
n = 1130 late/moderately preterm infants
n = 1255 term controls

Sample analysed after exclusions - N = 1403
n = 638 late/moderately preterm infants
n = 765 term controls

Characteristics
<table><tr><td>Characteristic</td><td>Term infants (n = 765)</td><td>Late/moderatepreterm infants (n = 638)</td></tr><tr><td>Gestational age</td><td></td><td></td></tr></table></td><td>Risk factors

Gestational age
Ethnicity
Socioeconomic status
Preeclampsia
Gender</td><td>Setting

Births in one of four maternity centres, a midwifery-led birthing unit and home births.

Method(s) of measurement for risk factor(s)

Mothers participated in a semi-structured interview after birth, and obstetric and neonatal data were collected from medical records at discharge.</td><td>Outcome(s) at age

At 2 years corrected age:
<u>Risk of cognitive impairment</u>
Gestational age
Term: Reference
Late/moderately preterm: RR 2.09 (1.19-3.64)††adjusted for sex, socioeconomic status and small for gestational age
Ethnicity
White ethnic group: Reference
Non-white ethnic group: RR 2.06 (1.10-3.83)‡
Socioeconomic status
Low risk: Reference</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias (Although only 57% of preterm participants and 62% of controls completed the 2 year follow up, baseline characteristics are reported for those who dropped out of</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>and moderate prematurity: A population-based cohort study, Archives of Disease in Childhood: Fetal and Neonatal Edition, 100, F301-F308, 2015

Country/ies where the study was carried out

UK

Study type

Prospective cohort study.

Aim of the study

To assess neurodevelopmental outcomes at 2 years of age following late and moderate prematurity.

Study dates</td>
<td>
<table>
<tr><td>32-33 weeks , n (%)</td><td></td><td>87 (13.6)</td></tr>
<tr><td>34-36 weeks, n (%)</td><td></td><td>551 (86.4)</td></tr>
<tr><td>37-38 weeks, n (%)</td><td>241 (31.5)</td><td></td></tr>
<tr><td>39-40 weeks, n (%)</td><td>357 (46.7)</td><td></td></tr>
<tr><td>41-42 weeks, n (%)</td><td>167 (21.8)</td><td></td></tr>
<tr><td>Multiple births, n (%)</td><td>151 (19.7)</td><td>107 (16.8)</td></tr>
<tr><td>Birth weight, g, mean (SD)</td><td>3322 (535)</td><td>2435 (502)</td></tr>
<tr><td>SGA, n (%)</td><td>48 (6.3)</td><td>67 (10.5)</td></tr>
<tr><td>Male, n (%)</td><td>384 (50.2)</td><td>343 (53.8)</td></tr>
<tr><td>Maternal age < 20, n (%)</td><td>16 (2.3)</td><td>19 (3.2)</td></tr>
<tr><td>Maternal age ≥ 35, n (%)</td><td>188 (27.3)</td><td>114 (19.5)</td></tr>
<tr><td>Ethnicity</td><td></td><td></td></tr>
</table>
</td>
<td></td>
<td>To quantify socioeconomic status a composite score was computed using five proxy variables that measured mothers' occupation, education, social support, income and wealth. Total SES scores (range 0-12) were used to define three socioeconomic risk groups: low (scores 0-2), moderate (scores 3-5) and high (scores ≥6).

Outcome(s) ascertainment/measures

At 2 years corrected age, cognitive impairment was assessed using the Parent Report of Children's Abilities-Revised (PARCA-R). Scores for non-verbal cognition and expressive language were combined to give a total parent report composite. These scores are strongly correlated with scores on gold standard developmental tests.</td>
<td>Medium risk: RR 2.86 (1.24-6.57)‡
High risk: RR 2.36 (1.02-5.48)‡
Preeclampsia
No: Reference
Yes: RR 2.51 (1.33-4.70)‡
Sex
Female: Reference
Male: RR 7.04 (2.52-19.67)‡ ‡adjusted for all other variables in the model - see analysis section.</td>
<td>the study. The authors identify that those mothers lost to follow up were younger, more likely to be non-white, non-English speaking and single parents, to have lower occupational status and educational qualifications, to be struggling financially and have poorer health than responders. Some of these differences are identified as factors which significantly affect the risk of cognitive impairment in the study and therefore the results may be different if these women/their infants had participated in the follow up)
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias.</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>September 2009 to December 2010: Period of data collection (patient enrolment)
2 years of corrected age: follow-up assessment

Source of funding

National Institute for Health Research.</td>
<td>
<table>
<tr><td>White, n (%)</td><td>569 (82.5)</td><td>461 (78.5)</td></tr>
<tr><td>Mixed, n (%)</td><td>7 (1.0)</td><td>12 (2.0)</td></tr>
<tr><td>Asian, n (%)</td><td>77 (11.2)</td><td>86 (14.7)</td></tr>
<tr><td>Black, n (%)</td><td>30 (4.4)</td><td>21 (3.6)</td></tr>
<tr><td>Chinese or other, n (%)</td><td>7 (1.0)</td><td>6 (1.0)</td></tr>
<tr><td>Unknown, n (%)</td><td>0 (0)</td><td>1 (0.2)</td></tr>
<tr><td>Socioeconomic status</td><td></td><td></td></tr>
<tr><td>Low risk, n (%)</td><td>339 (49.1)</td><td>256 (43.6)</td></tr>
<tr><td>Medium risk, n (%)</td><td>209 (30.3)</td><td>184 (31.4)</td></tr>
<tr><td>High risk, n (%)</td><td>142 (20.6)</td><td>147 (25.0)</td></tr>
</table>
Inclusion criteria

Preterm babies: All babies born from 32 to 36+6 weeks of gestation within a geographically defined region of the East Midlands.
Term babies: a random sample of term babies born during the same time period and in the same geographical region, including all term born multiples.
</td>
<td></td>
<td>Moderate/severe cognitive impairment was identified as a score corresponding to with PRC scores < 2.5th percentile in the term reference group.

Statistical methods

Neurodevelopmental outcomes were compared between term and late/moderate preterm infants with adjustment for major confounders (sex, socioeconomic status and small for gestational age).
A multivariable model was constructed to identify risk of cognitive impairment in the late/moderate preterm group, accounting for maternal age, ethnicity, socioeconomic status, infertility treatment, maternal hypertension, maternal diabetes, smoking, alcohol consumption, recreational drug use, preeclampsia,</td>
<td></td>
<td>Overall: moderate quality</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
	Exclusion criteria Infants with congenital abnormalities. No completed questionnaire data received (n = 490 term, n = 492 preterm).		infection during pregnancy, gestational diabetes, pre-labour rupture of membranes >24 hours, antenatal corticosteroids, induction of labour, raised CRP during labour, mode of delivery, absent or reversed end diastolic flow, male gender, gestational age, multiple birth, small for gestational age, need for resuscitation at birth, respiratory support received, intracranial abnormalitites, jaundice requiring phototherapy, hypoglycaemia, hypothermia, antibiotic administration and any breast milk at discharge. **Length of follow-up** 2 years (corrected age).		
Ref Id 397352 **Full citation**	**Sample size** n=219 extremely preterm children (<26 GA weeks) **Characteristics**	**Risk factors** Sex, maternal ethnicity, maternal age, SES, antenatal steroids, postnatal steroids for	**Setting** National cohort study (EPICure Study) of extremely preterm children born at <26	**Outcome(s) at age** <u>At age 11 years</u> **SEN provision** Male sex: OR 3.08 (1.48-6.40)	**Limitations** Limitations Based on the NICE manual 2014 checklist for

Study details	Participants		Risk factors	Methods	Outcomes and Results	Comments
Johnson, S., Wolke, D., Hennessy, E., Marlow, N., Educational outcomes in extremely preterm children: neuropsychological correlates and predictors of attainment, Developmental Neuropsychology, 36, 74-95, 2011 **Country/ies where the study was carried out** UK & Ireland **Study type** Population-based cohort study (EPICure Study) **Aim of the study** To investigate educational outcomes at 11 years of age in children born		Children born at <26 weeks, assessed at 11 years n=219	chronic lung disease, abnormal cerebral ultrasound, necrotising enterocolitis	weeks of gestation in the UK and Ireland between March and December 1995. **Method(s) of measurement for risk factor(s)** Maternal and infant characteristics, and perinatal information was collected at discharge from hospital. **Outcome(s) ascertainment/measures** Teachers completed a questionnaire about if special educational needs (SEN) provision was utilized by the child. **Statistical methods** Multiple logistic regression adjusting for sex, gestational age, birth weight, maternal ethnicity, maternal age, maternal education, SES, antenatal	Abnormal last cerebral ultrasound: OR 3.72 (1.16-11.91) NEC: not significant (not reported) Any antenatal steroids: not significant (not reported) Any postnatal steroids for chronic lung disease: not significant (not reported) Maternal age (per 10 years): not significant (not reported) SES: not significant (not reported) Chorioamnionitis (suspected or proven): not significant (not reported)	prognostic studies and QUIPS **Participants:** low risk of bias **Attrition:** moderate risk of bias Of the 3017 children who survived until 11 years of age, 219 were assessed (71%). **Prognostic factor measurement:** moderate risk of bias No details are given about the risk factors. **Outcome measurement:** moderate risk of bias Little information is given about the outcome of interest (SEN provision). **Confounding:** moderate risk of bias It is not clearly stated how the regression model was built but presumably all the perinatal and neonatal factors were included in the model. **Analysis and reporting:** moderate risk of bias Only statistically significant findings are reported and it is
	<=23 GA wks, %	10.5				
	24 GA wks, %	32.0				
	25 GA wks, %	57.5				
	Birth weight in grams, median	740				
	Male sex, %	46.1				
	White maternal ethnicity, %	82.1				
	Mother education up to 16 yrs of age, %	76.0				
	Mother's education post-16	24.0				

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
extremely preterm compared with term-born classmates in order to quantify the effect of extremely preterm birth on school performance in middle childhood; using outcome data obtained at 6 years to investigate social and neuropsychological antecedents of attainment in reading and mathematics at 11 years and to examine the relative impact of these antecedents between children born extremely preterm and at term; to examine neonatal variables and early neurodevelopmental outcomes at 30 monhts of age as predictors of	<table><tr><td>years of age, %</td><td></td></tr><tr><td>High SES at 11y, %</td><td>43.9</td></tr><tr><td>Medium SES at 11 y, %</td><td>24.4</td></tr><tr><td>Low SES at 11 y, %</td><td>31.7</td></tr><tr><td>Age at assessment, mean (SD)</td><td>10.9 (0.38)</td></tr></table> **Inclusion criteria** All infants born <26 weeks of gestation and admitted for neonatal intensive care in the UK and Ireland from March through December 1995 and survived. **Exclusion criteria** None reported.		steroids, preterm premature rupture of membranes, vaginal breech delivery, chorioamnionitis, fetal heart rate >100 bpm at 5 minutes, admission temperature <35c, CRIB score, NEC, postnatal steroids for chronic lung disease, any breast milk given, duration of NICU admission. **Length of follow-up** 11 years		not clear which risk factors were actually considered for the outcome of interest. Overall quality: low

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td>attainment in reading and mathematics and the need for special educational needs provision in children born extremely preterm at 11 years of age.

Study dates

Children born between March and December 1995, follow-up at 11 years.

Source of funding

None reported.</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Ref Id

243107

Full citation

Kerstjens,J.M., Bocca-Tjeertes,I.F., de Winter,A.F., Reijneveld,S.A., Bos,A.F., Neonatal morbidities and</td><td>Sample size

Overall sample
N = 1145 moderately preterm children

Sample included in follow up
N = 832

Characteristics

<table><tr><td>Characteristics</td><td>32-35 week</td><td>32-33 week</td><td>34-35 week</td></tr></table></td><td>Risk factors

Gestational age
Male gender
SGA (<10th centile)
Sepsis</td><td>Setting

National prospective cohort study.

Method(s) of measurement for risk factor(s)

Data on neonatal morbidities were collected from hospital records, bedside</td><td>Outcome(s) at age

<u>At 43-49 months</u>
Risk of abnormal ASQ total problems score
Low gestational age
34 to 35+6 weeks: Reference
32 to 33+6 weeks: not significant on univariate analysis

Male gender
Female: Reference</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
>20% of participants were lost to follow up.</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
developmental delay in moderately preterm-born children, Pediatrics, 130, e265-e272, 2012 **Country/ies where the study was carried out** The Netherlands. **Study type** Community based prospective cohort study. **Aim of the study** To determine which neonatal morbidities were associated with developmental delay at preschool age for moderately preterm children.	<table><tr><td></td><td>n = 832</td><td>N = 268</td><td>N = 564</td></tr><tr><td>Septicaemia</td><td>30 (3.6%)</td><td>17 (6.3%)</td><td>13 (2.3%)</td></tr><tr><td>SGA <10th percentile</td><td>76 (9.1%)</td><td>25 (9.3%)</td><td>51 (9.0%)</td></tr><tr><td>Male gender</td><td>471 (56.6%)</td><td>145 (54.1%)</td><td>326 (57.8%)</td></tr><tr><td>Low maternal education</td><td>246 (29.7%)</td><td>91 (34.1%)</td><td>155 (27.7%)</td></tr></table> **Inclusion criteria** Children born during the study dates with a gestational age of 32 to 35+6 weeks. **Exclusion criteria** Major congenital malformations, congenital infections and all children with syndromes. No ASQ data within specified time window (43-49 months).		charts and preventive health care records. Septicaemia was defined as both clinical symptoms and at least one positive blood culture result. SGA was defined as a birth weight < 10th percentile, according to the Dutch growth curves. Low gestational age was defined as <34 weeks gestation. **Outcome(s) ascertainment/measures** Parents completed the Dutch version of the 48 months Ages and Stages Questionnaire. This measures development in 5 domains: communication, fine motor, gross motor, problem solving ability and personal-social functioning. The scores on each domain add up to an ASQ total problems score. A score of >2SDs below the mean for the Dutch reference group was	Male: OR 3.12 (1.70-5.75) **SGA** No: Reference Yes: OR 2.62 (1.36-5.05) **Septicaemia** Not significant on univariate analysis Variables included in the final model were: birth asphyxia, tertiary NICU admission, hypoglycaemia, hyperbilirubinaemia, SGA and gender. Numbers for subgroups are not stated.	**Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and Reporting:** low risk of bias. Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study dates Children born in 2002 and 2003. **Source of funding** The Research Foundation of the Beatrix Children's Hospital, the Cornelia Foundation for the Handicapped Child, the A. Bulk Preventive Child Health Care Research Fund, the Dutch Brain Foundation, and unrestricted investigator-initiated research grants from Friso Infant Nutrition, FrieslandCampina, and Pfizer Europe.			considered to indicate developmental delay. **Statistical methods** The association between all perinatal and neonatal variables with rates of abnormal ASQ score was assessed with univariate logistic regression. Then all risk factors with univariate associations of p <0.1 were included simultaneously in a multivariable logistic regression model. **Length of follow-up** 43-49 months. Chronological age is assumed, but not stated by the authors.		
Ref Id 410819 **Full citation** Kerstjens, J. M., de Winter, A. F.,	**Sample size** Sample recruited - N = 2517 n = 698 gestation < 32 weeks n = 1145 gestation 32-35 weeks n = 674 gestation 38-41 weeks Sample analysed after exclusions - N = 1983 n = 512 gestation < 32 weeks	**Risk factors** Gestational age	**Setting** Multicentre and community based prospective cohort study.	**Outcome(s) at age** **At age 4 years** Risk of developmental delay (ASQ total score <2SD below the mean) Term: Reference <32 weeks: OR 3.2 (1.88-5.37)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Bocca-Tjeertes, I. F., ten Vergert, E. M., Reijneveld, S. A., Bos, A. F., Developmental delay in moderately preterm-born children at school entry, Journal of Pediatrics, 159, 92-8, 2011

Country/ies where the study was carried out

The Netherlands.

Study type

Population based prospective cohort study (Lollypop).

Aim of the study

To determine the prevalence and nature of developmental delay at</td>
<td>n = 927 gestation 32-35 weeks
n = 544 gestation 38-41 weeks

Characteristics
<table>
<tr><th>Characteristics</th><th>Early preterm< 32 weeksn = 512</th><th>Moderate preterm32-35+6 weeksn = 927</th><th>Full term38-41+6 weeksn = 544</th></tr>
<tr><td>Male, n (%)</td><td>263 (51.4)</td><td>532 (57.4)</td><td>270 (49.6)</td></tr>
<tr><td>Multiplepregnancy, n (%)</td><td>178 (34.8)</td><td>259 (27.9)</td><td>6 (1.1)</td></tr>
<tr><td>SGA <10th percentilen (%)</td><td>97 (19.1)</td><td>85 (9.2)</td><td>45 (8.4)</td></tr>
<tr><td>Maternal age</td><td></td><td></td><td></td></tr>
<tr><td>< 20 yrs, n (%)</td><td>5 (1)</td><td>11 (1.2)</td><td>3 (0.6)</td></tr>
<tr><td>36-46 yrs, n (%)</td><td>66 (12.9</td><td>119 (12.9)</td><td>87 (16.0)</td></tr>
<tr><td>Maternal education</td><td></td><td></td><td></td></tr>
<tr><td>17+ years, n (%)</td><td>154 (30.2)</td><td>247 (26.8)</td><td>165 (30.4)</td></tr>
</table>
</td>
<td></td>
<td>Method(s) of measurement for risk factor(s)

Gestational age obtained from medical records held by the preventive child healthcare centres, confirmed by early ultrasound measurements in >95% of cases.

Outcome(s) ascertainment/measures

The Dutch version of the age 48 month form of the Ages and Stages questionnaire was used to assess development. The ASQ covers five domains: communication, fine motor function, gross motor function,personal-social functioning and problem solving. The total score was calculated by adding all the domain scores and dividing by five. The individual domain scores, and the total score were</td>
<td>32-35+6 weeks: OR 1.5 (0.89-2.52) 32-33+6 weeks: OR 1.5 (0.81-2.92) 34-35+6 weeks: OR 1.5 (0.84-2.52) Further analysis from Kerstjens 2012 shows that, when gestational age was analysed as a continuous variable, the odds of developmental delay were 1.13 (1.08-1.18) for each decreasing week of gestational age. This implies that the risk of developmental delay rises from 1.93 for children born at 35 weeks, to 7.14 for children born at 25 weeks.
<u>Risk of fine motor impairment (ASQ Fine motor score <2SD below the mean)</u>
Term: Reference <32 weeks: OR 3.6 (2.02-6.38) 32-35+6 weeks: OR 2.0 (1.17-3.54) 32-33+6 weeks: OR 2.5 (1.32-4.87) 34-35+6 weeks: OR 1.8 (1.01-3.22) Further analysis from Kerstjens 2012 shows that, when gestational age was analysed as a continuous variable, the odds of impaired fine motor development were 1.13 (1.08-1.18) for each decreasing week of gestational age.</td>
<td>Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias
Overall: moderate quality</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
preschool age in infants born moderately preterm. **Study dates** Study recruitment during 2005-2007. **Source of funding** The research foundation of Beatrix Children's Hospital, the Cornelia Foundation for the Handicapped Child, the A. Bulk Preventive Child Health Care Research Fund, the Dutch Brain Foundation, and an unrestricted research grant from FrieslandCampina, Friso Infant Nutrition, Abbott and Pfizer Europe.	<table><tr><td>13-16 years, n (%)</td><td>204 (41.0)</td><td>307 (34.6)</td><td>201 (38.0)</td></tr><tr><td><12 years, n (%)</td><td>142 (27.8)</td><td>314 (35.4)</td><td>151 (28.5)</td></tr></table> **Inclusion criteria** From a community based preventive child healthcare (PCHC) cohort of 45455 children born in 2002 and 2003 all children with a gestational age of <36 weeks were sampled. For every second preterm child, then next term born child from the cohort was selected as a comparison. The cohort was expanded with very preterm children (<32 weeks) born in 2003 who had been admitted to any of five tertiary neonatal intensive care units. Children were recruited during a routine visit to their local PCHC centre at the age of 43 to 49 months Completed ASQ within the timeframe 43-49 months. **Exclusion criteria** Major congenital malformations, syndromes and congenital infections.		dichotomized at 2SD below the mean score of the Dutch reference group as normal/abnormal. **Statistical methods** Multivariate logistic regression analyses were used to examine the relationship between gestational age group and abnormal ASQ scores. Adjustment was conducted for maternal age, mother's birth country, parental education, single-parent family, sex, multiple birth and SGA. **Length of follow-up** 4 years	<u>Risk of gross motor impairment (ASQ Gross motor score <2SD below the mean)</u> Term: Reference <32 weeks: OR 3.5 (2.04-5.94) 32-35+6 weeks: OR 1.3 (0.75-2.21) 32-33+6 weeks: OR 1.0 (0.46-2.06) 34-35+6 weeks: OR 1.4 (0.81-2.50) Further analysis from Kerstjens 2012 shows that, when gestational age was analysed as a continuous variable, the odds of impaired fine motor development were 1.13 (1.08-1.19) for each decreasing week of gestational age. All OR are adjusted for sex, SGA, parental education, mother's birth country and multiple birth.	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Ref Id

327136

Full citation

Kerstjens,J.M., de Winter,A.F., Sollie,K.M., Bocca-Tjeertes,I.F., Potijk,M.R., Reijneveld,S.A., Bos,A.F., Maternal and pregnancy-related factors associated with developmental delay in moderately preterm-born children, Obstetrics and Gynecology, 121, 727-733, 2013

Country/ies where the study was carried out

The Netherlands

Study type

Population based</td>
<td>Sample size

n=834 moderately preterm children (32-35 weeks)

Characteristics

<table>
<tr><td></td><td>%</td></tr>
<tr><td>Preexisting maternal somatic illness</td><td>5.5</td></tr>
<tr><td>Preexisting maternal mentai llness</td><td>1.6</td></tr>
<tr><td>Prepregnancy obesity (BMl >30)</td><td>11.5</td></tr>
<tr><td>Maternal age younger than 20y</td><td>0.6</td></tr>
<tr><td>HELLP or (pre-)eclampsia</td><td>19.4</td></tr>
<tr><td>Preexisting or gestational diabetes</td><td>2.4</td></tr>
<tr><td>Antepartum haemorrhage</td><td>11.6</td></tr>
</table>
</td>
<td>Risk factors

SGA, sex, antenatal steroids, maternal pre-existing mental illness (depression, psychosis, other), maternal age <20y, multiple pregnancy</td>
<td>Setting

Part of the Longitudinal Preterm Outcome Project (Lollipop), a community-based cohort of 45,455 children born in 2002-2003 in the Netherlands.

Method(s) of measurement for risk factor(s)

Data on pre-existing maternal and pregnancy-related factors were collected from the hospital records of both mothers and children, preventive child health care centre records, the Dutch Central Perinatal Registration, and a parental questionnaire at age 4 years. The data from different sources were crosschecked whenever possible.

Outcome(s) ascertainment/measures</td>
<td>Outcome(s) at age

<u>At 43-49 months of age</u>
Abnormal ASQ total problems score
Antenatal steroids: OR not significant in the univariate regression
Maternal pre-existing mental illness (depression, psychosis, other): OR 1.32 (0.14-12.3)
Maternal age <20 years: not significant in the univariate regression
Multiple pregnancy: OR 1.86 (1.02-3.42)

SGA: OR 2.75 (1.25-6.08)

Male sex: OR 4.20 (2.09-8.46)

The final multivariable model adjusted for maternal somatic and mental illness, maternal obesity, in vitro fertilisation, SGA, sex, multiple pregnancy, breech presentation, induced labour, CS, assisted delivery, SES and parity.</td>
<td>Limitations

Limitations
Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: low risk of bias
834 of the 960 children included in the study completed the follow-up.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounding: mod erate risk of bias
Not completely clear if regression model 2 actually adjusted for all the variables in model 1 plus the additional sociodemographic variables or just the sociodemographic variables.
Analysis and reporting: low risk of bias
Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
prospective cohort study **Aim of the study** To estimate the association between pre-existing maternal and pregnancy-related factors and developmental delay in early childhood in moderately preterm-born children. **Study dates** 2002-2003, follow-up at 43-49 months uncorrected age (2005-2007). **Source of funding** Lollipop study is supported by grans from the Research Foundation of the Beatrix	Antenatal steroids (full course) 19.1 In vitro fertilisation 7.2 SGA 9.1 Male sex 56.5 Multiple pregnancy 29.1 GA 32-33 weeks 32.3 Clinical infection in mother, child, or both perinatally or proven placental infection 15.0 Prolonged preterm rupture of membranes 23.3 Breech presentation 14.9 CS 36.0		Parents completed the Dutch version of the 48 months ASQ. The scores on each domain add up to an ASQ total problems score. A score of >2SDs below the mean for the Dutch reference group was considered to indicate developmental delay. **Statistical methods** Logistic multivariable regression including all variables with p-values <0.20 in univariate analyses. Thus, the final model adjusted for maternal somatic and mental illness, maternal obesity, in vitro fertilisation, SGA, sex, multiple pregnancy, breech presentation, induced labour, CS, assisted delivery, SES and parity. **Length of follow-up** 43-49 months chronological age		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Children's Hospital, the Cornelia Foundation for the Handicapped Child, the A. Bulk Preventive Child Health Care Research Fund, the Dutch Brain Foundation, and unrestricted investigator-initiated research grants from Friso Infant Nutrition, Friesland-Campina, Abbott, and Pzifer Europe.	Assisted delivery 9.0 Apgar score at 5 min <7 3.9 Multiparity 35.3 Non-Dutch ethnicity 5.4 Maternal education <12 years 29.8 Paternal education <12 years 35.9 Low family income (<=850€/mo) 6.8 More than one unit of alcohol/week 4.8 Any smoking 21.9 **Inclusion criteria**				

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
	Children with a gestational age between 32+0 and 35+6 weeks born in 2002 and 2003. **Exclusion criteria** Children with major congenital malformations, congenital infections and syndromes.				
Ref Id 412875 **Full citation** Larroque, B., Ancel, P. Y., Marchand-Martin, L., Cambonie, G., Fresson, J., Pierrat, V., Roze, J. C., Marpeau, L., Thiriez, G., Alberge, C., Breart, G., Kaminski, M., Marret, S., Epipage Study, group, Special care and school difficulties in 8-year-old very preterm children: the Epipage cohort study, PLoS ONE [Electronic Resource], 6, e21361, 2011	**Sample size** Original sample: n = 2901 very preterm children (22-32 weeks) n = 667 term controls (39-40 weeks) Included in follow up: n = 1439 preterm children n = 327 term controls. **Characteristics** Not reported in this article. **Inclusion criteria** Preterm: born between 22 and 32 weeks in one of nine regions of France during the study dates. Term: one of every four children born at 39-40 weeks during one week of 1997. **Exclusion criteria** Death before follow up or declined follow up. Severe motor deficiencies (cerebral palsy, unable to walk without aid), or severe sensory deficiencies (visual acuity <3/10 for both eyes or severe auditory deficiency).	**Risk factors** Gestational age.	**Setting** Population based cohort study in France. **Method(s) of measurement for risk factor(s)** Gestational age refers to the number of completed weeks of amenorrhoea. **Outcome(s) ascertainment/measures** A postal questionnaire investigating school outcome, special care and behavioural problems was sent to parents in the first trimester of 2006, when the children would have been in the third grade of primary school.	**Outcome(s) at age** <u>At the age of 8 years</u> **Risk of being in an institution or special school/class** Term (n = 3/277): Reference Preterm (n = 52/1292): OR 3.0 (0.9-9.8) **Risk of being in a mainstream class with the year repeated** Term (n = 11/277): Reference Preterm (n = 223/1292): OR 4.4 (2.3-8.2) **Risk of needing special care and/or support at school** Term (n = 103/276): Reference Preterm (n = 742/1289): OR 2.0 (1.5-2.6) All OR are adjusted for maternal age, parity, mother born in France/abroad, maternal level of education, SES and sex.	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias **Attrition:** moderate risk of bias More than 20% of participants were lost to follow up. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Country/ies where the study was carried out France. **Study type** Population based prospective cohort. **Aim of the study** To investigate school difficulties, special care and behavioural problems in 8 year old very preterm children. **Study dates** 1997. **Source of funding** INSERM, the Directorate General for			Schooling outcomes included whether the child attended an institution or special school, whether they were in a special class within mainstream schooling and whether they had repeated a school year. Support at school was defined according to whether the child was enrolled at a particular institution, special school or class, or a mainstream class with support at school (extra teacher in or outside of the class room, extra teaching hours at school, intervention of a psychologists or other person at school). **Statistical methods** Type of schooling, special care/support at school were compared between preterm children and the reference group using logistic regression models to control for potentially confounding variables. Factors known to be		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Health at the Ministry for Social Affairs, Merck-Sharp and Dohme-Chibret, Medical Research Foundation, and "Hospital Program for Clinical Research 2001 n°AOM01117" of the French Department of Health. The eight year follow up was supported by the "Hospital Program for Clinical REsearch 2004/054/HP" at the French Department of Health and the Wyeth Foundation for Children and Adolescents.			related to school outcome or behaviour were included in the models: maternal age at childbirth, parity, maternal level of education, maternal birth place, SES and sex. **Length of follow-up** 8 years. Assumed to be chronological age, but not stated by the authors.		
Ref Id 412882 **Full citation** Laughon, M., O'Shea, M. T., Allred, E. N.,	**Sample size** Sample recruited - N = 1506 Sample eligible for assessment - N = 1190 Sample analysed after exclusions - N = 915 **Characteristics**	**Risk factors** BDP- bronco pulmonary dysplasia (chronic lung disease [CLD] at 36 weeks) Antenatal steroids	**Setting** The Extremely low gestational age newborn (ELGAN) study identified characteristics and exposures that increase the risk of	**Outcome(s) at age** **Outcome assessed at 2 years:** Psychomotor Developmental Index [PDI] <70	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. Participants: low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Bose, C., Kuban, K., Van Marter, L. J., Ehrenkranz, R. A., Leviton, A., Chronic lung disease and developmental delay at 2 years of age in children born before 28 weeks' gestation, Pediatrics, 124, 637-648, 2009 **Country/ies where the study was carried out** USA (14 Centres in 5 States) **Study type** Prospective cohort study **Aim of the study** To explore to what extent chronic lung disease (CLD) and its antecedents influence the risk of developmental	No details given **Inclusion criteria** Children included in the extremely low gestational age newborns (ELGANs) study sample Children who were assessed at 24 months of age with the BSID-II or the Vineland Adaptive Behavior Scales (VABS) Children who were able to walk independently (Gross Motor Function Classification System [GMFCS] < 1) **Exclusion criteria** Children who were not able to walk independently (GMFCS ≥1) at the 24-month follow-up assessment		structural and functional neurologic disorders in ELGANs newborns. During the years 2002-2004, women delivering before 28 weeks' gestation at 1 of 14 participating institutions were asked to enrol in the study. **Method(s) of measurement for risk factor(s)** The diagnosis of CLD was made at 36 weeks' postmenstrual age (PMA). If an infant was receiving supplemental oxygen, the infant was classified as having CLD. Antenatal steroids, defined as a complete course of antenatal steroids **Outcome(s) ascertainment/measures** Psychomotor Developmental Index (PDI) at 24-months adjusted age at 24-	CLD without mechanical ventilation [MV]: 1.1 (0.6–2.0) CLD with MV: 1.9 (0.97–3.9) Complete course of ANS: 2.4 (1.5-3.8)	Attrition: low risk of bias Prognostic factor measurement: low risk of bias Outcome measurement: low risk of bias Confounding: moderate risk of bias (No sufficient information about the measurement and the definition of all measured confounders) Analysis and Reporting: low risk of bias Overall: moderate quality

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
delays at 24-months adjusted age, as assessed with the Bayley Scales of Infant Development-2nd Edition (BSID-II), among infants without gross motor function impairments. **Study dates** 2002-2004: Period of data collection (patient enrolment) 24 month: follow-up Assessment **Source of funding** Grant Support 5U01NS040069-04/NS/NINDS NIH HHS/United States U01 NS040069-04/NS/NINDS NIH HHS/United States Financial Disclosure: The			months using the Bayley Scales of Infant Development-2nd Edition (BSID-II). **Statistical methods** Data analysis focused to test the hypothesis that antecedents of CLD, and not CLD itself, contribute to suboptimal performance on the BSID-II. We assessed associations between antecedents (antenatal and postnatal variables and CLD) and low MDIs and PDIs. Relationships between risk factors and low MDIs and PDIs were assessed with Pearson's $\chi 2$, and variables associated with both CLD and a low BSID-II at a P value of ≤.30 were considered for logistic regression analyses. Risk factors in logistic regression models were ordered in a temporal pattern.		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td>authors have indicated they have no financial relationships relevant to this article to disclose</td><td></td><td></td><td>Length of follow-up

2 years</td><td></td><td></td></tr>
<tr><td>Ref Id

412942

Full citation

MacKay, D. F., Smith, G. C., Dobbie, R., Pell, J. P., Gestational age at delivery and special educational need: retrospective cohort study of 407,503 schoolchildren, PLoS Medicine / Public Library of Science, 7, e1000289, 2010

Country/ies where the study was carried out

UK

Study type</td><td>Sample size

Overall sample:
N = 407503

Relevant sample included for this analysis
N = 152757
n = 130798 full term (40 weeks)
n = 18035 preterm (33-36 weeks)
n = 3449 preterm (28-32 weeks)
n = 475 preterm (24-27 weeks)

Characteristics
<table><tr><td>Characteristic</td><td>No special educational need
n =387682</td><td>Special educational need
n = 19821</td></tr><tr><td>Gestation at delivery

n (%)</td><td></td><td></td></tr><tr><td>24-27 weeks</td><td>335 (0.09)</td><td>140 (0.7)</td></tr><tr><td>28-32 weeks</td><td>3006 (0.8)</td><td>443 (2.2)</td></tr><tr><td>33-36</td><td>16754 (4.3)</td><td>1281 (6.5)</td></tr></table></td><td>Risk factors

Gestational age</td><td>Setting

National survey.

Method(s) of measurement for risk factor(s)

Data on gestational age were collected from the Scottish Morbidity Record (SMR2), which collects data on all women discharged from maternity hospitals, including maternal and infant characteristics, clinical management and obstetric complications. Gestational age is defined as completed weeks of gestation on the basis of the estimated date of delivery in the woman's clinical record.</td><td>Outcome(s) at age

<u>At 5-18 years of age</u>
Risk of SEN according to gestational age
40 weeks : Reference
33-36 weeks : OR 1.53 (1.43-1.63)
28-32 weeks : OR 2.66 (2.38-2.97)
24-27 weeks : OR 6.92 (5.58-8.58)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: moderate risk of bias
>20% of potentially eligible participants were excluded due to missing data.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: low risk of bias
Overall quality: moderate</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Retrospective study using national registry data.

Aim of the study

To investigate the risk of special educational needs across the whole spectrum of gestational age at delivery.

Study dates

Data from the 2005 school census.

Source of funding

NHS Health Scotland.</td>
<td>
<table>
<tr><td>37</td><td>18617 (4.8)</td><td>1217 (6.1)</td></tr>
<tr><td>38</td><td>48810 (12.6)</td><td>2759 (13.9)</td></tr>
<tr><td>39</td><td>77217 (19.9)</td><td>3848 (19.4)</td></tr>
<tr><td>40</td><td>125067 (32.3)</td><td>5731 (28.9)</td></tr>
<tr><td>41</td><td>81607 (21.1)</td><td>3530 (17.8)</td></tr>
<tr><td>42</td><td>15936 (4.1)</td><td>850 (4.3)</td></tr>
<tr><td>43</td><td>333 (0.08)</td><td>22 (0.11)</td></tr>
<tr><td>Male gender n (%)</td><td>193034 (49.8)</td><td>13887 (70.1)</td></tr>
<tr><td>Birth weight centile
n (%)</td><td></td><td></td></tr>
<tr><td>1-3</td><td>11447 (3.0)</td><td>1084 (5.5)</td></tr>
<tr><td>4-10</td><td>27037 (7.0)</td><td>1865 (9.4)</td></tr>
<tr><td>Median maternal age y (IQR)</td><td>27 (23-31)</td><td>28 (24-31)</td></tr>
</table>
Inclusion criteria

Primary and secondary school children included in the 2005 school census in Scotland.
</td>
<td></td>
<td>Outcome(s) ascertainment/measures

Special educational need (SEN) was identified through the school census data. This includes information on children with learning disabilities (including dyslexia, dyspraxia, autism, Asperger's syndrome and attention deficit hyperactivity disorder) as well as children with physical disabilities that impact on learning (including some children with hearing, motor and visual inmpairment).

Statistical methods

The associations between obstetric factors and the risk of SEN were analysed using univariate and multivariate logistic regression and presented as odds ratios. The covariates included in the model were infant sex, maternal age and</td>
<td></td>
<td></td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td>Exclusion criteria

Unable to link school census data to obstetrics record (n = 93340). Age <4 years or >19 years at the time of the census. Births were the maternal height was measured as <100cm or >200cm, birth weight recorded as <400g or >5000g, or the gestation was recorded as <24 weeks or >43 weeks. Multiple births.</td><td></td><td>height, marital status, parity, birth weight centile, induction of labour, mode of delivery, year of delivery, previous spontaneous and therapeutic abortions and 5 minute Apgar score.

Length of follow-up

5 to 18 years.
Adjusted ages are not described, therefore chronological age is assumed.</td><td></td><td></td></tr>
<tr><td>Ref Id

411047

Full citation

MacKay, D. F., Smith, G. C. S., Dobbie, R., Cooper, S. A., Pell, J. P., Obstetric factors and different causes of special educational need: Retrospective cohort study of 407 503 schoolchildren,</td><td>Sample size

Overall sample:
N = 407503

Relevant sample included for this analysis
N = 237894
n = 215935 full term (40-41 weeks)
n = 18035 preterm (33-36 weeks)
n = 3449 preterm (28-32 weeks)
n = 475 preterm (24-27 weeks)

Characteristics
<table><tr><td>Type of SEN</td><td>Preterm 24-27 wks n = 475</td><td>Preterm 28-32 wks</td><td>Preterm 33-36 wks</td><td>Term 40-41 wks</td></tr></table></td><td>Risk factors

Gestational age.</td><td>Setting

National survey.

Method(s) of measurement for risk factor(s)

Data on gestational age were collected from the Scottish Morbidity Record (SMR2), which collects data on all women discharged from maternity hospitals, including maternal and infant characteristics, clinical management and</td><td>Outcome(s) at age

At 5-18 years of age
Risk of sensory SEN according to gestational age
40-41 weeks : Reference
33-36 weeks : OR 1.73 (1.18-2.52)
28-32 weeks : OR 4.44 (2.56-7.71)
24-27 weeks : OR 23.64 (12.03-46.45)

Risk of physical or motor SEN according to gestational age
40-41 weeks : Reference
33-36 weeks : OR 2.99 (2.27-3.95)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: moderate risk of bias >20% of potentially eligible participants were excluded due to missing data.
Prognostic factor measurement: low risk of bias</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>BJOG: An International Journal of Obstetrics and Gynaecology, 120, 297-307, 2013

Country/ies where the study was carried out

UK

Study type

Retrospective study using national registry data.

Aim of the study

To determine whether relationships with gestational age and birth weight centile vary between specific causes of special educational need.</td>
<td>
<table>
<tr><td></td><td></td><td>n = 3449</td><td>n = 18035</td><td>n = 130798</td></tr>
<tr><td>No SEN</td><td>335</td><td>3006</td><td>16754</td><td>206674</td></tr>
<tr><td>Sensory</td><td>14</td><td>17</td><td>40</td><td>243</td></tr>
<tr><td>Physical or motor</td><td>29</td><td>98</td><td>84</td><td>302</td></tr>
<tr><td>Language</td><td>3</td><td>13</td><td>42</td><td>438</td></tr>
<tr><td>Social, emotional or behavioural</td><td>6</td><td>32</td><td>169</td><td>1358</td></tr>
<tr><td>Specific learning difficulties</td><td>10</td><td>49</td><td>235</td><td>2233</td></tr>
<tr><td>Intellectual</td><td>67</td><td>165</td><td>521</td><td>3021</td></tr>
<tr><td>Autism Spectrum Disorder (ASD)</td><td>5</td><td>34</td><td>75</td><td>882</td></tr>
<tr><td>Unspecified</td><td>6</td><td>35</td><td>115</td><td>784</td></tr>
</table>
</td>
<td></td>
<td>obstetric complications. Gestational age is defined as completed weeks of gestation on the basis of the estimated date of delivery in the woman's clinical record.

Outcome(s) ascertainment/measures

Data on SEN were identified through the 2005 school census. SEN includes: language impairments; specific learning difficulties (such as dyslexia or dyscalculia); intellectual disabilities; other developmental disorders that impair learning (including autism, Asperger's syndrome and attention deficit hyperactivity disorder); social, emotional or behavioural problems that impair learning; and physical disabilities that impact on learning (including some sensory</td>
<td>28-32 weeks : OR 16.01 (11.78-21.75)
24-27 weeks : OR 29.69 (17.49-50.40)

Risk of language SEN according to gestational age
40-41 weeks : Reference
33-36 weeks : OR 1.03 (0.72-1.48)
28-32 weeks : OR 1.88 (0.99-3.55)
24-27 weeks : OR 1.64 (0.22-12.02)

Risk of social, emotional or behavioural SEN according to gestational age
40-41 weeks : Reference
33-36 weeks : OR 1.34 (1.12-1.61)
28-32 weeks : OR 1.24 (0.80-1.92)
24-27 weeks : OR 1.90 (0.60-6.07)

Risk of specific learning difficulties SEN according to gestational age
40-41 weeks : Reference
33-36 weeks : OR 1.26 (1.09-1.46)
28-32 weeks : OR 1.54 (1.13-2.12)
24-27 weeks : OR 3.56 (1.80-7.05)</td>
<td>Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: low risk of bias
Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study dates School census data from 2005. **Source of funding** No external funding source.	**Inclusion criteria** Primary and secondary school children included in the 2005 school census in Scotland. **Exclusion criteria** Unable to link school census data to obstetrics record (n = 93340). Age <4 years or >19 years at the time of the census. Births where the maternal height was measured as <100cm or >200cm, birth weight recorded as <400g or >5000g, or the gestation was recorded as <24 weeks or >43 weeks. Multiple births.		impairments, or physical or motor disabilities). In the database, the groups are mutually exclusive. Children with more than one cause of SEN are classified on the basis of their main impairment. For the purposes of this study the intellectual disability groups (moderate, severe and profound intellectual disabilties, with or without additional complex needs) were aggregated into one group. **Statistical methods** The associations between obstetric factors and the risk of each cause of SEN were analysed using a single univariate, then multivariable polytomous logistic regression model using no SEN as the common referent category. The covariates included in the multivariable analysis were infant sex, maternal age and	**Risk of intellectual SEN according to gestational age** 40-41 weeks : Reference 33-36 weeks : OR 1.93 (1.74-2.14) 28-32 weeks : OR 3.11 (2.56-3.77) 24-27 weeks : OR 11.67 (8.46-16.10) **Risk of ASD SEN according to gestational age** 40-41 weeks : Reference 33-36 weeks : OR 0.93 (0.72-1.21) 28-32 weeks : OR 1.95 (1.29-2.96) 24-27 weeks : OR 2.56 (0.80-8.20) **Risk of unspecified SEN according to gestational age** 40-41 weeks : Reference 33-36 weeks : OR 1.56 (1.26-1.94) 28-32 weeks : OR 2.42 (1.60-3.65) 24-27 weeks : OR 5.01 (2.16-11.64)	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			height, marital status, parity, induction of labour, mode of delivery, year of delivery, previous spontaneous and therapeutic abortions, and the 5 minute Apgar score. **Length of follow-up** 5-18 years. Adjusted ages are not described, therefore chronological age is assumed.		
Ref Id 86775 **Full citation** Martin,C.R., Dammann,O., Allred,E.N., Patel,S., O'Shea,T.M., Kuban,K.C., Leviton,A., Neurodevelopment of extremely preterm infants who had necrotizing enterocolitis with or without late bacteremia, Journal of	**Sample size** Overall sample: N = 1155 preterm infants born at 23 to 27+6 weeks gestation. **Characteristics** Not reported. **Inclusion criteria** Preterm infants born at 23 to 27+6 weeks gestation during the study dates, at one of 14 participating institutions. **Exclusion criteria**	**Risk factors** NEC and late bacteraemia	**Setting** Multicentre prospective study. **Method(s) of measurement for risk factor(s)** NEC was defined by modified Bell's staging criteria. Stage I included infants who had suspected NEC and, despite the absence of pneumatosis on abdominal radiographs, were treated with antibiotics and suspension of	**Outcome(s) at age** <u>At 2 years</u> **Risk of Bayley PDI <70** No NEC or late bacteraemia: Reference Medical NEC: OR 0.8 (0.3-1.9) Surgical NEC: OR 2.7 (1.2-6.4) Late bacteraemia: OR 1.3 (0.9-1.9) All models are adjusted for public insurance, maternal or fetal initiator for delivery, gestational age (23-24, 25-26, 27 weeks), birth weight Z score 1 and thrombosis of the fetal stem vessels of the	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Pediatrics, 157, 751-756, 2010 **Country/ies where the study was carried out** USA **Study type** Multicentre prospective cohort study. **Aim of the study** To evaluate the developmental correlates of NEC with and without accompanying bacteraemia. **Study dates** 2002-2004. **Source of funding** The National Institutes of Neurological	NEC or late bacteraemia status unknown (n = 143). Isolated perforation (n = 49). No head ultrasound scanning (n = 3). Did not survive to 2 years (n = 156).		enteral feeding for at least one week. Stage IIa represented infants who had pneumatosis bu did not experience clinical deterioration or laboratory derangements. Stage IIb included infants with pneumatosis and metabolic (acidosis) or haematologic changes (thrombocytopenia). Stage IIIa included infants with stage IIb criteria p;lus respiratory or cardiovascular deterioration (e,g, increased need for respiratory support, new vasopressor requirements, oliguria, disseminated intravascular coagulation). Finally, stage IIIb identified those infants who required surgical intervention, an exploratory laparotomy or placement of a Penrose drain. For analysis, NEC was classified as medical (stages IIa, IIb and IIIa) and surgical(IIIb). Early bacteraemia was defined as a positive	placenta and include a random effect cluster term for birth hospital.	**Analysis and Reporting:** low risk of bias. Overall quality: high

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Diseases and Stroke and a program project grant from the National Institute of Child Health and Human Development.			blood culture results in the first postnatal week. Late bacteraemia was defined as a positive blood culture results in weeks 2,3 or 4. All positive culture results were included in the analysis, regardless of species. **Outcome(s) ascertainment/measures** At 24 months corrected age, a comprehensive, standardised neurological examination was conducted by an examiner unaware of the infants neonatal course. The Bayley Scales of Infant Development-Second Edition was administered by examiners unaware of the infant's medical history. A score of < 70 (more than 2SD below the mean) was taken to represent significant psychomotor delay (Psychomotor		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			Development Index, PDI). **Statistical methods** Odds ratios were calculated to compare the risk of outcomes for infants with and without medical NEC, surgical NEC and late bacteraemia. **Length of follow-up** 2 years corrected age.		
Ref Id 411165 **Full citation** Michael O'Shea, T., Kuban, K. C., Allred, E. N., Paneth, N., Pagano, M., Dammann, O., Bostic, L., Brooklier, K., Butler, S., Goldstein, D. J., Hounshell, G., Keller, C., McQuiston, S., Miller, A., Pasternak, S.,	**Sample size** Enrolled n=1505 Without qualifying cranial ultrasound n=51 (lost to follow-up) Deaths before follow-up n=257 (lost to follow-up) No assessment of mental and/or motor development n=181 (lost to follow-up) Children followed-up at 24 mo n=1017 **Characteristics** No information. **Inclusion criteria** Women delivering before 28 weeks of gestation. Maternal consent before or shortly after delivery.	**Risk factors** Intraventricular haemorrhage (IVH) (defined as blood within the ventricles, excluding haemorrhage localized to the subependymal region) Periventricular leukomalacia (PVL), early and cystic. Periventricular hemorrhagic infarction (PVHI)	**Setting** 14 hospitals in 11 cities in 5 states in the US. **Method(s) of measurement for risk factor(s)** Cranial ultrasound scans were performed routinely by technicians at the hospitals, up to 3 sets of scans per child were performed. First scan between 1st and 4th days, second between 5th and 14th	**Outcome(s) at age** **Outcomes assessed at 24 months' corrected age:** PDI <70 (delayed psychomotor development) No IVH: reference IVH: RR 2.10 (95% CI 1.50-2.90) No early PVL: reference Early PVL:RR 2.10 (95% CI 1.40-3.20) No cystic PVL: reference Cystic PVL:RR 4.30 (95% CI 2.30-8.10) No PIVH: reference PIVH: RR 4.00 (95% CI 2.20-7.00)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Study participation:** moder ate risk of bias Sample characteristics are not described. **Study attrition:** moderate risk of bias The ones who survived but were lost to follow-up due to missing the assessment of the outcome differed in

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Plesha-Troyke, S., Price, J., Romano, E., Solomon, K. M., Jacobson, A., Westra, S., Leviton, A., Neonatal cranial ultrasound lesions and developmental delays at 2 years of age among extremely low gestational age children, Pediatrics, 122, e662-e669, 2008 **Country/ies where the study was carried out** USA **Study type** Prospective cohort study **Aim of the study** To describe the relationships between cranial ultrasound abnormalities	**Exclusion criteria** >=28 weeks of gestation No consent		days, and third between 15th day and 40th week. Before patient enrollment, sonologists created a manual and data collection form. Each set of scan was first read by one sonologist at the institution of the infant's birth, then digital images were sent to another sonologist at another study institution for a second reading. When two readers differed in their recognition of cranial abnormalities, the images were sent to a third reader (tie-breaker) who did not know what the initial readers reported. **Outcome(s) ascertainment/measures** Developmental assessment at around 24 months' corrected age included the Bayley Sacaes of Infant Development - Second Edition (BSID-II), a neurological examination, and	Models adjusted for gestational age (23-24, 25-26, or 27 weeks), receipt of a complete course of antenatal corticosteroid, ceasarean delivery, and Medicaid insurance at 2 years' corrected age.	their characteristics: younger mothers, less well educated mothers, mothers less likely to be married, mothers less likely to support themselves via their own employment, mother more likely to have Medicaid or other public insurance. No difference in the ones included in the analysis and lost to follow-up in relation gender, gestational age, plurality, birth weight, birth weight z-score, Score for Neonatal Acute Physiology II, or the frequency of ultrasound lesions. **Prognostic factor measurement:** low risk of bias Two (or three, if the first two had differing findings) trained, experienced sonologists independently assessed the ultrasound images. **Outcome measurement:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
and delayed development at 2 years of age in extremely premature infants. **Study dates** Enrollment between 2002-2004. Follow-up at around 24 months' corrected age. **Source of funding** National Institute of Neurological Disorders and Stroke grant NS 40069.			when the child was classified as untestable on the BSID-II (when child's impairment(s) precluded administration of the BSID-II or when >2 items were omitted or judged to be unscoreable), an interview of the parent was conducted using the Vineland Adaptive Behavior Scales (VABS). Certified examiners administered and scored the BSID-II. Psychomotor Development Indec (PDI) of <70 considered delayed psychomotor development. Children who could not be tested using BSID-II were assessed using VABS: <70 on VABS motor skills domain score were combined with the children with <70 on PDI. **Statistical methods**		Validated tools used to assess outcome. However, not all children were assessed in the same way: when children were untestable on BSID-II, another tool VABS was used. **Study confounding:** low risk of bias The analyses adjusted for several important confounders, however, the potential confounding factors are not described in detail. **Statistical analysis and reporting:** moderate risk of bias The statistical analysis (calculating RRs with 95% CI) seems appropriate, however, details of the methods are not reported. Also, it is not clear whether in the main results table (Table 6), they included only children assessed through BSID-II or also children assessed through VABS. Also,

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>For each ultrasound lesion, the proportion of children who had an MDI or PDI of <70 were computed.

Risk ratios (RR) with 95% CI were calculated for the relationship between ultrasound lesions and developmental delay.

Length of follow-up

24 months' corrected age.</td><td></td><td>the factors that the model adjusted for (in Table 6) differ from the factors that were listed in the text (e.g. ceasarial delivery not mentioned in text but was adjusted for according to Table 6, whereas SES mentioned in text but not on Table 6).

Overall quality: moderate</td></tr>
<tr><td>Ref Id

413008

Full citation

Migraine, A., Nicklaus, S., Parnet, P., Lange, C., Monnery-Patris, S., Des Robert, C., Darmaun, D., Flamant, C., Amarger, V., Roze, J. C., Effect of preterm birth and birth weight on eating behavior at 2 y of age, American Journal of</td><td>Sample size

n = 234 children born <33 weeks GA
(n=54 children 32 weeks GA; n=78 children 30-31 weeks GA; n=54 children 28-29 weeks GA; n=48 children <28 weeks GA)
n = 245 term controls (>37 weeks)

Characteristics

<table><tr><td>Characteristic</td><td>Preterm infants n = 234</td><td>Term infants n=245</td></tr><tr><td>Maternal age</td><td></td><td></td></tr><tr><td>< 25 years</td><td>13 (6.4%)</td><td>16 (6.7%)</td></tr></table></td><td>Risk factors

Gestational age.</td><td>Setting

Observational multicentre study in France.

Method(s) of measurement for risk factor(s)

Not reported.

Outcome(s) ascertainment/measures

The Children's Eating Difficulties Questionnaire was completed by parents</td><td>Outcome(s) at age

<u>At 24 months of age</u>
Low drive to eat
>37 weeks: Reference
32 weeks: OR 1.33 (0.59-2.98)
30-31 weeks: OR 1.17 (0.54-2.55)
28-29 weeks: OR 2.01 (0.89-4.56)
<28 weeks: OR 1.63 (0.69-3.81)

Low food variety
>37 weeks: Reference
32 weeks: OR 0.87 (0.39-1.94)
30-31 weeks: OR 1.10 (0.55-2.21)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
Although original numbers are not reported, only 70% of those infants enrolled at birth agreed to participate in this follow up study. No information is provided regarding differences between</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Clinical Nutrition, 97, 1270-7, 2013

Country/ies where the study was carried out

France

Study type

Prospective multicentre study.

Aim of the study

To determine whether eating behaviours and eating habits at 2 years of corrected age differ between children born preterm and full term and, if so, to identify maternal and neonatal factors that predispose individuals to later alterations of eating behaviours at 2 years of age.</td>
<td>
<table>
<tr><td>25-35 years</td><td>157 (77.7%)</td><td>193 (80.7%)</td></tr>
<tr><td>>35 years</td><td>32 (15.8%)</td><td>30 (12.6%)</td></tr>
<tr><td>Mother's educational level</td><td></td><td></td></tr>
<tr><td>less than high school</td><td>102 (43.6%)</td><td>45 (18.4%)</td></tr>
<tr><td>high school or greater</td><td>132 (56.4%)</td><td>200 (81.6%)</td></tr>
<tr><td>Male gender</td><td>122 (52.1%)</td><td>131 (53.5%)</td></tr>
<tr><td>Birth weight z score</td><td></td><td></td></tr>
<tr><td>less than -1SD</td><td>44 (18.8%)</td><td>35(14.3%)</td></tr>
<tr><td>-1 to -0.51SD</td><td>36 (15.4%)</td><td>70 (17.1%)</td></tr>
<tr><td>-0.50 to 0SD</td><td>40 (17.1%)</td><td>68 (27.8%)</td></tr>
<tr><td>>0SD</td><td>114 (48.7%)</td><td>72 (29.4%)</td></tr>
</table>
Inclusion criteria

Two separate cohorts were used for this analysis. Preterm infants were enrolled by the POLYNUCA study and were born at <33 weeks gestational age, hospitalised in the neonatal intensive care unit of Nantes University Hospital.
</td>
<td></td>
<td>when the child reached 2 years of age. It assesses four dimensions: neophobia, pickiness, low appetite and low food enjoyment. Each item was rated on a 5 point scale, where higher scores indicate more eating difficulties for that dimension. 2 broader categories were then generated representing a narrow food repertoire (comprising neophobia and pickiness) and low drive to eat (comprising low appetite and low food enjoyment). Scores for these categories were split into quintiles, and those in the highest quintile were regarded as having eating disorders.

Statistical methods

Logistic regression analysis was used to calculate crude and adjusted ORs of risk factors for a low drive to eat or narrow food repertoire. Each model included maternal age,</td>
<td>28-29 weeks: OR 0.97 (0.42-2.24)
<28 weeks: OR 0.75 (0.31-1.82)

Numbers in subgroups not reported.</td>
<td>those who did and did not participate.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and Reporting: low risk of bias.
Overall quality: moderate</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Study dates

September 2005 to July 2009.

Source of funding

The Regional Health Agency of Pays de la Loire, the Regional Council of Burgundy and the French National Research Agency.</td>
<td>Term infants were enrolled by the OPALINE cohort and were born at >37 weeks gestation.

Exclusion criteria

Not reported.</td>
<td></td>
<td>maternal BMI, maternal education level, breastfeeding, gestational age, birth-weight z score and gender.

Length of follow-up

24 months of age (corrected age for preterm participants).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ref Id

307507

Full citation

Odd,D., Evans,D., Emond,A., Preterm Birth, Age at School Entry and Educational Performance, PLoS ONE, 8, -, 2013</td>
<td>Sample size

n = 722 preterm infants (<37 weeks)
n = 11268 term infants (37-42 weeks)
Note that these numbers represent the full cohort, but data on Low KS1 score was obtained for 11169 children and data on special educational needs was obtained for 6174 children. Numbers in different GA group not reported by outcome.

Characteristics

<table>
<tr><td>Characteristics</td><td>Preterm <37 weeks n = 722</td><td>Term 37-42 weeks n = 11268</td></tr>
</table>
</td>
<td>Risk factors

Gestational age.</td>
<td>Setting

Regional prospective cohort.

Method(s) of measurement for risk factor(s)

Data on gestational age were extracted from information routinely recorded in the clinical notes. If the gestation was recorded as <37 weeks (based on last menstrual period,</td>
<td>Outcome(s) at age

<u>At 8 years of age</u>
Risk of special education needs when matched by actual date of birth (i.e. chronological age)
Term: Reference
Preterm < 37 weeks: OR 1.57 (1.19-2.07)
Preterm 32-36 weeks: OR 1.53 (1.15-2.03)
Preterm < 32 weeks: OR 1.98 (0.82-4.82)

Risk of special education needs when matched by expected date of delivery (i.e. corrected age)</td>
<td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounding: low risk of bias</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Country/ies where the study was carried out

UK

Study type

Regional prospective cohort study.

Aim of the study

To investigate if a lack of age correction and year of education might explain some of the school failure seen in ex-preterm infants.

Study dates

Born from April 1991 to December 1992.

Source of funding

None reported.</td>
<td>
<table>
<tr><td>Maternal age, yrs, mean (SD)</td><td>27.5 (4.9)</td><td>27.9 (4.9)</td></tr>
<tr><td>Maternal socioeconomic group</td><td></td><td></td></tr>
<tr><td>Professional</td><td>22 (4.0%)</td><td>2758 (29.5%)</td></tr>
<tr><td>Managerial</td><td>163 (29.6%)</td><td>3692 (39.6%)</td></tr>
<tr><td>Skilled non-manual</td><td>223 (40.6%)</td><td>1124 (12.0%)</td></tr>
<tr><td>Skilled manual</td><td>76 (12.8%)</td><td>1038 (11.1%)</td></tr>
<tr><td>Semi-skilled</td><td>52 (9.5%)</td><td>238 (2.6%)</td></tr>
<tr><td>Non-white ethnicity</td><td>60 (8.5%)</td><td>562 (5.1%)</td></tr>
<tr><td>Multiple birth</td><td>136 (18.8%)</td><td>179 (1.6%)</td></tr>
<tr><td>Male gender</td><td>411 (56.9%)</td><td>5757 (51.1%)</td></tr>
<tr><td>Birth weight, g, mean (SD)</td><td>2356 (624)</td><td>3455 (485)</td></tr>
</table>
Inclusion criteria

Not reported.
</td>
<td></td>
<td>ultrasound or paediatric assessment) then gestational age was confirmed by a single paediatrician after reviewing the clinical records.

Outcome(s) ascertainment/measures

At the age of 8 years, the child's teacher was sent a questionnaire, which asked the teacher to identify "has this child ever been recognised as having special educational needs?" (SEN).

Statistical methods

The association between gestational age group and SEN was initially assessed by randomly matching each preterm infant with up to 10 infants with a date of birth within the same calendar month. Conditional regression models were derived</td>
<td>Term: Reference
Preterm < 37 weeks: OR 1.59(1.20-2.11)
Preterm 32-36 weeks: OR 1.51 (1.13-2.03)
Preterm < 32 weeks: OR 2.36 (0.98-5.67)

Risk of special education needs when matched by expected date of delivery and year of schooling
Term: Reference
Preterm < 37 weeks: OR 1.13 (0.81-1.56)
Preterm 32-36 weeks: OR 1.11 (0.80-1.55)
Preterm < 32 weeks: OR 1.30 (0.41-4.16)

Adjusted for ethnicity, housing, crowding and maternal education, socioeconomic group, car ownership, age, gender, parity, weight, length and head circumference at birth, mode of delivery, maternal hypertension and pyrexia. Numbers in subgroups are not reported.</td>
<td>Analysis and reporting: low risk of bias

Overall quality: high</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
	Exclusion criteria No primary outcome measure available (reported key stage 1 score or special educational needs, n = 1997).		using outcome and exposure measures (as binary variables) and grouping on the month of birth. Adjustment for potential confounders was performed by adding variables to the models in blocks of common variables (e.g. social factors). The analysis was repeated two further times. In the second analysis, preterm infants were matched to 10 infants by their expected date of delivery, rather than their actual date of birth. In the third analysis, infants were matched by expected date of delivery and by year of school attendance. **Length of follow-up** 8 years of age.		
Ref Id 316738 **Full citation** Odd,D.E., Lingam,R.,	**Sample size** Overall: n = 741 moderate/late preterm infants n = 13102 term infants With data on abnormal heel-to-toe score: n=331 preterm	**Risk factors** Gestational age	**Setting** Regional prospective cohort study.	**Outcome(s) at age** <u>At age 7-8 years</u> **Abnormal heel-to-toe score** Term: Reference	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS:

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Emond,A., Whitelaw,A., Movement outcomes of infants born moderate and late preterm, Acta Paediatrica, 102, 876-882, 2013

Country/ies where the study was carried out

UK.

Study type

Regional prospective cohort study (Avon Longitudinal Study of Parents and Children, ALSPAC).

Aim of the study

To investigate whether infants born at late or moderate preterm gestations have increased risk of</td>
<td>n=6501 full-term
With data on abnormal bean-bag score:
n=332 preterm
n=6512 full-term
With data on abnormal peg-score and abnormal coordination summary score:
n=328 preterm
n=6414 full-term

Characteristics
<table>
<tr><th>Characteristics</th><th>Term infants n = 13102</th><th>Preterm infants n = 741</th></tr>
<tr><td>Maternal age</td><td>28 yrs 0 months</td><td>27 yrs 8 months</td></tr>
<tr><td>Maternal socioeconomic group</td><td></td><td></td></tr>
<tr><td>1 - Professional</td><td>6.1%</td><td>4.6%</td></tr>
<tr><td>2 - Managerial</td><td>31.0%</td><td>30.2%</td></tr>
<tr><td>3N - Skilled nonmanual</td><td>38.3%</td><td>40.3%</td></tr>
<tr><td>3M - Skilled manual</td><td>11.7%</td><td>13.5%</td></tr>
<tr><td>4 - Semiskilled</td><td>10.6%</td><td>9.0%</td></tr>
<tr><td>5 - Unskilled</td><td>2.4%</td><td>2.4%</td></tr>
</table>
</td>
<td></td>
<td>Method(s) of measurement for risk factor(s)

Data on gestational age were extracted from the clinical notes (based on the last menstrual period, ultrasound or paediatric assessment). If the recorded gestational age was <37 weeks, this was confirmed by a single paediatrician after reviewing the clinical records. If the LMP date was considered unreliable then the earliest ultrasound measurement was used.

Outcome(s) ascertainment/measures

Motor skills were assessed using the ALSPAC coordination tests. This consisted of three of the eight subtests of the Movement Assessment Battery for Children (MABC). These subtests were</td>
<td>Moderate/late preterm: OR 1.27 (0.98-1.63)

Abnormal bean-bag score
Term: Reference
Moderate/late preterm: OR 1.17 (0.91-1.50)

Abnormal peg score
Term: Reference
Moderate/late preterm: OR 1.40 (1.08-1.81)

Abnormal coordination summary score
Term: Reference
Moderate/late preterm: OR 1.39 (1.12-1.72)

All OR are adjusted for ethnicity, housing, crowding and maternal education, socioeconomic group, car ownership, maternal age, gender, parity, weight, length and head circumference at birth, mode of delivery, maternal hypertension, pyrexia and need for resuscitation at birth.</td>
<td>Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: high</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>cerebral palsy or poor motor skills at school age than those born at term.

Study dates

Children born between April 1991 and December 1992.

Source of funding

The UK Medical Research Council, the Wellcome Trust and the University of Bristol.</td>
<td>
<table>
<tr><td>Non-white ethnicity</td><td>5.4%</td><td>8.9%</td></tr>
<tr><td>Multiple birth</td><td>1.5%</td><td>18.5%</td></tr>
<tr><td>Male gender</td><td>51.4%</td><td>57.0%</td></tr>
<tr><td>Birthweight (g)</td><td>3456 (485)</td><td>2495(489)</td></tr>
</table>
Inclusion criteria

Children born in the Bristol area, England, during the study dates, between 32 and 42 weeks of gestation.

Exclusion criteria

Not reported.
</td>
<td></td>
<td>selected to test the three realms of coordination: manual dexterity (placing pegs task), ball skills (throwing bean bag into box) and balance (heel-toe walking). A summary score of all three tests was derived (range 0-15). Lower scores indicate better performance. The top 5th centile of this summed score was used to define severe motor coordination difficulties.

Statistical methods

Regression models were used to investigate the association between gestational group and the outcome measures. Adjustment for potential confounders was performed by adding the variables to the models in blocks of common variables (e.g. socio-economic factors). Variables included were: maternal age, socio-</td>
<td></td>
<td></td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			economic group, education, car ownership, housing, crowding index, ethnicity, gender, parity, birthweight, length and head circumference, mode of delivery, multiple birth, maternal hypertension and pyrexia and need for resuscitation at birth. **Length of follow-up** 7-8 years. Chronological age is assumed, but not stated by the authors.		
Ref Id 411396 **Full citation** Peacock, P. J., Henderson, J., Odd, D., Emond, A., Early school attainment in late-preterm infants, Archives of Disease in Childhood, 97, 118-20, 2012	**Sample size** n=10279 children in total (n=9683 childen born at 37-41 wks and n=596 born at 32-36 wks) **Characteristics** 15% of the late-preterm born children were born at 32-33 weeks gestation and 85% at 34-36 weeks. The majority of term and late pre-term infants were from a white ethnic background. Late-preterm infants had lower birth weights and lengths and were more likely to be male, were more likely to be from a multiple pregnancy, and born by CS. Mothers of late-preterm infants tended to have less qualifications and lower incomes.	**Risk factors** Gestational age (32-36 weeks)	**Setting** Avon Longitudinal Study of Parents and Children (ALSPAC) in Avon, UK in 1991-1992. **Method(s) of measurement for risk factor(s)** Gestational age was retrieved from computerised medical records. Children were considered late preterm if they were	**Outcome(s) at age** <u>At 5-7 years</u> **Success in KS1 overall assessment** (at least level 2 in reading, writing and mathematics) Term (37-41 wks): Reference Preterm (32-36 wks): OR 0.74 (0.59-0.92) **Success in KS1 reading assessment** (at least level 2) Term (37-41 wks): Reference	**Limitations** Limitations Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias **Attrition:** moderate risk of bias Not clearly stated how many participants were lost to follow-up.

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Country/ies where the study was carried out UK **Study type** Population-based longitudinal study **Aim of the study** To investigate whether infants born late-preterm have poorer school attainment compared to those born at term. **Study dates** Children born in 1991-1992, follow-up at 5-7 years. **Source of funding**	**Inclusion criteria** Pregnant women due to deliver in 1991 and 1992 were recruited to participate. No other criteria reported. **Exclusion criteria** Infants born at <32 and >=42 weeks gestation.		born at 32-36+6 weeks of gestation. Term (comparison) was defined as 37-41+6 weeks of gestation. **Outcome(s) ascertainment/measures** Data on Key Stage 1 assessments were obtained from local education authorities. The results for the three assessment domains (reading, writing and mathematics) were dichotomized, with success defined as achieving at least level 2, the expected level of attainment. Overall KS1 score defined as having at least level 2 in all three domains. **Statistical methods** Logistic regression model, adjusting for possible confounders which included gender, age at testing, birth weight z score for gestational age and	Preterm (32-36 wks): OR 0.74 (0.58-0.94) **Success in KS1 writing assessment** (at least level 2) Term (37-41 wks): Reference Preterm (32-36 wks): OR 0.74 (0.59-0.94) **Success om KS1 mathematics assessment** (at least level 2) Term (37-41 wks): Reference Preterm (32-36 wks): OR 0.62 (0.48-0.80)	**Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
The UK Medical Research Council, the Wellcome Trust, and the University of Bristol provided core support for ALSPAC study, no separate funding was obtained for this analysis. The lead author is supported by a National Institute for Health Research (NIHR) Academic Clinical Fellowship.			sex, pregnancy size, maternal age, parity, mode of delivery, maternal smoking, maternal education and scoail class, ethcnicity, housing tenure and crowding, car use, family income and single parenthood. Multiple imputation by chained equations was used to impute missing covariate data. **Length of follow-up** School years 1 and 2 (5-7 years).		
Ref Id 413180 **Full citation** Potijk, M. R., de Winter, A. F., Bos, A. F., Kerstjens, J. M., Reijneveld, S. A., Behavioural and emotional problems in moderately preterm children with low	**Sample size** Original sample: n = 995 moderately preterm children (32-35+6 weeks' gestation) n = 577 term controls (38-41+6 weeks' gestation) Sample included in follow up: n = 915 moderately preterm children n = 543 term children **Characteristics** Characteristics for moderately preterm children compared to term children are not described, only for the whole cohort according to socioeconomic status.	**Risk factors** Gestational age Socioeconomic status	**Setting** Multicentre cohort study in the Netherlands. **Method(s) of measurement for risk factor(s)** Information on gestational age was obtained through parental questionnaires, then cross-checked with	**Outcome(s) at age** <u>At age 4 years</u> **Total behavioural problems** Gestational age: OR 1.24 (1.00-1.56) SES: OR 1.42 (1.14-1.77) **Externalizing problems** Gestational age: OR 1.31 (1.05-1.63) SES: OR 1.21 (0.99-1.50) **Internalizing problems** Gestational age: OR 1.41 (1.13-1.73)	**Limitations** Based on the NICE manual 2014 checklist for prognnostic studies and QUIPS **Participants:** low risk of bias **Attrition:** low risk of bias. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** mod erate risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
socioeconomic status: a population-based study, European Child & Adolescent Psychiatry, 24, 787-95, 2015 **Country/ies where the study was carried out** The Netherlands. **Study type** Multicentre prospective cohort study (LOLLIPOP). **Aim of the study** To determine the independent and joint effects of moderately preterm birth and low socioeconomic status on behavioural and emotional problems in a	**Inclusion criteria** Preterm children: born at 32+0 to 35+6 weeks' gestation. Term controls: born at 38-41+6 weeks' gestation. **Exclusion criteria** Congenital malformations or syndromes, gestational age out of range or could not be verified, or if families had moved between sampling and inclusion.		information from the medical records. In more than 95% of cases gestational age was calculated by using the last date of menstruation, and confirmed by early ultrasound measurements. When inconsistencies were found these were checked against information in discharge letters. Socioeconomic status was determined on the basis of education, income and occupation. Data on the highest completed educational level of both parents were collected by a general questionnaire when the children were aged 4 years. The categories were defined as: primary school or less, low-level technical and vocational training (<12 years of education), high school or medium-level technical and vocational training (12-16 years education), and university or high-level technical and	SES: OR 1.26 (1.03-1.54) OR represent the risk per standard deviation decrease in socioeconomic status and gestational age. Note that all study participants are included in these analyses (term and preterm).	Who assessed the child using CBCL is not reported. **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
large population based sample. **Study dates** Children born in 2002 and 2003. **Source of funding** The research foundation of Beatrix Children's Hospital, the Cornelia Foundation for the Handicapped Child, the A. Bulk-Child Health Care Research Fund, the Dutch Brain Foundation and unrestricted research grants from FrieslandCampina, Friso Infant Nutrition, Abbott and Pfizer Europe.			vocation training (>16 years of education). Parents were also asked to indicate their net monthly income in euros: ≤850; 851-1150; 1151-1750; 1751-3050; 3051-3500; and >3500. Data on occupational level were collected retrospectively from the medical birth registers kept by the preventive child health care centres. Occupational levels of both parents were classified according to the International Standard Classification of Occupations. A composite socioeconomic status (SES) score was then computed on the basis of five indicators: educational level of father, education level of mother, family income, occupational level of father and occupational level of mother. Each of the indicators was ranked and standardised and the mean SES was calculated using all indicators available for		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			that child. Subsequently a composite and standardised SES measure was computed - a continuous variable with a mean of 0 and a standard deviation of 1. **Outcome(s) ascertainment/measures** Behavioural and emotional problems were measured at the age of 4 years using the Dutch version of the Child Behaviour Checklist for 1.5-5 years. By summing the ratings for sets of items a score for internalising problems, externalising problems and a total problems score was generated. The authors state that "American cut-offs" were used to identify clinically relevant scores. **Statistical methods**		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			Logistic regression models were used to examine independent and joint effects of moderately preterm birth and socioeconomic status on behavioural and emotional problems. In these analyses standardised measures were used for gestational age and SES, meaning that both of these risk factors had a mean of 0 and a SD of 1. Results were adjusted for the effect of confounders identified in the literature and differences in background characteristics. To prevent over adjustment for factors that highly correlated with SES, family composition and mother's ethnicity were not included in the adjustment. **Length of follow-up** 4 years. Chronological age is assumed, but not stated by the authors.		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Ref Id 411485 **Full citation** Quigley, M. A., Poulsen, G., Boyle, E., Wolke, D., Field, D., Alfirevic, Z., Kurinczuk, J. J., Early term and late preterm birth are associated with poorer school performance at age 5 years: a cohort study, Archives of Disease in Childhood Fetal & Neonatal Edition, 97, F167-73, 2012 **Country/ies where the study was carried out** UK **Study type** Population-based cohort study	**Sample size** Total; N=7650 <32 wks; very preterm; N=84 32–33 wks; moderately preterm; N=92 34–36 wks; late preterm; N=471 37–38 wks; early term; N=1596 39–41 wks; full term; N=5407 **Characteristics** Among the 7650 children in our study, 8.4% were born preterm and 1.1% were born very preterm. The median gestational age in the very preterm group was 29 weeks, and 63% of this group had a gestational age of 29–31 weeks. Increasing prematurity was associated with multiple births, caesarean section, lower birth weight, longer length of stay in hospital and shorter duration of breastfeeding. Some of the maternal characteristics also varied according to gestational age, but there was no strong dose-response effect across gestational age. **Inclusion criteria** Infants born in England and Wales between September 2000 and August 2001, and in Scotland and Northern Ireland between November 2000 and January 2002, who were alive and living in the UK at age 9 months and at follow-up were attending school in England (because foundation stage is not used in other UK countries). **Exclusion criteria**	**Risk factors** Gestational age	**Setting** Nationally representative longitudinal study in the UK. **Method(s) of measurement for risk factor(s)** Gestational age in weeks was calculated using the mother's report of the expected due date, which corresponded well with data in routine hospital records. **Outcome(s) ascertainment/measures** Foundation stage profile (FSP) records the child's achievement as measured by their teacher at the end of their first school year. Teachers are trained in how to conduct the assessments, which are based on observations during the whole year. The FSP captures the	**Outcome(s) at age** **Assessed at 5 years** Results presented as RR (95% CI) Not good level of overall achievement 23-31 wks:1.19 (1.00-1.42) 32-33 wks: 1.19 (0.98-1.45) 34-36 wks: 1.12 (1.04, 1.22) 39-41 wks: reference Not working securely in all three scales of personal, social and emotional development 23-31 wks: 1.53 (1.16, 2.00) 32-33 wks: 1.25 (0.92, 1.72) 34-36 wks: 1.14 (0.99, 1.32) 39-41 wks: reference Not working securely in all four scales of communication, language and literacy 23-31 wks: 1.17 (0.99, 1.39) 32-33 wks: 1.21 (0.98, 1.48) 34-36 wks: 1.11 (1.02, 1.22) 39-41 wks: reference Not working securely in all three scales of mathematical development 23-31 wks: 1.56 (1.21, 2.01) 32-33 wks: 1.35 (1.02, 1.8) 34-36 wks: 1.16 (1, 1.34) 39-41 wks: reference	**Limitations** Limitations Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias **Attrition:** moderate risk of bias Out of the 9319 children who were attending in England at follow-up, 7644 (82%) were included in the analysis. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Aim of the study To compare school performance at age 5 years in children born at full term (39–41 weeks gestation) with those born at early term (37–38 weeks gestation), late preterm (34–36 weeks gestation), moderately preterm (32–33 weeks gestation) and very preterm (<32 weeks gestation). **Study dates** Children born in 2000–2001 and followed-up in 2006. **Source of funding** This study was funded by a	Children who died within the first 9–10 months after birth. Children attending school during follow-up outside of England.		'Early Learning Goals' as a set of 13 assessment scales across six areas of learning: 1) personal, social and emotional development, 2) communication, language and literacy, 3) mathematical development, 4) Knowledge and understanding of the world, 5) Physical development, and 6) Creative development. Also, the following categories were assessed: working securely in all the six above-mentioned areas of learning; good level of overall achievement (see details pf scoring below). For each scale, the teacher gives the child 1–9 points according to the child's progress in achieving the learning goals. Children achieving a scale score of <6 points are classified as not working securely within the Early Learning Goals and	<u>Not working securely in the 'knowledge and understanding of the world' scale</u> 23-31 wks: 1.32 (0.9, 1.93) 32-33 wks: 1.47 (0.93, 2.33) 34-36 wks: 1.30 (1.08, 1.56) 39-41 wks: reference <u>Not working securely in the 'physical development' scale</u> 23-31 wks: 1.82 (1.12, 2.96) 32-33 wks: 1.64 (0.99, 2.73) 34-36 wks: 1.27 (0.92, 1.74) 39-41 wks: reference <u>Not working securely in the 'creative development'</u> 23-31 wks: 1.77 (1.3, 2.41) 32-33 wks: 1.46 (0.94, 2.27) 34-36 wks: 1.22 (1.02, 1.46) 39-41 wks: reference RR adjusted for child's sex, ethnicity, whether firstborn, multiple birth, breastfeeding duration, month of birth (age within the school year) and mother's age, marital status, education, social class and whether languages other than English were spoken at home.	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
grant from the Bupa Foundation (Grant number TBF-08-007).			are classified as not having achieved a good level of development. Children who achieve a score of <78 points across the 13 assessment scales (ie, an average of 6 points per scale) and a score of <6 in each of the three 'personal, social and emotional development' scales and the four 'communication, language and literacy' scales are classified as not reaching a good level of overall achievement. **Statistical methods** Modified Poisson regression was used to estimate RR for these outcomes across gestational age groups compared with term children, with adjustment for multiplicity and the following factors which were significantly ($p<0.05$) associated with the primary outcome: child's sex, ethnicity, whether the		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>child was the firstborn for the mother, breastfeeding duration, month of birth (ie, age within the school year) and the mother's age at delivery, marital status, education, social class and languages spoken in the child's home.

Length of follow-up

5 years</td><td></td><td></td></tr>
<tr><td>Ref Id

397631

Full citation

Rautava, L., Andersson, S., Gissler, M., Hallman, M., Hakkinen, U., Korvenranta, E., Korvenranta, H., Leipala, J., Tammela, O., Lehtonen, L., Development and behaviour of 5-year-old very low birthweight infants, European Child & Adolescent</td><td>Sample size

Original sample size:
n = 924 preterm/very low birth weight infants
n = 381 term controls

Included in follow up
n = 588 preterm/very low birth weight infants

n = 176 term controls

Characteristics
<table><tr><td>Characteristics</td><td>Very low birth weight infants n = 588</td><td>Term controls n = 176</td></tr><tr><td>Gestational age</td><td>29 4/7 (2 3/7)</td><td>39 6/7 (1 0/7)</td></tr></table></td><td>Gestational age.</td><td>National population based cohort.

Method(s) of measurement for risk factor(s)

Background information was obtained from the Finnish National Medical Birth Register, the Hospital Discharge Register, the Register of Congenital Malformations and the Cause of Death Register.</td><td><u>At age 5 years</u>
Motor skills
Term: Reference
Preterm: RR 2.22 (1.83-2.69)
Gross motor skills
Term: Reference
Preterm: RR 2.89 (2.16-3.86)
Fine motor skills
Term: Reference
Preterm: RR 1.91 (1.59-2.30)

Hyperactive/impulsive
Term: Reference
Preterm: RR 1.28 (1.07-1.53)
Attention
Term: Reference</td><td>Limitations

Based on the NICE manual 2014 checklist for prognnostic studies and QUIPS
Participants: low risk of bias
Attrition: moderate risk of bias.
More than 20% of participants did not complete the follow up questionnaire, and no information is reported regarding difference between these individual and those included in followup.</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Psychiatry, 19, 669-77, 2010 **Country/ies where the study was carried out** Finland. **Study type** Population based prospective cohort study. **Aim of the study** To evaluate the development and behavioural outcome of very low birth weight infants compared with full term controls. **Study dates** 2001-2002. **Source of funding**	<table><tr><td>weeks and days mean (SD)</td><td></td><td></td></tr><tr><td>Birthweight grams, mean (SD)</td><td>1249 (382)</td><td>3570 (436)</td></tr><tr><td>Female sex (%)</td><td>43</td><td>41</td></tr><tr><td>Maternal age at delivery mean (SD)</td><td>30.7 (5.8)</td><td>30.0 (5.6)</td></tr><tr><td>Maternal years of education mean (SD)</td><td>14.6 (2.8)</td><td>15.5 (2.8)</td></tr></table> **Inclusion criteria** Very low birth weight infants: all surviving infants born at <32 weeks or with a birthweight of ≤1500g in Finland during the study period. Term controls: born at 38-42 weeks', next in order after every third VLBW infant. **Exclusion criteria** Incomplete personal identification number in the National Medical Birth Register, major disparity between gestational age and birth weight or missing data in either of these variables suggestive of an error in the database, birth at a level 1 hospital or at a hospital with less than 3 deliveries of VLBW infants		**Outcome(s) ascertainment/measures** Behavioural outcomes were assessed using the Five to Fifteen Questionnaire (FTF), which was completed by the parents. Questions on development and behaviour were rated by the parents as 0="does not describe", 1="describes to some extent" and 2="describes well" the individual child. **Statistical methods** The FTF developmental and behavioural scores of VLBW infants were compared to term controls. Comparisons were adjusted for sex, the mother's and the father's years of education and current employment status, and family structure. Analyses were performed using generalised linear models. Results are given as rate ratios	Preterm: RR 1.81 (1.47-2.23) **Hypoactive** Term: Reference Preterm: RR 2.63 (1.88-3.66) **Planning/Organising** Term: Reference Preterm: RR 1.34 (1.07-1.68) **Memory** Term: Reference Preterm: RR 1.26 (1.01-1.58) **Language** Term: Reference Preterm: RR 1.64 (1.33-2.01) **Comprehension** Term: Reference Preterm: RR 1.61 (1.25-2.07) **Expressive language skills** Term: Reference Preterm: RR 1.65 (1.31-2.07) **Communication** Term: Reference Preterm: RR 1.76 (1.30-2.38) **Emotional/behavioural problems** Term: Reference Preterm: RR 1.49 (1.20-1.84) **Internalising**	**Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
The Finnish Academy (Research Program on Health Services Research), the South-West Finnish Fund of Neonatal Research, the University Hospital EVO Funds and the Turku University Hospital Foundation.	within the study period, lethal congenital malformations. Term controls were also excluded if they required hospital admission during the first 7 days of life.		with 95% confidence intervals. **Length of follow-up** 5 years of chronological age.	Term: Reference Preterm: RR 1.56 (1.19-2.05) **Externalising** Term: Reference Preterm: RR 1.39 (1.09-1.78) **Obsessive compulsive** Term: Reference Preterm: RR 1.79 (1.22-2.62) The rate ratio (RR) estimates describe how many times higher scores preterm children have when compared to term controls. All RR are adjusted for sex, family structure and teh motehr's and father's years of education and employment status.	
Ref Id 413212 **Full citation** Raynes-Greenow, C. H., Hadfield, R. M., Cistulli, P. A., Bowen, J., Allen, H., Roberts, C. L., Sleep apnea in early childhood associated with	**Sample size** Sample recruited N = 429305 Sample analysed after exclusions N = 403106 (n=3115 children born at <32 weeks; n=22039 children born at 32-36 weeks; n=377952 children born at >36 weeks) **Characteristics** N=398961: Babies born at ≥ 20 weeks gestation or weighing ≥ 400 g: N=4145: (1.0%) children, with a first diagnosis of sleep apnea after 12 months of age N=394816: children with no sleep apnea diagnosis	**Risk factors** Different gestational ages Sex Small for gestational age Maternal age (yrs) Substance abuse (Any smoking during pregnancy)	**Setting** This was a longitudinal, population-based study including all live births in New South Wales (NSW) during the period 2000 to 2004. NSW is the most populous state of Australia with a current population of > 7.0 million and > 90,000 births per annum.	**Outcome(s) at age** **Different gestational ages - Adjusted hazard ratios (aHR) for sleep apnea diagnosis (95% CI)** < 32 weeks = 2.74 (2.16, 3.49)32-36 weeks = 1.19 (1.03, 1.34)> 36 weeks = 1.0 Referent **Sex - Adjusted hazard ratios (aHR) for sleep apnea diagnosis (95% CI)** Male = 1.48 (1.39, 1.58)Female = Referent	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** moderate risk of bias (No sufficient details given)

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
preterm birth but not small for gestational age: a population-based record linkage study, Sleep, 35, 1475-80, 2012 **Country/ies where the study was carried out** Australia **Study type** Prospective cohort study (using record linked population health data) **Aim of the study** To investigate the relationship between gestational age and weight for gestational age and sleep apnea diagnosis in a cohort of children aged up to 6 years old.	The mean length of follow-up was 5.04 years (SD 1.3) for children with sleep apnea compared to 5.02 years (SD 1.5) for children with no sleep apnea. The mean age at first diagnosis for sleep apnea was 44.2 months (SD 13.9). In only those children with ≥ 5 years follow up (n = 2,121), the mean age at first diagnosis was 47.4 months (SD 14.8). **Inclusion criteria** See Exclusion criteria and population Characteristics **Exclusion criteria** Children were excluded if: Outliers (identified for each gestational age using the Tukey method): Those babies with birthweight lying 3 interquartile ranges greater than the 75th percentile or less than the 25th percentile were removed from the analysis. Died in the perinatal period were excluded, as were any infants who died < 12 months. Had any a major identified congenital anomaly. Anomalies seen among children with a subsequent sleep apnea diagnosis included congenital malformation syndromes affecting facial appearance and associated with short stature, cleft palate, congenital laryngomalacia, Down syndrome, tracheomalacia, Hirschsprung disease, and achondroplasia.		**Method(s) of measurement for risk factor(s)** Data from births from 2000–2004 were obtained via the NSW Midwives Data Collection, a legislated population-based surveillance system that includes information on all babies born at ≥ 20 weeks gestation or weighing ≥ 400 g. No further details reported. **Outcome(s) ascertainment/measures** The primary outcome was sleep apnea diagnosis in childhood, first diagnosed between 1 and 6 years of age. Children with sleep apnea were identified from those hospital records with the ICD-10 code G47.3: sleep apnea, central or obstructive.	**Small for gestational age - Adjusted hazard ratios (aHR) for sleep apnea diagnosis (95% CI)** (< 10th) SGA = 0.95 (0.86, 1.06)Appropriate for their gestational age (AGA) = Referent(> 90th) LGA = 1.05 (0.95, 1.16) **Maternal age (yrs) - Adjusted hazard ratios (aHR) for sleep apnea diagnosis (95% CI)** < 25 = 0.65 (0.58, 0.72)25-29 = Referent≥ 30 = 1.09 (1.01, 1.17) **Substance abuse (Any smoking during pregnancy) - Adjusted hazard ratios (aHR) for sleep apnea diagnosis (95% CI)** No = Referent Yes = 0.76 (0.70, 0.84)	**Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and Reporting:** low risk of bias **Overall:** moderate quality

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study dates 2000 to 2004.: Period of data collection (patient enrolment) 2007 (2.5 to 6 years): follow-up assessment **Source of funding** This was not an industry supported study. The authors have indicated no financial conflicts of interest			**Statistical methods** Contingency tables and Fisher exact test were used to analyse the crude relationship between childhood sleep apnea risk factors. Cox proportional hazard model was used to investigate the association between childhood sleep apnea and risk factors, and adjust for the differential follow-up. Crude odds ratios (ORs) with 95% confidence intervals were estimated for the explanatory variables. Adjusted HRs were calculated by entering the proposed explanatory variables into the hazard model and retaining only variables for which the hazard ratio changed by ~10% or more when the factor was fitted were retained in the models **Length of follow-up**		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>2007 (2.5 to 6 years)</td><td></td><td></td></tr>
<tr><td>Ref Id

413217

Full citation

Reijneveld, S. A., de Kleine, M. J., van Baar, A. L., Kollee, L. A., Verhaak, C. M., Verhulst, F. C., Verloove-Vanhorick, S. P., Behavioural and emotional problems in very preterm and very low birthweight infants at age 5 years, Archives of Disease in Childhood Fetal & Neonatal Edition, 91, F423-8, 2006

Country/ies where the study was carried out

The Netherlands.

Study type</td><td>Sample size

Original sample size:
n = 431 children born at <32 weeks of gestation or with a birth weight of <1500g

Sample included in follow up:
n = 402 preterm children
n = 6007 reference population

Two representative general population samples were used to provide term reference data for the study. 6007 children of the same age (5 years) as the preterm group were included.

Characteristics

<table><tr><td>Characteristic</td><td>Preterm cohort n/N (%)</td><td>General population n/N (%)</td></tr><tr><td>Male sex</td><td>219/402 (54.5)</td><td>3021/6007 (50.3)</td></tr><tr><td>5 years of age</td><td>394/402 (98.0)</td><td>5998/6007 (98.0)</td></tr><tr><td>Maternal education*</td><td></td><td></td></tr><tr><td>Low</td><td>19/300 (6.3)</td><td>205/5883 (3.5)</td></tr><tr><td>Medium</td><td>205/300 (68.3)</td><td>4109/5883 (69.8)</td></tr><tr><td>High</td><td>76/300 (25.3)</td><td>1569/5883 (26.7)</td></tr></table></td><td>Risk factors

Gestational age.</td><td>Setting

Prospective cohort in The Netherlands with population based control.

Method(s) of measurement for risk factor(s)

Not reported.

Outcome(s) ascertainment/measures

The Child Behaviour Checklist was used to assess behavioural and emotional problems. This contains 120 problem items used to compute a total problems score. 9 individual syndrome scales were also generated (withdrawn, somatic complaints, anxious/depressed, social problems, thought problems, attention problems, delinquent behaviour, aggressive behaviour and sex problems). These syndrome</td><td>Outcome(s) at age

<u>At 5 years of age</u>
Total problems
General population: Reference
Preterm/very low birthweight: OR 1.60 (1.18-2.17)

Internalising problems
General population: Reference
Preterm/very low birthweight: OR 1.06 (0.71-1.57)

Externalising problems
General population: Reference
Preterm/very low birthweight: OR 1.48 (1.08-2.03)

Withdrawn
General population: Reference
Preterm/very low birthweight: OR 1.72 (0.82-3.60)

Somatic complaints
General population: Reference
Preterm/very low birthweight: OR 1.90 (1.10-3.28)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Population: moderate risk of bias. Preterm/VLBW cohort was compared to a general population reference sample, which may itself have included preterm/VLBW participants. However, this would tend to result in an underestimation of the risks for the preterm/VLBW population.
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: low risk of bias</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Prospective population based cohort study. **Aim of the study** To assess academic outcomes, behavioural and emotional problems for preterm children. **Study dates** Cohort of preterm children was identified between 1992 and 1995. **Source of funding** The Dutch Health Organisations Praeventifonds and The Netherlands Organisation for Health Research and Development (ZonMW).	*Defined as • Low: primary school or less, maximum 8 years • Moderate: high school, or technical and vocational training for 12-16 years • High: technical and vocational training for >16 years (including university) **Inclusion criteria** Not reported. **Exclusion criteria** Not reported.		scales were combined to generate two broad groups of syndromes designated internalising (withdrawn, somatic complaints and anxious/depressed) and externalising (delinquent and aggressive behaviour). Children were allocated to a normal or a clinical range of the scoring distribution based on the Dutch normative sample. Cut-offs were set at the 97th centile for the syndrome scales and at the 90th centile for the total problems, internalising and externalising scales. **Statistical methods** Logistic regression was used to compare the dichotomised syndrome scores for the preterm/very low birthweight group as compared to the population reference group. Analyses were repeated with adjustment for differences in	**Anxious/depressed** General population: Reference Preterm/very low birthweight: OR 1.15 (0.41-3.20) **Social problems** General population: Reference Preterm/very low birthweight: OR 2.62 (1.38-5.16) **Thought problems** General population: Reference Preterm/very low birthweight: OR 2.72 (1.49-4.94) **Attention problems** General population: Reference Preterm/very low birthweight: OR 3.45 (2.02-5.89) **Delinquent behaviour** General population: Reference Preterm/very low birthweight: OR 2.65 (1.39-5.08) **Aggressive behaviour** General population: Reference	Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			background characteristics between the samples. The authors state that "repetition of the anlyses with adjustment for background characteristics did not affect differences in any important way". **Length of follow-up** 5 years. Assumed to be chronological age, but not stated by the authors.	Preterm/very low birthweight: OR 1.58 (0.90-2.77) **Sex problems** General population: Reference Preterm/very low birthweight: OR 1.48 (0.68-3.24)	
Ref Id 378586 **Full citation** Samara, M., Johnson, S., Lamberts, K., Marlow, N., Wolke, D., Eating problems at age 6 years in a whole population sample of extremely preterm children, Developmental Medicine & Child	**Sample size** Overall sample: N = 308 preterm children alive at 30 months Included in follow up: n = 223 preterm children n = 148 full-term controls **Characteristics** Baseline characteristics not reported for term versus preterm children (only for dropouts versus included). **Inclusion criteria**	**Risk factors** Gestational age.	**Setting** National population based study. **Method(s) of measurement for risk factor(s)** Prospective collection of data on neonatal course and perinatal variables for study participants.	**Outcome(s) at age** <u>At age 6 years</u> **Total eating difficulties** Controls: Reference Preterm: OR 2.5 (1.3-4.8) **Oral motor problems** Controls: Reference Preterm: OR 2.7 (1.3-5.7) **Refusal-faddy problems** Controls: Reference Preterm: OR 1.6 (0.8-3.3) **Behavioural problems** Controls: Reference Preterm: OR 1.6 (0.7-3.6)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** low risk of bias **Outcome measurement:** mod erate risk of bias Questionnaire used is not described to

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Neurology, 52, e16-22, 2010 **Country/ies where the study was carried out** UK and Ireland. **Study type** National population based prospective cohort study (EPICure). **Aim of the study** To assess the prevalence of clinically relevant eating problems in extremely preterm children, and to identify whether eating problems can be accounted for by comorbidity. **Study dates** March to December 1995.	Preterm children: all children born at a gestation of < 26 weeks in the UK and Ireland during the study dates. Controls: age and sex matched classmates. **Exclusion criteria** Death before follow up, no completed questionnaire data.		**Outcome(s) ascertainment/measures** When the child reached 6 years of age, parents completed a specially developed eating questionnaire. The scale included 19 items, which were grouped into four categories: refusal-faddy eating problems, oral motor problems, oral hypersensitivity problems and behavioural problems around meals. A total eating problems score was also constructed. Higher scores on each scale indicate more problems. To derive clinical categories, each scale was dichotomised into normal versus clinical (scores above the 90th centile or near according to the comparison group). **Statistical methods** To test for the presence of specific eating problems,	**Hypersensitivity problems** Controls: Reference Preterm: OR 1.9 (0.8-4.7) All OR are adjusted for cognitive, neuromotor and pervasive behaviour difficulties.	give enough information. **Confounders:** low risk of bias **Analysis and Reporting:** low risk of bias. Overall quality: moderate

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td>Source of funding

BLISS, the preterm infant charity; the Health Foundation; and Well-being of Women.</td><td></td><td></td><td>logistic regressions adjusted for cognitive disability, neuromotor disability and pervasive behaviour disability.

Length of follow-up

6 years.
Assumed to be chronological age, but not stated.</td><td></td><td></td></tr>
<tr><td>Ref Id

397686

Full citation

Schendel, D. E., Stockbauer, J. W., Hoffman, H. J., Herman, A. A., Berg, C. J., Schramm, W. F., Relation between very low birth weight and developmental delay among preschool children without disabilities, American Journal of</td><td>Sample size

n = 320 very low birth weight children (<1500 g)
n= 512 moderately low birth weight children (1500-2499 g)
n = 524 normal birth weight children (>=2500 g)

Characteristics
<table><tr><td>Characteristics</td><td>VLBW
n = 367</td><td>NBW
n = 555</td></tr><tr><td>Male, n (%)</td><td>180 (49.1)</td><td>290 (52.2)</td></tr><tr><td>Maternal age, n (%)</td><td></td><td></td></tr><tr><td>< 20 years</td><td>86 (23.4)</td><td>131 (23.6)</td></tr><tr><td>20-34 years</td><td>245 (66.8)</td><td>385 (69.4)</td></tr></table></td><td>Risk factors

Gestational age (birth weight used as proxy measure, mean GA weeks for each group reported)</td><td>Setting

Regional prospective study.

Method(s) of measurement for risk factor(s)

Cases and controls were identified through delivery room logs with records of birth weight. Birth certificate files were used to identify perinatal characteristics.

Outcome(s) ascertainment/measures</td><td>Outcome(s) at age

<u>At 9-34 months</u>
Risk of questionable overall performance (>=2 cautions)
NBW: Reference
VLBW: OR 2.74 (1.74-4.31)

MLBW: Reference
VLBW: OR 1.66 (1.09-2.51)

Risk of abnormal overall performance (>=2 delays)
NBW: Reference
VLBW: OR 4.81 (2.51-9.23)

MLBW: Reference
VLBW: OR 2.02 (1.18-3.45)

Risk of ≥ 1 caution in language outcomes
NBW: Reference
VLBW: OR 2.16 (1.39-3.37)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias>20% of participants were lost to follow up. No information is provided regarding differences between those who did and did not participate.
Prognostic factor measurement: moderate risk of bias
It is not explained who performed the assessment of the</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Epidemiology, 146, 740-9, 1997

Country/ies where the study was carried out

USA

Study type

Regional prospective cohort study.

Aim of the study

To assess the prevalence of developmental delay in a population of young singleton very low birth weight children, and to compare it to control children.

Study dates

Participants born between December 1989 and March 1991.</td>
<td>
<table>
<tr><td>≥35 years</td><td>36 (9.8)</td><td>39 (7.0)</td></tr>
<tr><td>Maternal education</td><td></td><td></td></tr>
<tr><td><High school, n (%)</td><td>105 (29)</td><td>148 (26.9)</td></tr>
<tr><td>≥High school, n (%)</td><td>257 (71)</td><td>403 (73.1)</td></tr>
<tr><td>Maternal race</td><td></td><td></td></tr>
<tr><td>Black, n (%)</td><td>130 (36.5)</td><td>221 (40.5)</td></tr>
<tr><td>Nonblack, n (%)</td><td>226 (63.5)</td><td>325 (59.5)</td></tr>
</table>
Inclusion criteria

VLBW: birth weight <1500g during the study dates.
NBW: birth weight ≥2500g during the study dates.
MLBW: birth weight 1500 - 2499g.

Exclusion criteria

Multiple pregnancy, physical or other limitations (including cerebral palsy, chronic health conditions, Down's syndrome, blindness, brain injury, orthopaedic problems). Loss to follow up.
</td>
<td></td>
<td>The Denver II was used to screen children for possible developmental delay. Nine outcomes were used in this analysis. Eight of the outcomes were based on two measures of performance in each of four domains: personal-social, language, fine motor adaptive skills and gross motor skills. One of the two domain specific measures was whether the child failed a task in each domain for which 75-90% of children of the same (adjusted) age would pass. This was denoted as receiving a caution score in a given domain. The other measure was whether a child failed on or more tasks in each domain for which at least 90% of children of the same age would be expected to pass (denoted as receiving a delay score in that domain).
The ninth outcome, overall test performance, was</td>
<td>
MLBW: Reference
VLBW: OR 1.41 (0.93-2.12)

Risk of ≥ 1 delay in language outcomes
NBW: Reference
VLBW: OR 2.97 (1.61-5.47)

MLBW: Reference
VLBW: OR 1.79 (1.04-3.09)

Risk of ≥ 1 caution in fine motor-adaptive outcomes
NBW: Reference
VLBW: OR 2.10 (1.26-3.50)

MLBW: Reference
VLBW: OR 1.42 (0.88-2.28)

Risk of ≥ 1 delay in fine motor-adaptive outcomes
NBW: Reference
VLBW: OR 4.88 (2.34-10.20)

MLBW: Reference
VLBW: OR 1.6 (0.9-2.84)

Risk of ≥ 1 caution in gross motor outcomes
NBW: Reference
VLBW: OR 4.95 (2.89-8.47)

MLBW: Reference
VLBW: OR 2.16 (1.39-3.34)

Risk of ≥ 1 delay in gross motor outcomes
NBW: Reference</td>
<td>child. Also what is meant by "caution" and "delay" are not explained thoroughly.
Outcome measurement: low risk of bias
Confounders: moderate risk of bias
Covariables in the multiple logistic regression model are not explained.
Analysis and Reporting: low risk of bias.
Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Source of funding The National Institute of Child Health and Human Development, and the Centers for Disease Control and Prevention.			based on the total number of caution and/or delay scores received across all domains, and was categorised as : 1. Questionable - received 2 or more caution scores and/or a maximum of one delay score 2. Abnormal - received two or more delay scores 3. Normal - received a maximum of one caution score 4. Untestable - refused to perform one of more tasks. **Statistical methods** Adjusted odds ratios were used to estimate the relative risk of developmental delay for VLBW compared to NBW children, using	VLBW: OR 6.26 (2.87-13.65) MLBW: Reference VLBW: OR 2.54 (1.38-4.68) **Risk of >=1 caution in personal-social outcomes** NBW: Reference VLBW: OR 2.12 (1.38-3.24) MLBW: Reference VLBW: OR 1.64 (1.09-2.48) **Risk of >=1 delay in personal-social outcomes** NBW: Reference VLBW: OR 3.21 (1.51-6.68) MLBW: Reference VLBW: OR 2.74 (1.36-5.53) Adjusted for gender, maternal age, maternal education, maternal race, marital status, medicaid use, maternal residence, maternal smoking and alcohol intake.	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			unconditional logistic regression to control for multiple confounders. **Length of follow-up** Between 9 and 34 months. Age was adjusted for prematurity for children aged <2 years. About 50% of children in each group had been tested by the age of 15 months.		
Ref Id 411731 **Full citation** Shah, T. A., Meinzen-Derr, J., Gratton, T., Steichen, J., Donovan, E. F., Yolton, K., Alexander, B., Narendran, V., Schibler, K. R., Hospital and neurodevelopmental outcomes of extremely low-birth-weight infants with	**Sample size** n=1722 infants survived >12h n=995 infants who survived NICU discharge and were included in the NICHD NRN high-risk infant follow-up (criteria was changed for infants born 1/1/2006 or later to include only the ones born <27 weeks of gestation). n=20 children died before follow-up n=110 no neurodevelopmental follow-up data available **n=865 included in analysis** n=785 without NEC or SIP n=30 with medical NEC n=32 with surgical NEC n=18 with SIP **Characteristics**	**Risk factors** Necrotising enterocolitis (NEC) defined as Modified Bell's classification stage IIA or greater. Subgroups: NEC with surgical intervention, medical NEC (without surgical intervention)	**Setting** Population-based study in the greater Cincinnati region from 1998 to 2009, utilizing data from the National Institute of Child Health Neonatal Research Network registry and the Cincinnati Collaborative Outreach Program Database. **Method(s) of measurement for risk factor(s)**	**Outcome(s) at age** **Outcomes assessed at 18 to 22 months:** <u>MDI <70</u> No NEC: reference NEC: OR 2.04 (0.96-4.34) <u>PDI <70</u> No NEC: reference NEC: OR 2.64 (1.18-5.91) <u>Any disability*</u> No NEC: reference NEC: OR 2.59 (1.44-4.66)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moder ate risk of bias Inclusion and exclusion criteria not very clearly reported. **Attrition:** moderate risk of bias Losses to follow-up not very clearly reported, no information provided if those lost to follow up differed compared

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>necrotizing enterocolitis and spontaneous intestinal perforation, Journal of Perinatology, 32, 552-8, 2012

Country/ies where the study was carried out

United States

Study type

Population-based cohort study

Aim of the study

To determine the incidence of necrotising enterocolitis (NEC) and spontaneous intestinal perforation (SIP) in surviving extremely low-birth-weight (<1000g birth weight) infants and to establish</td>
<td>Characteristics of no NEC, NEC, medical NEC, surgical NEC and SIP groups with NICU outcomes
<table>
<tr><th>No NEC or SIP, n = 1459</th><th>NEC, n = 208</th><th>Medical NEC, n = 87</th><th>Surgical NEC, n = 121</th><th>NEC vs no NEC or SIP, P-value</th><th>Medical vs surgical NEC, P-value</th></tr>
<tr><td colspan="6">Perinatal factors</td></tr>
<tr><td>Antenatal antibiotics, n (%)</td><td>792 (54)</td><td>123 (59)</td><td>42 (48)</td><td>81 (67)</td><td>0.18</td><td>0.005</td></tr>
<tr><td>Antenatal steroids, n (%)</td><td>1173 (80)</td><td>175 (84)</td><td>72 (83)</td><td>103 (85)</td><td>0.16</td><td>0.55</td></tr>
</table>
</td>
<td></td>
<td>Modified Bell's classification state IIA or greater.

Outcome(s) ascertainment/measures

Neurological examination was based on the Amiel-Tison assessments. Gross motor skills examination was developed from the work of Russell and Palisano.
Bayley Scales of Infant Development-II (BSID-II) (for infant born before 2006) and Bayley Scales of Infant Development-III (BSID-III) (for infants born after 1/1/2006) was used to obtain mental development index (MDI) and psychomotor developmental index (PDI).

Impaired mental development defined as a MDI score <70. Impaired psychomotor development defined as PDI score <70.</td>
<td>*Any of the following: MDI score <70, PDI score <70, cerebral palsy (CP), hearing impairment, or visual impairment.

No significant differences were detected when comparing outcomes between medical NEC and surgical NEC (effect estimates not reported).</td>
<td>to those included in analysis.
Prognostic factor measurement: moderate risk of bias
No description of how NEC was diagnosed.
Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: moderate</td>
</tr>
</table>

Study details	Participants							Risk factors	Methods	Outcomes and Results	Comments
the impact of NEC on outcomes by hospital discharge and at 18 to 22 months adjusted age. **Study dates** 1998 to 2009, follow-up at 18 to 22 months of corrected age. **Source of funding** National Instititute of Child Health and Human Development Eunice Kennedy Shriver Neonatal Research Network (U10 HD 027853).	Multiple, *n* (%)	356 (24)	62 (30)	22 (25)	40 (33)	0.09	0.23		"Any disability" defined as a composite variable including any one of the following condition s: MDI score <70 PDI score <70 Cerebral palsy (CP), defined as a non-progressive central nervous system disorder characterized by abnormal muscle tone in at least 1 extremity and abnormal control of movement and posture. Hearing impairment, defined as any restriction or lack of ability to perform within the range of considered as normal, resulting in impairment, or if there was chronic otitis media associated with delayed speech skills. Visual impairment, defined as need for corrective lenses, blindness with some functional vision or blindness with no functional vision. All neurological assessmented		
	ROM >24 h, *n* (%)	227 (16)	38 (18)	11 (13)	27 (22)	0.32	0.08				
	Neonatal factors										
	Birth weight (g), mean (s.d.)	783 (144)	759 (145)	769 (140)	753 (148)	0.03	0.43				
	GA (week), mean (s.d.)	26.2 (2.0)	25.9 (2.0)	26.1 (1.8)	25.7 (2.1)	0.03	0.15				
	Race Black, *n* (%)	823 (56)	136 (65)	60 (69)	76 (63)	0.01	0.36				
	Male, *n* (%)	674 (46)	107 (51)	45 (52)	62 (51)	0.39	0.95				
	Abbreviations: GA, gestational age; NEC, necrotizing enterocolitis; NICU, newborn intensive care unit; ROM, rupture of membranes; SIP, spontaneous intestinal perforation.										

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
	Inclusion criteria Extremely low-birth-weight (<1000 g). Infants who survived 12 h. **Exclusion criteria** Birth weight >=1000 g. Infants with extremely low-birth-weight who died <12 h of birth.		performed by one of two certified, masked developmental specialists over the entire study period. BSID-II was administered by a single, experienced gold standard examiner. **Statistical methods** Regression analysis done to compare the outcome between children without NEC (reference) and children without NEC. The model adjusted for birth weight, race, gender, multiple births, antenatal steroids, surfactant, bronchopulmonary dysplasia, sepsis, and any intraventricular hemorrhage. **Length of follow-up** 18 to 22 months.		
Ref Id	**Sample size**	**Risk factors**	**Setting**	**Outcome(s) at age** Assessed at 3 years:	**Limitations**

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
411763 **Full citation** Singer, L. T., Hawkins, S., Huang, J., Davillier, M., Baley, J., Developmental outcomes and environmental correlates of very low birthweight, cocaine-exposed infants, Early Human Development, 64, 91-103, 2001 **Country/ies where the study was carried out** USA **Study type** Prospective cohort study **Aim of the study** To assess a cohort of very low birthweight,	Sample recruited - N = 82 very low birthweight infants (41 mothers cocaine-positive + 41 mothers cocaine-negative) Developmental outcomes are reported for 69 very low birthweight infants (31 mothers cocaine-positive + 38 mothers cocaine-negative) **Characteristics** Very low birthweight (VLBW) (<1500 g) infants: with positive findings of maternal cocaine use were compared with an equal number of noncocaine-exposed infants of similar race, social class and age, from the same study population (African–American) receiving public assistance **Inclusion criteria** No details given – see population characteristics **Exclusion criteria** No details given – see population characteristics	**Social/environmental/ maternal** Substance use (Maternal use of cocaine)	Population based study in the US **Method(s) of measurement for risk factor(s)** Cocaine status was determined through prospective urine screening or clinical interview at the time of the infant's birth, or both. Urine samples were obtained immediately before or after labor and delivery in the NICU in which the majority (85%) of infants were recruited. They were analyzed by enzyme immunoassay, using the Syva EMIT method (Syva, Palo Alto, CA), for the presence of cocaine's primary metabolite, benzoylecgonine and for heroin, phencyclidine, methadone, opiates, barbiturates and marijuana.	**Psychomotor Developmental Index [PDI] <70** "When the baseline differences […the effects of IVH, the only neonatal neurologic complication which differed between the groups…] were controlled, the effects of cocaine on these developmental outcomes remained significant"	**Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.** **Participants:** moderate risk of bias Inclusion and exclusion criteria not described properly. **Attrition:** moderate risk of bias Attrition was higher in the cocaine-exposed cohort. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** high r isk of bias No sufficient information about the measurement and the definition of confounders measured in the study. **Analysis and Reporting:** high risk of bias Presentation of data in narrative way for some important outcomes. Potential risk of selective reporting.

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
cocaine-exposed infants and a comparison group of nonexposed infants who were identified at birth and followed to 3 years of age, assessing 1) developmental outcome measures, 2) early maternal–child interactions, 3) maternal psychological characteristics and environmental factors conceptualized to be important for child outcome **Study dates** Not reported: Period of data collection (patient 'enrolment') – 2001: date of publication 3 years: follow-up assessment			**Outcome(s) ascertainment/measures** The Bayley Scales of Infant Development that is described as widely used assessment toll of infant development: the psychomotor index (PDI) measures gross and fine motor control and coordination. **Statistical methods** The χ2 test for comparisons of categorical data, and Student's *t*-test or ANOVA for continuous data were used. The study hypothesis was that that cocaine-exposed children would have poorer behavioral ratings and developmental outcomes at follow-up, based on the outcome assessment at 17 months Analyses of covariance were used to compare developmental outcomes with control for confounding		**Overall:** low quality

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Source of funding Supported by Grants MCJ-390592 and 390715 from the Maternal and Child Health Program (Title V, Social Security Act) Health Resources and Services Administration, Department of Health and Human Services and from NIH-HL-38193, NIDA 07957.			variables, when necessary. **Length of follow-up** 3 years		
Ref Id 411840 **Full citation** Stene-Larsen, K., Brandlistuen, R. E., Lang, A. M., Landolt, M. A., Latal, B., Vollrath, M. E., Communication impairments in early term and late preterm children: A	**Sample size** Sample recruited N = 101624 (Original sample in Mother and Birth Cohort Study) Sample analysed after exclusions N = 32314 children (n=1673 children born at 34-36 weeks; n=30641 children born at 39-41 weeks) For the purposes of this analysis children born at early term (37 to 38+6 weeks, n = 7109) were excluded, and comparisons between preterm and full term children were used. **Characteristics**	**Risk factors** Gestational age	**Setting** Population based cohort study of pregnant women. **Method(s) of measurement for risk factor(s)** Information on gestational age based on ultrasound examination was retrieved from the	**Outcome(s) at age** **Outcome(s) at 18 months** Communication impairments Term: Reference Late preterm: OR 1.74 (1.41 to 2.14) **Outcome(s) at 36 months** Communication impairments Term: Reference Late preterm: OR 1.19 (0.96 to 1.47)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias (Only 45125 participants had follow up data at 36 months, whilst the study cohort included 101624 participants.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>prospective cohort study following children to age 36 months, Journal of Pediatrics, 165, 1123-1128, 2014

Country/ies where the study was carried out

Norway.

Study type

Prospective population based cohort study.

Aim of the study

To examine communication impairments in children born late preterm and early term.

Study dates

Participants who gave birth between 1999 and 2008 were</td>
<td>
<table>
<tr><td>Characteristic</td><td>Late preterm34-36+6 n = 1673</td><td>Term39-41+6 n = 30641</td></tr>
<tr><td>Maternal age, yearsmedian (range)</td><td>31 (16-44)</td><td>30 (16-47)</td></tr>
<tr><td>Higher education, %</td><td>66.1</td><td>68.9</td></tr>
<tr><td>Male sex, %</td><td>51.3</td><td>50.4</td></tr>
<tr><td>Caesarean delivery, %</td><td>29.5</td><td>9.7</td></tr>
<tr><td>Multiple gestation, %</td><td>12.5</td><td>0.4</td></tr>
<tr><td>SGA, %</td><td>8.2</td><td>3.4</td></tr>
</table>
Inclusion criteria

A complete set of study questionnaires from gestational week 17, child age 18 months and child age 36 months.

Exclusion criteria

Severe malformations or syndromes, severe hearing deficits, and cerebral palsy.
Gestation longer than 41+6 weeks or shorter than 33+6 week</td>
<td></td>
<td>Medical Birth Registry of Norway.

Outcome(s) ascertainment/measures

Child communication impairments at the age of 18 months were measured using 3 specifically selected items from the Ages and Stages Questionnaire (ASQ), as rated by the child's mother. Two of these assess receptive communication skills and the other assesses expressive communication skills. To identify children at risk for clinically significant communication impairments, a cutoff of 2SD above the cohort mean was set. Communication impairments at 36 months were assessed using 6 items from the ASQ measuring expressive (3 items) and receptive (3 items) communication skills, as rated by the child's</td>
<td>Expressive language impairments
Term: Reference
Late preterm: OR 1.37 (1.09 to 1.73)

All OR adjusted for prenatal and postnatal risk factors and emergency Caesarean delivery, as described above.</td>
<td>Data on differences between those lost to follow up are not presented, so it is not clear whether there may be systematic differences in those who were able to participate)
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias.

Overall: moderate quality</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
invited to participate in the Norwegian Mother and Child Cohort Study. Of those invited, 38.7% agreed to participate. **Source of funding** The Norwegian Ministry of Health and the Ministry of Education and Research, the National Institutes of Health/National Institute of Environmental Health Sciences, NIH/National Institute of Neurological Disorders and Stroke, and the Norwegian Research Council/FUGE			mother. A cutoff of 2SD above the cohort mean was set to identify children at risk. Expressive communication impairment was measured using the parent-based assessment of grammar abilities (Dale et al 2003). Mothers are asked to select which category best describes how their child talks: (1) not yet talking, (2) talking, but not understandably, (3) talking in single word utterances, such as "milk", (4) child is talking in 2-3 word phrases, such as "me got ball", (5) child is talking in fairly complete sentences, such as "can I go outside?" and (6) child is talking in long and complicated sentences, such as "when I went to the park, I went on the swings". The measure was dichotomised so that a score of ≥5 was coded 0 and a score of ≤4 was coded 1.		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			Statistical methods Logistic regression analysis was applied to explore the association between early term/late preterm birth and communication impairments at age 18 and 36 months. Confounder adjustment was performed in three steps. First, adjustment was made for prenatal risk factors only, then for emergency Caesarean delivery, and finally for postnatal risk factors in addition to prenatal risk factors and Caesarean delivery. Prenatal risk factors were: maternal gestational diabetes, preeclampsia/HELLP syndrome, multiple gestation, small for gestational age. Postnatal risk factors were: 5 minute Apgar score ≤6, diagnosis of respiratory distress or intracranial bleeding and use of mechanical ventilation after birth.		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>Length of follow-up

18 months and 36 months.</td><td></td><td></td></tr>
<tr><td>Ref Id

411856

Full citation

Stoll, B. J., Hansen, N. I., Adams-Chapman, I., Fanaroff, A. A., Hintz, S. R., Vohr, B., Higgins, R. D., Neurodevelopmental and growth impairment among extremely low-birth-weight infants with neonatal infection, Journal of the American Medical Association, 292, 2357-2365, 2004

Country/ies where the study was carried out

United States</td><td>Sample size

n=6314

Characteristics
<table><tr><th></th><th>Uninfected (n=2161)</th><th>Clinical infection alone (n=1538)</th><th>Sepsis alone (n=1922)</th><th>Sepsis + NEC (n=279)</th><th>Meningitis with or without sepsis (n=193)</th></tr><tr><td>Maternal age <=19 y, %</td><td>16</td><td>16</td><td>18</td><td>18</td><td>16</td></tr><tr><td>ROM >24 h, %</td><td>23</td><td>25</td><td>23</td><td>29</td><td>25</td></tr><tr><td>Antenatal antibiotics, %</td><td>59</td><td>64</td><td>67</td><td>65</td><td>72</td></tr><tr><td>Antenatal steroids, %</td><td>73</td><td>72</td><td>70</td><td>70</td><td>74</td></tr></table></td><td>Risk factors

Sepsis alone
Sepsis plus NEC
Meningitis with or without sepsis</td><td>Setting

Data obtained from the National Institute of Child Health and Human development (NICHD) Neonatal Research Network registry, participants born in the different centers of the network between 1993-2001.

Method(s) of measurement for risk factor(s)

Sepsis alone, defined by a positive blood culture and antibiotic therapy for 5 or more days.
Sepsis plus necrotizing enterocolitis (NEC), NEC classified according to the system of Bell et al.
Meningitis with or without sepsis, meningitis defined by a positive cerebrospinal fluid</td><td>Outcome(s) at age

Outcomes assessed at 18-22 months' corrected age:
ORs (95% CI) presented, the logistic regression model adjusted for study center, gestational age, birth weight, sex, race/ethnicity, rupture of membranes >24 h, CS, multiple birth, antenatal antibiotics, antenatal steroids, postnatal steroids, surfactant use, respiratory distress syndrome, bronchopulmonary dysplasia, patent ductus arteriosus, intraventricular haemorrhage grade 3-4, periventricular leukomalacia, maternal age at time of delivery, caregiver's level of education.

<u>PDI <70</u>
No infection:reference
Sepsis alone: 1.5 (1.2-1.9)
Sepsis + NEC: 2.4 (1.7-3.4)
Meningitis with or without sepsis: 1.7 (1.1-2.5)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
20% of the eligible ones for follow-up were lost to follow-up. Baseline characteristics were not compared but the risk factor of interest (different types or levels of infection) were compared between ones lost to follow-up and ones included. Infants who survived bu did not complete follow-up were more likely to be uninfected and the percentages in each infection group were 1-2% lower for the ones lost to follow-up than the</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Study type

Multicentre cohort study

Aim of the study

To determine if neonatal infections in extremely low birth weight infants are associated with increased risks of adverse neurodevelopmental and growth sequelae in early childhood.

Study dates

1993-2001, follow-up at 18-22 months corrected age.

Source of funding

Grants from the National</td>
<td>
<table>
<tr><td>CS, %</td><td>65</td><td>57</td><td>55</td><td>56</td><td>47</td></tr>
<tr><td>Caregiver education: high school graduate, %</td><td>75</td><td>75</td><td>75</td><td>74</td><td>77</td></tr>
<tr><td>Birth weight 401-500 g, %</td><td><1</td><td>2</td><td>2</td><td>2</td><td>3</td></tr>
<tr><td>Birth weight 591-750 g, %</td><td>23</td><td>40</td><td>48</td><td>46</td><td>44</td></tr>
<tr><td>Birth weight 751-1000 g, %</td><td>77</td><td>59</td><td>50</td><td>52</td><td>53</td></tr>
<tr><td>GA <25 wk, %</td><td>8</td><td>22</td><td>27</td><td>25</td><td>25</td></tr>
<tr><td>GA 25-28 wk, %</td><td>69</td><td>69</td><td>66</td><td>70</td><td>73</td></tr>
<tr><td>GA 29-32 wk, %</td><td>22</td><td>9</td><td>6</td><td>6</td><td>3</td></tr>
<tr><td>GA >=33 wk, %</td><td>1</td><td><1</td><td><1</td><td>0</td><td>0</td></tr>
</table>
</td>
<td></td>
<td>culture and antibiotic therapy for 5 or more days.

Outcome(s) ascertainment/measures

Psychomotor developmental index (PDI) <70, assessed with Bayley Scales of Infant Development II (BSID-II)

Statistical methods

Multiple logistic regression, adjusting for study center, gestational age, birth weight, sex, race/ethnicity, rupture of membranes >24 h, CS, multiple birth, antenatal antibiotics, antenatal steroids, postnatal steroids, surfactant use, respiratory distress syndrome, bronchopulmonary dysplasia, patent ductus arteriosus, intraventricular haemorrhage grade 3-4, periventricular leukomalacia,</td>
<td></td>
<td>ones included in analysis (p=0.001).
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: Moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Institutes of Health.	<table><tr><td>SGA at birth, %</td><td>24</td><td>14</td><td>14</td><td>13</td><td>16</td></tr><tr><td>Male, %</td><td>41</td><td>51</td><td>48</td><td>53</td><td>41</td></tr><tr><td>Race/ethnicity black, %</td><td>44</td><td>46</td><td>46</td><td>50</td><td>50</td></tr><tr><td>Race/ethnicity white, %</td><td>41</td><td>39</td><td>35</td><td>38</td><td>34</td></tr><tr><td>Race/ethnicity hispanic, %</td><td>11</td><td>13</td><td>16</td><td>10</td><td>15</td></tr><tr><td>Race/ethnicity other, %</td><td>3</td><td>2</td><td>3</td><td>3</td><td>2</td></tr></table> **Inclusion criteria** Surviving infants who weighed 1000 g or less at birth. **Exclusion criteria** Infants with major congenital malformations/syndromes, and those with ventricular shunts. Infants with positive blood cultures but who received antibiotic therapy for less than 5 days (and therefore considered probable contaminants).		maternal age at time of delivery, caregiver's level of education. **Length of follow-up** 18-22 months' corrected age.		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr>
<td>Ref Id

412062

Full citation

Vohr, B. R., Wright, L. L., Dusick, A. M., Mele, L., Verter, J., Steichen, J. J., Simon, N. P., Wilson, D. C., Broyles, S., Bauer, C. R., Delaney-Black, V., Yolton, K. A., Fleisher, B. E., Papile, L. A., Kaplan, M. D., Neurodevelopmental and functional outcomes of extremely low birth weight infants in the National Institute of Child Health and Human Development Neonatal Research Network, 1993-1994, Pediatrics, 105, 1216-1226, 2000</td>
<td>Sample size

Sample recruited - N = 2498
Sample eligible for assessment - N = 1527
Sample analysed after exclusions - N = 1151

Characteristics

<table>
<tr><td></td><td>%</td></tr>
<tr><td>Less than high school graduate</td><td>28</td></tr>
<tr><td>Infant not living with biologic mother</td><td>13</td></tr>
<tr><td>Not married</td><td>49</td></tr>
<tr><td>Age <=19 y</td><td>18</td></tr>
<tr><td>Income <$20,000</td><td>57</td></tr>
<tr><td>Meidcaid</td><td>65</td></tr>
</table>
</td>
<td>Risk factors

Neonatal risk factors:
Intraventricular haemorrhage (IVH) or periventricular leukomalacia (PVL) grade III-IV
Postnatal steroids
Chronic lung disease (i.e. bronchopulmonary dysplasia BPD, received oxygen at 36 weeks)
Antenatal steroids
Early-onset sepsis
Late-onset sepsis
Necrotizing enterocolitis (NEC)

Biological risk factors:
Small for gestational age (SGA)
Race, white
Sex, boy</td>
<td>Setting

12 centres of the National Institute of Child Health and Human Development Neonatal Research Network

Method(s) of measurement for risk factor(s)

Participating centres collected pregnancy and delivery data. Neonatal outcome data were assessed at 129 days after birth, at discharge from neonatal units or death, whichever came first.
All data were abstracted from hospital records by trained study coordinators.

Neonatal risk factors:
Intraventricular haemorrhage (IVH) or periventricular leukomalacia (PVL) grade III-IV
Postnatal steroids, any doses or courses of</td>
<td>Outcome(s) at age

<u>Outcome(s) at 18-22 months corrected age</u>
No independent feeding
<u>Neonatal risk factors:</u>
IVH/PVL grade III-IV: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 4)
Postnatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4)
NEC: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4)
CLD (i.e. BPD): Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 4)
Late-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4)
Early-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4)
Antenatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4)Biological risk factors:</td>
<td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias (Out of 1527 infants who were initially included in the study, 3% died 21% were otherwise lost to follow-up before 18-22 months' corrected age)
Prognostic factor measurement: moderate risk of bias (Not explained how the all risk factors were measured or defined)
Outcome measurement: moderate risk of bias (Not clear how problems outcomes -no independent feeding, no independent walking- outcomes were assessed)
Confounders: high risk of bias (They report that the logistic regression</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Country/ies where the study was carried out USA **Study type** Multicentre prospective cohort study **Aim of the study** To report the neurodevelopmental, neurosensory, and functional outcomes of 1551 extremely low birth weight (401-1000 g) survivors cared for in the 12 participating centres of the National Institute of Child Health and Human Development Neonatal Research Network and to identify medical, social and environmental	Race black 51 Race white 35 Race hispanic 12 Race other 2 Primary language English 88 Primary language Spanish 9 Primary language other 3 **Inclusion criteria** Live-born infant with birth weight 401-1000 g born between Jan 1993 and Dec 1994 who were admitted to level II units in any of the 12 centres of the National Institute of Child Health and Human Development Neonatal Research Network. **Exclusion criteria** Children were excluded if:		steroids for chronic lung disease Chronic lung disease (i.e. bronchopulmonary dysplasia BPD, received oxygen at 36 weeks) Antenatal steroids, indicates beta-methasone (2 doses, 12 and 24 hours apart) or dexamethasone (4 doses, 6 hours apart). Early-onset sepsis, positive blood culture result within the first 72h. Late-onset sepsis, positive blood culture result >72h obtained in the presence of clinical signs of septicaemia. Necrotizing enterocolitis (NEC) Social/maternal/environmental risk factors: Parent less than high school graduate Biological risk factors: Small for gestational age (SGA) Race, white Sex, boy	<u>Biological risk factors:</u> sex, male (vs female): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) SGA: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) Race white (vs black??): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) <u>Social/maternal/environmental risk factors:</u> Parent less than high school graduate: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) **No independent walking** <u>Neonatal risk factors:</u> IVH/PVL grade III-IV: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Postnatal steroids: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 3) NEC: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) CLD (i.e. BPD): Significantly increased odds, OR (95% CI) not	models adjusted for different maternal and demographic variables but do not specify which ones) **Analysis and reporting:** moderate risk of bias (ORs (95% CI) are not reported numerically, only on forest plots for many outcomes) **Overall: low quality**

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
factors associated with these outcomes. **Study dates** • **1993-1994:** Period of data collection (patient enrolment) • **18-22 months corrected age**: follow-up assessment **Source of funding** Grants: source not reported	died before admission to the nursery units died before follow-up.		**Outcome(s) ascertainment/measures** No independent feeding, not clear how assessed but they report that a basic, functional, gross motor skills were assessed derived from the work of Russell et al. and Palisano et al. No independent walking, not clear how assessed but they report that a basic, functional, gross motor skills were assessed derived from the work of Russell et al.d Palisano et al. Psychomotor Developmental Index (PDI) score <70, assessed with Bayley Scale of Infant Development II (BSID-II) **Statistical methods** Logistic regressions were used to identify associations among biologic, social, demographic factors and the major neurologic,	reported numerically, only on a forest plot Figure 3) Late-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Early-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Antenatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) <u>Biological risk factors:</u> sex, male (vs female): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) SGA: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Race white (vs black??): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) **PDI <70 (Bayley)** <u>Neonatal risk factors:</u> IVH/PVL grade III-IV: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Postnatal steroids: Significantly increased	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			developmental and functional outcomes. Maternal and neonatal risk factors that are known to be associated with increased neurodevelopmental outcome were entered into the model. **Length of follow-up** 18-22 months corrected age.	odds, OR (95% CI) not reported numerically, only on a forest plot Figure 2) NEC: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 2) CLD (i.e. BPD): Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Late-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Early-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Antenatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) <u>Biological risk factors:</u> sex, male (vs female): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) SGA: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Race white (vs black??): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2)	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td><u>Social/maternal/environmental risk factors:</u>
Parent less than high school graduate: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2)</td><td></td></tr>
<tr><td>Ref Id

412158

Full citation

Woythaler, M. A., McCormick, M. C., Smith, V. C., Late preterm infants have worse 24-month neurodevelopmental outcomes than term infants, Pediatrics, 127, e622-9, 2011

Country/ies where the study was carried out

USA.

Study type

Prospective national cohort study.</td><td>Sample size

Sample recruited:
N = 9050

Sample analysed after exclusions
n = 1200 late preterm babies
n = 6300 term babies

N.B. Article states that "all unweighted sample sizes included in this analysis were rounded to the nearest 50 to protect the confidentiality of respondents as specified in the restricted data license agreement".

Characteristics
<table><tr><td>Characteristics</td><td>Late preterm</td><td>Term</td></tr><tr><td>Maternal age, years, mean (SD)</td><td>27.5 (6.9)</td><td>27.3 (7.9)</td></tr><tr><td>Ethnicity, %</td><td></td><td></td></tr><tr><td>White</td><td>75.1</td><td>81.4</td></tr><tr><td>Black</td><td>14.8</td><td>20.4</td></tr></table></td><td>Risk factors

Gestational age</td><td>Setting

The Early Childhood Longitudinal Study-Birth Cohort, a prospective national longitudinal study assessing the early health care and developmentally influential experiences of children born in 2001 and their families.

Method(s) of measurement for risk factor(s)

Maternal and infant descriptive characteristics were obtained from birth certificates and maternal surveys.

Outcome(s) ascertainment/measures</td><td>Outcome(s) at age

Outcome assessed at 24 months choronological age:
<u>Risk of severe psychomotor developmental delay (PDI score <70)</u>
Gestational age
Term: Reference
Late preterm: OR 1.56 (1.29-1.88)

<u>Risk of mild psychomotor developmental delay (PDI score 70-84)</u>
Gestational age
Term: Reference
Late preterm: OR 1.58 (1.37-1.83)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
17% of participants were lost to follow up. The authors report that these participants were significantly more likely to have a high school education, be impoverished and have less prenatal care than those who remained in the study.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Aim of the study To compare the neurodevelopmental outcomes of late preterm to term infants. **Study dates** Cohort established during 2001. Follow up at 24 months chronological age. **Source of funding** The US Department of Education's National Center for Education Statistics in the Institute of Education Sciences.	<table><tr><td>Other</td><td>4.5</td><td>4.3</td></tr><tr><td>Male infants, %</td><td>52.6</td><td>51.4</td></tr><tr><td>SGA, %</td><td>8.9</td><td>10.1</td></tr><tr><td>Multiple births, %</td><td>14.7</td><td>1.5</td></tr></table> **Inclusion criteria** Infants with >34 weeks completed gestation who had complete developmental assessments at 24 months. **Exclusion criteria** Infants who were not assessed, or who were unable to be adequately assessed because of a major congenital anomaly or blindness.		Psychomotor development index (PDI) using the Bayley Short Form Research edition (BSF-R). This was administered in the child's home by trained personnel. Each administrator's testing and scoring were validate through in person quality control visits and videotaped interviews. Score of <70 considered a delay. **Statistical methods** For multivariable analysis, generalized estimating equation models were used to generate odds ratios and 95% confidence intervals. These account for clustering of data in siblings. OR were adjusted for gestational age, plurality, maternal race, education, marital status, depression, prenatal care, primary language, infant gender, poverty level, delivery type, fetal		**Confounders:** low risk of bias **Analysis and reporting:** low risk of bias. Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			growth and any breast milk feeding. **Length of follow-up** 24 months of chronological age.		
Ref Id 347713 **Full citation** Adams-Chapman, I., Hansen, N. I., Stoll, B. J., Higgins, R., Neurodevelopmental outcome of extremely low birth weight infants with posthemorrhagic hydrocephalus requiring shunt insertion, Pediatrics, 121, e1167-e1177, 2008 **Country/ies where the study was carried out** USA	**Sample size** n=9486 children eligible for follow-up (did not die before follow-up and did not have major malformations or syndromes) n=7776 children completed follow-up (82% follow-up rate) n=7693 children studied (of the n=7776, n=56 had no IVH information, n=27 received a shunt but had not IVH, thus, excluded) **n=6161 children with severe IVH or no IVH studied in depth in this study**, and classified into 5 groups: 1) no IVH/no shunt n=5163 2) IVH grade 3/no shunt n=459 3) IVH grade 3/shunt n=103 4) IVH grade 4/no shunt n=311 5) IVH grade 4/shunt n=125 **Characteristics** Maternal and Neonatal Characteristics of Study Population	**Risk factors** Intraventricular haemorrage (IVH) grade 3-4 (with or without shunt)	**Setting** Infants born in 19 centers of the National Institute of Child Health and Human Development Neonatal Research Network, neonatal data obtained from the Generic Database of the research network, follow-up examinations done prospectively. **Method(s) of measurement for risk factor(s)** Intraventricular haemorrage (IVH) grade 3-4 (with or without shunt), defined on the basis of Papile criteria. Cranial sonograms reviewed by the staff radiologists at each center.	**Outcome(s) at age** **Outcome assessment at 18-22 months' corrected age:** RRs (95% CI) for the following neurodevelopmental outcomes, adjusted for study center, gestational age, birth weight, gender, race, caesarean section delivery, multiple birth, antenatal steroid exposure, postnatal steroid exposure, surfactant use, respiratory distress syndrome, bronchopulmonary dysplacia (BPD), patent ductus arteriosus, periventricular leukomalacia (PVL), infection group, caregivers' education. <u>PDI <70</u> IVH 3/no shunt: Reference IVH 3/shunt: 1.61 (1.32-1.96) No IVH/no shunt: Reference	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Study participation:** low risk of bias **Study attrition:** moderate risk of bias 82% follow-up rate at 18-22 months overall (n=7776 out of n=9486 eligible), although the analyses of interest further excluded children so the cohort included in analyses of interest actually included only n=6161 out of the original n=9486 (64.9%). Potential differences between the ones included and lost to follow-up not reported.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Study type

Multicentre cohort study

Aim of the study

To evaluate neurodevelopmental and growth outcomes among extremely low birth weight infants who had severe intraventricular haemorrhage (IVH) that required shunt insertion compared with infants without shunt insertion.

Study dates

1993-2002, follow-up at 18-22 months' corrected age.

Source of funding</td>
<td>
<table>
<tr><th>Characteristic[a]</th><th colspan="5">Group, n (%)</th></tr>
<tr><th></th><th>No IVH/No Shunt (n = 5163)</th><th>IVH 3/No Shunt (n = 459)</th><th>IVH 3/Shunt (n = 103)[b]</th><th>IVH 4/No Shunt (n = 311)</th><th>IVH 4/Shunt (n = 125)[c]</th></tr>
<tr><td colspan="6">Maternal</td></tr>
<tr><td>Age ≤19 y</td><td>791/5161 (15)</td><td>84/459 (18)</td><td>17/103 (17)</td><td>55/310 (18)</td><td>26/125 (21)</td></tr>
<tr><td>ROM >24 h</td><td>1199/5062 (24)</td><td>98/443 (22)</td><td>19/102 (19)</td><td>66/297 (22)</td><td>20/120 (17)</td></tr>
<tr><td>Antenatal antibiotics</td><td>3290/5154 (64)</td><td>312/455 (69)</td><td>78/103 (76)</td><td>201/310 (65)</td><td>72/121 (60)</td></tr>
<tr><td>Antenatal steroids</td><td>3999/5157 (78)</td><td>297/456 (65)</td><td>75/102 (74)</td><td>186/310 (60)</td><td>67/122 (55)</td></tr>
<tr><td>Cesarean section</td><td>3368/5157 (65)</td><td>208/458 (45)</td><td>54/103 (52)</td><td>148/309 (48)</td><td>75/125 (60)e</td></tr>
<tr><td>Caregiver education: high school graduated</td><td>3897/5093 (77)</td><td>328/456 (72)</td><td>81/102 (79)</td><td>226/311 (73)</td><td>94/124 (76)</td></tr>
<tr><td colspan="6">Neonatal</td></tr>
<tr><td>Birth weight, g</td><td></td><td></td><td></td><td></td><td></td></tr>
</table>
</td>
<td></td>
<td>All neonatal information was recorded in the Generic Database and obtained from there.

Outcome(s) ascertainment/measures

Psychomotor Development Index (PDI) <70, assessed by Bayley Scales of Infant Development IIR, administered by certified examiners)

Statistical methods

Poisson regression analysis, adjusting for study center, gestational age, birth weight, gender, race, caesarean section delivery, multiple birth, antenatal steroid exposure, postnatal steroid exposure, surfactant use, respiratory distress syndrome, bronchopulmonary dysplacia (BPD), patent ductus arteriosus, periventricular</td>
<td>IVH 3/shunt: 2.45 (2.06-2.91)

IVH 4/no shunt: Reference
IVH 4/shunt: 1.94 (1.61-2.34)

No IVH/no shunt: Reference
IVH 4/shunt: 2.90 (2.45-3.43)</td>
<td>Prognostic factor measurement: low risk of bias
Risk factors are appropriately defined and measured. PVL diagnosis procedure differed between infants born before or after August 1998 (timing of cranial sonogram to diagnose PVL differed), however, PVL was not the primary risk factor at hand so has relatively little impact on the overall results.
Outcome measurement: moderate risk of bias
CP not defined. Visual impairment defined as use of corrective lenses or blindness in 1 or both eyes, definition thus limited, not sure if use of corrective lenses is "severe" enough to be considered an outcome in our review. However, the composite outcome (NDI) considered only "blind in both eyes".</td>
</tr>
</table>

Study details	Participants						Risk factors	Methods	Outcomes and Results	Comments
National Institutes of Health and the National Institute of Child Health and Human Development	401–500	88/5163 (2)	9/459 (2)	0/103 (0)	3/311 (1)	2/125 (2)		leukomalacia (PVL), infection group, caregivers' education. **Length of follow-up** 18-22 months' corrected age.		**Study confounding:** low risk of bias Models adjusted for appropriate factors and this was clearly reported. **Statistical analysis and reporting:** moderate risk of bias Not clear why Poisson regression was used, however, likely to be an appropriate method. Not significant findings for sub-group analysis (among children with severe IVH and shunt) not reported. **Overall quality:** moderate
	501–750	1817/5163 (35)	210/459 (46)	38/103 (37)	162/311 (52)	50/125 (40)				
	751–1000	3258/5163 (63)	240/459 (52)	65/103 (63)	146/311 (47)	73/125 (58)				
	GA, wk									
	<25	835/5162 (16)	151/459 (33)	33/103 (32)	114/311 (37)	28/124 (23)e				
	25–28	3567/5162 (69)	288/459 (63)	67/103 (65)	183/311 (59)	92/124 (74)				
	29–32	724/5162 (14)	20/459 (4)	3/103 (3)	13/311 (4)	4/124 (3)				
	≥33	36/5162 (1)	0/459 (0)	0/103 (0)	1/311 (<1)	0/124 (0)				
	SGA at birth	1019/5162 (20)	38/459 (8)	5/103 (5)	25/311 (8)	6/124 (5)				
	HC at <10th percentile at birth	784/5007 (16)	31/448 (7)	6/101 (6)	22/294 (7)	8/119 (7)				
	Male	2308/5163 (45)	245/459 (53)	63/103 (61)	162/311 (52)	60/125 (48)				
	Race									
	Black	2280/5161 (44)	207/459 (45)	48/103 (47)	149/311 (48)	64/125 (51)				

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments

White	2026/5161 (39)	163/459 (36)	42/103 (41)	105/311 (34)	49/125 (39)
Hispanic	698/5161 (14)	75/459 (16)	13/103 (13)	48/311 (15)	10/125 (8)
Other	157/5161 (3)	14/459 (3)	0/103 (0)	9/311 (3)	2/125 (2)

[a]Information was missing for mother's age (3), ROM at >24 hours before birth (137), antenatal antibiotics (18), antenatal steroids (14), cesarean section (9), caregiver high school degree (75), GA (2), SGA (2), HC at birth (192), and race (2).

[b]There were no statistically significant comparisons between IVH 3/shunt versus IVH 3/no shunt. Comparisons between IVH 3/shunt versus no IVH/no shunt were statistically significant for antenatal antibiotics ($P < .05$), cesarean section birth ($P < .01$), GA ($P < .001$), SGA ($P < .001$), HC at the <10th percentile ($P < .01$), and male gender ($P < .001$).

[c]Statistically significant comparisons between IVH 4/shunt versus IVH 4/no shunt are shown. Comparisons between IVH 4/shunt versus no IVH/no shunt were statistically significant for antenatal steroids ($P < .001$), GA ($P < .01$), SGA ($P < .001$), and HC < 10th percentile ($P < .01$).

[d]The mother was the caretaker for 91% of the infants.

[e]$P \leq .05$ for IVH 4/shunt versus IVH 4/no shunt by the χ^2 test.

Inclusion criteria

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td>Surviving infants of the 19 participating neonatal centers of the National Institute of Child Health and Human Development Neonatal Research Network who were born between 1 Jan 1993 and 31 Dec 2002.
Birth weight <1000 grams.
Infants who participated in the Generic Database and Follow-up Studies.

Exclusion criteria

Infants with major malformations or syndromes, including central nervous system defects, congenital heart defects, gastrointestinal defects, and chromosomal abnormalities.</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Ref Id

336075

Full citation

Allred, E. N., Capone Jr, A., Fraioli, A., Dammann, O., Droste, P., Duker, J., Gise, R., Kuban, K., Leviton, A., O'Shea, T. M., Paneth, N., Petersen, R., Trese, M., Stoessel, K., Vanderveen, D., Wallace, D. K., Weaver, G., Retinopathy of prematurity and</td><td>Sample size

n=1,085

Characteristics
<table><tr><td></td><td>Gestational age</td><td></td><td>Birth weight</td><td></td></tr><tr><td>ROP</td><td>23-24 weeks</td><td>25-26 weeks</td><td><-2SD</td><td>>=-2SD to <-1SD</td></tr><tr><td>Stage 3-5, %</td><td>37</td><td>50</td><td>10</td><td>17</td></tr><tr><td>Stage <=3, %</td><td>14</td><td>45</td><td>4</td><td>12</td></tr></table></td><td>Risk factors

Retinopathy of prematurity (ROP)</td><td>Setting

14 participating institutions in the Extremely Low Gestational Age Newborn (ELGAN) Study during 2002-2004 in the United States

Method(s) of measurement for risk factor(s)

Severe retinopathy of prematurity (ROP), defined according to the following criteria: 1) stage 3 or higher, 2) zone I disease, 3) any prethreshold or worse, and 4) plus disease.</td><td>Outcome(s) at age

Outcomes assessed at 24 months:
ORs (95% CI) obtained by multiple logistic regression model adjusting for gestational age, birth weight z-score categories, hyperoxemia (a PaO2 in the highest quartile on 2 of the first 3 postnatal days), Score of Neonatal Acute Physiology-II (SNAP-II) in the highest quartile, culture-proven bacteremia in the first 28 days, mechanical or high frequency on 14 or more days, and growth velocity in the lowest quertile.

PDI <55</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: moderate risk of bias
Baseline characteristics of the sample are limited: only <23-24 and 25-26 weeks' gestational age and <-2SD and >=-2SD to <-1SD birth weight are reported (no p-values).
Attrition: moderate r isk of bias
This study had a strict inclusion</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
brain damage in the very preterm newborn, Journal of AAPOS, 18, 241-247, 2014 **Country/ies where the study was carried out** United States **Study type** Prospective cohort study **Aim of the study** To evaluate how much of the association between retinopathy of prematurity (ROP) and brain disorders can be explained by low gestational age, abnormally high Scores for Neonatal Acute Physiology, hyperoxemia, bacteremia, fetal and postnatal	<table><tr><td></td><td></td><td></td><td></td><td></td></tr><tr><td>Plus disease, %</td><td>48</td><td>45</td><td>9</td><td>20</td></tr><tr><td>No plus disease, %</td><td>17</td><td>46</td><td>5</td><td>12</td></tr><tr><td></td><td></td><td></td><td></td><td></td></tr><tr><td>Zone 1, %</td><td>46</td><td>53</td><td>62</td><td>36</td></tr><tr><td>No zone 1, %</td><td>18</td><td>46</td><td>34</td><td>45</td></tr></table> **Inclusion criteria** Infants who were born <28 weeks of gestation at one of the 14 participating institutions in the Extremely Low Gestational Age Newborn (ELGAN) Study during 2002-2004, whose mothers gave consent, who had an eye examination for retinopathy for prematurity (ROP) while in the intensive care nursery, and who survived to 2 years of corrected age, and who had a developmental assessment at 24 months. **Exclusion criteria** None reported.		ROP was examined by ophthalmologic examination by 31 weeks postmenstrual age or 4 weeks actual age, whichever was later. **Outcome(s) ascertainment/measures** Psychomotor Development Index (PDI), assessed by Bayley Scales of Infant Development (2nd edition) by certified examiners: PDI <55 PDI 56-69 **Statistical methods** Multiple logistic regression model adjusting for gestational age, birth weight z-score categories, hyperoxemia (a PaO2 in the highest quartile on 2 of the first 3 postnatal days), Score of Neonatal Acute Physiology-II (SNAP-II) in the highest quartile, culture-	No ROP stage 3+: reference ROP stage 3+: 1.6 (1.03-2.4) No ROP plus disease: reference ROP plus disease: 1.8 (1.1-3.1) No ROP zone 1: reference ROP zone 1: 1.1 (0.6-2.2) No ROP threshold: reference ROP threshold: 1.8 (0.6-5.0) No ROP pre-threshold: reference ROP pre- threshold: 1.9 (1.1-3.1) <u>PDI 56-69</u> No ROP stage 3+: reference ROP stage 3+: 1.6 (1.03-2.5) No ROP plus disease: reference ROP plus disease: 1.4 (0.7-2.6) No ROP zone 1: reference ROP zone 1: 2.2 (1.2-4.2) No ROP threshold: reference	criteria that only included the ones who survived, who had ROP data and who have follow-up data, thus, attrition is low, however, 13.1% of the original source population (n=1,249 infants with maternal consent) were lost to follow-up either because of death prior to 2-year follow-up or because of lack of ROP data or no follow-up assessment. The characteristics of these were not described. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** moderate risk of bias The definition and diagnosis of CP is poorly reported: "The topographic diagnosis of CP (quadriparesis, diparesis, or hemiparesis) was based on an algorithm using these data.". **Confounding:** mode rate risk of bias

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td>growth restriction, and prolonged ventilator assistance.

Study dates

2002-2004, follow-up at 24 months.

Source of funding

None reported.</td><td></td><td></td><td>proven bacteremia in the first 28 days, mechanical or high frequency on 14 or more days, and growth velocity in the lowest quertile.

Length of follow-up

24 months</td><td>ROP threshold: 2.1 (0.7-6.6)

No ROP pre-threshold: reference
ROP pre-threshold: 1.6 (0.9-2.9)</td><td>Missing some potentially important confounders (e.g. gender, parental characteristics, multiple birth) and some confounding factors are unclearly described (e.g. SNAP-II).
Analysis and reporting: low risk of bias
All main outcomes and presented, statistical methods are approapriate.

Overall quality: moderate</td></tr>
<tr><td>Ref Id

173586

Full citation

Hintz,S.R., Kendrick,D.E., Stoll,B.J., Vohr,B.R., Fanaroff,A.A., Donovan,E.F., Poole,W.K., Blakely,M.L., Wright,L., Higgins,R., Neurodevelopmental and growth outcomes of</td><td>Sample size

n=4933 extremely low birth weight infants survived >12h
n=3814 survived to discharge
n=2948 followed up at 18-22 months' corrected age (n=2703 with no NEC, n=245 with NEC)

Characteristics

<table><tr><td></td><td>Surg NEC</td><td>Med NEC</td><td>No NEC</td><td>Surg NEC vs No NEC p-</td><td>Med NEC vs No NEC p-</td></tr></table></td><td>Risk factors

Necrotising enterocolitis (NEC), Modified Bell's classification stage IIA or greater.
Subgroups: surgically managed NEC or medically managed NEC.</td><td>Setting

Data from a multicentre National Institute of Child Health and Human Development Neonatal Research Network Very Low Birth Weight Registry in the US.

Method(s) of measurement for risk factor(s)

Necrotising enterocolitis (NEC),</td><td>Outcome(s) at age

Outcomes assessed at 18-22 months' corrected age:
Multiple logistic regression models showing OR (95% CI), adjusted for network centre, use of antenatal glucocorticoids, rupture of membranes >24h, outborn status, estimated gestational age, gender, race, birth weight, small for gestational age, surfactant therapy, intraventricular haemmorrhage grade 3 or 4 or cystic periventricular leukomalacia, sepsis,</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
Of the ones included in the study overall (ELBW infants who survived >12h), 40.2% were lost to follow-up. Of the ones who survived to</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>extremely low birth weight infants after necrotizing enterocolitis, Pediatrics, 115, 696-703, 2005

Country/ies where the study was carried out

USA

Study type

Multicentre cohort study, retrospective analysis.

Aim of the study

To compare growth, neurologic and cognitive outcomes among extremely low birth weight infants with surgically managed necrotising enterocolitis (NEC) and</td>
<td>
<table>
<tr><td></td><td></td><td></td><td></td><td>value</td><td>value</td></tr>
<tr><td>Birth weight, mean g +- SD</td><td>757 +- 129</td><td>762 +- 133</td><td>792 +- 132</td><td>0.003</td><td>0.01</td></tr>
<tr><td>Estimated GA <28 weeks, %</td><td>82</td><td>83</td><td>77</td><td>ns</td><td>ns</td></tr>
<tr><td>ROM >24h, %</td><td>35</td><td>27</td><td>25</td><td>0.014</td><td>ns</td></tr>
<tr><td>Antenatal antibiotics, %</td><td>68</td><td>75</td><td>66</td><td>ns</td><td>0.07</td></tr>
<tr><td>Inborn, %</td><td>87</td><td>88</td><td>91</td><td>ns</td><td>ns</td></tr>
<tr><td>Male, %</td><td>52</td><td>49</td><td>47</td><td>ns</td><td>ns</td></tr>
<tr><td>Race black, %</td><td>42</td><td>51</td><td>44</td><td>ns</td><td>ns</td></tr>
</table>
</td>
<td></td>
<td>Modified Bell's classification stage IIA or greater. Data obtained from the National Institute of Child Health and Human Development Neonatal Research Network Very Low Birth Weight Registry.
Subgroups:
Surgically managed NEC, any surgical intervention (drain, laparotomy, or both).
Medically managed NEC, no surgical intervention.

Outcome(s) ascertainment/measures

Psychomotor development index (PDI) <70, assessed through the Bayley Scales of Infant Development-II (BSID-II).
All neurologic assessments were performed by certified, masked developmentalists who had been trained in the examination procedure in an</td>
<td>postnatal steroid treatment, bronchopulmonary dysplasia, and highest level of education attained by the primary caregiver.

<u>PDI <70</u>
No NEC: reference
Surgical NEC: 1.95 (1.25-3.04)

No NEC: reference
Medical NEC: 1.08 (0.66-1.80)</td>
<td>hospital discharge, 22.7% were lost to follow-up. No information provided whether or not the ones lost to follow-up have different characteristics than the ones included in analysis.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias
Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
medically managed NEC with infants without history of NEC at 18 to 22 months' corrected age. **Study dates** 1995-1998, follow-up at 18-22 months' corrected age. **Source of funding** National institutes of health	<table><tr><td>Race white, %</td><td>39</td><td>36</td><td>40</td><td>ns</td><td>ns</td></tr><tr><td>Race hispanic, %</td><td>16</td><td>9</td><td>13</td><td>ns</td><td>ns</td></tr><tr><td>Multiple birth, %</td><td>24</td><td>25</td><td>22</td><td>ns</td><td>ns</td></tr><tr><td>SGA, %</td><td>14</td><td>17</td><td>18</td><td>ns</td><td>ns</td></tr><tr><td>Antenatal steroids, %</td><td>73</td><td>81</td><td>77</td><td>ns</td><td>ns</td></tr></table> **Inclusion criteria** Infants with birth weight of 401-1000 g who were born from 1 Jan 1995 to 31 Dec 1998 and were admitted to a National Institute of Child Health and Human Development Neonatal Research Network center within 14 days of birth and survived >12h. **Exclusion criteria** None reported.		aanual 2-day workshop. **Statistical methods** Logistic regression model to evaluate NEC management-related risk (surgical NEC or medical NED vs. no NEC) for CP, MDI <70, PDI <70, and NDI, adjusting for differences in perinatal and neonatal variables: network centre, use of antenatal glucocorticoids, rupture of membranes >24h, outborn status, estimated gestational age, gender, race, birth weight, small for gestational age, surfactant therapy, intraventricular haemmorrhage grade 3 or 4 or cystic periventricular leukomalacia, sepsis, postnatal steroid treatment, bronchopulmonary dysplasia, and highest level of education attained by the primary caregiver.		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			Length of follow-up 18 to 22 months' corrected age.		
Ref Id 357477 **Full citation** Shankaran, S., Johnson, Y., Langer, J. C., Vohr, B. R., Fanaroff, A. A., Wright, L. L., Poole, W. K., Outcome of extremely-low-birth-weight infants at highest risk: Gestational age <24 weeks, birth weight <750 g, and 1-minute Apgar <3, American Journal of Obstetrics and Gynecology, 191, 1084-1091, 2004 **Country/ies where the study was carried out** US	**Sample size** N= 246 **Characteristics** Seen at follow-up (n=246) Black race (n):146 Complete steroids (n):70 Maternal age (mean year, SD):26.7 (6.9) Male (n):110 Gestational age (mean week, SD):23.6 (0.7) Grade III-IV ICH (n):79 PVL (n): 21 BPD (n): 157 Steroids for BPD (n):200 Household income <20k (n):135 **Inclusion criteria** Extremely-low-birth-weight infants, all of whom had 3 characteristics: gestational age (GA)≤24 wks, birth weight ≤750g, and 1-minute Apgar score ≤3. **Exclusion criteria** Not reported	**Risk factors** ICH grades 3 - 4; PVL; Any antenatal steriods; Male; Black; Household income < 20k; BPD;	**Setting** Neonatal Intensive Care Unit (NICU) of the 12 participating centres; **Method(s) of measurement for risk factor(s)** Data are abstracted onto standardized forms from the mothers' and infants' charts by trained research nurses, who use definitions that were developed by the investigators and described in the study manual of operations. **Outcome(s) ascertainment/measures** The Bayley Scales of Infant Development (BSID-II) to assess Psychomotor	**Outcome(s) at age** **Outcomes assessed at age 18-22 months' corrected age;** **<u>Psychomotor developmental delay (PDI < 70): OR (95%CI)</u>** ICH grade 3-4: 1.1 (0.6-2.3) PVL: 3.1 (1.1-9.4) Any antenatal steriods: 0.9 (0.5-1.7) Male: 1.3 (0.7-2.6) Black: 1.2 (0.6-2.5) Household income < 20K: 1.5 (0.7-3.2) BPD: Not signficant (NS) -risk factors were adjusted for each other, plus surfactant administration, steriods for BPD, Medicaid,	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** Low risk of bias **Attrition:** moderate risk of bias (n=58 were not seen at follow up) **Prognostic factor measurement:** High risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: low

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study type Prospective study **Aim of the study** To evaluate neuro-developmental outcome in extremely low-birth-wight infants, all of whom had 3 characteristics: gestational age <= 24 weeks, birth weight < 750 g, and 1-minute Apgar score <=3. **Study dates** 1993-1999 **Source of funding** National Institute of Child Health and Human Development			Developmental Index (PDI), was administered by clinical psychologists or psychometricians trained to reliability, PDI score <70 considered as delay. **Statistical methods** Multivariate analysis was performed to identify association between risk factors and outcomes of cerebral palsy, developmental disability (MDI <70, PDI <70, or NDI), or death after NICU discharge, and results expressed as odds ratios and 95% confidence intervals. **Length of follow-up** Around 2 years.	No high school degree, 2-parent household;	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>
Ref Id

317215

Full citation

Vohr,B.R., Wright,L.L., Poole,W.K., McDonald,S.A., Neurodevelopmental outcomes of extremely low birth weight infants <32 weeks' gestation between 1993 and 1998, Pediatrics, 116, 635-643, 2005

Country/ies where the study was carried out

USA

Study type

A multicentre cohort study

Aim of the study

This study evaluated the impact of
</td>
<td>
Sample size

n=7398 infants fit the inclusion criteria
n=4761 infants survived until discharge or 120 days
n=124 post-discharge deaths
n=858 infants lost to follow-up
n=118 infants with incomplete follow-up data
n=3785 infants included in analysis (51% of the original sample, 79.5% of the ones who survived up to discharge or 120 days)

Characteristics
<table>
<tr><td></td><td colspan="2">1993-94</td><td colspan="2">1995-96</td><td colspan="2">1997-98</td></tr>
<tr><td></td><td>22-26 weeks</td><td>27-32 weeks</td><td>22-26 weeks</td><td>27-32 weeks</td><td>22-26 weeks</td><td>27-32 weeks</td></tr>
<tr><td>Evaluated at 18 mo, n</td><td>665</td><td>444</td><td>716</td><td>538</td><td>910</td><td>512</td></tr>
<tr><td>White, %</td><td>33.8</td><td>35.6</td><td>32.4</td><td>38.3</td><td>37.1</td><td>46.2</td></tr>
<tr><td>Maternal age <19 y, %</td><td>14.6</td><td>10.4</td><td>11.6</td><td>11.7</td><td>11.5</td><td>11.1</td></tr>
<tr><td>Maternal education <12 y, %</td><td>34.4</td><td>26.6</td><td>27.2</td><td>23.3</td><td>28.7</td><td>24.0</td></tr>
<tr><td>Medicaid, %</td><td>63.8</td><td>63.7</td><td>65.3</td><td>55.5</td><td>58.8</td><td>51.6</td></tr>
</table>
</td>
<td>
Risk factors

Periventricular leucomalasia (PVL)
Grade 3-4 IVH
Postnatal steroids
Broncho pulmonary dysplasia (BPD)
Sepsis
Antenatal steroids
</td>
<td>
Setting

Using data collected from 12 different centers of the National Institute of Child Health and Human Development Neonatal Research Network in the US.

Method(s) of measurement for risk factor(s)

Perinatal data collected prospectively by study nurses using standard registry forms. Definitions of risk factors or measurements of them are not described in the publication, they refer to other studies which cannot be accessed.
Periventricular leucomalasia (PVL), not described
Grade 3-4 IVH, not described
Postnatal steroids, not described
Broncho pulmonary dysplasia (BPD), O2 requirement at 36 weeks
Sepsis, not described
</td>
<td>
Outcome(s) at age

Outcomes assessed at 18-22 months of corrected age:
Variables included in the model: epoch; gestational age group; birth weight; gender; small for gestational age; multiple births; surfactant; grades 3 to 4 IVH; PVL; sepsis; oxygen requirement at 36 weeks; white vs. non-white race; outborn vs. inborn status ceasarean section vs. vaginal delivery; maternal education <12 years vs. >=12 years; private health insurance vs. public; conventional ventiolation vs. none; adjusted age at the time of assessment; centre; and the 4 interventions of interest: antenatal steroids (yes, no), high-frequency ventilation vs. none; days to regain birth weight, and postnatal steroids (yes, no).

<u>PDI <70</u>
No PVL: reference
PVL: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 2).
</td>
<td>
Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: moderate risk of bias
No description of baseline sample characteristics (only of the ones who were followed-up).
Attrition: moderate risk of bias
Almost half (49%) of original sample were lost to follow-up, of the ones surviving to discharge 20.5% were lost to follow-up. These infants (the 20.5%) were more often outborn, had had less prenatal care, had received less antenatal steroids, had had less surfactant use, they had higher birth weight, less chronic lung disease, lower percentage of multiple birth, fewer days at the hospital, fewer postnatal steroids and fewer days on a ventilator.
</td>
</tr>
</table>

Study details	Participants							Risk factors	Methods	Outcomes and Results	Comments
changes in perinatal management of neurodevelopmental impairment at 18 to 22 months' corrected age of low gestation (22-26 weeks) and higher gestation (27-32 weeks) extremely low birth weight infants (401-1000 g birth weight) who were cared for in the National Institute of Child Health and HUman Development Neonatal Research Network during 3 epochs (1993-1994, 1995-1996, and 1997-1998). It was hypothesized that outcomes would improvae over the 3 epochs. **Study dates**	Outborn, %	13.1	11.7	11.6	7.6	9.1	8.6		Antenatal steroids, not described **Outcome(s) ascertainment/measures** Psychomotor Development Index (PDI) <70, assessed through Bayley Scales of Infant Development II (BSID-II) or a gross motor assessment (not defined). **Statistical methods** Multiple logistic regression. Variables included in the model: epoch; gestational age group; birth weight; gender; small for gestational age; multiple births; surfactant; grades 3 to 4 IVH; PVL; sepsis; oxygen requirement at 36 weeks; white vs. non-white race; outborn vs. inborn status ceasarean section vs. vaginal delivery; maternal education <12 years vs. >=12 years; private	No grade 3-4 IVH: reference Grade 3-4 IVH: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 2). No postnatal steroids: reference Postnatal steroids: AOR 1.99 (1.56-2.55) No BPD: reference BPD: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 2). No sepsis: reference Sepsis: Not significant, AOR and 95% CI not reported, only in a forest plot (Fig 2). No antenatal steroids: reference Antenatal steroids: AOR 0.66 (0.52-0.84)	**Prognostic factor measurement:** moderate risk of bias Poor description of risk factors or their measurements, the publication refers to other publications with more description (cannot be accessed). **Outcome measurement:** high risk of bias MDI and PDI assessed through either BSID-II or "neurologic examination and gross motor assessment", thus, not the same for all the participants. **Analysis and reporting:** moderate risk of bias Statistical methods seem appropriate, however, reporting of exact effect estimates is limited. **Overall quality:** moderate
	Ceasarean section, %	41.6	68.8	46.0	73.9	50.7	73.0				
	Birth weight, mean g	752.6	858.4	750.4	857.7	744.9	860.2				
	SGA, %	4.1	38.1	3.3	37.2	4.7	35.3				
	Surfactant, %	75.8	62.6	79.9	68.2	84.9	67.8				
	IVH grades 3-4, %	28.0	14.0	28.4	12.9	17.2	9.5				
	PVL, %	7.3	5.2	8.8	7.0	6.2	4.7				
	O2 at 36 weeks, %	47.7	30.2	51.9	33.8	54.3	34.5				
	Days on ventilator, mean	36.6	16.5	34.7	15.7	35.2	14.5				
	Sepsis, %	48.0	31.1	45.1	29.4	43.4	28.1				
	Multiple births, %	18.3	20.9	17.2	19.1	24.0	25.6				

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
1993-1998, follow-up at 18 to 22 months of corrected age. **Source of funding** National Institute of Child Health and Human Development through Cooprative Agreements HD 27904, Brown University; U10 HD27856, Indiana University; U10 HD27853, Cincinnati University; U10 HD27851, Emory University; U10 HD21364, Case Western University; U10 HD21373, University of Texas-Houston; U10 HD21397, Miami University; U10 HD21385, Wayne State University; U10 HD21415,	<table><tr><td>Days in hospital, mean</td><td>114.4</td><td>86.0</td><td>109.8</td><td>83.30</td><td>108.7</td><td>77.7</td></tr><tr><td>Coorected age, months</td><td>19.4</td><td>19.6</td><td>19.3</td><td>19.4</td><td>19.6</td><td>19.9</td></tr></table> **Inclusion criteria** Infants born prematurely at 22-32 weeks of gestation with an extremely low birth weight (401-1000 g) who were being cared for in 1 of the 12 centres of the National Institute of Child Health and Human Development Neonatal Research Network during 1993-1998. Deaths in the delivery room were included. **Exclusion criteria** None reported.		health insurance vs. public; conventional ventiolation vs. none; adjusted age at the time of assessment; centre; and the 4 interventions of interest: antenatal steroids (yes, no), high-frequency ventilation vs. none; days to regain birth weight, and postnatal steroids (yes, no). **Length of follow-up** 18-22 months' corrected age		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
University of Tennessee; U10 HD27880, Stanford University; U10 HD27881, University of New Mexico; U10 HD27871, Yale University, and U01 HD36790, RTI International.					
Ref Id 434950 **Full citation** Farooqi, A., Hagglof, B., Sedin, G., Gothefors, L., Serenius, F., Mental health and social competencies of 10- to 12-year-old children born at 23 to 25 weeks of gestation in the 1990s: a Swedish national prospective follow-up study,	**Sample size** Total sample: n=169 Extremely immature (EI) children born before 26 completed weeks of gestation (n=83) Controls (n=86) children with normal birth weight born at term at the same hospital, of the same gender and nearest in birth date (7 days) to the extremely immature child. **Characteristics** At 11 years of age, 13 EI children (15%) had neurosensory impairments, which included 1 of the following conditions: CP for 5, severe visual impairment (including unilateral or bilateral blindness) for 10, and sensorineural disability requiring a hearing aid for 5. In the control group, the corresponding rate was 2% (n=2; 1 child had CP, and 1 had severe visual impairment).25 Of the 86 EI children, 73 (85%) were in mainstream schools and 13 (15%) were receiving full-time special education.	**Risk factors** GA	**Setting** National cohort in Sweden. **Method(s) of measurement for risk factor(s)** Not reported how GA was measured/estimated. **Outcome(s) ascertainment/measures** For assessment of the parents' and teachers' perceptions of the children's behavior,	**Outcome(s) at age** **Assessed at 11 years** Parent's report on child's behaviour: <u>Anxious/depressed</u> Children born at <26 wks: 2.56(1.06–6.18) Term control group: reference <u>Withdrawn:</u> Children born at <26 wks: 2.9(1.27–6.63) Term control group: reference <u>Somatic complaints</u>:	**Limitations** Limitations Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias (of the 89 surviving extremely immature children, 83 were included in the analyses) **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Pediatrics, 120, 118-33, 2007 **Country/ies where the study was carried out** Sweden **Study type** Nationally-representative population-based cohort study **Aim of the study** investigate a national cohort of extremely immature children with respect to behavioral and emotional problems and social competencies, from the perspectives of parents, teachers, and children themselves.	The corresponding rates for the control group were 82 (95%) and 4 (5%). The overall prevalence of 1 major disability was 21% for the EI children and 6% for the control participants (n=2 ——————————— 7.03; P ——————————— .006).25 There were no statistically significant differences between the EI and control participants regarding family structure, maternal education, maternal mental health risk index, SES, and family function **Inclusion criteria** Survivors of a national cohort of 247 consecutive, live-born, extremely immature (<26 weeks of gestation) infants born during the period from April 1990 through March 1992 in the whole of Sweden. **Exclusion criteria** None reported.		the parents completed the Child Behavior Checklist (CBCL) for ages 4 to 18 years and the teachers completed the analogous Teacher Report Form (TRF). Both forms include 118 items for scoring particular behavior/emotional problems, plus 2 open-ended problem items. The list contains 118 items on difficult behaviors, all scored 0 (not true), 1 (somewhat or sometimes true), or 2 (very true or often true). Principal-component analyses reveal 8 sets of behaviors: **withdrawn, somatic complaints, anxious or depressed, social problems, thought problems, attention problems, delinquent behavior, and aggressive behavior.** Principal-factor analyses of the 8 categories produce 2 broad groupings, namely, **internalizing**, derived from the sum of the items in the first	Children born at <26 wks: 1.26(0.42–3.72) Term control group: reference <u>Social problems:</u> Children born at <26 wks: 1.92(0.79–4.63) Term control group: reference <u>Thought problems:</u> Children born at <26 wks: 1.78(0.71–4.5) Term control group: reference <u>Attention problems:</u> Children born at <26 wks: 3.46(1.40–8.54) Term control group: reference <u>Aggressive behaviour:</u> Children born at <26 wks: 0.99(0.36–2.73) Term control group: reference <u>Delinquent behaviour:</u>	**Confounders:** low risk of bias **Analysis and Reporting:** low risk of bias Overall quality: high

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study dates Children born between 1990 and 1992, assessed at 11 years. **Source of funding** The study was supported by the Oskarfonden Foundation and the Sven-Jerrings Fond Foundation.			3 sets, and **externalizing**, derived from the last 2 (delinquent behavior and aggressive behavior). The remaining 3 categories (social, thought, and attention problems) represent problems that fit either broad grouping. Respondents were asked to base their answers on the preceding 6 months. For all TRF and CBCL problem subscales, scores above the 90th percentile for the control subjects of the same gender were classified as being in the abnormal range. The percentile distribution of the total CBCL problem scores for our control group was similar to that for a Swedish reference population. Children completed a self-report with a **depression** self-rating scale (DSRS).32 The DSRS is an 18-item self-report questionnaire composed of a psychiatric symptom checklist that	Children born at <26 wks: 0.87(0.31–2.49) Term control group: reference <u>Internalizing behaviours:</u> Children born at <26 wks: 3.35(1.38–8.11) Term control group: reference <u>Externalizing behaviours:</u> Children born at <26 wks: 0.76(0.22–2.61) Term control group: reference <u>Total problems:</u> Children born at <26 wks: 2.86(1.17–7.0) Term control group: reference	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			measures anxiety and depression. The child is asked to rate his or her own situation during the past month, on a 3-point scale. Scores of 2, 1, and 0 refer to most of the time, sometimes, and never, respectively. For the DSRS, scores above the 90th percentile for the control subjects of the same gender were classified as being in the abnormal range. **Statistical methods** Multivariate logistic regression analyses were also performed to examine differences in dichotomous behavioral outcomes between the groups. Social risk score, family function, gender, maternal mental health risk score, and presence of a chronic medical condition were entered as covariates. **Length of follow-up**	Teacher's report on child's behaviour: <u>Anxious/depressed:</u> Children born at <26 wks: 3.54(1.39- 9.03) Term control group: reference <u>Withdrawn:</u> Children born at <26 wks: 3.15(1.25–8.0) Term control group: reference <u>Somatic complaints:</u> Children born at <26 wks: 3.94(1.37–11.32) Term control group: reference <u>Social problems:</u> Children born at <26 wks: 2.86(1.08–7.58) Term control group: reference <u>Thought problems:</u> Children born at <26 wks: 5.04(1.87–13.61) Term control group: reference <u>Attention problems:</u>	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			11 years	Children born at <26 wks: 3.43(1.26–9.35) Term control group: reference <u>Aggressive behaviour:</u> Children born at <26 wks: 1.33(0.53–3.33) Term control group: reference <u>Delinquent behaviour</u>: Children born at <26 wks: 2.20(0.89–5.45) Term control group: reference <u>Internalizing behaviours:</u> Children born at <26 wks: 3.51(1.41–8.78) Term control group: reference <u>Externalizing behaviours:</u> Children born at <26 wks: 1.76(0.65–4.76) Term control group: reference <u>Total problems:</u> Children born at <26 wks: 3.1(1.19–8.07)	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td>Term control group: reference

ORs (95% CI) adjusted for gender, socialrisk, familyfunction, maternal mental health risk score, and presence of a chronic medical condition.

<u>Children's self-report on depression self-rating scale:</u>
Term control: Reference
Children born at <26 wks: OR 1.27 (9%% CI 0.46–3.54)</td><td></td></tr>
<tr><td>Ref Id

433188

Full citation

Gurka, M. J., LoCasale-Crouch, J., Blackman, J. A., Long-term cognition, achievement,</td><td>Sample size

n=1298 (of which n=53 born at 34-36 weeks of gestation, the rest at term)

Characteristics
<table><tr><td></td><td>Full-term</td><td>Late-preterm</td></tr><tr><td>Male sex, %</td><td>50.9</td><td>56.6</td></tr></table></td><td>Risk factors

Gestational age (34-36 weeks vs 37-41 weeks).</td><td>Setting

National Institute of Child Health and Development Study of Early Child Care and Youth Development, 10 sites in the US, 1991-2007.</td><td>Outcome(s) at age

From 4 to 15 years of age (full-term vs late-preterm):
<u>External behaviours</u>: No significant difference between the groups over time.
<u>Internal behaviours:</u> No significant difference between the groups over time.</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: moder ate risk of bias
The exclusion criteria in this study was very tight, basically only healthy children of</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>socioemotional, and behavioral development of healthy late-preterm infants, Archives of pediatrics & adolescent medicine, 164, 525-32, 2010

Country/ies where the study was carried out

US

Study type

Prospective cohort study

Aim of the study

To compare healthy late-preterm inbfants with their full-term counterparts from age 4 through 15 years for numerous standard cognitive, achievement, socioemotional</td>
<td>
<table>
<tr><td>White race, %</td><td>76.4</td><td>77.4</td></tr>
<tr><td>Black race, %</td><td>12.7</td><td>13.2</td></tr>
<tr><td>Hispanic race, %</td><td>5.9</td><td>7.6</td></tr>
<tr><td>Other race, %</td><td>5</td><td>1.9</td></tr>
<tr><td>Mother had health problems during pregnancy, %</td><td>31.8</td><td>45.2</td></tr>
<tr><td>Vaginal delivery, %</td><td>79.2</td><td>79.3</td></tr>
<tr><td>Planned CS, %</td><td>9</td><td>1.9</td></tr>
<tr><td>Emergency CS, %</td><td>11.7</td><td>18.9</td></tr>
<tr><td>Never breastfed, %</td><td>29.7</td><td>34</td></tr>
<tr><td>Breastfed 0-6 mo, %</td><td>42.1</td><td>40</td></tr>
<tr><td>Breastfed >6 mo, %</td><td>28.1</td><td>26</td></tr>
<tr><td>Mother did not smoke or stopped before pregnancy, %</td><td>81.1</td><td>84.4</td></tr>
<tr><td>Mother smoked during pregnancy but stopped, %</td><td>8.3</td><td>6.7</td></tr>
<tr><td>Mother smoked throughout pregnancy, %</td><td>10.6</td><td>8.9</td></tr>
</table>
</td>
<td></td>
<td>Method(s) of measurement for risk factor(s)

The gestational age was calculated based on birth date and due date, as reported by the mother in the hospital.

Outcome(s) ascertainment/measures

Behavioural and emotional problems: externalising behaviours; internalising behaviours; aggressive behaviours; anxiety/depression, assessed with the Child Behaviour Checklist (CBCL) completed by parents. The CBCL has been age-standardized on large samples of children in the US and abroad. Each of the 118 problem items is scored on a Likert scale based on the preceding 6 months. Scores on each item are summed to give a</td>
<td><u>Aggresive behaviours:</u> No significant difference between the groups over time.
<u>Anxiety/depression:</u> No significant difference between the groups over time.</td>
<td>healthy mothers were included.
Attrition: moderate risk of bias
At the final phase of the study (when the children were 14-15 years), 77% of the included children were still enrolled.
Prognostic factor measurement: moderate risk of bias
GA was estimated using due date (and birth date) obtained from the mother, not antenatal care/medical records.
Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: moderate risk of bias
Behavioural/emotional problems reported by graphs without numerical values for effect estimates and confidence intervals.

Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
and behavioural outcomes. **Study dates** 1991-2007 **Source of funding** Eunice Kennedy Shriver National Institute of Child Health and Development	<table><tr><td>Older sibling, %</td><td>55.9</td><td>50.9</td></tr><tr><td>Maternal education, y</td><td>14.3</td><td>14.3</td></tr><tr><td>Maternal age, y</td><td>28.1</td><td>29.5</td></tr><tr><td>Family income-to-needs ratio</td><td>3.4</td><td>3.6</td></tr><tr><td>Maternal depression score (CES-D)</td><td>9.8</td><td>9.9</td></tr><tr><td>Maternal PPVT-R score</td><td>99.2</td><td>99.0</td></tr></table> **Inclusion criteria** Children born in 10 sites of the study in 1991. The children were eligible if mother was age >18 years and spoke English, the mother was healthy, the baby was a singleton not given up for adoption, the family lived within 1 hour of the research site and the neighbourhood was sufficiently safe for researchers to visit. **Exclusion criteria** Children born before 34 weeks of gestation or at 42-43 weeks of gestation. Infants who had been in the hospital for more than 7 days. Infants who and whose mothers were seriously ill. Infants whose family expected to move within 3 years, infants whose family could not be reached after 3 contact attempts. Infants born to mothers known to be addicted to drugs or alcohol, having chromosomal or genetic abnormality evident at birth that causes severe		raw total problem score, which is then converted to a T-score (mean [SD]=50 [10]). Higher scores indicare more behavioral and emotional problems. Four of the scales in the study were used in the study to examine behavioural and emotional functioning. **Statistical methods** Linear mixed models were used for continuous variables. The outcomes were also modeled as quadratic functions across time (months), including term status (late preterm vs full term) and its interaction with both time components (linear and quadratic). Thus, this model allowed fro the examination of either a constant difference across time between the 2 groups or a difference in the trajectory across time. Of primary interest was the estimated		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
	developmental handicap or disfigurement (e.g. Down syndrome and trisomy 18), possessing congenital defect that causes severe developmental handicap or disfigurement (e.g. spina bifida, orthopedic handicap, cleft palate, congenital heart disease, deafness and blindness), having cerebral palsy, having a congenital infection (e.g. HIV, syphilis, rubella, herpes, toxoplasmosis, and cytomegalovirus) and having genetic or metabolic condition that causes significant developmental handicap not evident in the perinatal period (e.g. hypothyroidism and phenylketonuria).		difference between the 2 groups and its 95% CI. Other covariates included in the model were child race (white vs nonwhite), maternal age (in years), maternal education (in years), whether the mother experiences health problems during the pregnancy, delivery type (vaginal vs caesarean), mean Home Observation for Measurement of the Environment scores during the first 3 years of life (a measure of the quality of the home environment), mean maternal depression scores (Center for Epidemiological Studies-Depression Scales) during the first 3 years of the child's life, and the mother's verbal ability, assessed using the Peabody Picture Vocabulary Test-Revised. **Length of follow-up** From 4 to 15 years.		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>Ref Id

443759

Full citation

Higa Diez, M., Yorifuji, T., Kado, Y., Sanada, S., Doi, H., Preterm birth and behavioural outcomes at 8 years of age: a nationwide survey in Japan, Archives of Disease in Childhood, 101, 338-43, 2016

Country/ies where the study was carried out

Japan

Study type

Prospective cohort design

Aim of the study

To analyse the effect of different preterm birth</td>
<td>Sample size

n=34163 neonates born in Japan in 2001
of which
n=356 born at <34 weeks
n=1287 born at 34-36 weeks
n=9885 born at 37-38 weeks
n=22635 born at 39-41 weeks (reference population)

Characteristics

<table>
<tr><th></th><th><34 wks (n=356)</th><th>34-36 wks (n=1287)</th><th>39-41 wks (n=22635)</th></tr>
<tr><td>Male, %</td><td>56.5</td><td>60.1</td><td>49.7</td></tr>
<tr><td>Multiple birth, %</td><td>21.1</td><td>20.3</td><td>0.2</td></tr>
<tr><td>Multiparity, %</td><td>59</td><td>56.2</td><td>47.8</td></tr>
<tr><td>Mean maternal age at delivery, y</td><td>21.2</td><td>30.7</td><td>30.1</td></tr>
<tr><td>Maternal education university or higher, %</td><td>11.8</td><td>13.3</td><td>15.1</td></tr>
</table>
</td>
<td>Risk factors

Gestational age (<34 weeks and 34-36 weeks vs 39-41 weeks)</td>
<td>Setting

Longitudinal Survey of Babies in the 21st Century in Japan, nationally representative data.

Method(s) of measurement for risk factor(s)

GA was calculated in weeks and obtained from birth records.

Outcome(s) ascertainment/measures

Some questions of the standardised and validated version of the Child Behaviour Checklist 9CBCL) 4-18 for Japan was used. A total of 7 behavioural outcomes were used, three related to attention problems: 1) interrupting people, 2) inability for the child to wait his/her turn during play, and 3) failure to pay attention to the surrounding area when crossing a</td>
<td>Outcome(s) at age

<u>Assessed at 8 years</u>
Attentional problems:
Interrupting people
39-41 wks: Reference
34-36 wks: OR 1.05 (0.93-1.19)
<34 wks: OR 1.10 (0.89-1.38)

Inability to wait his/her turn:
39-41 wks: Reference
34-36 wks: OR 1.28 (1.03-1.59)
<34 wks: OR 1.72 (1.22-2.43)

Failure to pay attention crossing street:
39-41 wks: Reference
34-36 wks: OR 0.98 (0.85-1.14)
<34 wks: OR 1.09 (0.84-1.42)

Subjects who presented adverse outcomes for all attentional problems:
39-41 wks: Reference
34-36 wks: OR 1.43 (0.98-2.09)
<34 wks: OR 2.21 (1.24-3 95)

Delinquent/aggressive behaviours:
Lying
39-41 wks: Reference</td>
<td>Limitations

Limitations
Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: moderate risk of bias
The original study cohort consisted of 53575 participants but by 8 years, only 34163 remained followed-up.
Prognostic factor measurement: low risk of bias
Outcome measurement: mod erate risk of bias
Not clearly described if CBCL was used as such or adapted somehow, they report "...information is related to some questions of the standardised and validated version of the CBCL 4-18 for Japan".
Confounding: low risk of bias
Analysis and reporting: low risk of bias</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr>
<td>categories on behavioural outcomes.

Study dates

Children born in 2001, assessed at 8 years.

Source of funding

Supported by Health and Labour Sciences Research Grants on Health Research on Children, Youth and Families grant and by Efficient Operation of the University grant.</td>
<td>
<table>
<tr><td>Maternal education junior college, &</td><td>40.7</td><td>42</td><td>42.6</td></tr>
<tr><td>Maternal education <= high school, %</td><td>45.2</td><td>42.2</td><td>40.6</td></tr>
<tr><td>Paternal education university or higher, %</td><td>34.3</td><td>37.5</td><td>37.5</td></tr>
<tr><td>Paternal education junior college, %</td><td>15.2</td><td>14.4</td><td>15.8</td></tr>
<tr><td>Paternal education <= high school, %</td><td>47.8</td><td>44.5</td><td>44.1</td></tr>
<tr><td>Mother smoking, %</td><td>13.5</td><td>14.9</td><td>13.7</td></tr>
<tr><td>Mother working, %</td><td>53.9</td><td>53.2</td><td>55.8</td></tr>
</table>
</td>
<td></td>
<td>street; and four related to delinquent/aggressive behaviour: 1) lying, 2) destroying toys or books, 3) hurting other people, and 4) causing disturbances in public. Binary outcomes for each were used. Combined outcome for both attention and delinquent/aggressive behaviour was also used, defined as participants who present adverse for all attention or delinquent/aggressive behaviours.

Statistical methods

Multiple logistic regression, adjusting for potential confounders. Covariates included sex, singleton or not, maternal age at deliverty, attainment of maternal education, maternal smoking habit.

Length of follow-up

8 years.</td>
<td>34-36 wks: OR 1.10 (0.96-1.26)
<34 wks: OR 1.15 (0.96-1.46)

Destroying toys/books
39-41 wks: Reference
34-36 wks: OR 1.15 (0.95-1.39)
<34 wks: OR 1.46 (1.07-1.99)

Hurting other people
39-41 wks: Reference
34-36 wks: OR 1.08 (0.90-1.29)
<34 wks: OR 1.23 (0.90-1.69)

Disturbance in public
39-41 wks: Reference
34-36 wks: OR 1.20 (1.04-1.38)
<34 wks: OR 1.14 (0.89-1.48)

Subjects who presented adverse outcomes for all delinquent/aggressive behaviours
39-41 wks: Reference
34-36 wks: OR 1.02 (0.63-1.65)
<34 wks: OR 1.46 (0.71-3.00)</td>
<td>Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
	Inclusion criteria Neonates born in Japan in 2001 between 10 and 17 January and between 10 and 17 July. **Exclusion criteria** Participants with missing information on gestational age, or those who were born after 41 weeks. Participants who were lost to follow-up or those without information on behavioural outcomes at 8 years of age.				
Ref Id 445954 **Full citation** Fevang, S. K. E., Hysing, M., Markestad, T., et al.,, Mental Health in Children Born Extremely Preterm Without Severe Neurodevelopmental Disabilities, Pediatrics, 2016 **Country/ies where the study was carried out** Norway	**Sample size** N=216 extremely preterm/extremely low birth weight (EP/ELBW) children (born at <28 weeks of gestation or with birth weight <1000 g) N=1767 reference children with parental reported data and N=1880 reference children with teacher reported data **Characteristics** The proportion of fathers with high education was lower in the EP/ELBW than the reference group (42% vs 52%, P = .009), but there were no significant differences in proportions of mothers with high education (59% vs 54%, P = .2) or proportion of boys (49% vs 47%, P = .6, respectively). Characteristics Assessed vs Not Assessed n (%) or mean +- SD Mother high education at delivery: 86 (47) vs 28 (34) Mother age at delivery, y: 30 ± 5 vs 30 ± 6 Boys: 105 (49) vs 76 (62) Birth weight, g: 868 ± 164 vs 861 ± 177 Gestational age, wk: 27 ± 2 vs 26 ± 2 Gestational age <28 wk: 161 (75) vs 98 (80)	**Risk factors** Gestational age	**Setting** National cohort of extremely preterm or extremely LBW children in Norway born in 1999 and 2000. **Method(s) of measurement for risk factor(s)** Not reported. **Outcome(s) ascertainment/measures** Mental health assessment was based on 5 questionnaires, all containing items scored on a 3-point	**Outcome(s) at age** **Assessed at 11 years of age** Autism spectrum disorder symptoms (ASSQ >=95th percentile) *Parent report* Term: reference EP/ELBW: OR 2.3 (1.4-3.8) *Teacher report* Term: reference EO/ELBW: OR 6.6 (4.3-10) Inattention symptoms (SNAP-IV) *Parent report* Term: reference EP/ELBE: OR 4.8 (3.2-7.6) *Teacher report* Term: reference EP/ELBE: OR 5.6 (3.6-8.7) Hyperactivity/impulsivity symptoms (SNAP-IV) *Parent report* Term: reference EP/ELBE: OR 3.3 (2.1-5.2) *Teacher report*	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias **Attrition: high risk of bias** 36% of the children eligible for follow-up were lost to follow-up. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding: high risk of bias** The models only adjusted for paternal educational attainment, because it was the only

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study type National prospective cohort study **Aim of the study** To describe the prevalence and gender characteristics of mental health problems in extremely preterm/extremely low birth weight (EP/ELBW) children without intellectual disabilities, blindness, deafness, or severe cerebral palsy compared with a reference group at 11 years of age. **Study dates** Children born in 1999 and 2000, followed up at 11 years of age.	Small for gestational age: 42 (19) vs 19 (16) Prenatal steroids: 152 (70) vs 82 (67) Preeclampsia: 55 (26) vs 29 (24) Cesarean delivery: 149 (69) vs 74 (61) Multiple births: 52 (24) vs 24 (20) Bronchopulmonary dysplasiae: 105 (49) vs 44 (36) Necrotizing enterocolitis (proven or suspected): 11 (5) vs 2 (2) Normal cerebral ultrasound: 144 (67) vs 89 (73) No retinopathy of prematurity: 161 (75) vs 77 (64) No NDD at 5 y of age: 93 (51) vs 42 (45) Minor NDD at 5 y of age: 83 (46) vs 41 (45) Moderate NDD at 5 y of age: 6 (3) va 9 (10) Ambulatory CP: 7 (3) vs 9 (7) SDQ total difficulties at 5 y: 52 (32) vs 28 (40) **Inclusion criteria** All extremely preterm/extremely LBW children born in Norway in 1999 and 2000. **Exclusion criteria** Children who at 5 years had an IQ <70, nonambulatory CP (class 4 or 5 on the Gross Motor Function Classification for CP), deafness, or blindness were excluded.		scale. The Screen for Child Anxiety Related Emotional Disorders (SCARED) and the Symptoms of Obsessive-Compulsive Disorder questionnaires were completed by parents, and the other questionnaires by both parents and teachers. A scale score ≥95th percentile for the reference group was classified as a high score for all the questionnaires except for the Strengths and Difficulties Questionnaire (SDQ), for which the total difficulties score ≥90th percentile (TDS90) is accepted as a high score. The Autism Spectrum Screening Questionnaire (ASSQ) consists of 27 items reflecting symptoms of ASD, for example, social interaction, communication, restricted and repetitive behavior, motor clumsiness, and tics. The Swanson, Noland, and Pelham	Term:reference EP/ELBW: OR 2.7 (1.6-4.6) <u>Anxiety symptoms (SCARED)</u> *Parent report* Term: reference EP/ELBW: OR 2.3 (1.4-3.7) <u>OCD symptoms</u> *Parent report* Term: reference EP/ELBW: OR 2.6 (1.6-4.3) <u>SDQ total difficulties</u> *Parent report* Term: reference EP/ELBW: OR 3.1 (2.1-4.6) *Teacher report* Term: reference EP/ELBW: OR 4.0 (2.7-5.8) Adjusted for father's educational status.	variable that was significantly different between the groups. However, other potentially important confounders should have been considered. They do not report the sociodemopgrahic characteristic for the reference group. **Analysis and reporting:** Low risk of bias Overall quality: low

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Source of funding The study was funded by the University of Bergen, Per Risteigens Foundation, Nasjonalt Kompetansesenter for AD/HD, Tourettes Syndrom og Narkolepsi, Johan Ludwig Mowinckel Foundation, Renèe og Bredo Grimegaard's Foundation, and Eckboes Foundation.			Questionnaire, Revision IV (SNAP-IV) is a screening tool for ADHD. It contains 9 items on inattention and 9 items on hyperactivity/impulsivity that correspond to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition criteria for ADHD. A 5-item parental version of SCARED to assess anxiety symptoms. Five unvalidated OCD questions derived from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition and International Classification of Diseases, 10th Edition guidelines were used. They have been recommended to identify symptoms of OCD. The SDQ is a general behavioral screening questionnaire consisting of 20 items regarding emotional, peer, conduct, and hyperactivity/ inattention problems. These items are		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			collapsed to form the total difficulties score. **Statistical methods** Logistic regression analysis, adjusting for fathers' educational levels, since this factor was significantly different between the 2 groups. **Length of follow-up** 11 years		
Ref Id 433234 **Full citation** Johnson, S., Matthews, R., Draper, E. S., Field, D. J., Manktelow, B. N., Marlow, N., Smith, L. K., Boyle, E. M., Early Emergence of Delayed Social Competence in Infants Born Late and Moderately Preterm, Journal of	**Sample size** n=625 late and moderately preterm (LMPT, 32-36 weeks) n=760 term controls **Characteristics** Compared with term-born controls, LMPT infants were more likely to be born small for gestational age (SGA) and to be multiple births. LMPT infants were also more likely to have cognitive impairment at 2 years corrected age. There were no significant between-group differences in infants' sex and age at assessment. There was no statistical difference between the groups in ethnicity, maternal age, SES index. **Inclusion criteria**	**Risk factors** Gestational age Ethnicity SES Maternal substance abuse Antenatal steroids Multiple pregnancy SGA Sex	**Setting** Geographically defined region of the East Midlands of England, study called the Late And Moderately preterm Birth Study (LAMBS). Births within this region were derived from 4 large maternity hospitals, a midwifery-led birthing unit, and home births during the study period. **Method(s) of measurement for risk factor(s)**	**Outcome(s) at age** **At 2 years corrected age** <u>Behaviour problem</u> Term: reference 32-36 weeks: RR 1.13 (0.8-1.42) <u>Delayed competence</u> Term: reference 32-36 weeks: RR 1.28 (1.03-1.58) <u>Problem or delay</u> Term: reference 32-36 weeks: RR 1.17 (1.00-1.38) <u>Problem and delay</u> Term: reference 32-36 weeks: RR 1.34 (0.91-1.97) Adjusted for age, sex, SES-index category, SGA, infant cognitive impairment.	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias **Attrition:** high risk of bias 44% of the children eligible for follow-up were lost to follow-up. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Developmental & Behavioral Pediatrics, 36, 690-9, 2015 **Country/ies where the study was carried out** UK **Study type** Prospective population-based cohort study **Aim of the study** To assess behavioral outcomes and social competence at 2 years of age in infants born late and moderately preterm (LMPT; 32–36 wk gestation). **Study dates** Children born 2009-2010,	All babies born late and moderately preterm from September 1, 2009 to December 31, 2010 within a geographically defined region of the East Midlands of England. **Exclusion criteria** Infants with major structural or chromosomal congenital anomalies were recruited but were excluded from the present analyses.		Data about obstetric factors and pre-pregnancy health conditions were collected by research midwives from mothers' medical notes, and data relating to infants' neonatal course were obtained from their medical notes at discharge from hospital using standard clinical record forms and following a study data extraction manual. All forms were checked by a consultant neonatologist (EB) and any missing data or queries verified against the medical notes and amended as necessary. Mothers participated in a semistructured interview after birth to obtain sociodemographic data (SES index). **Outcome(s) ascertainment/measures** At 2 years corrected age, parents were	<u>Delayed socioemotional competence</u> *Ethnicity* White: reference Non-white: RR 1.68 (1.26-2.24) *SES-index* Low risk: reference Medium risk: RR 1.60 (1.14-2.24) High risk: RR 1.98 (1.41-2.75) *Maternal substance abuse* Non-drug user: reference Recreational drugs use during pregnancy: RR 1.70 (1.03-2.82) *Antenatal steroids* Antenatal steroids not given: reference Antenatal steroid given: NS *Sex* Female: reference Male: RR 1.27 0.96-1.67) *Gestational age* 36 wks: reference 35 wks: RR 0.89 (0.64-1.23) 34 wks: RR 0.80 (0.53-1.19) 32-33 wks: RR 0.97 (0.65-1.45) *Multiple pregnancy* Singleton: reference Multiple pregnancy: NS *SGA* AGA: reference SGA: NS Variables that were significant (p<.05) in	**Confounding:** low risk of bias **Analysis and reporting:** moderate risk of bias Not clearly reported which variables were in the final model. Overall quality: low

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
follow-up at 2 years corrected age **Source of funding** National Institute for Health Research (NIHR) under its Programme Grants for Applied Research (PGfAR) Programme (Grant Reference Number RP-PG-0407–10029). The views expressed are those of the author(s) and not necessarily those of the National Health Service (NHS), the NIHR or the Department of Health. N. Marlow receives a proportion of funding from the Department of Health's NIHR Biomedical Research			asked to complete a study questionnaire that comprised a series of parent report measures to assess children's developmental and behavioral outcomes. To assess behavioral outcomes, parents completed the Brief Infant Toddler Social Emotional Assessment (BITSEA). This 42-item questionnaire comprises 2 scales to assess behavior problems and social competence and has previously been shown to have excellent test-retest reliability, interrater reliability and predictive validity for psychiatric disorders at school age in both term and preterm populations. The BITSEA "problem scale" comprises 31 items that -ssess behavior problems in the areas of externalizing problems, internalizing difficulties, dysregulation, maladaptive	univariable analyses were all entered into the model. Variables that were not significant in this model were dropped in turn until only those variables significant at $p < .05$ were included in the final model. Variables that had been dropped were entered back into this final model one at a time to assess their significance.	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Centres funding scheme at UCLH/UCL.			behaviors, and atypical behaviors. Individual item scores are summed to provide a total problem scale score with higher scores indicating greater problems. Using the published age- and sexspecific norm-referenced cutoffs, infants were identified as having behavior problems if they scored >25th percentile of the BITSEA standardization sample. The BITSEA "competence scale" comprises 11 items that assess areas of attention, compliance, mastery motivation, prosocial peer relations, empathy, imitation/play skills, and social relatedness and is designed to identify children who have delays or deficits in the acquisition of social-emotional competencies (irrespective of whether behavior problems are present). Individual item scores were summed to		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			provide a total competence score with lower scores indicating poorer social competence. Infants were identified as having delayed social competence if their total competence score was <15th percentile of children of the same age and sex in the BITSEA standardization sample. **Statistical methods** Prevalence of behaviour problems and delayed social competence was compared between LMPT and term-born infants using Poisson regression with differences quantified using relative risks (RRs) with 95% confidence intervals. Adjusting for sex, age (month of corrected age), SES-Index category and SGA status and cognitive impairment at 2 years. Variables that were significant (p<.05) in univariable analyses		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			were all entered into the model. Variables that were not significant in this model were dropped in turn until only those variables significant at p <.05 were included in the final model. Variables that had been dropped were entered back into this final model one at a time to assess their significance. **Length of follow-up** 2 years (corrected age)		
Ref Id 433537 **Full citation** Johnson, S., Matthews, R., Draper, E. S., Field, D. J., Manktelow, B. N., Marlow, N., Smith, L. K., Boyle, E. M., Eating difficulties in children born late and moderately preterm at 2 y of	**Sample size** N=628 late and moderately preterm (LMPT) children (32-36 weeks) N=759 term controls (>=37 weeks) **Characteristics** LMPT infants were significantly more likely to be born SGA than were termborn controls (10.7% compared with 4.0%) and to have received mechanical ventilation (8.8% compared with 0.7%) and nasogastric feeding (31.8% compared with 1.5%). At 2 y of age, LMPT infants were also at increased risk of cognitive impairment (5.4% compared with 2.6%), behavioral problems (20.4% compared with 17.2%), and delayed social competence (25.6% compared with 17.9%). There were no significant differences	**Risk factors** Gestational age SGA SES	**Setting** The Late and Moderately Preterm Birth Study (LAMBS) study took place in a geographically defined region of the East Midlands of England from September 2009 through December 2010. This comprised infants delivered at 4 large maternity centers, a midwifery-led birthing unit, and at home.	**Outcome(s) at age** **Assessed at 2 years corrected age** <u>Total feeding problems</u> *Gestational age* Term: reference 32-36 wks: RR 1.44 (1.01-2.03) *SES-index* Low risk: reference Medium risk: NS in univariate analysis High risk: NS in univariate analysis *SGA* AGA: reference SGA: RR 1.57 (0.99-2.49)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias **Attrition:** high risk of bias More than 40% of the children eligible for follow-up were lost to follow-up. **Prognostic factor measurement:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
age: a prospective population-based cohort study, American Journal of Clinical Nutrition, 103, 406-14, 2016 **Country/ies where the study was carried out** UK **Study type** Prospective population-based cohort study **Aim of the study** The aims were to assess the prevalence of eating difficulties in infants born LMPT at 2 y corrected age and to explore the impact of neonatal and neurodevelopmental factors.	between mothers of infants born LMPTand those of infants born at term. **Inclusion criteria** All infants born LMPT (32+0–36+6 wk) to mothers resident in a geographically defined region of the East Midlands of England from September 2009 through December 2010 were invited to participate in the Late and Moderately Preterm Birth Study. **Exclusion criteria** Infants with major structural or chromosomal congenital anomalies, including cardiovascular malformations, and neurosensory impairment were excluded from the analyses.		**Method(s) of measurement for risk factor(s)** Information about mothers' sociodemographic status was obtained via a semistructured postnatal interview conducted by research midwives. Obstetric and neonatal data were collected from mothers' and infants' medical notes, respectively, at discharge from the hospital. SGA was classified by using birth weight less than the third percentile for sex and gestation by using customized antenatal growth charts. **Outcome(s) ascertainment/measures** At 2 y corrected age, parents were asked to complete a questionnaire comprising measures to assess infants' eating behavior, cognitive	<u>Refusal/picky eating</u> Term: reference 32-36 wks: RR 1.30 (0.84-1.98) <u>Oral motor problems</u> Term: reference 32-36 wks: RR 1.65 (1.05-2.58) <u>Oral hypersensitivity</u> Term: reference 32-36 wks: RR 1.22 (0.69-2.13) <u>Eating behaviour problems</u> Term: reference 32-36 wks: RR 0.88 (0.53-1.45) The analyses between term and LMPT group were adjusted for sex, SGA, SES index score, and nasogastric tube feeding >2 weeks. The analyses within the LMPT group included the following variables: behaviour problems, delayed social competence, SGA and nasogastric tube feeding.	**Outcome measurement:** low risk of bias **Confounding:** mode rate risk of bias The covariables included in the analyses within the LMPT group potentially lack some important confounders (e.g. sex, maternal age, SES). **Analysis and reporting:** moderate risk of bias Not clearly reported why e.g. sex of the child was not analysed in the multiple variable mode, even though it is significant in the univariate analysis. Overall quality: low

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Study dates Children born between September 2009 and December 2010, follow-up at 2 years corrected age. **Source of funding** Supported by the National Institute for Health Research under its Programme Grants for Applied Research (PGfAR) program (grant RP-PG-040710029).			development, behavior and emotional problems, and neurosensory impairment. A validated eating behavior questionnaire (4) was used to assess the presence of eating difficulties in the 4 domains of refusal/picky eating (e.g., poor appetite, food refusal, selective eating), oral motor problems (e.g., problems biting, chewing, or swallowing; gagging; or choking on food), oral hypersensitivity (e.g., aversion to being touched around the mouth or having things put in the mouth), and eating behavior problems (e.g., has tantrums or makes a mess during meals). For each of 17 items, parents were asked to state whether their child exhibited the problem behavior never, occasionally, or often. Each item was scored 0, 1, or 2, respectively, from which a total eating difficulties score was		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			computed (range: 0–34) and 4 subscale scores for refusal/picky eating (7 items; range: 0–14), oral motor problems (5 items; range: 0–10), oral hypersensitivity (2 items; range: 0–4), and eating behavior problems (3 items; range: 0–6); for all scales, higher scores indicate greater problems. >90th percentile of the term control group were used to identify children with clinically significant eating difficulties. **Statistical methods** Among LMPT infants, Poisson regression was used to explore factors associated with eating difficulties at 2 y. Between-group differences in total feeding difficulties between term and LMPT infants were then adjusted for the following: sex, SGA, SES, and prolonged nasogastric tube feeding.		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and Results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>Length of follow-up

2 years (corrected age)</td><td></td><td></td></tr>
<tr><td>Ref Id

451626

Full citation

Hornman, J, de Winter, AF, Kerstjens, JM, Bos, AF, Reijneveld, SA, Emotional and Behavioral Problems of Preterm and Full-Term Children at School Entry, Pediatrics, 137, 2016

Country/ies where the study was carried out

Netherlands

Study type

Population-based cohort study (LOLLIPOP)</td><td>Sample size

n=1054 preterm children
(n=653 moderately preterm children [32-35 weeks]
n=401 early preterm children [25-31 weeks])
n=389 term children as comparisons

Characteristics

<table><tr><th></th><th>Preterm (n=1054)</th><th>Term (n=389)</th></tr><tr><td>GA, median (IQR)</td><td>33 (30-35)</td><td>40 (39-40)</td></tr><tr><td>Boy, %</td><td>54.6</td><td>47.6</td></tr><tr><td>SGA, %</td><td>14.2</td><td>6.7</td></tr><tr><td>Smoking during pregnancy, %</td><td>19.3</td><td>11.9</td></tr><tr><td>Twin, %</td><td>27.4</td><td>1.3</td></tr><tr><td>Multiparity, %</td><td>29.9</td><td>62.9</td></tr><tr><td>1-parent family, %</td><td>6.3</td><td>2.1</td></tr></table></td><td>Risk factors

Gestational age</td><td>Setting

A population-based cohort of preterm babies born in the Netherlands in 2002 and 2003.

Method(s) of measurement for risk factor(s)

Gestational age on >95% of the cases was based on early ultrasound measurements and measured in completed weeks. In the remaining cases, only clinical estimates based on last menstrual date were available, these were checked against clinical estimates of GA after birth.

Outcome(s) ascertainment/measures</td><td>Outcome(s) at age

At age 4 and 5 years
<u>Total emotional/behavioural problems (CBCL >=84th percentile)</u>
Emerging problems (normal score at 4 y, abnormal at 5 y)
Term: Reference
<36 weeks: OR 1.58 (0.71-3.49)
32-35 weeks: OR 1.42 (0.62-3.27)
25-31 weeks: OR 1.88 (0.78-4.52)
Resolving problems (abnormal score at 4 y, normal score at 5 y)
Term: Reference
<36 weeks: OR 2.71 (1.43-5.15)
32-35 weeks: OR 3.10 (1.61-5.96)
25-31 weeks: OR 1.94 (0.92-4.12)
Persistent problems (abnormal score at both 4 and 5 y)
Term: Reference
<36 weeks: OR 2.02 (1.07-3.81)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: High risk of bias
The preterm sample included 1443 children, out of the 3300+ original sample (less than half).
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias
Overall: moderate quality</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Aim of the study To assess individual stability of emotional and behavioural problems in preterm compared with term children first before school entry and again 1 year after school entry, and variation in stability within the preterm group. **Study dates** Children in 2002-2003, follow-up at ages 4 and 5 years. **Source of funding** The research foundation of Beatrix Children's	<table><tr><td>Low education level of both parents, %</td><td>16.1</td><td>11.9</td></tr><tr><td>Low education level mother, %</td><td>25.5</td><td>22.2</td></tr><tr><td>Low education level father, %</td><td>29.2</td><td>25.3</td></tr><tr><td>Non-Dutch birth country of parent or child, %</td><td>8.3</td><td>4.7</td></tr></table> **Inclusion criteria** Children born at <36 weeks of gestation in 2002 and 2003. **Exclusion criteria** Children with major congenital malformations, congenital infections, or syndromes, children with unclear or missing GA, children lost to follow-up or other reasons.		Emotional and behavioural problems were assessed with the validated Dutch version of the Child Behaviour Checklist (CBCL), applicable for ages 1.5-5 years. The CBCL consists of 99 problem items, each item can be rated by the parents as not true (0), somewhat/sometimes true (1), or very/often true (2). From these ratings, the total, internalising, and externalising problem scales were constructed. >=84th percentile of the scale was considered subclinical or clinical. The dichotomised CBCL outcomes at ages 4 and 5 years were combined, resulting in 4 categories: consistently normal (normal score at both 4 and 5 years), emerging problems (normal score at 4 years, abnormal score at 5 years), resolving problems (abnormal score at 4 years, normal score at 5	32-35 weeks: OR 1.93 (0.99-3.74) 25-31 weeks: OR 2.17 (1.07-4.41) <u>Internalising problems</u> Emerging problems (normal score at 4 y, abnormal at 5 y) Term: Reference <36 weeks: OR 1.23 (0.72-2.09) 32-35 weeks: OR 1.17 (0.67-2.05) 25-31 weeks: OR 1.34 (0.73-2.49) Resolving problems (abnormal score at 4 y, normal score at 5 y) Term: Reference <36 weeks: OR 2.18 (1.16-4.09) 32-35 weeks: OR 2.16 (1.13-4.15) 25-31 weeks: OR 2.22 (1.09-4.51) Persistent problems (abnormal score at both 4 and 5 y) Term: Reference <36 weeks: OR 2.04 (1.21-3.45) 32-35 weeks: OR 1.90 (1.10-3.29) 25-31 weeks: OR 2.31 (1.28-4.17) <u>Externalising problems</u>	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Hospital, the Cornelia Foundation for the Handicapped Child, The A. Bulk Preventive Child Health Care Research Fund, the Dutch Brain Foundation, and an unrestricted research grant from **FrieslandCampina, Friso Infant Nutrition, Abbvie, and Pfizer Europe**.			years), and persistent problems (abnormal score at both 4 and 5 years). **Statistical methods** Odds ratios were computed to assess the risk of persistent, emerging and resolving problems. The multivariable model adjusted for gender, SGA, smoking during pregnancy, being part of a multiple pregnancy, multiparity, low education level of parents, and 1-parent family. **Length of follow-up** 4 and 5 years.	Emerging problems (normal score at 4 y, abnormal at 5 y) Term: Reference <36 weeks: OR 2.54 (1.21-5.32) 32-35 weeks: OR 2.63 (1.23-5.63) 25-31 weeks: OR 2.37 (1.03-5.47) Resolving problems (abnormal score at 4 y, normal score at 5 y) Term: Reference <36 weeks: OR 1.59 (0.90-2.81) 32-35 weeks: OR 1.85 (1.03-3.32) 25-31 weeks: OR 1.07 (0.53-2.17) Persistent problems (abnormal score at both 4 and 5 y) Term: Reference <36 weeks: OR 2.25 (1.26-4.03) 32-35 weeks: OR 2.31 (1.26-4.23) 25-31 weeks: OR 2.14 (1.10-4.15) All analyses adjusted for gender, SGA, smoking during pregnancy, being part of a multiple pregnancy, multiparity, low education level of parents, and 1-parent family.	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Ref Id 474264 **Full citation** Farooqi, A., Adamsson, M., Serenius, F., Hagglof, B., Executive functioning and learning skills of adolescent children born at fewer than 26 weeks of gestation, PLoS ONE, 11 (3) (no pagination), 2016 **Country/ies where the study was carried out** Sweden **Study type** Regional cohort study **Aim of the study** To assess the cognitive and	**Sample size** N=134 extremely preterm infants (<26 weeks of gestation) N=103 term infants **Characteristics** <u>Maternal characteristics</u> Maternal age (mean years, SD): 29.9 (5.3) Maternal education (n, %): <9 years: 18 (13.6) 10-12 years: 68 (51.5) >12 years: 46 (34.8) Family income (n, %) Low income: 40 (27) Social risk, any (n, %): 50 (37.9) <u>Neonatal characteristics</u> Gestational age (n) 23 wks GA: 16 24 wks GA: 42 25 wks GA: 74 Female (n, %):72 (54.5) Birth weight (mean, SD, g): 718 (129) Multiple birth (n,%): 23 (17.4) SGA (n, %): 21 (15.9) Antenatal steroids, any (n,%): 92 (69.7) Major neurosensory impairment at 12 years (n, %): 17 (12.9) **Inclusion criteria** Surviving infants born at 23-25 weeks of gestation **Exclusion criteria** Not reported	**Risk factors** GA	**Setting** Two university hospitals of Uppsala and Umea (perinatal referral centres) in the northern region of Sweden, with NICU serving the Uppsala region and the northern region of Sweden **Method(s) of measurement for risk factor(s)** Not reported **Outcome(s) ascertainment/measures** Participants were seen for half-day session by trained psychologists Executive function (cognitive function and behavioural function) was measured using the following tests: Wechsler Intelligence Scale for Children (WISC-III-R) to assess general intelligence (full scale IQ), cognitive assessment	**Outcome(s) at age** <u>At 10 to 15 years</u> <u>Executive function (EPT (23-25 wks GA) vs control, in total population, scoring <-2SD on WISC-III-R)</u> Verbal working memory (digit span): aOR 12.8 (95%CI 3-56) Non-verbal memory (coding): aOR 10.0 (95%CI 2.9-35.0) Spatial conceptualisation (block design): aOR 18.0 (95%CI 4-77) Visual reasoning (picture arrangement): aOR 4.7 (95%CI 1.8-12.7) Planning ability (Tower test): aOR 26.0 (95%CI 3.4-192) <u>Executive function (EPT (23-25 wks GA) vs control, in those children who did not have NSI and had FSIQ >70) (scoring <-2SD on WISC-III-R)</u> Verbal working memory (digit span): aOR 3.6 (95%CI 0.7-19) Non-verbal memory (coding): aOR 5.5 (95%CI 1.1-27) Memory, attention, distractibility (Arithmetic): aOR 7.9 (95%CI 1.7-37) Visual reasoning (picture arrangement): aOR 2.1 (95%CI 0.6-7.3)	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias Of the whole population of 261 infants, only 132 were available for follow-up (49.4% lost to follow-up). **Prognostic factor measurement:** moderate risk of bias (not reported how GA was assessed in the study) **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias **Overall quality:** low

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
behavioural aspects of executive functioning and learning skills in extremely preterm children compared with term control children aged 10 to 15 years **Study dates** Children born in 1992-1998, assessed at 10 to 15 years age **Source of funding** ALF Vasterbotten Umea University Vastebotten county council			(inhibition, working memory and shifting strategy) Tower test of Delis-Kaplan Executive Function Scale (D-KEFS) was used to visual attention and visual spatial skills (spatial planning, rule learning, Inhibition, establishing and maintaining cognitive set/problem solving) Five to Fifteen (FTF) was used to assess attention, hyperactivity/impulsivity, hypoactivity, planning/organisation, and working memory. The domains of the parent and teacher FTF were collapsed into a primary Executive Function Composite Score (EFCS) domain) FTF was used to assess learning skills (teacher and parent reported) in school subjects (maths, reading and writing, as well as coping in learning). Impairments in the individual domains of executive function and learning skills were defined as	Planning ability (Tower test): P 0.007 Spatial conceptualisation (block design): P <0.001 <u>Executive function: Behavioural assessment (EPT (23-25 wks GA) vs control, in total population, scoring >2SD above mean on FTF)</u> Executive function composite score (parent): aOR 16.1 (95%CI 2.1-122.1) Executive function composite score (teacher): aOR 5.7 (95%CI 2.1-15.4) Attention (parent): aOR 13.5 (95%CI 1.8-104.0) Attention (teacher): aOR 5.6 (95%CI 2.2-14.0) Hyperactivity/impulsivity (parent): P <0.001 Hyperactivity/impulsivity (teacher): aOR 2.6 (95%CI 0.95-67.0) Hypoactivity (parent): aOR 4.4 (95%CI 1.2-15.7) Hypoactivity (teacher): aOR 5.0 (95%CI 1.8-13.8) Planning/organisation (parent): aOR 4.6 (95%CI 1.9-10.9) Planning/organisation (teacher): aOR 8.6 (95%CI 2.9-25.4) Working memory (parent): aOR 5.6 (95%CI 1.9-16.8) Working memory (teacher: aOR 9.6 (95%CI 3.3-28.6)	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			2 SD (>95th percentile) greater than the normative mean in the parent FTF or 2SD above the mean z scores for controls in the teacher FTF, corresponding to significant difficulties **Statistical methods** Multivariate logistic regression analyses were carried out to examine differences in the categorical outcomes between the groups after making adjustments for important explanatory variables including sex, composite social risk, and mother's country of origin. P values <0.05 were considered significant. **Length of follow-up** 10 to 15 years	<u>Executive function: Behavioural assessment (EPT (23-25 wks GA) vs control, in those children who did not have NSI and had FSIQ>70, scoring >2SD above mean on FTF)</u> Executive function composite score (parent): P= 0.003 Executive function composite score (teacher): aOR 5.8 (95%CI 1.6-21.1) Attention (parent): P= 0.002 Attention (teacher): aOR 4.2 (95%CI 1.5-11.9) Hyperactivity/impulsivity (parent): P=0.007 Hyperactivity/impulsivity (teacher): aOR 1.8 (95%CI 0.85-6.0), P=0.35 Hypoactivity (parent): aOR 10.7 (95%CI 1.3-89.9) Hypoactivity (teacher): aOR 6.3 (95%CI 1.8-22.4) Planning/organisation (parent): aOR 3.3 (95%CI 1.2-9.6) Planning/organisation (teacher): aOR 6.7 (95%CI 1.8-24.2) Working memory (parent): aOR 10.2 (95%CI 1.3-83.2) Working memory (teacher): aOR 9.9 (95%CI 2.1-45.0) <u>Executive function: Learning skills (EPT (23-25 wks GA) vs control, in those children who did not have</u>	

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
				NSI and had FSIQ >70, scoring >2SD on FTF) Reading/writing (parent): aOR 12.5 (95%CI 1.6-99.1) Reading/writing (teacher): aOR 3.6 (95%CI 1.3-9.7) Mathematics (parent): aOR 21.4 (95%CI 2.8-165.2) Mathematics (teacher): aOR 8.8 (95%CI 3.5-22.2) General learning (parent): P <0.001 General learning (teacher): aOR 18.2 (95%CI 2.3-142.6) Coping in learning (parent): aOR 15.0 (95%CI 2.0-117) Coping in learning (teacher): aOR 6.3 (95%CI 2.3-17.6)	
Ref Id 476772 **Full citation** Sullivan, S., Joinson, C., Heron, J., Factors Predicting Atypical Development of Nighttime Bladder Control, Journal of Developmental & Behavioral	**Sample size** N= 13,973 singleton/twin births, alive at 12 months n=8769 children with 3 or more bedwetting measures (included in the analysis) n=460 children born at <37 weeks GA n=640 children born =>42 weeks GA **Characteristics** Not reported in this publication **Inclusion criteria** Children assessed at 18 months corrected age who completed a questionnaire developed by ALSPAC (including items from Denver Developmental Screening Test)	**Risk factors** GA	**Setting** Pregnant women were enrolled who were resident in the former Avon Health Authority in south-west England **Method(s) of measurement for risk factor(s)** Gestation was derived from the date of	**Outcome(s) at age** 4 to 9 years age Infrequent delayed bedwetting <37 wks GA: OR 1.19 (95%CI 0.76-1.85) compared to >37 wks GA Infrequent persistent bedwetting <37 wks GA: OR 1.02 (95%CI 0.64-1.63) compared to >37 wks GA Frequent delayed bedwetting <37 wks GA: OR 0.94 (95%CI 0.39-2.26) compared to >37 wks GA	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** unclear risk of bias **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Pediatrics, 36, 724-33, 2015 **Country/ies where the study was carried out** United Kingdom **Study type** Prospective cohort study (ALSPAC study) **Aim of the study** To examine whether there are specific risk factors that might enable us to distinguish between different atypical patterns of bedwetting (whether children who experience a natural resolution of their bedwetting can be distinguished	**Exclusion criteria** Participants who responded more than 4 weeks either side of the intended age (18 months corrected age) were excluded Isolated occurrences of maternal bedwetting around the perinatal period		delivery, date of last menstrual period (reported at enrollment), and using ultrasound data where available **Outcome(s) ascertainment/measures** Repeated measures of bedwetting At ages 4.5, 5.5, 6.5, 7.5 and 9.5 years (4-9 years), parents were asked about how often their child wets their bed (never, less than once a week, about once a week, 2 to 5 times a week, nearly every night, or more than once a night). The frequency of bedwetting was further divided into three categories: no current bed wetting, infrequent bedwetting, and frequent bedwetting. Frequent bedwetting corresponded to the frequency of bedwetting required for a DSM-V diagnosis of nocturnal enuresis. The three categories of frequency of	<u>Frequent persistent bedwetting</u> <37 wks GA: OR 0.82 (95%CI 0.40-1.70) compared to >37 wks GA (adjusted for gender, social class, and family adversity)	**Analysis and Reporting:** high risk of bias. Information regarding characteristics of the population was not reported Explanation of the referent group for risk factor and outcome was not clear. The referent group was reported as the normative outcome group, but it would be likely that the referent group would include children born >37 weeks of gestation Overall quality: Low

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
from those with bedwetting that persists into late childhood) **Study dates** 1991-1992 **Source of funding** Medical Research Council (Increasing understanding of risk factors and outcomes associated with continence problems in children and adolescents) The UK Medical Research Council			bedwetting were further subdivided into the following groups: a "normative class" with low probability of bedwetting at any time point and comprising 71.5% of the sample. • "infrequent delayed" (14.3%)—delayed attainment of night time bladder control and decreasing probability of infrequent bedwetting from 4 to 9 years; • "infrequent persistent" (8.6%)—relatively high probability of infrequent bedwetting; "frequent delayed" (2.4%)—high probability of frequent bedwetting at age 4 years, which decreased		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
The Wellcome Trust University of Bristol provide core support for ALSPAC			and became more infrequent at 6 to 9 years; • "frequent persistent" (3.2%)—relatively high probability of bedwetting at least twice a week from 4 to 9 years. **Statistical methods** Association between the risk factors and class membership using a series of univariable multinomial logistic regression models and employing the normative latent class as the baseline category (reference group) for the outcome before reparameterizing to derive comparisons across the other outcome classes. Models were adjusted for the confounders including gender and socioeconomic status, and a		

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			multivariate model was built on the basis of those variables that were included in the unvariate model. **Length of follow-up** 4 to 9 years		
Ref Id 461027 **Full citation** Odd, D., Evans, D., Emond, A., Preterm Birth, Age at School Entry and Long Term Educational Achievement, PLoS ONE [Electronic Resource], 11, e0155157, 2016 **Country/ies where the study was carried out** UK **Study type** A cohort study (ALSPAC)	**Sample size** N=12 586 total sample including term and preterm N=775 children born at <37 weeks of gestation **Characteristics** Compared to the term born infants, the preterm infants were more likely to be male and need resuscitation after birth, had lower Apgar scores, they were more likely to be born as multiple births and less likely to be born through spontaneous cephalic birth and more likely to be born through emergency caesarean section. The mothers of preterm born children were more likely be of non-white ethnicity and have maternal hypertension. **Inclusion criteria** Not reported in this publication. **Exclusion criteria** Not reported.	**Risk factors** Derived from clinical notes and if under 37 weeks was confirmed by reviewing the clinical records.	**Setting** ALSPAC longitudinal cohort study from Bristol, UK. **Method(s) of measurement for risk factor(s)** Derived from clinical notes and if under 37 weeks was confirmed by reviewing the clinical records. **Outcome(s) ascertainment/measures** Mandatory UK educational assessments done at 4 stages, the stages are Key Stage (KS) 1 at 5-7 years, KS2 at 7-11 years, KS3 at 11-14 years, and KS4 at	**Outcome(s) at age** At 5-7 years Low score at KS1 Matched for date of birth Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.44 (95% CI 1.17-1.77) At 7-11 years Low score at KS2 Matched for date of birth Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.20 (95% CI 0.99-1.46) At 11-14 years Low score at KS3 Matched for date of birth Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.11 (95% CI 0.91-1.35) At 14-16 years Low score at KS4 Matched for date of birth	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** low risk of bias Data on gestational age were derived from the clinical notes and if recorded as less than 37 weeks then was confirmed by reviewing the clinical records

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
Aim of the study To investigate if the detrimental impact of year of entering education in preterm infants persists into adolescence. **Study dates** Children born April 1991 to December 1992, follow-up at 5-7 years, 7-11 years, 11-14 years and 14-16 years. **Source of funding** North Bristol NHS Trust Springboard Fund			14-16 years. The test is done at the end of each stage. Governmental standards set the minimum standard expected at each stage of the first 3 stages and this was used as the cut-off for a low score. At the end of KS4 children take their school exams and an a-priori cut-off of 5 General Certificates of Secondary Education (GCSE) or equivalent at A* to C level was used to define a normal score at this age. At KS4, <5 passes at A* to C level was considered as poor/low attainment at KS4. Children identified as having special educational needs (SEN) in KS4 were identified from the Pupil Level Annual School Census (PLASC). **Statistical methods** Multivariate analysis adjusted for ethnicity,	Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.10 (95% CI 0.91-1.34) At 14-16 years <u>SEN</u> Matched for date of birth Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.39 (95% CI 1.14-1.68)	**Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and Results	Comments
			maternal education, socio-economic group, age, gender, maternal parity, weight at birth, length and birth, head circumference at birth, mode of birth, maternal hypertension. **Length of follow-up** 7 years (KS1), 11 years (KS2), 14 years (KS3) and 16 years (KS4 and SEN).		

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2 Risk of developmental disorders

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Ref Id 347713 **Full citation** Adams-Chapman, I., Hansen, N. I., Stoll, B. J., Higgins, R., Neurodevelopmental outcome of extremely low birth weight infants with	**Sample size** n=9486 children eligible for follow-up (did not die before follow-up and did not have major malformations or syndromes) n=7776 children completed follow-up (82% follow-up rate) n=7693 children studied (of the n=7776, n=56 had no IVH information, n=27 received a shunt but had not IVH, thus, excluded) **n=6161 children with severe IVH or no IVH studied in depth in this study**, and classified into 5 groups: 1) no IVH/no shunt n=5163 2) IVH grade 3/no shunt n=459 3) IVH grade 3/shunt n=103 4) IVH grade 4/no shunt n=311	**Risk factors** Primary risk factor: Intraventricular haemorrage (IVH) grade 3-4 (with or without shunt) Additional risk factors in sub-analysis among children with severe IVH and shunts (n=228): Antenatal steroids Postnatal steroids Periventricular Leukomalacia (PVL)	**Setting** Infants born in 19 centers of the National Institute of Child Health and Human Development Neonatal Research Network, neonatal data obtained from the Generic Database of the research network, follow-up examinations done prospectively.	**Outcome(s) at age** **Outcome assessment at 18-22 months' corrected age:** MDI <70: IVH 3/shunt: RR 1.19 (0.97-1.44) IVH 3/no shunt: Reference IVH 3/shunt: RR 1.41 (1.18-1.68) No IVH/no shunt:Reference	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Study participation:** low risk of bias **Study attrition:** moderate risk of bias 82% follow-up rate at 18-22 months overall (n=7776 out of

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posthemorrhagic hydrocephalus requiring shunt insertion, Pediatrics, 121, e1167-e1177, 2008 **Country/ies where the study was carried out** United States **Study type** Multicentre cohort study **Aim of the study** To evaluate neurodevelopmental and growth outcomes among extremely low birth weight infants who had severe intraventricular haemorrhage (IVH) that required shunt insertion compared with	5) IVH grade 4/shunt n=125 **Characteristics** **Maternal characteristics:** 15 to 21% of mothers across the 5 groups were aged ≤19 years. ROM >24 h ranged from 19 to 24% across the groups. 60 to 76% of mothers had antenatal antibiotics. 60 to 78% of mothers had antenatal steroids. 45 to 65% of mothers had caesarean section. 72 to 79% of mothers were high school graduates. **Neonatal characteristics**: **Birth weight:** Across the 5 groups, 47 to 63% had a birth weight of 751-1000g, 35 to 52% had a birth weight of 501-750g and 1 to 2% had a birth weight of 401-500g. **Gestational age (week):** Across the 5 groups, 16 to 37% were born at <25 weeks, 59 to 74% were born at 25 -28 weeks, 3 to 14% were born at 29 -32 weeks, and up to 1% were born at ≥33 weeks. **SGA at birth**: 20% of infants in the no IVH/no shunt group were born SGA, and 5 to 8% SGA infants across the other four groups **Male gender**: The percentage of males across the 5 groups ranged from 45 to 61% **Ethnicity**: Across the 5 groups: black 44 to 51%; white 34-41%; Hispanic 8 to 16%; other 2 to 3% Information was missing for mother's age (3), ROM at >24 hours before birth (137), antenatal antibiotics (18), antenatal steroids (14), cesarean section (9), caregiver high school degree (75), GA (2), SGA (2), HC at birth (192), and race (2). **Inclusion criteria**	Chronic lung disease or bronchopulmonary dysplasia (BPD) Necrotising enterocolitis (NEC) Sepsis Meningitis	**Method(s) of measurement for risk factor(s)** Intraventricular haemorrage (IVH) grade 3-4 (with or without shunt), defined on the basis of Papile criteria. Cranial sonograms reviewed by the staff radiologists at each center. Addition risk factors in the subgroup analysis of children with severe IVH and shunt: Antenatal steroids (recorded in the Generic Database) Postnatal steroids (recorded in the Generic Database) Periventricular Leukomalacia (PVL), diagnosed on the basis of finding of cystic echolucencies in the periventricular white matter. Cranial sonograms reviewed by the staff radiologists at each center. Due to changes in data collection during the study period, PVL was diagnosed on the basis of a sonogram findings at >=2 weeks for infants who were born before	IVH 4/shunt: RR 1.48 (1.24-1.78) IVH 4/no shunt: Reference IVH 4/shunt: RR 1.72 (1.47-2.02) No IVH/no shunt: Reference PDI <70 IVH 3/shunt: RR 1.61 (1.32-1.96) IVH 3/no shunt: Reference IVH 3/shunt: RR 2.45 (2.06-2.91) No IVH/no shunt: Reference IVH 4/shunt: RR 1.94 (1.61-2.34) IVH 4/no shunt: Reference IVH 4/shunt: RR 2.90 (2.45-3.43) No IVH/no shunt: Reference Cerebral palsy (CP) IVH 3/shunt: RR 2.08 (1.63-2.66) IVH3/no shunt: reference IVH 3/shunt: RR 3.44 (2.76-4.29)	n=9486 eligible), although the analyses of interest further excluded children so the cohort included in analyses of interest actually included only n=6161 out of the original n=9486 (64.9%). Potential differences between the ones included and lost to follow-up not reported. **Prognostic factor measurement:** low risk of bias Risk factors are appropriately defined and measured. PVL diagnosis procedure differed between infants born before or after August 1998 (timing of cranial sonogram to diagnose PVL differed), however, PVL was not the primary risk factor at hand so has relatively little impact on the overall results. **Outcome measurement:** moderate risk of bias CP not defined. Visual impairment defined as use of corrective lenses or

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infants without shunt insertion. **Study dates** 1993-2002, follow-up at 18-22 months' corrected age. **Source of funding** National Institutes of Health and the National Institute of Child Health and Human Development	Surviving infants of the 19 participating neonatal centers of the National Institute of Child Health and Human Development Neonatal Research Network who were born between 1 Jan 1993 and 31 Dec 2002. Birth weight <1000 grams. Infants who participated in the Generic Database and Follow-up Studies. **Exclusion criteria** Infants with major malformations or syndromes, including central nervous system defects, congenital heart defects, gastrointestinal defects, and chromosomal abnormalities.		Aug 1998 and within 28 days or at 36 weeks' postconceptional age for infants born after Aug 1998. Chronic lung disease or bronchopulmonary dysplasia (BPD), defined as need for supplemental oxygeb at 36 weeks postmenstrual age. Necrotising enterocolitis (NEC), defined as modified Bell's stage IIA or greater. Sepsis, defined as positive blood culture and antibiotic therapy for >=5 days. Meningitis, defined by a positive cerebrospinal fluid culture and antibiotics therapy >=5 days. All neonatal information was recorded in the Generic Database and obtained from there. **Outcome(s) ascertainment/measures** Mental Development Index (MDI) <70, assessed by Bayley Scales of Infant Development IIR,	No IVH/no shunt: reference IVH 4/shunt: RR 1.83 (1.47-2.28) IVH 4/no shunt: reference IVH 4/shunt: RR 3.96 (3.19-4.92) No IVH/no shunt: reference <u>Vision impairment</u> IVH 3/shunt: RR 1.26 (0.87-1.82) IVH 3/no shunt: reference IVH 3/shunt: RR 1.65 (1.18-2.31) No IVH/no shunt: Reference IVH 4/shunt: RR 1.72 (1.19-2.46) IVH 4/no shunt: Reference IVH 4/shunt: RR 2.39 (1.71-3.35) No IVH/no shunt: Reference <u>Hearing impairment</u> IVH 3/shunt: RR 0.33 (0.09-1.30) IVH 3/no shunt: reference	blindness in 1 or both eyes, definition thus limited, not sure if use of corrective lenses is "severe" enough to be considered an outcome in our review. However, the composite outcome (NDI) considered only "blind in both eyes". **Study confounding:** low risk of bias Models adjusted for appropriate factors and this was clearly reported. **Statistical analysis and reporting:** moderate risk of bias Not clear why Poisson regression was used, however, likely to be an appropriate method. Not significant findings for sub-group analysis (among children with severe IVH and shunt) not reported. **Overall quality:** moderate

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			administered by certified examiners) Psychomotor Development Index (PDI) <70, assessed by Bayley Scales of Infant Development IIR, administered by certified examiners) Cerebral palsy (CP) (not defined) Visual impairment, defined as the need for corrective lenses or blindness in 1 or both eyes. Hearing impairment, defined by hearing aid use in 1 or both ears. Neurodevelopmental impairment (NDI), a composite outcome defined as 1 or more of the following: MDI <70, PDI <70, CP, blind in both eyes, or hearing aids in both ears. **Statistical methods** Poisson regression analysis, adjusting for study center, gestational age, birth weight, gender, race, caesarean section delivery, multiple birth, antenatal steroid exposure, postnatal steroid exposure,	IVH 3/shunt: RR 0.88 (0.23-3.35) No IVH/no shunt: reference IVH 4/shunt: RR 1.41 (0.56-3.59) IVH 4/no shunt: reference IVH 4/shunt: RR 2.13 (0.96-4.76) No IVH/no shunt: reference <u>Neurodevelopmental impairment (NDI)</u> IVH 3/shunt: RR 1.29 (1.11-1.48) IVH 3/no shunt: Reference IVH 3/shunt: RR 1.57 (1.38-1.78) No IVH/no shunt:Reference IVH 4/shunt: RR 1.44 (1.27-1.64) IVH 4/no shunt: Reference IVH 4/shunt: RR 1.81 (1.62-2.03) No IVH/no shunt: Reference Outcomes adjusted for study centre, gestational age, birth weight, gender, race,	

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			surfactant use, respiratory distress syndrome, bronchopulmonary dysplacia (BPD), patent ductus arteriosus, periventricular leukomalacia (PVL), infection group, caregivers' education. **Length of follow-up** 18-22 months' corrected age.	caesarean section delivery, multiple birth, antenatal steroid exposure, postnatal steroid exposure, surfactant use, respiratory distress syndrome, bronchopulmonary dysplasia (BPD), patent ductus arteriosus, periventricular leukomalacia (PVL), infection group, caregivers' education <u>NDI in a subgroup of children with severe IVH and shunts (n=228):</u> PVL: RR 1.12 (1.02-1.24) No PVL: reference P=0.02 In this subgroup, no other significant findings were found when studying the risk of different neonatal factors (BPD, NEC, sepsis, meningitis, antenatal steroids, postnatal steroids) on NDI.	
Ref Id 336075 **Full citation**	**Sample size** n=1085	**Risk factors** Retinopathy of prematurity (ROP)	**Setting** 14 participating institutions in the Extremely Low Gestational Age	**Outcome(s) at age** **Outcomes assessed at 24 months:** ORs (95% CI) obtained by multiple logistic	**Limitations** Based on the NICE manual 2014 checklist for

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Allred, E. N., Capone Jr, A., Fraioli, A., Dammann, O., Droste, P., Duker, J., Gise, R., Kuban, K., Leviton, A., O'Shea, T. M., Paneth, N., Petersen, R., Trese, M., Stoessel, K., Vanderveen, D., Wallace, D. K., Weaver, G., Retinopathy of prematurity and brain damage in the very preterm newborn, Journal of AAPOS, 18, 241-247, 2014 **Country/ies where the study was carried out** United States **Study type** Prospective cohort study	**Characteristics** **<u>Characteristics of study population</u>** <u>According to ROP stage:</u> <u>Stage 3 to 5:</u> Gestational age: 37% born at 23-24 weeks GA, 50% born at 25-26 weeks GA Birth weight: 10 % with birth weight <-2SD, 17% with birth weight >=-2SD to <-1SD <u>Stage <=3:</u> Gestational age: 14% born at 23-24 weeks GA, 45% born at 25-26 weeks GA Birth weight: 4% with birth weight <-2SD, 12% with birthweight >=-2SD to <-1SD <u>Plus disease:</u> Gestational age: 48% born at 23-24 weeks GA, 45% born at 25-26 weeks GA Birth weight: 9% with birth weight <-2SD, 20% with birth weight >=-2SD to <-1SD <u>No plus disease:</u> Gestational age: 17% born at 23-24 weeks GA, 46% born at 25-26 weeks GA Birth weight: 5% with birth weight <-2SD, 12% with birth weight >=-2SD to <-1SD <u>Zone 1:</u> Gestational age: 46% born at 23-24 weeks GA, 53% born at 25-26 weeks Ga Birth weight: 62% with birth weight <-2SD, 36% with birth weight >=-2SD to <-1SD <u>No zone 1:</u> Gestational age: 18% born at 23-24 weeks GA, 46% born at 25-26 weeks GA Birth weight: 35% with birth weight <-2SD, 45% with birth weight >=-2SD to <-1SD **Inclusion criteria** Infants who were born <28 weeks of gestation at one of the 14 participating institutions in the Extremely Low		Newborn (ELGAN) Study during 2002-2004 in the United States **Method(s) of measurement for risk factor(s)** Severe retinopathy of prematurity (ROP), defined according to the following criteria: 1) stage 3 or higher, 2) zone I disease, 3) any prethreshold or worse, and 4) plus disease. ROP was examined by ophthalmologic examination by 31 weeks postmenstrual age or 4 weeks actual age, whichever was later. **Outcome(s) ascertainment/measures** • Mental Development Index (MDI), assessed by Bayley Scales of Infant Development (2nd edition) by	regression model adjusting for gestational age, birth weight z-score categories, hyperoxemia (a PaO2 in the highest quartile on 2 of the first 3 postnatal days), Score of Neonatal Acute Physiology-II (SNAP-II) in the highest quartile, culture-proven bacteraemia in the first 28 days, mechanical or high frequency on 14 or more days, and growth velocity in the lowest quartile. <u>MDI <55</u> ROP stage 3+ : OR 1.9 (1.2-2.9) No ROP stage 3+ : reference ROP plus disease: OR 1.9 (1.1-3.2) No ROP plus disease: reference ROP Zone 1: OR 1.5 (0.8-2.9) No ROP Zone 1: reference ROP threshold: OR 2.2 (0.8-6.2) No ROP threshold: reference	prognostic studies and QUIPS. **Participants:** moderate risk of bias Baseline characteristics of the sample are limited: only <23-24 and 25-26 weeks' gestational age and <-2SD and >=-2SD to <-1SD birth weight are reported (no p-values). **Attrition:** moderate risk of bias This study had a strict inclusion criteria that only included the ones who survived, who had ROP data and who have follow-up data, thus, attrition is low, however, 13.1% of the original source population (n=1,249 infants with maternal consent) were lost to follow-up either because of death prior to 2-year follow-up or because of lack of ROP data or no follow-up assessment. The characteristics of these were not described.

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Aim of the study To evaluate how much of the association between retinopathy of prematurity (ROP) and brain disorders can be explained by low gestational age, abnormally high Scores for Neonatal Acute Physiology, hyperoxemia, bacteremia, fetal and postnatal growth restriction, and prolonged ventilator assistance. **Study dates** 2002-2004, follow-up at 24 months. **Source of funding** None reported.	Gestational Age Newborn (ELGAN) Study during 2002-2004, whose mothers gave consent, who had an eye examination for retinopathy for prematurity (ROP) while in the intensive care nursery, and who survived to 2 years of corrected age, and who had a developmental assessment at 24 months. **Exclusion criteria** None reported.		certified examiners. ○ MDI <55 ○ MDI 56-69 • Psychomotor Development Index (PDI), assessed by Bayley Scales of Infant Development (2nd edition) by certified examiners. ○ PDI <55 ○ PDI 56-69 • Cerebral palsy (CP), topographic diagnosis of CP was based on an algorithm using the data of quadriparesis, diparesis, hemiparesis (not described further in the publication). ○ quadriparesis (affecting all four	ROP pre-threshold: OR 1.7 (1.00-2.7) No ROP pre-threshold: reference <u>MDI 56-69</u> ROP stage 3+ : OR 1.3 (0.8-2.1) No ROP stage 3+ : reference ROP plus disease: OR 2.1 (1.1-4.0) No ROP plus disease: reference ROP zone 1: OR 2.4 (1.2-4.7) No ROP zone 1: reference ROP threshold: OR 3.6 (1.3-10) No ROP threshold: reference ROP pre-threshold: OR 2.1 (1.2-3.8) No ROP pre-threshold: reference <u>PDI <55</u> ROP stage 3+ : OR 1.6 (1.03-2.4) No ROP stage 3+ : reference ROP plus disease: OR 1.8 (1.1-3.1)	**Prognostic factor measurement:** low risk of bias **Outcome measurement:** moderate risk of bias The definition and diagnosis of CP is poorly reported: "The topographic diagnosis of CP (quadriparesis, diparesis, or hemiparesis) was based on an algorithm using these data.". **Confounding:** moderate risk of bias Missing some potentially important confounders (e.g. gender, parental characteristics, multiple birth) and some confounding factors are unclearly described (e.g. SNAP-II). **Analysis and reporting:** low risk of bias All main outcomes and presented, statistical methods are approapriate. **Overall quality:** moderate

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			○ extremities) ○ diparesis (affecting either both arms or both legs) ○ hemiparesis (affecting either right or the left side of the body) **Statistical methods** Multiple logistic regression model adjusting for gestational age, birth weight z-score categories, hyperoxemia (a PaO2 in the highest quartile on 2 of the first 3 postnatal days), Score of Neonatal Acute Physiology-II (SNAP-II) in the highest quartile, culture-proven bacteremia in the first 28 days, mechanical or high frequency on 14 or more	No ROP plus disease: reference ROP zone 1: OR 1.1 (0.6-2.2) No ROP zone 1: reference ROP threshold: OR 1.8 (0.6-5.0) No ROP threshold: reference ROP pre-threshold: OR 1.9 (1.1-3.1) No ROP pre-threshold: reference <u>PDI 56-69</u> ROP stage 3+ : OR 1.6 (1.03-2.5) No ROP stage 3+ : reference ROP plus disease: OR 1.4 (0.7-2.6) No ROP plus disease: reference ROP zone 1: OR 2.2 (1.2-4.2) No ROP zone 1: reference ROP threshold: OR 2.1 (0.7-6.6) No ROP threshold: reference	

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			days, and growth velocity in the lowest quertile. **Length of follow-up** 24 months	ROP pre-threshold: OR 1.6 (0.9-2.9) No ROP pre-threshold <u>CP quadriparesis</u> ROP stage 3+ : OR 1.2 (0.7-2.0) No ROP stage 3+ : reference ROP plus disease : OR 1.2 (0.6-2.6) No ROP plus disease: reference ROP zone 1: OR 0.9 (0.4-2.3) No ROP zone 1: reference ROP threshold: OR 1.3 (0.3-4.8) No ROP threshold: reference ROP pre-threshold: OR 0.9 (0.5-1.9) No ROP pre-threshold: reference <u>CP diparesis</u> ROP stage 3+ : OR 1.2 (0.5-2.7) No ROP stage 3+ : reference ROP plus disease: OR 2.4 (0.99-5.9) No ROP plus disease: reference	

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				ROP zone 1: OR 2.1 (0.8-6.0) No ROP zone 1: reference ROP threshold: OR 1.5 (0.3-7.6) No ROP threshold: reference ROP pre-threshold: OR 2.2 (0.9-5.2) No ROP pre-threshold: reference <u>CP hemiparesis</u> ROP stage 3+ : OR 1.1 (0.4-3.1) No ROP stage 3+ : reference ROP plus disease: OR 1.3 (0.3-4.9) No ROP plus disease: reference ROP zone 1: OR 1.0 (0.2-5.1) No ROP zone 1: reference ROP threshold: No OR No ROP threshold: reference ROP pre-threshold: OR 0.9 (0.2-3.3) No ROP pre-threshold: reference	

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				ORs (95% CI) obtained by multiple logistic regression model adjusting for gestational age, birth weight z-score categories, hyperoxemia (a PaO2 in the highest quartile on 2 of the first 3 postnatal days), Score of Neonatal Acute Physiology-II (SNAP-II) in the highest quartile, culture-proven bacteraemia in the first 28 days, mechanical or high frequency on 14 or more days, and growth velocity in the lowest quartile	
Ref Id 409743 **Full citation** Ambalavanan, N., Carlo, W. A., Tyson, J. E., Langer, J. C., Walsh, M. C., Parikh, N. A., Das, A., Van Meurs, K. P., Shankaran, S., Stoll, B. J.,	**Sample size** Sample recruited - N = 14147 Sample analysed after exclusions - N = 13085 (T0 - Day 1) Sample analysed after exclusions - N = 7632 infants (death n = 4448 or loss to follow-up n = 1005) **Characteristics** Sample analysed after exclusions - N = 13085 (T0 - Day 1) Birth weight, mean ± SD: 738 ± 156 Gestational age, mean ± SD: 25.5 ± 2 SGA, %: 15.2	**Risk factors** Sex	**Setting** This was a population based study placed in the US. Data from all live-born infants with a birth weight of 401 to 1000 g born between January 1, 1998, and December 31, 2005 who were admitted to 18 centers of the National Institute of Child Health and Human Development Neonatal	**Outcome(s) at age** At 36 weeks: Intellectual disability (developmental delay – NDI: Mental Developmental Index [MDI <70]]) Sex (Male gender): OR [95% CIs] 1.62 (1.42–1.86) Referent group is not reported	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. Participants: low risk of bias (there is an adequate description of population of interest and of the inclusion/exclusion criteria)

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Higgins, R. D., Generic, Database, Subcommittees of the Eunice Kennedy Shriver National Institute of Child, Health, Human Development Neonatal Research, Network, Outcome trajectories in extremely preterm infants, Pediatrics, 130, e115-25, 2012 **Country/ies where the study was carried out** United States **Study type** Multicentre prospective cohort study. **Aim of the study** To develop serial predictions	Male gender, %: 50.2 Sample analysed after exclusions - N = 7632 infants (death n = 4448 or loss to follow-up n = 1005) n = 4029: Without NDI n = 2828: With NDI **Inclusion criteria** Live-born infants (both inborn and outborn if admitted within 14 days of birth) with a birth weight of 401- 1000 g Born between January 1, 1998, and December 31, 2005 Admitted to 18 centers of the National Institute of Child Health and Human Development Neonatal Research Network (NRN) **Exclusion criteria** Infants with gestational age <22 weeks (nonviable) or >32 weeks (severe growth retardation if >32 weeks and birth weight ≤1000 g) or with major malformation Infants discharged alive but with missing follow-up data		Research Network (NRN) were included. **Method(s) of measurement for risk factor(s)** Data available in the delivery room (birth) and at specified postnatal time points (postnatal age of 7 days or 28 days and 36 weeks PMA) in the development set were used. **Outcome(s) ascertainment/measures** NDI was defined as one or more of Mental Developmental Index <70 on Bayley Scales of Infant Development-II, Psychomotor Developmental Index <70, cerebral palsy, blind in both eyes, or needing hearing aids in both ears at follow-up at 18 to 22 months corrected age **Statistical methods** Multivariable forward stepwise logistic		Attrition: moderate risk of bias (reasons for loss to follow-up [7.6% of 13085] are partially reported) Prognostic factor measurement: low risk of bias Outcome measurement: low risk of bias Confounding: low risk of bias Analysis and Reporting: low risk of bias Overall quality: moderate

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of death or neurodevelopmental impairment in extremely premature neonates by using prognostic factors available over the course of Neonatal Intensive Care Unit (NICU) hospitalization. **Study dates** January 1998 - December 2005: Period of data collection (patient enrolment) 18-22 months (age corrected): follow-up assessment **Source of funding** The authors were supported by grants from the National Institute of Child Health and Human Development			regression models for predicting death/NDI (the primary outcome), death alone, and NDI in survivors were developed by using A prediction tool was developed that provides individual estimates of death/NDI (the primary outcome), death alone, and NDI in survivors at 18 to 22 months corrected age at each of the time points **Length of follow-up** 36 weeks		

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and the Department of Health and Human Services Funded by the National Institutes of Health (NIH).					
Ref Id 347034 **Full citation** Andrews, W. W., Cliver, S. P., Biasini, F., Peralta-Carcelen, A. M., Rector, R., Alriksson-Schmidt, A. I., Faye-Petersen, O., Carlo, W., Goldenberg, R., Hauth, J. C., Early preterm birth: association between in utero exposure to acute inflammation and severe neurodevelopmental disability at 6 years of age, American	**Sample size** N= 375 **Characteristics** Frequency of the neurodevelopmental outcomes according to demographic and other characteristics of the study cohort (n=261). <u>IQ<70 group:</u> Race: 19% African American Maternal age: 12.7% <20 years age, 19.2% 20-30 years age, 8.9% >30 years age Maternal education (<=12 years): 19.3% Income: 15.9% <$1600/month Maternal smoking/pregnancy: 9.1% Marital status at delivery: single: 19.1% Child gender: male: 18.3% <u>CP group:</u> Race: 1.3% African American Maternal age: 3.2% <20 years age, 4.7% 20-30 years age, 4.4% >30 years age Maternal education (<=12 years): 4.2% Income: 1.6% <$1600/month	**Risk factors** GA as continuous variable; Seizures; PVL IVH; NEC; African American ethnicity;	**Setting** Cohort study **Method(s) of measurement for risk factor(s)** Extensive pregnancy and neonatal (birth to discharge or death) outcome data were collected from these maternal-infant dyads by trained research nurses. **Outcome(s) ascertainment/measures** Each child was given a battery of tests assessing a wide range of psychometric measures (requiring approximately 3 hours to complete) including the	**Outcome(s) at age** **Outcomes assessed at age 6 years among children born between 23 and < 32 wks' GA:** **<u>For the outcome of IQ < 70 and a major disability:</u>** GA as a continuous variable: OR 0.75, 95% C.I. 0.6 – 0.9 PVL: OR 4.9, 95% C.I. 0.9 – 26.0 **<u>For the outcome of IQ < 70:</u>**	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** Low risk of bias Overall quality: High

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Journal of Obstetrics & Gynecology, 198, 466.e1-466.e11, 2008 **Country/ies where the study was carried out** United States **Study type** Prospective cohort study **Aim of the study** To determine the association between in utero exposure to acute inflammation and long-term major neurodevelopmental disability at age 6 years among children born prior to 32 weeks' gestation.	Maternal smoking/pregnancy: 10% Marital status at delivery: single: 1.3% Child gender: male: 3.5% <u>Major Neurodevelopmental disability group:</u> Race: 20.3% African American Maternal age: 19.1% <20 years age, 23.2% 20-30 years age11.1% >30 years age Maternal education (<=12 years): 24.1% Income: 20.6% <$1600/month Maternal smoking/pregnancy: 18.2% Marital status at delivery: single: 21.7% Child gender: male: 23.5% **Inclusion criteria** The study included a cohort of 424 consecutive single pregnancies delivered between 23 and <32 weeks during the interval from December 5, 1996 to December 31, 1999. **Exclusion criteria** Not reported		Wechsler Intelligence Scale for Children-IV (WISC-IV) or the Differential Ability Scales (DAS, for children who were not yet six-years-old or were unable to complete the WISC-IV) used to assess IQ. The primary outcome for this analysis was the presence of severe adverse neurodevelopment in the children at age 5 to 8 years. The IQ derived from the score on the WISC-IV or DAS was analyzed as a continuous and dichotomous (IQ <70 vs.≥ 70) variable. The children also underwent a complete physical and neurological examination including assessment of gross and finemotor function, hearing and vision screening evaluations performed	Seizures: OR 4.2, 95% C.I. 1.1 – 15.1 **<u>For the outcome of a major disability</u>**: Seizures: OR 4.2, 95% C.I. 1.1 – 15.2 **<u>For the outcome of CP:</u>** IVH (grade 3 or 4): OR 25.6, 95% C.I. 3.8 – 172.2 Seizures: OR 11.2, 95% C.I. 1.5 – 82.1 NEC: OR 5.7, 95% C.I. 0.9 –34.1 African American ethnicity: OR 0.1, 95% C.I. 0.01 – 0.6 -Counfounders adjusted in the final model (s): gestational age and ethnicity. The study did not clearly report on how many multiple regression models were	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Study dates 1996-1999 **Source of funding** Not reported			by a certified nurse practitioner under the supervision of a developmental pediatrician (AMP-C) **Cerebral palsy** was defined as an abnormal muscle tone in at least one extremity and abnormal control of movement and posture. **Major neurodevelopmental disability** was defined using a composite that included one or more of the following: IQ <70, CP, blindness, deafness, or other severe neurological motor deficit such as abnormal balance, impaired coordination, dystonia, or a seizure disorder that affected function. **Statistical methods** Logistic regression models were constructed to determine the adjusted odds ratio for adverse outcome for the two dichotomous outcome variables, and analysis of covariance models were developed for the continuous	run for the results reported.	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			variable IQ. All factors determined to be significant in bivariate analyses were included in initial modeling and were adjusted for gestational age, ethnicity, and socioeconomic status. Final models retained those factors with p < 0.1, adjusting for gestational age andethnicity. **Length of follow-up** 6 years		
Ref Id 409847 **Full citation** Beaino, G., Khoshnood, B., Kaminski, M., Marret, S., Pierrat, V., Vieux, R., Thiriez, G., Matis, J., Picaud, J. C., Roze, J. C., Alberge, C., Larroque, B., Breart, G., Ancel, P. Y., Epipage Study	**Sample size** N = 2901 Complete data on cognitive deficiency at 5 year follow up for 1503 participants. **Characteristics** Characteristics 24-26 weeks 6.8% 27-28 weeks 17.5% 29-30 weeks 27.2% 31-32 weeks 48.5% Male gender 51.2% Small for gestational age 8.8% Multiple pregnancy 31% Exposure to antenatal steroids 74.5% Maternal age < 25 years 19.5% Maternal age 25-29 years 36.6% Maternal age 30-34 years 27.8%	**Risk factors** Gestational age **Biological factors** Gender Small for gestational age **Neonatal factors** NEC BPD Cerebral lesions (IVH, PVL) **Social/maternal/environmental factors** Socioeconomic status **Postnatal factors** Postnatal corticosteroid	**Setting** National cohort. **Method(s) of measurement for risk factor(s)** Data on risk factors were recorded prospectively. For cranial ultrasound findings, two major types of cerebral lesion were assessed: intraventricular haemorrhage (IVH) and white matter disease (comprising intraparenchymal haemorrhage [IPH],	**Outcome(s) at age** All outcomes at age 5 years. **Gestational age** <u>≤ 28 weeks</u> No: Reference Yes: Mild cognitive deficiency OR 0.61 (0.40-0.93) Severe cognitive deficiency OR 1.28 (0.78-2.08) **Biological factors** <u>Male gender</u> No: Reference Yes: Mild cognitive deficiency OR 0.80 (0.60-1.07)	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias 434 participants were lost to follow up, but no further details are provided with regards to differences between these participants, and those who completed the follow up. A

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Group, Predictors of the risk of cognitive deficiency in very preterm infants: the EPIPAGE prospective cohort, Acta Paediatrica, 100, 370-8, 2011 **Country/ies where the study was carried out** France. **Study type** Population based prospective cohort. **Aim of the study** To assess cerebral lesions, medical and social characteristics as predictors of mild and severe cognitive deficiencies in	Maternal age ≥ 35 years 15.6% High socioeconomic status 16.1% High intermediate socioeconomic status 50.7% Low intermediate socioeconomic status 14.7% Low socioeconomic status 18.5% **Inclusion criteria** Any infant born between 22 and 32 weeks of gestation in nine regions of France throughout 1997. **Exclusion criteria** Infants who died before five year follow up (n=467). Moderate to severe neurosensory disabilities (defined as walking with aid or unable to walk, or having severe hearing or visual deficiency) (n=70). The protocol included the option of following at random only one of every two infants born at 32 weeks, to reduce the regional workload. Two regions exercised this option (n=77).		periventricular leucomalacia [PVL] and ventricular dilatation). Subependymal IVH was classified as grade I, intraventricular IVH as grade II and IVH associated with ventricular dilatation as grade III. PVL was defined as the presence of periventricular white matter echolucencies or echodensities persisting for more than 14 days without cyst formation. **Outcome(s) ascertainment/measures** Children were invited for a check up at 5 years, and assessed by trained psychologists blinded to their perinatal data. The assessment used the Kaufman Assessment Battery for Children (K-ABC) test. Overall cognitive ability was evaluated by the Mental Processing Composite score, which was available for 1503 infants. Cognitive deficiency was classified as mild when the MPC score was between 70	Severe cognitive deficiency OR 1.08 (0.74-1.57) <u>Small for gestational age</u> No: Reference Yes: Mild cognitive deficiency OR 1.01 (0.59-1.70) Severe cognitive deficiency OR 2.49 (1.41-4.40) **Neonatal factors** <u>NEC</u> No: Reference Yes: Mild cognitive deficiency OR 1.33 (0.64-2.76) Severe cognitive deficiency OR 0.84 (0.33-2.15) <u>BPD</u> No: Reference Yes: Mild cognitive deficiency OR 1.57 (0.97-2.54) Severe cognitive deficiency OR 1.09 (0.62-1.90) **Cerebral lesions** <u>Grade I IVH</u> No: Reference Yes: Mild cognitive deficiency OR 1.09 (0.67-1.76)	comparison is provided between the 239 participants with partial follow up data and those with complete data. This identified a significant difference in cerebral lesions and parental socioeconomic status between the two groups, both of which are likely to have an important effect on cognitive outcomes. Therefore it is possible that outcomes in the group with complete follow up will be different to those excluded due to partial follow up data, or loss to follow up. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
very preterm infants. **Study dates** 1997-2002. Cohort established in 1997. Follow up at 5 years of age. **Source of funding** French National Institute of Health and Medical Research, the Directorate General for Health of the Ministry for Social Affairs, Merck Sharp and Dohme-Chibret, the Medical Research Foundation, the 'Hospital Program for Clinical Research 2001 no. AOM01117' of the French Department of			and 84, and as severe when the MPC score was below 70 (-2SD below the norm). **Statistical methods** Multivariate multinomial logistic regression was used to assess independent predictors of mild and severe cognitive deficiencies. Predictor variables were chosen based on previous studies and results of univariate analysis. The model included medical factors (neonatal cerebral lesions, gestational age of 28 weeks or less, gender, small for gestational age, Apgar score below 7 at one minute, NEC, BPD at 36 weeks, acute anaemia, late-onset anaemia and postnatal corticosteroid), social factors (parental socioeconomic status, number of siblings) and breast feeding. **Length of follow-up** 5 years.	Severe cognitive deficiency OR 1.39 (0.74-2.60) Grade II IVH No: Reference Yes: Mild cognitive deficiency OR 1.15 (0.64-2.08) Severe cognitive deficiency OR 1.88 (0.95-3.72) Grade III IVH or echodensities or ventricular dilatation No: Reference Yes: Mild cognitive deficiency OR 1.33 (0.87-2.04) Severe cognitive deficiency OR 2.51 (1.53-4.11) Cystic PVL or IPH No: Reference Yes: Mild cognitive deficiency OR 1.98 (0.71-5.50) Severe cognitive deficiency OR 6.37 (2.46-16.54) **Social/maternal/environmental factors** High socioeconomic status Reference High-intermediate socioeconomic status Mild cognitive deficiency OR 1.42 (0.88-2.28)	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Health, La Fondation Motrice and the Ile-de-France Region.				Severe cognitive deficiency OR 1.23 (0.65-2.32) <u>Low-intermediate socioeconomic status</u> Mild cognitive deficiency OR 2.19 (1.26-3.82) Severe cognitive deficiency OR 2.89 (1.42-5.88) <u>Low socioeconomic status</u> Mild cognitive deficiency OR 3.43 (2.01-5.83) Severe cognitive deficiency OR 2.60 (1.29-5.24) **Postnatal factors** <u>Postnatal corticosteroid use</u> No: Reference Yes: Mild cognitive deficiency OR 1.33 (0.84-2.12) Severe cognitive deficiency OR 1.14 (0.66-1.97	
Ref Id 409848 **Full citation** Beaino, G., Khoshnood, B.,	**Sample size** Overall sample: N = 2901 live births, of which N = 2357 eligible for follow up. Sample followed up: n = 1812 with data for cerebral palsy at 5 years of age	**Risk factors** **Biological** Sex Small for gestational age **Neonatal** Cerebral lesions	**Setting** National population based study in France.	**Outcome(s) at age** At 5 years of age. <u>Cerebral palsy</u> **Gestational age** OR 1.00 (0.89-1.12) <u>Neonatal factors</u>	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPs

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Kaminski, M., Pierrat, V., Marret, S., Matis, J., Led, ESert B., Thiriez, G., Fresson, J., Roz, E. J. C., Zupan-Simunek, V., Arnaud, C., Burguet, A., Larroque, B., Br, EArt G., Ancel, P. Y., Predictors of cerebral palsy in very preterm infants: The EPIPAGE prospective population-based cohort study, Developmental Medicine and Child Neurology, 52, e119-e125, 2010

Country/ies where the study was carried out

France

Study type

Population based prospective</td>
<td>Characteristics
<table>
<tr><th>Characteristic</th><th>Number of responders (%), n = 1812</th><th>Number of non-responders (%), n = 545</th></tr>
<tr><td>Cerebral lesion</td><td>1788</td><td>517</td></tr>
<tr><td>Cystic PVL</td><td>4</td><td>4</td></tr>
<tr><td>IPH</td><td>0.3</td><td>0.4</td></tr>
<tr><td>Persistent echodensities or ventricular dilatation</td><td>13</td><td>14</td></tr>
<tr><td>Grade III IVH</td><td>2</td><td>0.4</td></tr>
<tr><td>Grade II IVH</td><td>7</td><td>8</td></tr>
<tr><td>Grade I IVH</td><td>10</td><td>6</td></tr>
<tr><td>None</td><td>64</td><td>67</td></tr>
<tr><td>Gestational age at birth (wks)</td><td>1812</td><td>545</td></tr>
<tr><td>24-28</td><td>25</td><td>18</td></tr>
<tr><td>29-30</td><td>26</td><td>26</td></tr>
</table></td>
<td>Necrotising enterocolitis
BPD
Postnatal corticosteroid use
Social/Environmental/ Maternal
Multiple pregnancy</td>
<td>Method(s) of measurement for risk factor(s)

Prospective data collection on all preterm births. Cranial ultrasonography is routinely performed in France on one to three occasions during the first 2 weeks of life, the once a week in the case of infants with lesions, or once every 2 weeks in infants without lesions. 97% of infants in the EPIPAGE study underwent cranial ultrasonography at least once during the neonatal period.

Outcome(s) ascertainment/measures

At five years' follow up medical information was collected through standardised questionnaires completed by physicians in centres specifically set up for the study (n = 1635), or from simplified questionnaires completed by regular treating physicians (n =</td>
<td>Cerebral lesions
None: Reference
Grade I IVH: OR 1.76 (0.90-3.45)
Grade II IVH: OR 2.56 (1.27-5.18)
Grade III IVH or echodensities or ventricular dilatation: OR 3.40 (2.07-5.60)
Cystic PVL or IPH: 28.41 (15.65-51.59)

NEC
No: Reference
Yes: OR 1.51 (0.64-3.55)

BPD at 36 weeks
No: Reference
Yes: OR 0.95 (0.53-1.71)

Postnatal corticosteroid use
No: Reference
Yes: OR 1.41 (0.82-2.43)

Infant sex
Female: Reference
Male: OR 1.52 (1.03-2.25)

Small for gestational age
No: Reference
Yes: OR 0.81 (0.34-1.92)</td>
<td>Participants: low risk of bias
Attrition: moderate risk of bias.
23% of participants were lost to follow up. There were significant differences between these participants and those who were followed up, with respect to the frequency of cerebral lesions, gestational age, birthweight and socioeconomic status.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: Moderate</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>cohort study (EPIPAGE).

Aim of the study

To assess the role of cerebral lesions and other neonatal and obstetric factors as potential predictors of cerebral palsy in preterm infants.

Study dates

Cohort established between 1 January and 31 December 1997.

Source of funding

INSERM (French National Institute of Health and Medical Research), Merck-Sharp, Dohme-Chibret,</td>
<td>
<table>
<tr><td>31-32</td><td>49</td><td>56</td></tr>
<tr><td>Birthweight (g)</td><td>1802</td><td>541</td></tr>
<tr><td>Mean (SD)</td><td>1367 (393)</td><td>1422 (388)</td></tr>
<tr><td>Male/female, n (% male)</td><td>935/877 (52)</td><td>303/242 (56)</td></tr>
<tr><td>Multiple pregnancy</td><td>1812 (31)</td><td>545 (28)</td></tr>
<tr><td>Parents' socioeconomic status</td><td>1616</td><td>424</td></tr>
<tr><td>High</td><td>19</td><td>10</td></tr>
<tr><td>Intermediate</td><td>44</td><td>25</td></tr>
<tr><td>Low</td><td>37</td><td>64</td></tr>
</table>
Numbers in italic are denominators for each characteristic

Inclusion criteria

All infants born between 22 and 32 weeks of gestation in nine regions of France in 1997.

Exclusion criteria

For this article: death before follow up period (n = 127 died in delivery room, n = 315 died in NICU, n = 15 died after hospital discharge but below the age of 5 years). The protocol allowed the option of following at</td>
<td></td>
<td>82) and parents or health services personnel (n=95). Experts reviewed questionnaires for children with abnormal neurological examination to validate the diagnosis.
The definition of CP was that proposed by the Surveillance of Cerebral Palsy in Europe (SCPE) collaborative group. Children were classified as having CP if they had involuntary movements (dyskinetic CP), loss of coordination (ataxic CP), or at least two of the following: abnormal posture or movement, increased tone or hyperreflexia (spastic CP).
.

Statistical methods

Associations of obstetric and neonatal risk factors with CP were first analysed with univariable logistic regression. Multivariable analyses were then conducted. The authors state that the model included "obstetric and</td>
<td>Multiple pregnancy
No: Reference
Yes: OR 0.67 (0.43-1.03)</td>
<td></td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td>the Medical Research Foundation, the French Ministry of Public Health, The General Directorate for Health of the French Ministry for Social Affairs, and the 'Hospital Program for Clinical Research 2001 No. AOM01117' of the French Department of Health. LaFondation Motrice and the Ile-de-France Region.</td><td>random only one of every two infants born at 32 weeks of gestation (to reduce the workload). 2 regions exercised this option, therefore 77 infants were not included in the follow up.
N.B. all infants born at 22 and 23 weeks of gestation died, therefore the results represent preterm infants aged 24-32 weeks.</td><td></td><td>neonatal factors" but it is not stated which factors these were. From the text it is assumed that they are: cystic PVL, intraparenchymal haemorrhage, gestational age, gender, SGA, multiple pregnancy, PPROM or preterm labour, maternal hypertension, RDS, NEC, maternal-fetal infection, BPD at 36 weeks, acute anaemia and postnatal corticosteroid use.

Length of follow-up

Until 5 years of age.</td><td></td><td></td></tr>
<tr><td>Ref Id

409920

Full citation

Bolisetty, S., Dhawan, A., Abdel-Latif, M., Bajuk, B., Stack, J., Lui, K., Intraventricular hemorrhage and neurodevelopmental outcomes in extreme preterm</td><td>Sample size

Overall sample:
N = 2701
Sample eligible for follow up:
N = 1968
Sample included in follow up:
N = 1472

Characteristics
<table><tr><td>Characteristic</td><td>No IVH
n = 1043</td><td>All IVH
n = 429</td></tr></table></td><td>Risk factors

Gestational age
Male gender
SGA (<10th percentile and <3rd percentile)
PVL
IVH
Sepsis
NEC
ROP grade 3-4</td><td>Setting

Multicentre study of 10 tertiary NICUs in New South Wales and the Australian Capital Territory.

Method(s) of measurement for risk factor(s)

The main outcome of this study was to investigate the effect of</td><td>Outcome(s) at age

At 2-3 years' corrected age
<u>Moderate to severe neurosensory impairment</u>
Gestational age
26-28 weeks' gestation: Reference
23-25 weeks' gestation: OR 1.56 (1.12-2.19)

Male gender
No: Reference</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: moderate risk of bias
25.2% of participants were lost to follow up.
Prognostic factor measurement: mode rate risk of bias</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>infants, Pediatrics, 133, 55-62, 2014

Country/ies where the study was carried out

Australia.

Study type

Retrospective multicentre cohort study (using prospectively collected data).

Aim of the study

To investigate the long term neurodevelopmental outcomes in relation to severity of IVH in a large cohort of extremely preterm infants.

Study dates</td>
<td>
<table>
<tr><td>Maternal age, y
median (IQR)</td><td>31 (26-35)</td><td>30 (23-34)</td></tr>
<tr><td>IUGR</td><td>103 (9.9%)</td><td>23 (5.3%)</td></tr>
<tr><td>Multiple pregnancy</td><td>288 (27.6%)</td><td>104 (24.2%)</td></tr>
<tr><td>Antenatal steroids</td><td>945 (90.4%)</td><td>377 (87.8%)</td></tr>
<tr><td>Gestational age, wk
mean (SD)</td><td>27 (2)</td><td>26 (2)</td></tr>
<tr><td>Birth weight, g
mean (SD)</td><td>956 (329)</td><td>915 (342)</td></tr>
<tr><td>SGA <10th percentile</td><td>121 (11.6%)</td><td>31 (7.2%)</td></tr>
<tr><td>Male gender</td><td>532 (51.0%)</td><td>254 (59.2%)</td></tr>
<tr><td>CLD</td><td>377 (36.1%)</td><td>219 (51%)</td></tr>
<tr><td>Postnatal steroids</td><td>256 (24.5%)</td><td>151 (35%)</td></tr>
<tr><td>NEC</td><td>62 (5.9%)</td><td>48 (11.2%)</td></tr>
<tr><td>ROP ≥3</td><td>110/1030 (10.7%)</td><td>77/425 (18.1%)</td></tr>
<tr><td>Systemic infection</td><td>383 (36.7%)</td><td>212 (49.4%)</td></tr>
</table>
</td>
<td></td>
<td>IVH on outcome. This risk factor is therefore described in detail: the interpretation of the head ultrasound was based on the reports of radiologists and/or neonatologists at each hospital. Papile classification was used to grade the severity of IVH. Porencephalic cysts are defined as parenchymal lesions corresponding to grade IV IVH. PVL refers to the ischaemic brain injury affecting the periventricular white matter in the boundary zones supplied by terminal branches of both the centripetal and centrifugal arteries. Overall agreement between the different reporters was found to be 88%. Measurement and definitions of other risk factors are not described.

Outcome(s) ascertainment/measures

The primary outcome measure was moderate to severe neurosensory</td>
<td>Yes: OR 1.81 (1.32-2.47)

SGA <10th percentile
No: Reference
Yes: OR 1.94 (1.09-3.46)

SGA <3rd percentile
No: Reference
Yes: OR 1.98 (1.00-3.92)

Grade I-II IVH
No: Reference
Yes: OR 1.61 (1.14-2.28)

Grade III-IV IVH
No: Reference
Yes: OR 3.81 (2.30-6.30)

Proven systemic infection
No: Reference
Yes: Or 1.20 (0.88-1.65)

NEC
No: Reference
Yes: OR 1.09 (0.65-1.82)

ROP grade 3-4
No: Reference
Yes: OR 2.13 (1.44-3.14)</td>
<td>Clear definitions are not provided for some prognostic factors.
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: Moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
January 1998 to December 2004. **Source of funding** No external funding.	<table><tr><td>PVL</td><td>9/999 (0.9%)</td><td>24/425 (5.6%)</td></tr></table> **Inclusion criteria** Infants borns between 23 and 28+6 weeks' gestation during the study dates. **Exclusion criteria** Major congenital malformations. Death before ultrasound examination. Lost to follow up.		impairment at 2-3 years' corrected age. Moderate neurosensory impairment was defined as the presence of developmental delay (Griffiths Mental Developmental Scale General Quotient or Bayley Scales of Infant Development MDI between 2 and 3 SD below the mean), moderate cerebral palsy (able to walk with the assistance of aids) or deafness (requiring amplification with bilateral hearing aids or unilateral/bilateral cochlear implant). Severe neurosensory impairment was defined as developmental delay (GMDS-GQ or MDI less than 3 SD below the mean), severe cerebral palsy (unable to walk with the assistance of aids) or bilateral blindness (visual acuity <6/60 in the better eye). **Statistical methods** Multivariate analysis using logistic regression models adjusted for significant clinical		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			characteristics were performed to determine the relationship between the study groups and neurodevelopmental outcome. Variables included in the model are not specified in the text, but analysis definitely includes the following: IVH, gestation (23-25 weeks versus 26-28 weeks), SGA, male gender, outborn, PVL, chronic lung disease, pregnancy induced hypertension, proven systemic infection, NEC and ROP grade 3-4. **Length of follow-up** 2 to 3 years' corrected age		
Ref Id 398250 **Full citation** Carlo, W. A., McDonald, S. A., Fanaroff, A. A., Vohr, B. R., Stoll, B. J., Ehrenkranz, R. A., Andrews, W. W., Wallace, D., Das, A., Bell, E.	**Sample size** n=10,541 infants born between 1993-2009 at 22-25 gestational weeks with birth weight 401-1000 g n=5,691 infants born between 1993 and 2008 who survived up to follow-up at 18-22 months of corrected age **n=4,924** infants with neurodevelopmental assessments at 18-22 months of corrected age (follow-up rate 86.5% of the ones who survived up to 18-22 months corrected age) n=3999 infants with exposure to antenatal corticosteroids	**Risk factors** Antenatal corticosteroid use.	**Setting** 23 National Institute of Child Health and Human Development Neonatal Research Network centers in the US between 1993 and 2009. **Method(s) of measurement for risk factor(s)**	**Outcome(s) at age** **Outcomes assessed at 18-22 months corrected age:** Logistic regression models adjusted for maternal variables (age, marital status, race, diabetes, hypertension/preeclampsia, rupture of membranes >24h, antepartum	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias Of the whole population of 10,541

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>F., Walsh, M. C., Laptook, A. R., Shankaran, S., Poindexter, B. B., Hale, E. C., Newman, N. S., Davis, A. S., Schibler, K., Kennedy, K. A., Sanchez, P. J., Van Meurs, K. P., Goldberg, R. N., Watterberg, K. L., Faix, R. G., Frantz, I. D., 3rd, Higgins, R. D., Eunice Kennedy Shriver National Institute of Child, Health, Human Development Neonatal Research, Network, Association of antenatal corticosteroids with mortality and neurodevelopmental outcomes among infants born at 22 to 25 weeks' gestation, JAMA, 306, 2348-58, 2011</td>
<td>n=925 infants with no exposure to antenatal corticosteroids
Subgroups:
22-25 GA weeks n=4924 (total)
22 GA weeks n=72
23 GA weeks n=553
24 GA weeks n=1755
25 GA weeks n=2544

Characteristics

Characteristics for infants born 22-25 gestational weeks between 1993-2009, n=10541
<table>
<tr><th></th><th>Antenatal corticosteroids</th><th>No antenatal corticosteroids</th></tr>
<tr><td>Study population, n</td><td>7808</td><td>2733</td></tr>
<tr><td>Birth weight, g</td><td>680+-121</td><td>657 +-124</td></tr>
<tr><td>SGA, %</td><td>6.1</td><td>3.5</td></tr>
<tr><td>Race black, %</td><td>43.1</td><td>57.2</td></tr>
<tr><td>Race white, %</td><td>52.9</td><td>39.6</td></tr>
<tr><td>Race other, %</td><td>4.0</td><td>3.2</td></tr>
</table>
</td>
<td></td>
<td>Infants were considered to be in the "antenatal corticosteroid" group if their mother received 1 or more doses of antenatal corticosteroids (dexamethasone or betamethasone).

Outcome(s) ascertainment/measures

1) Neurodevelopmental impairment at 18-22 months of corrected age, for infants born up to 2005, defined as 1 or more of the following:

• a Bayley II Mental Developmental index (MDI) <70
• a Bayley II Psychomotor Development index (PDI) <70
• moderate-severe cerebral palsy (CP)
• blindness (blind with no useful vision in either eye)
• deafness (functional hearing</td>
<td>haemorrhage, and delivery mode), multiple birth, gender, and center, unless otherwise stated.
<u>Neurodevelopmental impairment</u>
At 22 wks GA: Antenatal corticosteroids: 1.14 (0.39-3.28)* ; No antenatal corticosteroids: reference
*Only adjusted for gender due to convergence problems because of low outcome prevalence.
At 23 wks GA: Antenatal corticosteroids: 1.11 (0.72-1.71); No antenatal corticosteroids: reference
At 24 wks GA: Antenatal corticosteroids: 0.80 (0.60-1.08); No antenatal corticosteroids: reference
At 25 wks GA: Antenatal corticosteroids: 0.81 (0.62-1.04); No antenatal corticosteroids: reference</td>
<td>infants, only 5,691 survived to follow-up (46% lost to follow-up there). Of the ones who survived to to 18-22 months of corrected age, 13.5% were lost to follow-up, whether they differed compared to the ones included in analysis not reported.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
However, the neurodevelopmental outcomes were measured differently for children born after 2005, but validated tools were used at both times and they accounted for that in the statistical models.
Confounding: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: moderate</td>
</tr>
</table>

Study details	Participants			Risk factors	Methods	Outcomes and results	Comments
Country/ies where the study was carried out United States **Study type** Cohort study **Aim of the study** To determine if antenatal corticosteroid exposure in infants born at each gestational week from 22 to 25 weeks is associated with improvement in important outcomes, including primary outcome of death or childhood neurodevelopmental impairment. **Study dates** Infants born between 1993-	Male gender, %	52.5	53.9		impairment with aids on both ears) and for infants born after 2005, defined as 1 or more of the following: • Bayley III cognitive composite score <70 • gross motor function level 2 or greater • blindness (blind with some or little useful vision in either eye) • deafness (functional hearing impairment) 2) MDI <70 3) PDI <70 4) Bayley cognitive score <70 5) Moderate-severe CP 6) Blindness 7) Deafness Standardized comprehensive neurodevelopmental assessment was performed by certified	At 22-25 wks GA: Antenatal corticosteroids: **0.83 (0.70-0.99)**; No antenatal corticosteroids: reference MDI<70 At 22 wks GA: Antenatal corticosteroids: 2.16 (0.36-13.1); no antenatal corticosteroids: reference At 23 wks GA: Antenatal corticosteroids: 1.27 (0.79-2.03); no antenatal corticosteroids: reference At 24 wks GA: Antenatal corticosteroids: 0.85 (0.62-1.16); no antenatal corticosteroids: reference At 25 wks GA: Antenatal corticosteroids: 0.91 (0.69-1.20); no antenatal corticosteroids: reference At 22-25 wks GA: Antenatal corticosteroids: 0.93 (0.78-1.12); no	
	CS, %	52.8	36.6				
	APGAR <+3 at 5min, %	15.1	30.5				
	Intubation, %	88.6	91.4				
	Resuscitation, %	97.5	99.1				
	Surfactant use, %	87.4	80.3				
	Maternal age <=19, %	14.2	19.2				
	Mother not married, %	53.3	64.7				
	Mother < high school graduate, %	26.1	38.2				
	Income $<32,000, %	43.6	57.9				
	Medicaid, %	63.1	69.3				
	Mother not English speaking, %	16.7	14.6				

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
2009, follow-up at 18-22 months corrected age. **Source of funding** Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network	<table><tr><td>Follow-up rate, %</td><td>87.6</td><td>82.2</td></tr></table> **Inclusion criteria** Inclusion criteria for neurodevelopmental outcomes: Infants born at any of the 23 National Institute of Child Health and Human Development Neonatal Research Network centers between 1993* and 2008 (for analysis with death as outcome, infants born between 1993-2009 were included). Infants born at 22-25 weeks of gestation. Infants with birth weight of 401-1000 g. *In the text, there must be a typo because they report that only infants born between 2003 and 2008 are included but everywhere else they write about 1993 to 2008. **Exclusion criteria** Infants who died within 12 h after birth without receiving delivery room resuscitation. Children who died before follow-up at 18-22 months corrected age.		examiners unaware of exposure to antenatal corticosteroids. **Statistical methods** Logistic regression models were to used to estimate the relationship between antenatal corticosteroid use and outcome. **Length of follow-up** 18-22 months corrected age	antenatal corticosteroids: reference <u>PDI<70</u> At 22 wks GA: Antenatal corticosteroids: 1.47 (0.48-4.50)* no antenatal corticosteroids: reference At 23 wks GA: Antenatal corticosteroids: 0.93 (0.58-1.50); no antenatal corticosteroids: reference At 24 wks GA: Antenatal corticosteroids: **0.69 (0.49-0.95);** no antenatal corticosteroids: reference At 25 wks GA: Antenatal corticosteroids: 0.82 (0.60-1.11); no antenatal corticosteroids: reference At 22-25 wks GA: Antenatal corticosteroids: **0.79 (0.65-0.96)**; no antenatal corticosteroids: reference	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				Only adjusted for gender due to convergence problems because of low outcome prevalence. Bayley III Cognitive Score <70 (for infants born after 2005) At 22 wks GA: Antenatal corticosteroids: 1.28 (0.06-27.5) no antenatal corticosteroids: reference At 23 wks GA: Antenatal corticosteroids: **0.31 (0.09-0.998)****; no antenatal corticosteroids: reference At 24 wks GA: Antenatal corticosteroids: 0.57 (0.17-1.91); no antenatal corticosteroids: reference At 25 wks GA: Antenatal corticosteroids: 0.88 (0.34-2.24); no antenatal corticosteroids: reference At 22-25 wks GA: Antenatal corticosteroids: 0.63 (0.34-1.17); no	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				antenatal corticosteroids: reference *Only adjusted for gender due to convergence problems because of low outcome prevalence. **Only adjusted for gender and race due to convergence problems because of low outcome prevalence. <u>Moderate-severe CP</u> At 22 wks GA: Antenatal corticosteroids: 0.88 (0.23-3.34)* no antenatal corticosteroids: reference At 23 wks GA: Antenatal corticosteroids: **0.50 (0.30-0.85);** no antenatal corticosteroids: reference At 24 wks GA: Antenatal corticosteroids: 0.71 (0.47-1.08)**; no antenatal corticosteroids: reference At 25 wks GA: Antenatal corticosteroids: 0.97 (0.62-1.50); no antenatal	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				corticosteroids: reference At 22-25 wks GA: Antenatal corticosteroids: **0.76 (0.59-0.98);** no antenatal corticosteroids: reference *Only adjusted for gender due to convergence problems because of low outcome prevalence. **Only adjusted for gender, race and centre due to convergence problems because of low outcome prevalence <u>Blindness</u> At 22 wks GA: - At 23 wks GA: Antenatal corticosteroids: **0.31 (0.10-0.93);** no antenatal corticosteroids: reference At 24 wks GA: Antenatal corticosteroids: 1.17 (0.48-2.83)*; no antenatal corticosteroids: reference At 25 wks GA: Antenatal corticosteroids: 0.46 (0.19-1.10)**; no antenatal	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				corticosteroids: reference At 22-25 wks GA: Antenatal corticosteroids: 0.61 (0.36-1.03); no antenatal corticosteroids: reference *Only adjusted for gender and race due to convergence problems because of low outcome prevalence. **Only adjusted for gender due to convergence problems because of low outcome prevalence. <u>Deafness</u> At 22 wks GA: - At 23 wks GA: Antenatal corticosteroids**: 0.39 (0.17-0.93)*;** no antenatal corticosteroids: reference At 24 wks GA: Antenatal corticosteroids: 0.93 (0.45-1.90); no antenatal corticosteroids: reference At 25 wks GA: Antenatal corticosteroids: 0.91 (0.46-1.81)**; no antenatal	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				corticosteroids: reference At 22-25 wks GA: Antenatal corticosteroids: 0.76 (0.50-1.16); no antenatal corticosteroids: reference *Only adjusted for gender and race due to convergence problems because of low outcome prevalence. **Only adjusted for gender due to convergence problems because of low outcome prevalence.	
Ref Id 410201 **Full citation** Davis, N. M., Ford, G. W., Anderson, P. J., Doyle, L. W., Developmental coordination disorder at 8 years of age in a regional cohort of extremely-low-birthweight or very preterm infants,	**Sample size** N=298 consecutive preterms N=262 randomly selected infants **Characteristics** ELBW group: born at <28 weeks gestational age and/or birth weight <1000g (Children born ELBW and <1000g=170; ELBW and >999g=73) **Inclusion criteria** Children born with gestational age < 28 weeks or birth weigh <1000g Cut off of the 5th centile was used to denote children with DCD	**Risk factors** Male gender	**Setting** Children were consecutively enrolled, who were born in the state of Victoria, Australia The NBW cohort was selected from level III maternity hospitals in the state on the expected date of birth of an ELBW infant and matched for sex, mother's country of birth, and hospital insurance status All infants were enrolled in a prospective	**Outcome(s) at age** <u>Developmental Coordination Disorder at 8 and 9 years age</u> After adjustment for all other perinatal variables, only male sex increased the risk of a child having developmental coordination disorder, with P value 0.017	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. Participants: low risk of bias (there is an adequate description of population of interest and of the inclusion/exclusion criteria) Attrition: moderate risk of bias (8/298 were lost to follow up in the ELBW group,

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Developmental Medicine and Child Neurology, 49, 325-330, 2007 **Country/ies where the study was carried out** Australia **Study type** Prospective cohort study **Aim of the study** To (1) ascertain the rate of developmental coordination disorder occurring in a cohort of very preterm (<28 weeks) or extremely-low-birthweight (EL BW <1000g) children at age 8 to 9 years born in the 1990s compared with a cohort of NBW	**Exclusion criteria** Children with cerebral palsy or an IQ of more than 2 SDs below the mean and SD for the NBW controls were excluded from all analyses		longitudinal study of growth and development throughout childhood, with some outcomes at 2, 5, and 8 reported previously by the Victorian Infant Collaborative Study Group Written informed consent was obtained from parents of NBW children Follow-up was regarded as routine clinical care for the ELBW/very preterm children **Method(s) of measurement for risk factor(s)** **Outcome(s) ascertainment/measures** Fine and gross motor abilities were assessed using the Movement Assessment Battery for Children (MABC), age band 2 for 7 to 8 year olds Cut off of the 5th centile was used to denote children with DCD Cognitive ability was assessed using the		and 22/262 were lost to follow up in the NBW group. Reason for loss to follow up was not clearly reported) Prognostic factor measurement: low risk of bias Outcome measurement: low risk of bias Confounding: low risk of bias Analysis and Reporting: moderate risk of bias (male gender as a risk factor only reported narratively) Overall quality: low

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
(>2499g) children, (2) to determine the perinatal associations of DCD and (3) determine the cognitive, educational, and behavioural deficits that accompany DCD in ELBW or very preterm children **Study dates** January 1991 to December 1992 **Source of funding** National Health and Medical Research Council, Australia			Wechsler Intelligence Scale for Children (WISC-III) Full scale IQ was sued as a measure of general cognitive ability Parents and teachers completed the Behaviour Assessment System for Children **Statistical methods** Data were analysed by logistic function regression to determine the independent influence of perinatal variables on DCD Those perinatal factors that were significant in the univariate analysis were adjusted for in the multivariate analysis **Length of follow-up** Children were assessed at age 8 and 9 years by paediatricians and psychologists who were unaware of participant's perinatal status or of results of assessments earlier in childhood		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Ref Id 410213 **Full citation** De Jesus, L. C., Pappas, A., Shankaran, S., Li, L., Das, A., Bell, E. F., Stoll, B. J., Laptook, A. R., Walsh, M. C., Hale, E. C., Newman, N. S., Bara, R., Higgins, R. D., Outcomes of small for gestational age infants born at <27 weeks' gestation, Journal of Pediatrics, 163, 55-60.e3, 2013 **Country/ies where the study was carried out** United States **Study type** Retrospective cohort study	**Sample size** N=2971 **Characteristics** **Maternal:** Age (years, mean, SD): SGA group: 27.1 (6.2); non-SGA group: 26.8 (6.4) African American (n): SGA group:151; non-SGA group:971 Antenatal corticosteroids (n): SGA group:311; non-SGA group:1953 **Infant:** GA (Weeks, median, range): SGA group:25 (23-26); non-SGA group:25 (23-26) Multiple birth (n): SGA group: 76; non-SGA group: 615 Birth weight (mean g, SD): SGA group:524 (76); non-SGA group:761 (149) Male sex (n): SGA group: 201; non-SGA group:1381 **Inclusion criteria** Infants born between 23 0/7 and 26 6/7 weeks GA **Exclusion criteria** Infants with major congenital abnormalities or syndromes and those who declined neurodevelopmental follow-up	**Risk factors** Small for gestational age (SGA)	**Setting** Data collected prospectively from National Institute of Child Health and Human Development's Neonatal Research Network (NRN) and infants born in one of the NRN sites, and followed up at 18-22 weeks corrected age **Method(s) of measurement for risk factor(s)** Gestational age (GA) determined by 1. Best obstetric estimate, based on last menstrual period, obstetrical variables, and/or early prenatal ultrasound; 2. Best neonatologist estimate, based on Ballard score. SGA was defined as a birth weight <10th percentile for GA based on sex specific Olsen growth curves. Infants with birth weight ≥10th percentile for GA were classified as non-SGA	**Outcome(s) at age** **Outcomes assessed at 18-22 months corrected age:** **For the outcome of Death or neurodevelopmental impairment:** SGA: OR 3.91, 95%CI 2.91-5.25 **For the outcome of BSID III cognitive score <70:** SGA: OR 2.08, 95%CI 1.12-3.85 (P=0.018) **For the outcome of BSID III cognitive score <80:** SGA: OR 2.38, 95%CI 1.49-3.81 **For the outcome of moderate or severe CP:** SGA: OR 2.55, 95%CI 1.69-3.86 **For the outcome of hearing loss with or without amplification:** SGA: OR 1.38, 95%CI 0.44-4.36 (P=0.58) **For the outcome of blindness (<20/200 vision bilaterally):** SGA: OR 10.9, 95%CI 2.15-55.5 Covariates included centre as a random-effects variable, male	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias. The follow-up rate was 82.3%. Mothers lost to follow up were less likely to receive prenatal care and antenatal steroids and would experience pregnancy-induced hypertension. Infants lost to follow up were less likely to be born via C-section or to have growth failure at 36 weeks PMA and RDS, but tended to weigh more at birth and were more likely to have BPD, surgically treated patent ductus arteriosus, grade III-IV ICH, and cystic periventricular leukomalacia. **Prognostic factor measurement:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Aim of the study To determine whether small for gestational age (SGA) infants born at <27 weeks gestational age (GA) are at increased risk for mortality, morbidity, and growth and neurodevelopmental impairment at 18-22 months corrected age **Study dates** January 2006-July 2009 **Source of funding** National Institutes of Health			**Outcome(s) ascertainment/measures** The primary outcome for this analysis was risk of death or neurodevelopmental impairment. Neurodevelopmental impairment was defined as presence of at least one of the following: 1. A composite score <70 on the cognitive component of the Bayley Scales of Infant and Toddler Development (BSID-III); 2. Moderate or sever cerebral palsy (CP) based on presence of bilateral hearing loss (with or without amplification) or bilateral blindness (vision <20/200). Outcomes were analysed as a dichotomous variable (SGA or no SGA) A neurodevelopmental assessment, including a neurologic examination and assessment using the BSID-III was performed by a certified examiner trained for reliability	sex, multiple birth, GA, antenatal corticosteroid use, hypertension, and maternal education	**Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: Moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			Statistical methods Multivariate logistic regression models **Length of follow-up** 18-22 months corrected age		
Ref Id 410443 **Full citation** Foix-L'Helias, L., Marchand, L., Theret, B., Larroque, B., Ancel, P. Y., Blondel, B., Garel, M., Maillard, F., Missy, P., Sehili, F., Supernant, K., Durand, M., Matis, J., Messer, J., Treisser, A., Burguet, A., Abraham-Lerat, L., Menget, A., Roth, P., Schaal, J. P., Thiriez, G., Leveque, C., Marret, S., Marpeau, L.,	**Sample size** N = 2855 **Characteristics** Baseline characteristics not described in this publication. **Inclusion criteria** For this analysis, any birth between 24^{+0} and 32^{+6} weeks of gestation in all maternity units of nine French regions in 1997. **Exclusion criteria** Missing data on antenatal steroid use (n=89). For the purpose of this analysis children who died before 5 years were excluded. The protocol included the option of not following up one of every two infants born at 32 weeks (to reduce the workload). 2 regions exercised this option leading to the exclusion of 68 infants.	**Risk factors** Antenatal corticosteroid (ANC) exposure.	**Setting** All maternity units in nine regions of France. **Method(s) of measurement for risk factor(s)** Standardised questionnaires were completed prospectively, including data on ANC therapy, including the number of courses and whether they were complete or not. **Outcome(s) ascertainment/measures** Follow up was at 5 years of age, and involved a medical and	**Outcome(s) at age** **Risk of cerebral palsy** <u>24-27 week group</u> No exposure to ANC: Reference Any exposure to ANC: OR 1.69 (0.67 - 4.26) Exposure to complete course of ANC: OR 1.22 (0.46 - 3.26) <u>28-32 week group</u> No exposure to ANC: Reference Any exposure to ANC: OR 0.86 (0.54 - 1.38) Exposure to complete course of ANC: OR 0.71 (0.42 - 1.19) <u>All preterm infants (24-32 weeks)</u> No exposure to ANC: Reference Any exposure to ANC: OR 0.99 (0.65 - 1.52)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** Low risk of bias **Attrition:** Moderate risk of bias From the 2207 survivors at the time of 5 year follow up, cerebral palsy status was only known in 1781 infants, and MPC score was only available for 1508. Therefore 19% of the study population were unaccounted for in terms of CP status, and 32% unaccounted for in terms of MPC status. No information is presented on

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Boulot, P., Picaud, J. C., Donadio, A. M., Ledesert, B., Andre, M., Fresson, J., Hascoet, J. M., Arnaud, C., Bourdet-Loubere, S., Grandjean, H., Rolland, M., Leignel, C., Lequien, P., Pierrat, V., Puech, F., Subtil, D., Truffert, P., Boog, G., Rouger-Bureau, V., Roze, J. C., Ancel, P. Y., Breart, G., Kaminski, M., Du Mazaubrun, C., Dehan, M., Zupan-Simunek, V., Vodovar, M., Voyer, M., Impact of the use of antenatal corticosteroids on mortality, cerebral lesions and 5-year neurodevelopmental outcomes of very preterm infants: The EPIPAGE cohort			neuropsychological assessment. The definition of cerebral palsy was that established by the European Cerebral Palsy Network, which requires at least 2 of the following: abnormal posture or movement, increased tone and hyperreflexia. Cerebral palsy was considered to be severe if infants were unable to walk, or only able to walk with assistance. Cognitive ability was assessed using the mental processing composite (MPC) of the Kaufman Assessment Battery for Children. This score is standardised to a mean (±SD) of 100 (±15) based on a reference population of French children born in the late 1990s. MPC scores of less than 70 indicate cognitive impairment. **Statistical methods** Odds ratios for the outcomes (CP and MPC <70) were calculated for infants exposed to any	Exposure to complete course of ANC: OR 0.83 (0.52 - 1.31) **Risk of MPC < 70** <u>24-27 week group:</u> No exposure to ANC: Reference Exposure to any ANC: OR 1.61 (0.55 - 4.73) Exposure to complete course of ANC: OR 1.78 (0.59 - 5.38) <u>28-32 week group</u> No exposure to ANC: Reference Any exposure to ANC: OR 0.76 (0.48 - 1.18) Exposure to complete course of ANC: OR 0.85 (0.52 - 1.38) <u>All preterm infants (24-32 weeks)</u> No exposure to ANC: Reference Any exposure to ANC: OR 0.82 (0.54 - 1.24) Exposure to complete course of ANC: OR 0.91 (0.58 - 1.42) All OR adjusted for quintile of propensity score, social class of the family and gestational age	potential differences between these participants and those for whom data was available. **Prognostic factor measurement:** Low risk of bias **Outcome measurement:** Low risk of bias **Analysis and reporting:** Low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
study, BJOG: An International Journal of Obstetrics and Gynaecology, 115, 275-282, 2008 **Country/ies where the study was carried out** France. **Study type** Prospective population based cohort study. **Aim of the study** To assess the impact of antenatal steroids on neurodevelopmental outcome of infants born at 24-27 weeks and 28-32 weeks gestation.			antenatal corticosteroid compared to no antenatal corticosteroid, and for a completed course of antenatal corticosteroids compared to no corticosteroids. These are presented as crude ratios, and adjusted for gestational age, social class, sex and pregnancy complications. A propensity score method was then utilised to reduce bias, which included adjustment for: general characteristics (maternal age, parity, tobacco consumption, region and level of neonatal intensive care), maternal complications and pregnancy characteristics (previous stillbirth or preterm birth, uterine malformation, diabetes, hypertension, severe maternal disease, infertility treatment, single or multiple pregnancy, tocolysis, suspected chorioamnionitis, placenta praevia, threatened preterm labour, rupture of membranes, spontaneous preterm		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Study dates Recruitment took place in 1997. Follow up was at 5 years. **Source of funding** INSERM (National Institute of Health and Medical Research), Directorate General for Health of the Ministry for Social Affairs, Merck-Sharp and Dohme-Chibret, Medical Research Foundation, HAS (French National Authority for Health) and "Hospital Program for Clinical Research 2001 n° AOMO1117" of the French Department of Health.			labour, caesarean section before labour or induced delivery) and fetal complications (suspected intrauterine growth retardation, malformations and acute fetal distress). **Length of follow-up** 5 years.		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Ref Id

347156

Full citation

Goldstein, R. F., Cotten, C. M., Shankaran, S., Gantz, M. G., Poole, W. K., Influence of gestational age on death and neurodevelopmental outcome in premature infants with severe intracranial hemorrhage, Journal of Perinatology, 33, 25-32, 2013

Country/ies where the study was carried out

USA.

Study type

Retrospective cohort study.</td>
<td>Sample size

N = 5456

Characteristics

Characteristics of infants followed at 18-22 months.
<table>
<tr><th>Characteristic</th><th>N (%)</th></tr>
<tr><td>Gestational age (weeks) 23-25</td><td>1583 (43.1)</td></tr>
<tr><td>26-28</td><td>2089 (56.9)</td></tr>
<tr><td>Maternal education <HS degree</td><td>1939 (54.3)</td></tr>
<tr><td>Medicaid insurance</td><td>2164 (61.0)</td></tr>
<tr><td>Race- Black (non-Hispanic)</td><td>1547 (42.1)</td></tr>
<tr><td>White (non Hispanic)</td><td>1361 (37.1)</td></tr>
<tr><td>Hispanic</td><td>621 (16.9)</td></tr>
<tr><td>Other</td><td>143 (3.9)</td></tr>
</table>
</td>
<td>Risk factors

Gestational age
NEC</td>
<td>Setting

Neonatal Research Network hospital study.

Method(s) of measurement for risk factor(s)

Demographic, perinatal and neonatal morbidity variables were obtained from the Neonatal Research Network Registry of Morbidity and Mortality Generic Database. The presence and severity of ICH was determined by a cranial ultrasound performed in the first 28 days of life.

Outcome(s) ascertainment/measures

Data on neurodevelopmental outcome were obtained by trained staff using standard definitions listed in the study's Manual of Operations. The neurologic examination and administration of Bayley Scales of Infant Development were</td>
<td>Outcome(s) at age

<u>For infants without ICH</u>
Risk of cerebral palsy
GA 26-28 weeks: Reference
GA 23-25 weeks: OR 1.57 (1.01-2.44)

Risk of MDI <70
GA 26-28 weeks: Reference
GA 23-25 weeks: OR 1.41 (1.16-1.72)

Risk of PDI < 70
GA 26-28 weeks: Reference
GA 23-25 weeks: OR 1.38 (1.10-1.75)

Risk of blindness
GA 26-28 weeks: Reference
GA 23-25 weeks: OR 4.66 (1.5-14.52)

Risk of deafness
GA 26-28 weeks: Reference
GA 23-25 weeks: OR 2.67 (1.37-5.20)

<u>For infants with Grade III ICH</u>
Risk of cerebral palsy
GA 26-28 weeks: Reference
GA 23-25 weeks: OR 1.48 (0.64-3.41)</td>
<td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
8% of the original cohort were lost to follow up. No details are provided regarding whether the baseline characteristics of those lost to follow up differ from those who provided follow up data, therefore there is the potential for systematic differences between participants who were and were not followed up.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: low risk of bias.</td>
</tr>
</table>

Study details	Participants		Risk factors	Methods	Outcomes and results	Comments
Aim of the study To determine if neurodevelopmental outcome after severe intracranial haemorrhage differs by gestational age at birth. **Study dates** Not reported. States five year duration. **Source of funding** The National Institutes of Health and the Eunice Kennedy Shriver National Institute of Child Health and Human Development.	Gender-male	1713 (46.7)		performed by certified examiners who were blinded to the grade of ICH and trained to reliability at each participating network centre. Neurodevelopmental impairment (NDI) was defined as at least one of: moderate/severe cerebral palsy with Gross Motor Function score 3-5, Mental Development Index or Psychomotor Development Index < 70 on the BSID-II at 18-22 months corrected age, blindness (no functional vision in both eyes) or deafness (requiring amplification in both ears). **Statistical methods** Generalized linear mixed models were created to predict the risk of neurodevelopmental impairment among survivors at follow up. Models included gestational age, Apgar score at 5 minutes, antenatal steroids, early infection, postnatal steroids, NEC, late onset	**Risk of MDI <70** GA 26-28 weeks: Reference GA 23-25 weeks: OR 1.85 (1.06-3.25) **Risk of PDI < 70** GA 26-28 weeks: Reference GA 23-25 weeks: OR 1.06 (0.56-2.01) Risk of blindness unable to be calculated (number of infants too small) **Risk of deafness** GA 26-28 weeks: Reference GA 23-25 weeks: OR 3.36 (1.08-10.44) <u>For infants with Grade IV ICH</u> **Risk of cerebral palsy** GA 26-28 weeks: Reference GA 23-25 weeks: OR 0.84 (0.42-1.68) **Risk of MDI <70** GA 26-28 weeks: Reference GA 23-25 weeks: OR 2.01 (1.01-4.02) **Risk of PDI < 70**	Overall quality: moderate
	Small for gestational age	345 (9.4)				
	C-section delivery	2391 (65.2)				
	5-min Apgar <5	485 (13.3)				
	Antenatal steroids-none	624 (17.1)				
	No ICH	3057 (83.3)				
	Severe ICH	615 (16.7)				
	Grade 3/ Grade 4	335 (9.1) / 280 (7.6)				
	NEC- Medical/Surgical	170 (4.6) / 148 (4.0)				
	Early onset infection	56 (1.5)				

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
	Late onset infection 2475 (67.4) Cystic PVL 117 (3.2) Postnatal steroids 848 (23.1) **Inclusion criteria** Infants born between 23 and 28 completed weeks of gestation with a birthweight of 401-1000g, born at (or transferred before 2 weeks of age to) one of 18 Neonatal Research Network centres during a five year period. **Exclusion criteria** Grade 1 or 2 IVH.		infection, cystic PVL, ventriculoperitoneal shunt insertion, maternal education, Medicaid status and BPD at 36 weeks. **Length of follow-up** 18-22 months.	GA 26-28 weeks: Reference GA 23-25 weeks: OR 0.77 (0.38-1.57) Risk of blindness unable to be calculated (number of infants too small) **Risk of deafness** GA 26-28 weeks: Reference GA 23-25 weeks: OR 1.16 (0.42-3.24) **Risk of overall neurodevelopmental impairment** No NEC: Reference NEC: OR 6.89 (1.44-32.88)	
Ref Id 336410 **Full citation** Guellec, I., Lapillonne, A., Renolleau, S., Charlaluk, M. L., Roze, J. C., Marret, S., Vieux, R.,	**Sample size** n=2846 included originally n=1822 children with follow-up at 5 years on CP and cognitive outcome (disorders) n=1677 children with follow-up at 5 years on behavioural outcomes (problems) **Characteristics**	**Risk factors** Small for gestational age (SGA) (vs appropriate for gestational age AGA) Mild SGA (vs AGA)	**Setting** All maternity units in 9 regions of France. **Method(s) of measurement for risk factor(s)** SGA, a birth weight for gestational age at the	**Outcome(s) at age** **Outcomes assessed at 5 years of age:** **<u>Disorders</u>** <u>Cerebral palsy (CP)</u> 1) Infants born at 24-28 wks of gestation: AGA (>=20th centile): Ref M-SGA (10th-19th centile): 0.75 (0.25-2.23)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias Of the ones originally included in the study,

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Monique, K., Ancel, P. Y., Epipage Study Group, Neurologic outcomes at school age in very preterm infants born with severe or mild growth restriction, Pediatrics, 127, e883-91, 2011 **Country/ies where the study was carried out** France **Study type** Prospective observational study (cohort) **Aim of the study** To determine whether mild and severe growth restriction at birth among preterm infants	Among the 2846 infants born alive, 274 (9.6%) were M-SGA and 262 (9.2%) were SGA; 828 children were born between 24 and 28 weeks' gestation, and 2018 were born between 29 and 32 weeks' gestation. Among children in the 24- to 28-week group there was no significant association between weight for GA and social and maternal variables. In the 29- to 32-week group, the proportions of SGA and M-SGA were increased among nulliparous women older than 35 years and among women who received antenatal corticosteroids. **Inclusion criteria** Infants born at <33 weeks of gestation in all maternity units, regardless of the level of he hospital, of 9 regions of France between 1 Jan and 31 Dec 1997. **Exclusion criteria** None reported.		<10th centile, measured at birth. Mildly SGA (M-SGA), a birth weight for gestational age between the 10th and 19th centiles), measured at birth. **Outcome(s) ascertainment/measures** **Developmental disorders:** **Cerebral palsy (CP)**, defined according to the European CP Network definition, children were classified as having CP if they had abnormal posture or movement, increased tone or hyperreflexia (spastic CP), involuntary movements (dyskinetic CP), or loss of coordination (ataxic CP). Detailed medical and neurologic examintion in which tone, reflexes, postures and movements were assessed. Trained paediatricians reviewed data for children with abnormal results on neurologic examination to validate the diagnosis	SGA (<10th centile): 1.73 (0.54-5.60) Adjusted for gestational age, gender, spcial class of the family, type of pregnancy (single vs multiple). 2) Infants born at 29-32 wks of gestation: AGA (>=20th centile): Ref M-SGA (10th-19th centile): 0.57 (0.24-1.34) SGA (<10th centile): 0.39 (0.14-1.08) Adjusted for gestational age, gender, social class of the family, and type of pregnancy (single vs multiple). <u>Cognitive deficiency</u> 1) Infants born at 24-28 wks of gestation: AGA (>=20th centile): Ref M-SGA (10th-19th centile): 0.91 (0.38-2.16) SGA (<10th centile): 1.05 (0.34-3.19) Adjusted for gestational age, social class of the family, and age, nationality and parity of the mother at birth.	36% were lost to follow-up at 5 years for disorder outcomes and 41% for problems outcomes. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias However, note that cognitive deficiency considers MPC <85 (-1SD), so also "mild" definiciency. **Confounders:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
is associated with neonatal mortality and cerebral palsy and cognitive performance at 5 years of age and school performance at 8 years of age. **Study dates** 1997, follow-up at 5 and 8 years **Source of funding** None reported.			of CP and assess the severity. **Cognitive deficiency**, defined by an Mental processing Composite (MPC) <85 (-1SD) assessed by the French version of the Kaufman Assessment Battery for Children, administered by trained psychologist. **Developmental problems:** Inattention-hyperactivity symptoms, assessed with the French version of the Strength and Difficulties Questionnaire completed by the parents. Total behavioural difficulties, including a sum score of scales on hyperactivity-inattention, conduct, emotional and peer problems, assessed with the French version of the Strength and Difficulties Questionnaire completed by the parents. **Statistical methods** Multiple logistic regression, including covariates that were known risk factors and	2) Infants born at 29-32 wks of gestation: AGA (>=20th centile): Ref M-SGA (10th-19th centile): 1.87 (1.24-2.82) SGA (<10th centile): 1.73 (1.12-2.69) Adjusted for gestational age, social class of the family, and age, nationality and parity of the mother at birth. **Problems** Inattentional-hyperactivity symptoms 1) Infants born at 24-28 wks of gestation: AGA (>=20th centile): Ref M-SGA (10th-19th centile): 1.05 (0.41-2.70) SGA (<10th centile): 1.29 (0.37-4.46) Adjusted for gestational age, gender, social class of the family, age and parity of the mother at birth, type of pregnancy (single vs multiple) and antenatal corticosteroids. 2) Infants born at 29-32 wks of gestation:	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			found to be associated with the outcome at the 20% significance level in univariate analysis. **Length of follow-up** 5 years	AGA (>=20th centile): Ref M-SGA (10th-19th centile): 1.19 (0.69-2.03) SGA (<10th centile): 1.78 (1.10-2.89) Adjusted for gestational age, gender, social class of the family, age and parity of the mother at birth, type of pregnancy (single vs multiple) and antenatal corticosteroids. <u>Total behavioural difficulties</u> 1) Infants born at 24-28 wks of gestation: AGA (>=20th centile): Ref M-SGA (10th-19th centile): 1.24 (0.52-2.92) SGA (<10th centile): 2.30 (0.82-6.48) Adjusted for gestational age, gender, social class of the family, age and parity of the mother at birth, type of pregnancy (single vs multiple) and antenatal corticosteroids. 2) Infants born at 29-32 wks of gestation: AGA (>=20th centile):Ref	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				M-SGA (10th-19th centile): 1.66 (1.04-2.62) SGA (<10th centile): 0.98 (0.59-1.63) Adjusted for gestational age, gender, social class of the family, age and parity of the mother at birth, type of pregnancy (single vs multiple) and antenatal corticosteroids.	
Ref Id 347172 **Full citation** Hansen, B. M., Hoff, B., Uldall, P., Greisen, G., Kamper, J., Djernes, B., Hertel, J., Christensen, M. F., Andersen, E., Lillquist, K., Verder, H., Peitersen, B., Grytter, C., Agertoft, L., Andersen, E. A., Berg, A., Krag-Olsen, B., Sardeman, H., Jonsbo, F.,	**Sample size** N=252 **Characteristics** Boys (%): 49 Birthweight (mean g, SD): 923 (167) Gestational age (mean weeks, SD): 27.4 (1.8) Gestational age (range in weeks): 24.1-34.3 Mechanical ventilation (n): 95 Mechanical ventilation (mean number of days, range): 9 (1-53) Nasal CPAP (n): 248 Nasal CPAP (mean number of days, range): 39 (1-151) **Inclusion criteria** Infants born in 1994-1995 with 1) a birth weight below 1000 g or 2) a gestational age below 28wk.	**Risk factors** Male gender GA IVH grade 3 and 4 IVH 3-4/PVL Necrotizing enterocolitis (NEC)	**Setting** National cohort **Method(s) of measurement for risk factor(s)** Intellectual development was defined as IQ score below -2 standard deviations from the mean of a reference group, and classified children with intellectual disabilities. Motor performance was measured by the Movement ABC scale, with a high score indicating poor motor performance.	**Outcome(s) at age** **<u>Outcomes assessed at age 5 years:</u>** **<u>For the outcome of CP, OR (95%CI):</u>** Sex/boy: 0.5 (0.2-1.6) IVH 3-4/PVL: 19.9 (6.1-64.8) NEC: 19.1 (3.3-111.3) -risk factors were adjusted for each other in the multivariate analysis, as well as CRIB-score (high), chronic lung disease, and mechanic ventilation during neonatal course	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias. Loss to follow up or number of infants not in the analyses was not reported in the study **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Jorgensen, N. F., Christensen, N. C., Nielsen, F., Ebbesen, F., Pryds, O., Lange, A., Danish, Etfol Group, Perinatal risk factors of adverse outcome in very preterm children: a role of initial treatment of respiratory insufficiency?, Acta Paediatrica, 93, 185-9, 2004 **Country/ies where the study was carried out** Denmark **Study type** Prospective cohort **Aim of the study** To investigate risk factors of adverse outcome in a	**Exclusion criteria** One child with holoprosencephaly and one child with Sandoff disease were excluded from the analyses.		School education was scored on a 6 point scale from below average to upper secondary school (parents). Vocational training was scored on on a 5 point scale from no vocational training to academic education of at least 5 years duration (parents). The total score ranged from 2 to 11 and for each child a mean parental education score was calculated for the adults living with the child. **Outcome(s) ascertainment/measures** Cerebral palsy was diagnosed in accordance with the criteria as defined in the Surveillance of cerebral palsy in Europe Visual disability: a visual acuity at or below 0.3 on the best-corrected eye was defined as visual disability. Motor performance was evaluated by Movement Assessment Battery for	**For the outcome of IQ score below 2 -SD of the mean:** Sex/boy: 1.0 (0.5-2.0) IVH 3-4/PVL: 6.2 (2.3-16.5) NEC: 4.1 (0.8-20.8) -risk factors were adjusted for each other in the multivariate analysis, as well as CRIB-score (high), chronic lung disease, and mechanic ventilation during neonatal course	**Analysis and reporting:** low risk of bias Overall quality: Moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
cohort of very preterm children treated mainly with nasal continuous positive airway pressure (CPAP) during the neonatal course **Study dates** 1994-1995 **Source of funding** Danish Medical Research Council, Ronald McDonald Children's Charities in Denmark, Vill Heises Foundation.			Children, high score indicating poor motor performance. Intelligence test: Wechsler's Preschool and Primary Scale of Intelligence-Revised, WPPSI-R, was used as an intelligence test. Intellectual disability: An IQ score below -2 SD from the mean of a reference group classified children with intellectual disability. **Statistical methods** Multivariate logistic regression analysis was performed to investigate risk factors of adverse outcome in the entire cohort. Adverse outcomes were cerebral palsy and intellectual disability. CRIB score was used as an early indicator of clinical condition. NEC, IVH 3-4/PVL and CLD were predictors of adverse outcome. Male sex was entered in order to look for differences between mechanical ventilation and adverse outcome,		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			mechanical ventilation (dichotomous) was used as a predictor. A linear regression analysis was performed in three steps to investigate influence of risk factors on both IQ and motor performance. Children with CP, visual disability or a first language other than Danish were excluded. Children with gestational age >27 weeks (to reduce confounding by intrauterine growth) were excluded. Step 1: Parental education score was entered as an index of genetic and environmental influence together with gender and gestational age. Step 2: mechanical ventilation was entered to investigate influence of mechanical support. Step 3: CLD and IVH 3-4/PVL were entered to examine the influence on outcomes. NEC was not used as a variable due to low incidence in the subsample. There was normal distribution of		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			residuals in both analyses. **Length of follow-up** 5-year follow-up of a national prospective cohort		
Ref Id 410637 **Full citation** Helderman, J. B., O'Shea, T. M., Kuban, K. C., Allred, E. N., Hecht, J. L., Dammann, O., Paneth, N., McElrath, T. F., Onderdonk, A., Leviton, A., Elgan study Investigators, Antenatal antecedents of cognitive impairment at 24 months in extremely low gestational age newborns, Pediatrics, 129, 494-502, 2012 **Country/ies where the**	**Sample size** N=1506 Analysed n=921 **Characteristics** <u>Maternal characteristics</u> Racial identity (n): White:545 Black:242 Other:119 Age (years, n): <21: 125 21-35: 618 >35: 178 <u>Neonatal characteristics:</u> Babies born <28 weeks gestational age **Inclusion criteria** Babies born <28 weeks gestational age **Exclusion criteria**	**Risk factors** Male gender Gestational age	**Setting** Women participated 14 institutions in 11 cities in 5 states **Method(s) of measurement for risk factor(s)** **Outcome(s) ascertainment/measures** Developmental assessment was determined at 24 months corrected age 91% of children had the developmental assessment, which included a neurologic examination and the BSID II. All BSID II assessments were age adjusted Neurologic examiners were asked to rate the child on the Gross Motor Function	**Outcome(s) at age** Association of variables with low MDI (<55 or 55-59): Total sample (n=921) <u>MDI <55:</u> Gestational age 23-24 weeks: OR 1.9 (0.97-3.6) Gestational age 25-26 weeks: OR 1.2 (0.7-2.1) Gestational age 27 weeks: Reference Male gender: OR 2.5 (1.6-4.1) Ethnicity (white (ref) vs non-white): OR 2.3 (1.4-3.8) <u>MDI 55-69:</u> Gestational age 23-24 weeks: OR 1.0 (0.5-1.9) Gestational age 25-26 weeks: OR 0.8 (0.5-1.3) Gestational age 27 weeks: Reference Male gender: OR 2.0 (1.3-3.2)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** Low risk of bias **Attrition:** moderate risk of bias A total of 1200 infants survived to 24 months and 85% were assessed with BSID II or GMFCS. Infants with impaired GMFCS ≥1 were excluded, leaving 921 included in the analysis **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
study was carried out United States **Study type** Multicentre cohort study (ELGAN study) **Aim of the study** To identify risk factors that may increase the risk of cognitive impairment at 24 months corrected age in children who were born at extremely low gestational age **Study dates** 2002 to 2004 **Source of funding** The National Institute of Neurologic	Children who were not able to walk independently (GMFCS ≥1)		Classification System (GMFCS) separately from the neurologic examination Cognitive impairment was defined as a Mental Developmental Index (MDI) of <70. An MDI of <55 was considered as severe cognitive impairment The child was tested as non-testable on a scale of impairments prohibited standardised administration, or if >2 items were judged to be 'not applicable' Data analysis included adjustment for potential confounders by two multivariable models, each comparing children in 1 of the 2 abnormal outcome groups to the same referent group (i.e., those with MDI≥70) The models contained a hospital cluster term to account for the possibility that infants born at a particular hospital are more like each other than like infants born at other hospitals **Statistical methods**	Ethnicity (white (ref) vs non-white): OR 2.1 (1.3-3.5)	risk of bias (participant numbers in reported flow diagram do not add up) Overall quality: Moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Disorders and Stroke (NINDS), funded by the National Institutes of Health (NIH)			Data analysis included adjustment for potential confounders by two multivariable regression models, each comparing children in 1 of the 2 abnormal outcome groups to the same referent group (i.e., those with MDI≥70) The models contained a hospital cluster term to account for the possibility that infants born at a particular hospital are more like each other than like infants born at other hospitals **Length of follow-up** 24 months corrected age		
Ref Id 397305 **Full citation** Herber-Jonat, S., Streiftau, S., Knauss, E., Voigt, F., Flemmer, A. W., Hummler, H. D., Schulze, A., Bode, H., Long-term outcome at age 7-10 years	**Sample size** Enrolled n=128 Died before first discharge from hospital n=23 (excluded) Lost to follow-up n=26 **Included in outcome analysis n=79** (18 in GA 22-23 wks, 61 in GA 24 wks) **Characteristics** Children included in analysis (n=79):	**Risk factors** Intracerebral haemorrhage (ICH) >II ° (intraventricular haemorrhage, IVH) and/or Periventricular Leucomalasia (PVL) Retinopathy of prematurity (ROP) >II ° Necrotising enterocolitis (NEC) >IIB (results not reported) Chronic lung disease (CLD) (most likely	**Setting** Perinatal centres of the University of Munich and the University of Ulm in Germany. **Method(s) of measurement for risk factor(s)** Not described in the publication.	**Outcome(s) at age** **Outcomes assessed at 7-10 years of age:** Neurodevelopmental impairment No ROP >II ° (reference) ROP >II ° OR 3.18 (95% CI 1.09-9.31) Adjusted for gestational age, birthweight, antenatal steroid treatment.	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias 26 lost to follow-up (out of 105), no reason for loss to follow-up available.

Study details	Participants			Risk factors	Methods	Outcomes and results	Comments
after extreme prematurity - a prospective, two centre cohort study of children born before 25 completed weeks of gestation (1999-2003), Journal of Maternal-Fetal & Neonatal Medicine, 27, 1620-6, 2014 **Country/ies where the study was carried out** Germany **Study type** Prospective cohort study **Aim of the study** To determine the long-term neurodevelopmental outcome in extremely preterm infants of 22-23 completed	Gestational age, weeks (mean +- SD)		24.3 +- 0.4	meaning Bronchopulmonary dysplasia, BPD) (results not reported))	**Outcome(s) ascertainment/measures** **Composite neurodevelopmental impairment including components of motor, vision, cognitive, hearing.** Assessed through the following Motor function: neurologic examination assessed the ability to walk, complex motor function, and fine-motor function tests with special emphasis on the diagnosis of CP. Children classified as normal, mildly abnormal or severely abnormal. Functional activity was graded according to the Gross Motor Function Classification System (GMFCS). Fine and gross motor skills: an 18-item version of the Lincoln-Oseretsky Motor Development Scale (LOS KF-18). Visual impairment: based on ophthalmological records and classified as severely impaired, if at least one eye showed a	ICH >II ° not included in multiple regression model because all children with this complication showed moderate or severe impairment. NEC >IIB not reported, assumption is that was not significant. CLD not reported, assumption is that was not significant.	However, baseline characteristics did not differ between the ones lost to follow-up and the ones included in analysis. **Prognostic factor measurement:** high risk of bias No description of how prognostic factors (risk factors) were measured or defined. **Outcome measurement:** low risk of bias **Confounders:** high r isk of bias ICH >II ° and/or PVL were not included in the multivariate analysis. Not clear which factors were considered potential confounders. **Analysis and Reporting:** moderate risk of bias They report that backward stepwise logistic regression was conducted, at the same time they report that only univariate analysis was done on ICH >II ° and/or PVL. Therefore, not clear what was done and why. **Overall quality:** low
	Birthweight, g (mean +- SD)		645 +- 118				
	Head circumference, cm (mean +- SD)		21.9 +- 2.0				
	Length, cm (mean +- SD)		31.1 +- 2.2				
	Small for gestational age (<10.Perc.) n(%)		7 (9)				
	5 min APGAR <=5, n (%)		10 (13)				
	Antenatal steroids, n(%)	Complete	47 (60)				
		Incomplete	23 (29)				
		None	9 (11)				
	Female, n(%)		42 (53)				
	Inclusion criteria All children with a gestational age of 22-24 completed weeks born in the perinatal centre of the Universities of Munich and Ulm if they survived until the first discharge from the hospital.						

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
weeks' of gestation as compared to infants 24 weeks with immediate postnatal life support born in two German tertiary perinatal centres between 1999 and 2003. **Study dates** Enrollment between 1/1/1999 and 31/12/2003. Follow-up at 7-10 years. **Source of funding** Not reported.	**Exclusion criteria** Infants born before 22 completed weeks or after 24 completed weeks of gestation. Infants who died before first discharge from hospital.		refrectory error of +-10 dpt or a spectacle corrected visual acuity of <=0.5. A visual acuity of <=0.1 after best correction for ametropia in at least one eye rated the infant as blind. Cognitive: IQ score assessed through Wechsler Intelligence Scale for Children IV (WISC-IV) Severe hearing impairment: the need for hearing amplification for at least one ear **Composite outcomes:** Severe neurodevelopmental impairment defined as: an IQ score of >3 SD below the mean; and/or a GMFCS level of III-V on the basis of a severely abnormal neurological examination; and/or a hearing loss requiring amplification; and/or blindness. Moderate neurodevelopmental impairment defined as: any abnormal neurological examination with moderate immobility (GMFCS = II); and/or an IQ score of >2 to 3 SD below the mean; and/or		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>a severe visual or hearing impairment.

Statistical methods

A backward stepwise logistic regression model was applied to determine factors associated with any major neonatal morbidity and adverse neurodevelopmental outcome.

Length of follow-up

7 to 10 years</td><td></td><td></td></tr>
<tr><td>Ref Id

410652

Full citation

Hillemeier, M. M., Morgan, P. L., Farkas, G., Maczuga, S. A., Perinatal and socioeconomic risk factors for variable and persistent cognitive delay at 24 and 48 months of age in a national sample,</td><td>Sample size

n=7200

Characteristics

<table><tr><td></td><td>Mean (SD) or %</td></tr><tr><td>Male</td><td>50%</td></tr><tr><td>Child age in months (at 24 mo follow-up)</td><td>24.39 (1.16)</td></tr><tr><td>Child age in months (at 48 mo follow-up)</td><td>52.54 (4.10)</td></tr></table></td><td>Risk factors

Gestational age (very preterm <=32 weeks, moderately preterm 33-36 weeks, term >=37 weeks)</td><td>Setting

Nationally representative, longitudinal dataset, the Early Childhood Longitudinal Study, Bitrh Cohort (ECLS-B) in the US.

Method(s) of measurement for risk factor(s)

All socio-demographic data were collected in parent interviews and from birth certificates.</td><td>Outcome(s) at age

Outcomes assessed at 24 months:
<u>Cognitive delay</u>
Gestational age:
33-36 wks GA (moderate preterm) : 1.07 (NS, 95%CI not presented)
<=32 wks GA (very preterm) : 1.52 (NS)
Term: reference
The model adjusted for sex, age, race/ethnicity, socioeconomic variables, characteristics of</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Note that all sample sizes reported were rounded up to the nearest 50 as specified by the ECLS-B data confidentiality requirements.
Attrition: high risk of bias</td></tr>
</table>

Study details	Participants		Risk factors	Methods	Outcomes and results	Comments
Maternal and Child Health Journal, 15, 1001-1010, 2011 **Country/ies where the study was carried out** United States **Study type** Longitudinal cohort study **Aim of the study** To examine patterns of cognitive delay at 24 and 48 months and quantify the effects of perinatal and sociodemographic risk factors on persistent and variable cognitive delay. **Study dates**	Ethnicity:			Gestational age (very preterm <=32 weeks, moderately preterm 33-36 weeks, term >=37 weeks) **Outcome(s) ascertainment/measures** Cognitive delay, assessed with standardized cognitive assessments by trained interviewers at 24 and 48 months of age: at 24 months, using the Bayley Short Form-Research Ediution (BSF-R) (a modified version of the Bayley Scales of Infant Development, Second Edition (BSID-II)), the BSF-R was e4xtensively tested to esnure that the psychometric properties of the BSID-II were maintained and that it accurately measured children's performace over the entire ability distribution. Children scoring the lowest 10% of the BSF-R scale distribution were considered to have cognitive delay.	gestation and infant status at birth. **At 48 months:** <u>Cognitive delay</u> Gestational age: 33-36 wks GA (moderate preterm): 1.10 (NS) <=32 wks GA (very preterm): 1.86 (NS) Term: reference The model adjusted for sex, age, race/ethnicity, socioeconomic variables, characteristics of gestation and infant status at birth.	Out of the approximately 10,200 children in the original cohort, only 7,200 children had follow-up data and were included in the current analysis (29.4% lost to follow-up). **Prognostic factor measurement:** low risk of bias **Outcome measurement:** mode rate risk of bias Outcome measurement at 48 months seems to be not the same for everyone, not clear what was actually done. **Confounders:** low risk of bias **Analysis and reporting:** moderate risk of bias Confidence intervals are not reported, and p-values only reported if significant. Overall quality: low
	White, non-Hispanic	57%				
	Black	14%				
	Hispanic	22%				
	Asian	3%				
	Native American	0.4%				
	Other	4%				
	Maternal education at 24 mo follow-up:					
	<9th grade	3%				
	9th-12th grade	12%				
	high school graduate	31%				
	some training/college after high school	27%				
	4 y college degree and abive	26%				
	Family income at 24 month follow-up:					
	<$10,000	9%				

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
2001, follow-up at 24 and 48 months. **Source of funding** None reported.	<table><tr><td>$10,000-$20,000</td><td>14%</td></tr><tr><td>$20,001-$40,000</td><td>27%</td></tr><tr><td>$40,001-$75,000</td><td>26%</td></tr><tr><td>>$75,000</td><td>24%</td></tr><tr><td>Maternal age 35 y or older</td><td>14%</td></tr><tr><td>Multiple birth</td><td>3%</td></tr><tr><td>Very preterm (<=32 weeks)</td><td>2%</td></tr><tr><td>Moderately preterm (33-36 wks)</td><td>9%</td></tr><tr><td>Very low birth weight (<=1,500 g)</td><td>1%</td></tr><tr><td>Moderately low birth weight (1,501-2,500 g)</td><td>6%</td></tr></table> **Inclusion criteria** Children born in the US in 2001, oversamples of Asian and Pcific Islanders, Native Americans and Alaska Natives, low birth weight (1,500-2,500 g) and very low birth weight (<1,500 g) children and multiple births. **Exclusion criteria**		at 48 months, administration of the Bayley assessment was no longer age-approapriate, instead, a standardized assessment battery measuring literary, math conceptss, color knowledge, and receptive vocabulary skills was administered. the battery incorporated items from a number of standardized assessments developed for use in other large studies of child development such as the Head Start Impact Study and included elements of the Peabody Picture Vocabulary Test, the Preschool Comprehensive Test of Phonological and Print Processing, the PreLAS 2000, and the Test of Early Mathematics Ability-3. We converted children's scores on the measures of literacy, math concepts, color knowledge, and receptive vocabulary into z-scores and summed them to produce a summary cognitive score, children scoring lowest 10% were		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td>Children without cognitive assessment at 24 and 48 months.</td><td></td><td>considered to have cognitive delay.

Statistical methods

Multiple logistic regression model, adjusting for sex, age, race/ethnicity, socioeconomic variables, characteristics of gestation and infant status at birth.

Length of follow-up

24 months and 48 months</td><td></td><td></td></tr>
<tr><td>Ref Id

173586

Full citation

Hintz,S.R., Kendrick,D.E., Stoll,B.J., Vohr,B.R., Fanaroff,A.A., Donovan,E.F., Poole,W.K., Blakely,M.L., Wright,L., Higgins,R., Neurodevelopmental and growth</td><td>Sample size

n=4933 extremely low birth weight infants survived >12h
n=3814 survived to discharge
n=2948 followed up at 18-22 months' corrected age (n=2703 with no NEC, n=245 with NEC)

Characteristics

<table><tr><td></td><td>SurgNEC</td><td>MedNEC</td><td>No NEC</td><td>SurgNEC vs. No</td><td>MedNEC vs. No</td></tr></table></td><td>Risk factors

Necrotising enterocolitis (NEC), Modified Bell's classification stage IIA or greater.
Subgroups: surgically managed NEC or medically managed NEC.</td><td>Setting

Data from a multicentre National Institute of Child Health and Human Development Neonatal Research Network Very Low Birth Weight Registry in the US.

Method(s) of measurement for risk factor(s)

Necrotising enterocolitis (NEC), Modified Bell's</td><td>Outcome(s) at age

Outcomes assessed at 18-22 months' corrected age:
Multiple logistic regression models showing OR (95% CI), adjusted for network centre, use of antenatal glucocorticoids, rupture of membranes >24h, outborn status, estimated gestational age, gender, race, birth weight, small for gestational age, surfactant therapy,</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
Of the ones included in the study overall (ELBW infants who survived >12h), 40.2% were lost to follow-up. Of the ones</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
outcomes of extremely low birth weight infants after necrotizing enterocolitis, Pediatrics, 115, 696-703, 2005 **Country/ies where the study was carried out** United States **Study type** Multicentre cohort study, retrospective analysis. **Aim of the study** To compare growth, neurologic and cognitive outcomes among extremely low birth weight infants with surgically managed necrotising	<table><tr><td></td><td></td><td></td><td></td><td>NEC p-value</td><td>NEC p-value</td></tr><tr><td>Birth weight, mean g +-SD</td><td>757 +-129</td><td>762 +-133</td><td>792 +-132</td><td>0.003</td><td>0.01</td></tr><tr><td>Head circumference at birth, mean cm +-SD</td><td>23.2 +-1.6</td><td>23.2 +-1.4</td><td>23.6 +-1.6</td><td>0.0016</td><td>0.01</td></tr><tr><td>Estimated festaional age <28 weeks, %</td><td>82</td><td>83</td><td>77</td><td>ns</td><td>ns</td></tr><tr><td>Rupture of membranes >24h, %</td><td>35</td><td>27</td><td>25</td><td>0.014</td><td>ns</td></tr><tr><td>Antenatal antibiotics, %</td><td>68</td><td>75</td><td>66</td><td>ns</td><td>0.07</td></tr><tr><td>Inborn, %</td><td>87</td><td>88</td><td>91</td><td>ns</td><td>ns</td></tr><tr><td>Male, %</td><td>52</td><td>49</td><td>47</td><td>ns</td><td>ns</td></tr><tr><td>Race black, %</td><td>42</td><td>51</td><td>44</td><td>ns</td><td>ns</td></tr></table>		classification stage IIA or greater. Data obtained from the National Institute of Child Health and Human Development Neonatal Research Network Very Low Birth Weight Registry. Subgroups: Surgically managed NEC, any surgical intervention (drain, laparotomy, or both). Medically managed NEC, no surgical intervention. **Outcome(s) ascertainment/measures** Cerebral palsy (CP), defined as a nonprogressive central nervous system disorder characterized by abnormal muscle tone in at least 1 extremity and abnormal control of movement and posture. Deafness, defined as using hearing aids in both ears. Blindness, defined no useful vision in either eye. Mental development index (MDI) <70,	intraventricular haemmorrhage grade 3 or 4 or cystic periventricular leukomalacia, sepsis, postnatal steroid treatment, bronchopulmonary dysplasia, and highest level of education attained by the primary caregiver. <u>Cerebral palsy</u> Surgical NEC: 1.31 (0.80-2.14) No NEC: Reference Medical NEC: 0.68 (0.35-1.29) No NEC: reference <u>MDI <70</u> Surgical NEC: **1.61 (1.05-2.50)** No NEC: Reference Medical NEC: 1.16 (0.74-1.81) No NEC: reference <u>PDI <70</u> Surgical NEC: **1.95 (1.25-3.04)** No NEC: reference Medical NEC: 1.08 (0.66-1.80) No NEC: reference	who survived to hospital discharge, 22.7% were lost to follow-up. No information provided whether or not the ones lost to follow-up have different characteristics than the ones included in analysis. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** low risk of bias **Overall quality:** moderate

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>enterocolitis (NEC) and medically managed NEC with infants without history of NEC at 18 to 22 months' corrected age.

Study dates

1995-1998, follow-up at 18-22 months' corrected age.

Source of funding

HD27904/HD/NICHD NIH HHS/United States
U01
HD36790/HD/NICHD NIH HHS/United States
U10
HD21364/HD/NICHD NIH HHS/United States
U10
HD21373/HD/NICHD NIH</td>
<td>
<table>
<tr><td>Race white, %</td><td>39</td><td>36</td><td>40</td><td>ns</td><td>ns</td></tr>
<tr><td>Race hispanic, %</td><td>16</td><td>9</td><td>13</td><td>ns</td><td>ns</td></tr>
<tr><td>Multiple birth, %</td><td>24</td><td>25</td><td>22</td><td>ns</td><td>ns</td></tr>
<tr><td>SGA, %</td><td>14</td><td>17</td><td>18</td><td>ns</td><td>ns</td></tr>
<tr><td>Antenatal steroids, %</td><td>73</td><td>81</td><td>77</td><td>ns</td><td>ns</td></tr>
</table>
Inclusion criteria

Infants with birth weight of 401-1000 g who were born from 1 Jan 1995 to 31 Dec 1998 and were admitted to a National Institute of Child Health and Human Development Neonatal Research Network center within 14 days of birth and survived >12h.

Exclusion criteria

None reported.
</td>
<td></td>
<td>assessed through the Bayley Scales of Infant Development-II (BSID-II).
Psychomotor development index (PDI) <70, assessed through the Bayley Scales of Infant Development-II (BSID-II).
Neurodevelopmental impairment (NDI), defined as one of more of the above.
All neurologic assessments were performed by certified, masked developmentalists who had been trained in the examination procedure in an aanual 2-day workshop. The neurologic examination was based on a Amiel-Tison assessments and the gross motors skills examination was developed from the work of Russell et al., and Palisano et al.

Statistical methods

Logistic regression model to evaluate NEC management-related risk (surgical NEC or medical NED vs. no NEC) for</td>
<td><u>Neurodevelopmental impairment (NDI)</u>
Surgical NEC: 1.78 (1.17-2.73)
No NEC: reference

Medical NEC: 1.06 (0.69-1.63)
No NEC: reference</td>
<td></td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
HHS/United States U10 HD21385/HD/NICHD NIH HHS/United States U10 HD21397/HD/NICHD NIH HHS/United States U10 HD21415/HD/NICHD NIH HHS/United States U10 HD27851/HD/NICHD NIH HHS/United States U10 HD27853/HD/NICHD NIH HHS/United States U10 HD27856/HD/NICHD NIH HHS/United States U10 HD27871/HD/NICHD NIH HHS/United States U10 HD27880/HD/NICHD NIH			CP, MDI <70, PDI <70, and NDI, adjusting for differences in perinatal and neonatal variables: network centre, use of antenatal glucocorticoids, rupture of membranes >24h, outborn status, estimated gestational age, gender, race, birth weight, small for gestational age, surfactant therapy, intraventricular haemmorrhage grade 3 or 4 or cystic periventricular leukomalacia, sepsis, postnatal steroid treatment, bronchopulmonary dysplasia, and highest level of education attained by the primary caregiver. **Length of follow-up** 18 to 22 months' corrected age.		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td>HHS/United States
U10 HD27881/HD/NICHD NIH HHS/United States</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Ref Id

347185

Full citation

Hirvonen, M., Ojala, R., Korhonen, P., Haataja, P., Eriksson, K., Gissler, M., Luukkaala, T., Tammela, O., Cerebral palsy among children born moderately and late preterm, Pediatrics, 134, e1584-93, 2014

Country/ies where the study was carried out

Finland.

Study type

Population based</td><td>Sample size

Overall sample:
N = 1039263
Sample size after exclusions:
N = 1018302 (included for comparisons of cerebral palsy risk at different gestational ages)
Preterm infants included in the risk factor data shown here
N = 53078

Characteristics

<table><tr><th>Characteristic</th><th><32 weeks n = 6347</th><th>32-33+6 weeks n = 6799</th><th>34-36+6 weeks n = 39932</th><th>≥37 weeks n = 965224</th></tr><tr><td>Maternal age

mean (SD)</td><td>30.2 (5.8)</td><td>29.8 (5.7)</td><td>29.7 (5.5)</td><td>29.2 (5.3)</td></tr><tr><td>Singleton (%)</td><td>71.3</td><td>67.6</td><td>77.8</td><td>98.3</td></tr><tr><td>Male gender (%)</td><td>54.2</td><td>54.9</td><td>54.2</td><td>50.8</td></tr><tr><td>SGA (%)</td><td>16.1</td><td>13.0</td><td>8.1</td><td>1.7</td></tr></table></td><td>Risk factors

Gestational age
Sex
SGA
Maternal age
Multiple pregnancy
Antenatal steroids
Sepsis
Intracranial haemorrhage</td><td>Setting

Population based national registry.

Method(s) of measurement for risk factor(s)

Baseline characteristics were collected from the Medical Birth Register, containing information on the mother's health and interventions during pregnancy and delivery, and on the infant's health and procedures undergone during the first 7 days of life. Gestational age was based on early pregnancy ultrasound and correction of GA was made if the ultrasound-based assessment had a discrepancy of 5-7 days with the mother's LMP. Pregnancy and delivery related diagnoses were</td><td>Outcome(s) at age

By the age of 7 years
Cerebral palsy
Gestational age
Term: Reference
<32 weeks: OR 9.37 (7.34-11.96)
32^{+0} to 33^{+6} weeks: OR 5.12 (4.13-6.34)
34^{+0} to 36^{+6} weeks: OR 2.35 (1.99 to 2.77)

Within very preterm infants, <32 weeks gestation
Sex
Female: Reference
Male: OR 1.34 (1.11-1.61)

SGA
Appropriate for gestational age*: Reference
Small for gestational age: OR 0.75 (0.57-0.99)

Maternal age
< 40 years: Reference</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: moderate risk of bias
Registry data which may be incomplete or subject to regional variation in reporting.
Outcome measurement: mode rate risk of bias
Registry data used therefore no standard definition of cerebral palsy
Confounders: low risk of bias
Analysis and reporting: low risk of bias.

Overall quality: Low</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
retrospective cohort using national registry data. **Aim of the study** To compare the incidence of cerebral palsy among late and moderately preterm infants with that of very preterm and term infants, and to identify risk factors for cerebral palsy. **Study dates** Infants born between 1991 and 2008. **Source of funding** Pirkanmaa Hospital District and Central Finland Health Care District.	**Inclusion criteria** All infants born in Finland during the study dates. **Exclusion criteria** Death before the age of 1 year (n = 2613), children with at least one major congenital anomaly (n = 13007) and cases lacking data on gestational age (n = 5520). Data presented here refer only to the preterm children (<37 weeks, n = 53078).		collected from the Hospital Discharge Register, and diagnoses were classified according to the ICD-9 to 1995, and ICD-10 from 1996. SGA infants were defined as those with a birth weight <2SDs below the mean weight for GA. Intracranial haemorrhage diagnosis was based on the head ultrasound or MRI findings. **Outcome(s) ascertainment/measures** All inpatient and outpatient visits due to a CP diagnosis in public hospitals were registered. The diagnosis of CP in Finland is based on medical history, ultrasound and MRI data, and multidisciplinary evaluations in the paediatric neurology units of 20 secondary level central hospitals and 5 tertiary level university hospitals. The diagnosis is included in the database as soon as	≥ 40 years: OR 1.14 (0.69-1.89) **Multiple pregnancy** Singleton: Reference Twins: OR 0.94 (0.70-1.26) Higher order multiples: OR 1.24 (0.63-2.45) **Antenatal steroids** No: Reference Yes: OR 0.80 (0.49-1.30) **Sepsis** No: Reference Yes: OR 0.94 (0.62-1.43) **Intracranial haemorrhage** No: Reference Yes: OR 3.05 (2.08-4.47) *Within moderately preterm infants, 32^{+0} to 33^{+6} weeks gestation* **Sex** Female: Reference Male: OR 1.11 (0.80-1.55) **SGA** Appropriate for gestational age*: Reference	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			it has been established. A case of CP was recorded if the individual was detected in the Hospital Discharge Register and/or in the Reimbursement Register of the Social Insurance Institution. **Statistical methods** Risk factors for CP were sought by logistic regression analysis by using multivariate enter models for each gestational age group separately. All variables were entered simultaneously into the model for each GA group separately. Variables included in the model were: period of study (1991-1995, 1996-2001 or 2002-2008), maternal age, maternal smoking status, primiparous, previous C-section, maternal diabetes, multiple pregnancy, order of fetuses, assisted reproductive technology, cervical cerclage, chorionic villus sampling, PROM, preeclampsia, time of birth, antenatal	Small for gestational age: OR 1.10 (0.57-2.13) **Maternal age** < 40 years: Reference ≥ 40 years: OR 0.85 (0.33-2.17) **Multiple pregnancy** Singleton: Reference Twins: OR 0.83 (0.48-1.44) Higher order multiples: OR 0.88 (0.28-2.81) **Antenatal steroids** No: Reference Yes: OR 0.27 (0.09-0.80) **Sepsis** No: Reference Yes: OR 1.35 (0.60-3.05) **Intracranial haemorrhage** No: Reference Yes: OR 7.18 (3.60-14.3) *Within late preterm infants, 34^{+0} to 36^{+6} weeks gestation* **Sex** Female: Reference Male: OR 0.98 (0.75-1.28)	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			steroid use, place of birth, mode of delivery, gender, gestational weight, birth weight <1500g, Apgar score, umbilical artery pH, admission to neonatal unit, ventilator, resuscitation at birth, phototherapy, antibiotic therapy, RDS, sepsis, intracranial haemorrhage, convulsions and hyperbilirubinaemia. **Length of follow-up** 7 years.	**SGA** Appropriate for gestational age*: Reference Small for gestational age: OR 1.85 (1.25-2.75) **Maternal age** < 40 years: Reference ≥ 40 years: OR 1.40 (0.70-2.78) **Multiple pregnancy** Singleton: Reference Twins: OR 0.77 (0.47-1.27) Higher order multiples: OR 0.51 (0.07-3.92) **Antenatal steroids** No: Reference Yes: OR 1.01 (0.35-2.91) **Sepsis** No: Reference Yes: OR 1.50 (0.73-3.10) **Intracranial haemorrhage** No: Reference Yes: OR 12.8 (5.58-29.2) *infants who were large for gestational age excluded from this analysis	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Ref Id 410668 **Full citation** Hoffman, L., Bann, C., Higgins, R., Vohr, B., Eunice Kennedy Shriver National Institute of Child, Health, Human Development Neonatal Research, Network, Developmental outcomes of extremely preterm infants born to adolescent mothers, Pediatrics, 135, 1082-92, 2015 **Country/ies where the study was carried out** United States **Study type** Retrospective cohort study	**Sample size** Sample recruited - N = 3790 infants (456 born to adolescent mothers + 3364 born to adult mothers) Sample eligible for assessment - N = 2270 infants (255[56%] born to adolescent mothers + 2015 [60%] born to adult mothers) Sample analysed after exclusions - N = 1934 infants (211[83%] born to adolescent mothers + 1723[86%] born to adult mothers) **Characteristics** Infants born at <27 weeks' gestational age who were admitted to Neonatal Research Network (NRN) hospitals. **Inclusion criteria** Children enrolled in the Eunice Kennedy Shriver National Institute of Child Health and Human Development's (NICHD) Neonatal Research Network (NRN) Generic Database and Follow-Up studies Children born from 1/1/2008 through 30/6/2011 at less than 27 weeks' gestational age (EGA) Children who who underwent comprehensive neurologic and developmental assessments at 18 to 22 months corrected age **Exclusion criteria** Infants with major congenital anomalies or syndromes associated with adverse developmental outcomes	**Risk factors** **Social/environmental/ maternal** Maternal age **Biological** Race **Neonatal** Antenatal use of steroids	**Setting** This was a retrospective cohort analysis of data previously collected from the Eunice Kennedy Shriver National Institute of Child Health and Human Development's (NICHD) Neonatal Research Network (NRN) Generic Database and Follow-Up studies placed in the US. **Method(s) of measurement for risk factor(s)** Research nurses collected demographic, perinatal, and neonatal data using common definitions described in previous publications Antenatal steroid exposure (ANS) was defined as administration of any corticosteroids to accelerate fetal lung maturity in the present pregnancy. Intraventricular hemorrhage (IVH) was reported according to the classification of Papile et al. Early sepsis was defined as a positive blood	**Outcome(s) at age** Intellectual disability (Cognitive Composite <70 and <85; Language Composite <70 and <85; and Motor Composite <70) **Antenatal steroids** Cognitive Composite <70 - (RR [95% CIs]) Referent group is not reported0.94 (0.57–1.52) Cognitive Composite <85 - (RR [95% CIs]) Referent group is not reported0.72 (0.51–1.00) Language Composite <70 - (RR [95% CIs]) Referent group is not reported0.66 (0.46–0.96) Language Composite <85 - (RR [95% CIs]) Referent group is not reported0.84 (0.61–1.17) Motor Composite <70 - (RR [95% CIs]) Referent group is not reported0.75 (0.49–1.15) **Nonwhite race** Cognitive Composite <70 - (RR [95% CIs]) Referent group is not	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. Participants: low risk of bias Attrition: low risk of bias (There were no significant differences between rates of death before or after discharge, loss to follow-up, or insufficient follow-up) Prognostic factor measurement: low risk of bias Outcome measurement: low risk of bias Confounding high risk of bias (No information about the measurement and the definition of confounders) Analysis and Reporting: low risk of bias Overall: moderate quality

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Aim of the study To investigate the relationships between adolescents' complex social environments and the developmental and behavioral outcomes of their extremely preterm infants at 18 to 22 months corrected age: to evaluate the cognitive, language, and behavior outcomes of extremely preterm infants born to adolescent mothers (<20 years) compared with extremely preterm infants born to older mothers (≥20 years), and to explore the unique social and home constructs of			culture at >72 h of age, and late sepsis as a positive blood culture at >72 h of age. Necrotizing enterocolitis (NEC) was defined as modified Bell's classification stage IIA or greater . Bronchopulmonary dysplasia (BPD) was defined as receiving supplemental oxygen at 36 wk postmenstrual age or at hospital discharge, whichever occurred first. Postnatal steroid exposure (PNS) was defined as any steroid given for the prevention or treatment of BPD. If an ophthalmologic exam was performed, the stage of retinopathy of prematurity (ROP), and the presence or absence of plus disease was recorded. **Outcome(s) ascertainment/measures** The primary study outcomes were BSID-III composite cognitive and language scores. Secondary outcomes were BITSEA (Brief	reported0.79 (0.56–1.12) Cognitive Composite <85 - (RR [95% CIs]) Referent group is not reported1.02 (0.80–1.30) Language Composite <70 - (RR [95% CIs]) Referent group is not reported1.10 (0.83–1.46) Language Composite <85 - (RR [95% CIs]) Referent group is not reported1.41 (1.13–1.76) Motor Composite <70 - (RR [95% CIs]) Referent group is not reported0.63 (0.46–0.86) **Adolescent mother<20 y old** Cognitive Composite <70 - (RR [95% CIs]) Referent group is not reported1.42 (0.88–2.29 Cognitive Composite <85 - (RR [95% CIs]) Referent group is not reported0.83 (0.58–1.17) Language Composite <70 - (RR [95% CIs]) Referent group is not reported0.97 (0.64–1.47)	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
infants with adolescent mothers and the influences of these environmental factors on developmental and behavioural **Study dates** January 2008 - June 2011: Period of data collection (patient 'enrolment') 18-22 months (age corrected): follow-up assessment **Source of funding** Eunice Kennedy Shriver National Institute of Child Health and Human Development Research Network. Funded by the National Institutes of Health (NIH).			Infant Social Emotional Assessment) scores, NDI (moderate to severe cerebral palsy with Palisano Gross Motor Function Classification Scale ≥2, walks without assisted devices but with limitations walking outdoors), 18- to 22-month growth parameters and rates of rehospitalization. The cut point of 20 years was used be consistent with the Centers for Disease Control and Prevention's definition of teen pregnancy and previous NRN reports. **Statistical methods** The χ2 test for comparisons of categorical data, and Student's *t*-test or ANOVA for continuous data were used. Regression models were used to compare relative risk (RR) of adverse outcomes at 18 to 22 months, controlling for infant and maternal characteristics that varied significantly between groups	Language Composite <85 - (RR [95% CIs]) Referent group is not reported1.15 (0.83–1.59) Motor Composite <70 - (RR [95% CIs]) Referent group is not reported1.01 (0.67–1.52)	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
The authors have indicated they have no financial relationships relevant to this article to disclose.			When control variables were highly related or overlapped, only 1 control variable was included to avoid overestimation problems due to multicollinearity **Length of follow-up** 18–22 months		
Ref Id 410712 **Full citation** Hwang, Y. S., Weng, S. F., Cho, C. Y., Tsai, W. H., Higher prevalence of autism in Taiwanese children born prematurely: A nationwide population-based study, Research in Developmental Disabilities, 34, 2462-2468, 2013 **Country/ies where the**	**Sample size** N=1078 preterm children **Characteristics** **Number of children enrolled in the study:** Early preterm (n): 1078 Later preterm (n): 28, 947 Full term (n): 1,104,071 **Age (years, n) in 2009:** 8 years: early preterm:319; later preterm:6936; full term: 253,746 9 years: early preterm:279; later preterm: 8166; full term:302,498 10 years: early preterm:247; later preterm: 7188; full term: 281,087 11 years: early preterm: 233; later preterm: 6657; full term: 266,740 **Gender (n):** Male: early preterm: 549; later preterm: 16,077; full term: 57,060 Female: early preterm: 529; later preterm: 12,870; full term:529,011 **Age at first diagnosis of autism (mean age, SD):**	**Risk factors** Gender/male; Bronchopulmonary dysplasia (BPD)	**Setting** National cohort study **Method(s) of measurement for risk factor(s)** Children with autism were diagnosed and coded by their doctors based on ICD-9-CM definitions. Children with autism were those who were coded 299.0 (infantile autism). **Outcome(s) ascertainment/measures** Infantile autism: children with autism were diagnosed and coded by	**Outcome(s) at age** **Outcomes assessed at age 8 to 11 years;** **For the outcome of infantile autism, OR (95%CI):** Male: 4.1 (3.1-5.3) BPD: 1.5 (0.8-2.9) -risk factors were adjusted for each other, as well as birth weight and cerebral dysfunction	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moderate risk of bias. Participants were identified from patient registration files and original claim data, monthly claim summaries for inpatient claims, and details of ambulatory care orders. ICD codes were used for classification, therefore, not all characteristics of the participants were identified (eg, GA, IVH)

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
study was carried out Taiwan **Study type** National prospective cohort study **Aim of the study** To compare the prevalence of autism in preterm and full-term children and to identify neonatal risk factors for autism in preterm children using a large national health system database. **Study dates** 1998-2009 **Source of funding**	Male: early preterm: 4.2 (1.8); later preterm: 4.8 (2.3); full term: 4.8 (2.3) Female: early preterm: 4.5 (2.7); later preterm: 4.7 (2.9); full term: 4.9 (2.2) **Inclusion criteria** Children born between 1998 and 2001(i.e., 8-11 years old in 2009) were selected as the sample population for this study. **Exclusion criteria** Children without any medical records since 2 years old (i.e., those who died or moved out of Taiwan) were excluded.		their doctors based on ICD-9-CM definitions. The children with autism included in this study were those with a code of 299.02 (infantile autism). **Statistical methods** A multivariate logistic regression analysis was adjusted for potential confounding factors of the relationship between significant risk factors on autism prevalence in preterm children, and a P value of <0.05 was considered significant. **Length of follow-up** About 10 years		**Attrition:** moderate risk of bias. **Prognostic factor measurement:** mode rate risk of bias. Measurement of risk factors not reported. **Outcome measurement:** moderate risk of bias. Measurement of outcome not reported, only ICD code for infantile autism reported. **Confounders:** High risk of bias. Some characteristics of participants not identified due to ICD classification. Also, it was not possible to link children's data with demographic/health data of parents. Maternal and paternal factors may influence the risk of autism in this study population. **Analysis and reporting:** low risk of bias. Overall quality: low

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td>Chi Mei Foundation Hospital</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td>Ref Id

410783

Full citation

Kallen, K., Serenius, F., Westgren, M., Marsal, K., Express Group, Impact of obstetric factors on outcome of extremely preterm births in Sweden: prospective population-based observational study (EXPRESS), Acta Obstetricia et Gynecologica Scandinavica, 94, 1203-14, 2015

Country/ies where the study was carried out

Sweden.</td><td>Sample size

Overall sample
N = 1011
Sample surviving and eligible for follow up:
N = 491
Sample included in neurodevelopmental assessment at follow up:
N = 456

Characteristics

<table><tr><td>Characteristic</td><td>Surviving infants at 365 days (n = 497)
n (%)</td></tr><tr><td>Antibiotics</td><td>278 (55.9)</td></tr><tr><td>Tocolysis*</td><td>303/351 (86.3)</td></tr><tr><td>Corticosteroids</td><td>447 (89.9)</td></tr><tr><td>Electronic FHR monitoring</td><td>345 (69.4)</td></tr><tr><td>No information on EFM</td><td>56 (11.3)</td></tr><tr><td>Caesarean section</td><td>281 (56.5)</td></tr><tr><td>Delivery at level 3 hospital</td><td>413 (83.1)</td></tr></table>* for cases of spontaneous preterm labour only</td><td>Risk factors

SGA
Gender
Chorioamnionitis
Multiple birth
Antenatal corticosteroids</td><td>Setting

National population based cohort.

Method(s) of measurement for risk factor(s)

Data on perinatal variables was collected prospectively. Information on survival to 1 year was collected through linkage to the Swedish Population Register. Gestational age was based on ultrasound dating before 20 weeks in 95% of pregnancies. Small for gestational age was classified as being more than 2 SD below the mean expected birthweight. The diagnosis of chorioamnionitis was made clinically. Antenatal corticosteroid exposure was defined as at least one dose of betamethasone.</td><td>Outcome(s) at age

At 2.5 years corrected age
Neurosensory impairment
<u>Chorioamnionitis/Prolonged and premature rupture of membranes</u>
No: Reference
Yes: OR 0.8 (0.3-2.0)

<u>Multiple birth</u>
No: Reference
Yes: OR 0.8 (0.3-2.1)

<u>Antenatal corticosteroids</u>
No: Reference
Yes: OR 1.1 (0.3-4.8)

<u>Male gender</u>
No: Reference
Yes: OR 1.7 (0.8-3.5)

<u>SGA</u>
No: Reference
Yes: 1.1 (0.4-3.0)

Mental developmental delay
<u>Chorioamnionitis/Prolonged and premature rupture of membranes</u>
No: Reference
Yes: OR 0.9 (0.5-1.7)</td><td>Limitations

According to the NICE manual 2014 checklist for prognostic studies and QUIPs
Participants: low risk of bias
Attrition: low risk of bias (93% of eligible participants were included)
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: moderate risk of bias Only gestational age was accounted for in the multivariate analysis.
Analysis and reporting: low risk of bias

Overall quality: moderate</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Study type Population based prospective cohort study. **Aim of the study** To evaluate how obstetric factors and management influenced the neurodevelopmental outcome at 2.5 years for a group of extremely preterm infants. **Study dates** 1 April 2004 and 31 March 2007. **Source of funding** The Swedish Research Council, the Swedish National Board of Health and Welfare, Grants	**Inclusion criteria** All infants born before 27 completed gestational weeks during the study period. **Exclusion criteria** None reported.		**Outcome(s) ascertainment/measures** At 2.5 years of corrected age children were subjected to a clinical examination including vision and hearing. Motor, cognitive and language development was assessed using the Bayley Scales of Infant and Toddler development, 3rd Edition. In 41 cases information was obtained from their medical charts. Neurosensory impairment was defined as moderate/severe cerebral palsy or moderate/severe impairment regarding vision or hearing. Mental developmental delay was defined as a cognitive or language Bayley III scale <2SD below the mean, or moderate or severe developmental delay according to chart review. **Statistical methods**	<u>Multiple birth</u> No: Reference Yes: OR 1.5 (0.8-2.7) <u>Antenatal corticosteroids</u> No: Reference Yes: OR 0.7 (0.3-1.9) <u>Male gender</u> No: Reference Yes: OR 2.0 (1.2-3.3) <u>SGA</u> No: Reference Yes: 1.5 (0.8-2.8) OR are adjusted for gestational age.	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
to Researchers in the Public Health Care from the Swedish Government, the Uppsal-Örebro Regional Research Council grant RFR10234, and grants from the Research Council South East Region of Sweden, from the Evy and Gunnar Sandberg Foundation and from the Birigt and Håkan Ohlsson Foundation.			For each outcome and evaluated potential risk factor, odds ratios (OR) with 95% confidence interval s were calculated: crude, adjusted for gestational age and for birth weight standard deviation score. Variables with p values < 0.2 after adjustment for GA and BW SDS were entered into the final multiple models. **Length of follow-up** 2.5 years corrected age.		
Ref Id 410829 **Full citation** Kiechl-Kohlendorfer, U., Ralser, E., Pupp Peglow, U., Pehboeck-Walser, N., Fussenegger, B., Early risk predictors for	**Sample size** Sample recruited - N = 303 (children live birth with gestational age <32 weeks) Sample eligible for assessment - N = 223 Sample analysed after exclusions - N = 161 **Characteristics** No details given – see inclusion criteria **Inclusion criteria**	**Risk factors** **Social/environmental/ maternal** Smoking in pregnancy **Neonatal** Intracerebral haemorrhage BDP-bronco pulmonary dysplasia (chronic lung disease [CLD] at 36 weeks)	**Setting** The study survey area was Tyrol, a state in western Austria with 680000 inhabitants and about 7000 live births per year. **Method(s) of measurement for risk factor(s)**	**Outcome(s) at age** <u>Specific learning difficulty</u> (delayed numerical skills - Multivariable association between risk variables and delayed numerical skills at 5 years of age) <u>Smoking in pregnancy</u> - (OR [95% CIs]) Referent group is not reported: 4.26 (1.56–11.65)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. Participants: low risk of bias Attrition: low risk of bias Prognostic factor measurement: low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
impaired numerical skills in 5-year-old children born before 32weeks of gestation, Acta Paediatrica, International Journal of Paediatrics, 102, 66-71, 2013 **Country/ies where the study was carried out** Austria (Tyrol) **Study type** Prospective cohort study **Aim of the study** To detect potential risk predictors for impaired numerical development in formerly preterm infants at the age of 5 years	Children born before 32 completed weeks of pregnancy at Innsbruck Medical University in the neonatal intensive care unit **Exclusion criteria** Children with severe disabilities who were not able to perform tests as used in the study Children died Children whose families move out of the region/ were no residents.	Necrotizing enterocolitis –NEC (stage II or worse)= Sepsis (Pneumothorax; Late bacteremia) ROP - Retinopathy of prematurity	Gestational age was calculated from the first day of the last menstrual period. This was compared with assessment of gestational age by ultrasound scans performed before 24 weeks. CLD was defined as oxygen dependence at 36 weeks postconceptional age. NEC was defined according to Bell's criteria and was classified as medical (clinical symptoms and signs plus evidence of pneumatosis on abdominal X-ray) or surgical (histological evidence of NEC on surgical specimens of intestine). ICH was classified according to the method of Papile. Growth charts developed by Alexander et al. were used to classify infants as SGA at birth, defined as a birth weight lower than the 10th percentile for sex and gestational age. A diagnosis of early-onset (≤72 h of birth) or late-onset (>72 h) sepsis	Intracerebral haemorrhage of all grades- (OR [95% CIs]) Referent group is not reported: 4.66 (1.56–13.93) Chronic lung disease - (OR [95% CIs]) Referent group is not reported: 4.35 (1.11–17.01)	Outcome measurement: low risk of bias Confounding: high risk of bias (No information about the measurement and the definition of confounders) Analysis and Reporting: low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Study dates January 2003 - August 2006: Period of data collection (patient enrolment) 5 years: follow-up assessment **Source of funding** No details given			required signs of generalized infection, a positive blood culture and antibiotic therapy for 5 or more days. Smoking habits in pregnancy (yes/no) were based on self-reported data. **Outcome(s) ascertainment/measures** Delay in numerical skills was assessed individually with the TEDI-MATH which is a multi-componential dyscalculia test based on cognitive neuropsychological models of number processing and calculation [11]. The TEDI-MATH consists of several subtests designed for the assessment of preschoolers: In the counting principles subtest, children's mastery of the verbal counting sequence and its flexibility is tested (e.g. counting in steps of two, and counting backwards). Delay in numerical skills was		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>defined as a Sum T-score <40.

Statistical methods

Comparison of categorical data was made using the chi-squared or Fischer's exact test. Multivariate risk profiles for impaired calculation abilities in the fifth year of life were computed by means of logistic regression analysis using a stepwise forward selection procedure with inclusion and exclusion criteria as follows (PI < 0.05 and PE > 0.10). This analysis allowed for all the risk factors

Length of follow-up

5 years</td><td></td><td></td></tr>
<tr><td>Ref Id

321718

Full citation

Leversen,K.T., Sommerfelt,K., Ronnestad,A., Kaaresen,P.I., Farstad,T.,</td><td>Sample size

N = 376 preterm babies discharged home alive

Characteristics

<table><tr><td>Characteristic</td><td>Total</td></tr></table></td><td>Risk factors

Gestational age
Neonatal factors
Antenatal steroids
Sepsis
Bronchopulmonary dysplasia
Necrotising enterocolitis
Intraventricular haemorrhage</td><td>Setting

Population based cohort study in Norway.

Method(s) of measurement for risk factor(s)</td><td>Outcome(s) at age

Major neurosensory disability at the age of 2 years (corrected).
Gestational age
Per week: OR 0.9 (0.6-1.5)

Neonatal factors
Antenatal steroids</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: low risk of bias</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Skranes,J., Stoen,R., Elgen,I.B., Rettedal,S., Eide,G.E., Irgens,L.M., Markestad,T., Predicting neurosensory disabilities at two years of age in a national cohort of extremely premature infants, Early Human Development, 86, 581-586, 2010

Country/ies where the study was carried out

Norway.

Study type

Prospective population based cohort study.

Aim of the study</td>
<td>
<table>
<tr><td>Survivors, n

(% of all births/% of NICU admission)</td><td>373

(59%/81%)</td></tr>
<tr><td>Birth weight, median (IQR)</td><td>861g (740-975)</td></tr>
<tr><td>Male, n</td><td>201 (54%)</td></tr>
<tr><td>Singletons, n</td><td>290 (78%)</td></tr>
<tr><td>Small for gestational age</td><td>70 (19%)</td></tr>
<tr><td>Antenatal steroids</td><td>257 (69%)</td></tr>
<tr><td>NEC</td><td>18 (5%)</td></tr>
<tr><td>BPD</td><td>164 (44%)</td></tr>
<tr><td>Higher education of mother</td><td>149 (43%)</td></tr>
</table>
Inclusion criteria

All infants born with gestational age of 22 to 27+6 weeks, or birthweight of 500-999g, and discharged home alive.

Exclusion criteria

Death before discharge, or before 2 year follow up.
</td>
<td>Periventricular leucomalacia
Retinopathy of prematurity
Biological factors
Gender
Small for gestational age
Social/environmental/ maternal factors
Multiple pregnancy
Chorioamnionitis
Preeclampsia
Postnatal factors
Postnatal steroids</td>
<td>Data were extracted from the compulsory notification to the Medical Birth Registry of Norway and from registration forms developed for the study.

Outcome(s) ascertainment/measures

At the age of 2 years a paediatrician completed forms developed for the study on health and neurological status. For children who missed the planned follow up (n=30, 8%) data were collected in retrospect from the medical records if a routine follow up had been performed within 1 year of planned evaluation, and from an additional structured telephone interview. The outcome reported was a composite finding of "major neurosensory disabilities". This includes cerebral palsy, blindness (classified as legally blind) or complete deafness.</td>
<td>No: Reference
Yes: OR 0.5 (0.2-1.6)
<u>Sepsis</u>
No: Reference
Yes: 0.7 (0.2-2.3)

<u>Bronchopulmonary dysplasia</u>
No: Reference
Yes: OR 0.9 (0.3-2.9)

<u>Necrotising enterocolitis</u>
No: Reference
Yes: OR 2.0 (0.3-11.9)

<u>Cranial Ultrasound</u>
Normal: Reference
Minor pathology†: OR 2.5 (0.7-9.7)
Major pathology‡: OR 110.2 (23.4-518.5)
† periventricular haemorrhage grade 1-2, eventually 1-2 small PVL cysts
‡ periventricular haemorrhage grade 3-4 and/or multicystic PVL

<u>Retinopathy of prematurity</u>
No: Reference
ROP grade 1-2: OR 3.5 (1.1-11.6)
ROP grade > 2: OR 5.8 (1.0-32.5)

Biological factors
<u>Gender</u>
Female: Reference</td>
<td>Prognostic factor measurement: low risk of bias
Outcome measurement: moderate risk of bias
8% of participants did not attend the follow up interview and therefore outcome data was obtained from the medical records/telephone interviews. However, the outcomes measured are of such severity that this is reasonably likely to ensure that all relevant data were collected.
Confounders: low risk of bias
Analysis and Reporting: low risk of bias

Overall quality: Moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
To assess the predictive value of pre-, peri- and postnatal clinical characteristics in relation to neurosensory disabilities at 2 years of age in children born extremely premature. **Study dates** Cohort was recruited during 1999-2000. Follow up was at the age of 2 years corrected. **Source of funding** The Norwegian Foundation for Health and Rehabilitation through the Unexpected Child Death Society of Norway, the Research Council of Norway and			**Statistical methods** Multiple logistic regression was applied to analyse the risk of neurosensory disabilities at 2 years' corrected age, according to prenatal and NICU factors. The factors adjusted for are not specified in the text, but are assumed to be all factors listed in the table of variables, as the text states "Fully adjusted OR". These include: gestational age, gender, multiple pregnancy, chorioamnionitis, preeclampsia, antenatal steroids, PROM, Caesarean section, SGA, illness severity score (a score of the lowest and highest FiO2 requirements and the largest base deficit during the first 12 hours of life), septicaemia, BPD, patent ductus arteriosus, NEC, postnatal steroids, cranial ultrasound findings and retinopathy of prematurity.	Male: OR 1.3 (0.5-3.8) <u>Small for gestational age</u> No: Reference Yes: OR 3.0 (0.5-19.9) **Social/environmental/ maternal factors** <u>Multiple pregnancy</u> No: Reference Yes: OR 1.5 (0.4-5.8) <u>Chorioamnionitis</u> No: Reference Yes: OR 5.3 (1.4-20.4) <u>Preeclampsia</u> No: Reference Yes: OR 2.2 (0.4-12.4) **Postnatal factors** <u>Postnatal steroids</u> No: Reference < 21 days: OR 0.9 (0.2-3.7) ≥ 21 days: OR 5.0 (0.9-27.8)	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td>Helse Vest Hospital Trust.</td><td></td><td></td><td>Length of follow-up

2 years (corrected).</td><td></td><td></td></tr>
<tr><td>Ref Id

339498

Full citation

Marret, S., Ancel, P. Y., Marpeau, L., Marchand, L., Pierrat, V., Larroque, B., Foix-L'Helias, L., Thiriez, G., Fresson, J., Alberge, C., Roze, J. C., Matis, J., Breart, G., Kaminski, M., Epipage Study, Group, Neonatal and 5-year outcomes after birth at 30-34 weeks of gestation, Obstetrics & Gynecology, 110, 72-80, 2007

Country/ies where the study was carried out</td><td>Sample size

N = 2457 preterm infants born at 30 to 34^{+6} weeks.

Characteristics

<table><tr><td>Characteristic</td><td></td></tr><tr><td>Gestational age</td><td></td></tr><tr><td>30 weeks</td><td>507 (20%)</td></tr><tr><td>31 weeks</td><td>635 (26%)</td></tr><tr><td>32 weeks</td><td>878 (35%)</td></tr><tr><td>33 weeks</td><td>214 (9%)</td></tr><tr><td>34 weeks</td><td>243 (10%)</td></tr><tr><td>Multiple pregnancy</td><td>32.1%</td></tr><tr><td>Antenatal corticosteroids</td><td>71.8%</td></tr><tr><td>Male gender</td><td>54.4%</td></tr></table></td><td>Risk factors

Gestational age
Multiple pregnancy
Antepartum haemorrhage
Premature prolonged rupture of membranes
Gender
Socioeconomic status

Data on antenatal corticosteroid therapy is reported, but this data is already included in the review from L'Foix-Helias 2008.</td><td>Setting

Preterm births from nine regions of France.

Method(s) of measurement for risk factor(s)

Standardised questionnaires were used to collect contemporaneous data during the neonatal admission.

Outcome(s) ascertainment/measures

Children discharged alive from the neonatal unit underwent a medical and neuropsychological assessment at five years of age by experienced physicians and neuropsychologists. Cerebral palsy was defined as at least two of: abnormal posture or movement, increased tone and hyperreflexia.</td><td>Risk of cerebral palsy
Gestational age
30 weeks: Reference
31 weeks: OR 1.3 (0.7-2.4)
32 weeks: OR 0.6 (0.3-1.1)
33 weeks: OR 0.5 (0.2-1.3)
34 weeks: OR 0.08 (0.01-0.6)

Multiple pregnancy
No: Reference
Yes: OR 1.6 (0.7-3.8)

Complications within singleton pregnancies
IUGR/maternal hypertension: Reference
Antepartum haemorrhage: OR 0.4 (0.05-3.5)
Preterm labour: OR 5.1 (2.1-12.0)
Preterm PROM: OR 4.9 (2.2-11.0)
Other: OR 4.5 (1.3-15.9)

Gender</td><td>Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
2018 infants were eligible for 5 year follow up, but only 1461 were evaluated (72%). No further data is provided regarding the infants who were lost to follow up, therefore whether they differed at baseline from those participating in the follow up cannot be ascertained.
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
France. **Study type** Population based prospective cohort study. **Aim of the study** To assess outcomes at 5 years after birth at 30-34 weeks gestation. **Study dates** Preterm babies born between 30^{+0} and 32^{+6} were recruited throughout 1997. Preterm babies born between 33^{+0} and 34^{+6} weeks were recruited in April and October 1997 (babies at these gestations were only recruited durign 2 months of the year, due to the	**Inclusion criteria** All preterm babies born at 30^{+0} to 34^{+6} weeks gestation (according to the recruitment dates) in nine regions of France. **Exclusion criteria** Death before 5 years follow up. In two of the nine regions, follow up was only conducted in half of the children (at random) in the 32 week group to reduce the workload.		When the diagnosis of cerebral palsy was in doubt, a panel of trained paediatricians met to discuss the case. The Kaufman Assessment Battery for Children (K-ABC) was used to identify cognitive ability, recorded as a mental processing composite score (MPC). This is standardized to a mean score of 100 (±15). Scores on the MPC of less than 70 were defined as moderate/severe cognitive impairment. **Statistical methods** Linear mixed models were used, with adjustment for gestational age, multiple pregnancy, intrauterine growth restriction (IUGR), maternal hypertension, haemorrhage, preterm labout, preterm prolonged rupture of the membranes (PROM), antenatal corticosteroid exposure, gender and socioeconomic status. Singleton infants were divided into 5 mutually	Female: Reference Male: OR 1.5 (0.9-2.5) Risk of MPC< 70 (intellectual impairment) **Gestational age** 30 weeks: Reference 31 weeks: OR 1.0 (0.6-1.4) 32 weeks: OR 0.8 (0.5-1.5) 33 weeks: OR 0.7 (0.3-1.6) 34 weeks: OR 0.4 (0.2-1.2) **Multiple pregnancy** No: Reference Yes: OR 1.0 (0.6-1.7) **Complications within singleton pregnancies** IUGR/maternal hypertension: Reference Antepartum haemorrhage: OR 0.5 (0.1-1.4) Preterm labour: OR 0.8 (0.4-1.7) Preterm PROM: OR 0.9 (0.5-1.5) Other: OR 0.6 (0.1-2.5) **Gender** Female: Reference Male: OR 1.2 (0.8-1.8) **Socioeconomic status of the family**	**Analysis and reporting:** low risk of bias. Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
high number of births at 33 and 34 weeks). Follow up assessments were carried out at 5 years of age. **Source of funding** INSERM (National Institute of Health and Medical Research), Merck-Sharp and Dohme-Chibret, the Fondation de la Recherche Medicale and a grant "Programme hospitalier de Recherche Clinique" from the French Department of Health.			exclusive categories based on the reason for premature delivery. These were: maternal hypertension or IUGR, antepartum haemorrhage, spontaneous preterm labour, preterm PROM and other complications of pregnancy. For assessment of the risks of these variables on the outcomes (cerebral palsy and intellectual impairment), the category of maternal hypertension/IUGR was used as the reference. **Length of follow-up** 5 years.	Professional: Reference Intermediate: OR 1.9 (0.7-5.4) Office worker or self-employed: OR 2.8 (1.0-7.6) Service worker or shop assistant: OR 4.5 (1.6-12.3) Manual worker or unemployed: OR 6.0 (2.3-15.6)	
Ref Id 242831	**Sample size** National Institute of Child Health and Human Development Eunice Kennedy Shriver Neonatal Research Network (U10 HD 027853).	**Risk factors** IVH grade (I to IV) IVH laterality (unilateral vs. bilateral).	**Setting** Data collected at 2 hospitals in Cincinnati, US and for the study this	**Outcome(s) at age** **Outcomes assessed at 18-22 months corrected age:**	**Limitations** Based on the NICE manual 2014 checklist for

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Full citation

Merhar,S.L., Tabangin,M.E., Meinzen-Derr,J., Schibler,K.R., Grade and laterality of intraventricular haemorrhage to predict 18-22 month neurodevelopmental outcomes in extremely low birthweight infants, Acta Paediatrica, International Journal of Paediatrics, 101, 414-418, 2012

Country/ies where the study was carried out

United States

Study type

Cohort study with prospective data collection and retrospective analysis</td>
<td>Characteristics

Characteristic (N=166) Mean (SD)

<table>
<tr><td>Gestational age, weeks</td><td>26 (2)</td></tr>
<tr><td>Birth weight, grams</td><td>793.2 (131)</td></tr>
<tr><td>MDI</td><td>83.8 (18.7)</td></tr>
<tr><td>PDI</td><td>88.6 (18.6)</td></tr>
<tr><td></td><td>n (%)</td></tr>
<tr><td>Male</td><td>67 (40.4)</td></tr>
<tr><td>White</td><td>112 (67.5)</td></tr>
<tr><td>BPD</td><td>101 (60.8)</td></tr>
<tr><td>Postnatal steroids</td><td>63 (38.2)</td></tr>
<tr><td>Culture positive sepsis</td><td>67 (40.4)</td></tr>
<tr><td>Surgical NEC</td><td>8 (4.8)</td></tr>
<tr><td>IVH Grade !</td><td>112 (67.5)</td></tr>
<tr><td>IVH Grade II</td><td>15 (9)</td></tr>
</table>
</td>
<td>Sepsis
Postnatal steroids</td>
<td>data was obtained from the NICHD neonatal Research Network Generic Database and Follow-up Database.

Method(s) of measurement for risk factor(s)

IVH Grade I-IV was assessed through ultrasound screenings. First ultrasound scan was done at 7-10 days of life and the second was done at 28 days of life. For the study, the ultrasound scans were obtained for all the children and the reports were reviewed and the laterality and highest grade of IVH was entered into a new database.
Sepsis, considered when a culture positive sepsis was recorded in the database.
Postnatal steroids, data obtained from the database, no further description.</td>
<td><u>Neurodevelopmental impairment (NDI) (adjusted odds ratios)</u>
IVH grade I: reference
IVH grade II: 0.40 (0.06-2.6)
IVH grade III: 1.6 (0.52-4.9)
IVH grade IV: 3.5 (1.2-10.4)
Postnatal steroids: 2.8 (1.2-6.3)
Sepsis: 2.4 (1.0-5.3)
Bilateral (vs. unilateral): 2.1 (0.93-4.6)
(The final model included the above covariates)</td>
<td>prognostic studies and QUIPS.
Participants: low risk of bias
Relatively small sample. It should be noted that all the participants had IVH (grade and laterality of IVH was considered, not if IVH itself increases the odds of NDI).
Attrition: moderate risk of bias
48 out of 214 eligible children had no follow-up data (22.4%)
Prognostic factor measurement: moderate risk of bias
Head ultrasounds were obtained at different times from different infants due to clinical reasons and the scans were read by different radiologists so the presence and grade of of IVH might be subject to misclassification bias.
Outcome measurement: low risk of bias
Confounders: low risk of bias</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Aim of the study To determine the whether the laterality of Intraventricular haemorrhage (IVH, unilateral vs. bilateral) was a predictor of neurodevelopmental outcome at 18-22 months in a cohort of extremely low-birth-weight infants with Grades I-IV IVH. **Study dates** 1/1/1998-1/1/2006, follow-up at 18-22 months corrected age. **Source of funding** National Institute of Child Health and Human Development Eunice Kennedy	IVH Grade III: 19 (11.5) IVH Grade IV: 20 (12) Unilateral bleed: 81 (48.8) **Inclusion criteria** Infants who were born with extremely low-birth-weight (401-1000 g) between 1 Jan 1998 and 1 Jan 2006 and admitted to the NICU at Cincinnati Children's Hospital or Good Samaritan Hospital in Cincinnati. Infants who had at least one abnormal head ultrasound scan recorded at the database. Infants who survived to follow-up at 18-22 months corrected age. Infants with Grades I-IV IVH. **Exclusion criteria** Infants with lethal congenital malformations, chromosomial abnormalities, history of meningitis and PVL.		**Outcome(s) ascertainment/measures** Neurodevelopmental impairment (NDI) at 18-22 months corrected age, defined as the presence of any of the following: cerebral palsy (definition or measurement not reported) MDI <70 (Bayley Scales of Infant Development Second Edition Mental Development Index BSID-II MDI) PDI <70 (Bayley Scales of Infant Development Second Edition Psychomotor Development Index BSID-II PDI) blindness (definition or measurement not reported) hearing impairment (definition or measurement not reported) **Statistical methods** Multiple logistic regression, NDI as a dependent variable and IVH grade and laterality		**Analysis and reporting:** low risk of bias **Overall quality:** moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Shriver Neonatal Research Network (U10 HD 027853).			and potential confounding variables as independent variables. Potential confounders considered included gender, race, birth weight, presence of bronchopulmonary dysplasia, postnatal steroids, early or late culture positive sepsis, necrotising enterocolotis requiring surgery. Backward elimination strategy was used with p>0.1 as exit criteria. Interaction between laterality and IVH grade was tested to in initial models to determine if the relationship between IVH grade and neurodevelopmental impairment was modified by laterality of IVH but the interaction term was not significant so it was excluded from the final models. **Length of follow-up** 18-22 months corrected age		
Ref Id	**Sample size** Enrolled n=1505	**Risk factors**	**Setting**	**Outcome(s) at age**	**Limitations**

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
411165 **Full citation** Michael O'Shea, T., Kuban, K. C., Allred, E. N., Paneth, N., Pagano, M., Dammann, O., Bostic, L., Brooklier, K., Butler, S., Goldstein, D. J., Hounshell, G., Keller, C., McQuiston, S., Miller, A., Pasternak, S., Plesha-Troyke, S., Price, J., Romano, E., Solomon, K. M., Jacobson, A., Westra, S., Leviton, A., Neonatal cranial ultrasound lesions and developmental delays at 2 years of age among extremely low gestational age children, Pediatrics, 122, e662-e669, 2008 **Country/ies where the**	Without qualifying cranial ultrasound n=51 (lost to follow-up) Deaths before follow-up n=257 (lost to follow-up) No assessment of mental and/or motor development n=181 (lost to follow-up) Children followed-up at 24 mo n=1017 **Characteristics** No information. **Inclusion criteria** Women delivering before 28 weeks of gestation. Maternal consent before or shortly after delivery. **Exclusion criteria** >=28 weeks of gestation No consent	Intraventricular haemorrhage (IVH) (defined as blood within the ventricles, excluding haemorrhage localized to the subependymal region) Periventricular leukomalacia (PVL), early and cystic. Periventricular hemorrhagic infarction (PVHI)	14 hospitlas in 11 cities in 5 states in the US. **Method(s) of measurement for risk factor(s)** Cranial ultrasound scans were performed routinely by technicians at the hospitals, up to 3 sets of scans per child were performed. First scan between 1st and 4th days, second between 5th and 14th days, and third between 15th day and 40th week. Before patient enrollment, sonologists created a manual and data collection form. Each set of scan was first read by one sonologist at the institution of the infant's birth, then digital images were sent to another sonologist at another study institution for a second reading. When two readers differed in their recognition of cranial abnormalities, the images were sent to a third reader (tie-breaker) who did not know what the initial readers reported.	**Outcomes assessed at 24 months' corrected age:** <u>MDI <70 (delayed mental development)</u> No IVH: reference IVH: RR 1.70 (95%CI 1.20-2.50) No early PVL: reference PVL: RR 1.30 (95%CI 0.80-2.10) No cystic PVL: reference Cystic PVL: RR 1.90 (95%CI 0.98-3.50) No PIVH: reference PIVH: RR 2.20 (95%CI 1.20-4.00) <u>PDI <70 (delayed psychomotor development)</u> No IVH: reference IVH: RR 2.10 (95%CI 1.50-2.90) No early PVL: reference Early PVL: RR 2.10 (95%CI 1.40-3.20) No cystic PVL: reference Cystic PVL: RR 4.30 (95% CI 2.30-8.10) No PIVH: reference	Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Study participation:** moder ate risk of bias Sample characteristics are not described. **Study attrition:** moderate risk of bias The ones who survived but were lost to follow-up due to missing the assessment of the outcome differed in their characteristics: younger mothers, less well educated mothers, mothers less likely to be married, mothers less likely to support themselves via their own employment, mother more likely to have Medicaid or other public insurance. No difference in the ones included in the analysis and lost to follow-up in relation gender, gestational age, plurality, birth weight, birth weight z-score, Score for

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
study was carried out United States **Study type** Prospective cohort study **Aim of the study** To describe the relationships between cranial ultrasound abnormalities and delayed development at 2 years of age in extremely premature infants. **Study dates** Enrollment between 2002-2004. Follow-up at around 24 months' corrected age.			**Outcome(s) ascertainment/measures** Developmental assessment at around 24 months' corrected age included the Bayley Sacaes of Infant Development - Second Edition (BSID-II), a neurological examination, and when the child was classified as untestable on the BSID-II (when child's impairment(s) precluded administration of the BSID-II or when >2 items were omitted or judged to be unscoreable), an interview of the parent was conducted using the Vineland Adaptive Behavior Scales (VABS). Certified examiners administered and scored the BSID-II. Mental Development Index (MDI) of <70 considered delayed mental development and Psychomotor Development Indec (PDI) of <70 considered delayed psychomotor development. Children who could not	PIVH: RR 4.00 (95%CI 2.20-7.00) Models adjusted for gestational age (23-24, 25-26, or 27 weeks), receipt of a complete course of antenatal corticosteroid, ceasarean delivery, and Medicaid insurance at 2 years' corrected age.	Neonatal Acute Physiology II, or the frequency of ultrasound lesions. **Prognostic factor measurement:** low risk of bias Two (or three, if the first two had differing findings) trained, experienced sonologists independently assessed the ultrasound images. **Outcome measurement:** low risk of bias Validated tools used to assess outcome. However, not all children were assessed in the same way: when children were untestable on BSID-II, another tool VABS was used. **Study confounding:** low risk of bias The analyses adjusted for several important confounders, however, the potential confounding factors are not described in detail.

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Source of funding National Institute of Neurological Disorders and Stroke grant NS 40069.			be tested using BSID-II were assessed using VABS: <70 on VABS Adaptive Behavior Composite were combined with the children with <70 on MDI and <70 on VABS motor skills domain score were combined with the children with <70 on PDI. **Statistical methods** For each ultrasound lesion, the proportion of children who had an MDI or PDI of <70 were computed. Risk ratios (RR) with 95% CI were calculated for the relationship between ultrasound lesions and developmental delay. **Length of follow-up** 24 months' corrected age.		**Statistical analysis and reporting:** moderate risk of bias The statistical analysis (calculating RRs with 95% CI) seems appropriate, however, details of the methods are not reported. Also, it is not clear whether in the main results table (Table 6), they included only children assessed through BSID-II or also children assessed through VABS. Also, the factors that the model adjusted for (in Table 6) differ from the factors that were listed in the text (e.g. ceasarial delivery not mentioned in text but was adjusted for according to Table 6, whereas SES mentioned in text but not on Table 6). **Overall quality:** moderate
Ref Id 111065	**Sample size** n=206 children survived to 5 years of age **n=193** children with assessment at 5 years of age (94%)	**Risk factors** Absence of antenatal steroids.	**Setting** National cohort of extremely low birth weight infant survivors in	**Outcome(s) at age** **Outcomes assessed at 5 years of age:**	**Limitations** Based on the NICE manual 2014 checklist for

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Full citation

Mikkola,K., Ritari,N., Tommiska,V., Salokorpi,T., Lehtonen,L., Tammela,O., Paakkonen,L., Olsen,P., Korkman,M., Fellman,V., Neurodevelopmental outcome at 5 years of age of a national cohort of extremely low birth weight infants who were born in 1996-1997, Pediatrics, 116, 1391-1400, 2005

Country/ies where the study was carried out

Finland

Study type

National population-based prospective cohort study</td>
<td>Characteristics

<table>
<tr><td></td><td>All ELBW infants included in study n=206</td></tr>
<tr><td>Maternal age, y</td><td>31.6 +-5.8</td></tr>
<tr><td>Multiparity, %</td><td>45</td></tr>
<tr><td>Multiple pregnancy, %</td><td>26</td></tr>
<tr><td>Antenatal steroids, %</td><td>79</td></tr>
<tr><td>Premature rupture of membranes >24h, %</td><td>23</td></tr>
<tr><td>vaginal delivery, %</td><td>32</td></tr>
<tr><td>Gestational age, weeks</td><td>27.3 +-2.1</td></tr>
<tr><td>Birth weight, g</td><td>806 +-136</td></tr>
<tr><td>Birth weight SD score</td><td>-2.1 +-1.4</td></tr>
<tr><td>SGA <-2SD, %</td><td>51</td></tr>
<tr><td>Male, %</td><td>46</td></tr>
<tr><td>Surfactant treatment, %</td><td>61</td></tr>
</table>
</td>
<td>Intraventricular haemorrhage (IVH) grades 3-4.
Perforated necrotising enterocolitis (NEC).
Oxygen dependence at 36 weeks (indication of bronchopulmonary dysplasia BPD).
Treated retinopathy of prematurity (ROP) grade 3-4.</td>
<td>Finland, data collected prospectively into the Finnish National Research and Development Center for Welfare and Health register.

Method(s) of measurement for risk factor(s)

Data collected from hospital records and child welfare clinics.

Outcome(s) ascertainment/measures

Cerebral palsy (CP), defined as a nonprogressive motor disorder with abnormal muscle tone, persistent or exaggerated primitive reflexes, or a positive Babinski sign associated with delayed motor development.
Cognitive impairment, defined as IQ score <70, assessed by the Wechsler Preschool and Primary Scale of Intelligence-revised (WPPSI-R).</td>
<td>ORs (95% CI) for the following outcomes among ELBW children at 5 years of age.
<u>Cerebral palsy (CP)</u>
Antenatal steroids: reference
No antenatal steroids: 3.4 (1.3-9.0)
p-value: 0.013

<u>Cognitive impairment</u>
Antenatal steroids: reference
No antenatal steroids: 3.93 (1.3-12.2)
p-value: 0.018

No perforated NEC: reference
Perforated NEC: 12.47 (2.4-64)
p-value: 0.002

No O2 dependence at 36 weeks: reference
O2 dependence at 36 weeks (BPD): 5.62 (1.8-17.8)
p-value: 0.003

<u>Severe visual impairment</u>
No ROP (grade 3-4); reference
Treated ROP (grade 3-4): 10.6 (3.2-31.5)
p-value: 0.001</td>
<td>prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: low risk of bias
Low percentage lost to follow-up (6%, n=13), although the characteristics of the ones lost to follow-up versus those included not compared.
Prognostic factor measurement: low risk of bias
Outcome measurement: moderate risk of bias
Severe visual impairment classified differently in the methods section and in the footnotes of Figure 2 (methods section: "severe visual impairment defined as bilateral or unilateral amaurosis, or amblyopia, or a combination of myopia and severe astigmatism", in Figure 2: "severe visual impairment classified as bilateral or unilateral amaurosis, amblyopia, or hyperopia".</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Aim of the study To assess the 5-year outcome, especially neurodevelopmental and cognitive outcome, in 3 groups: in all extremely low birth weight infants who were born during the 2-year period of 1996-1997, in a subcohort born at <27 gestational weeks, and in those who were small for gestational age versus appropriate gestational age. **Study dates** 1996-1997, follow-up at 5 years of age.	Respirator treatment, % — 92 Respirator treatment in days — 19 +-18 IVH grade 3-4, % — 11 Perforated NEC, % — 6 O2 dependence at 36 weeks, % — 39 **Inclusion criteria** Children with a birth weight of <1000 g born in Finland between 1 Jan 1996 and 31 Dec 1997 who survived until 5 years of age. **Exclusion criteria** None reported.		Severe visual impairment, classified as bilateral or unilateral amaurosis (loss of sight without apparent lesion of the eye), or amblyopia ("lazy eye", uncorrectable decrease in vision in one or both eyes with no apparent structural abnormality seen to explain), or a combination. Somatic health data, including visual impairment at age 5, was collected from hospital records and child welfare clinics. Cognitive assessment was done b **Statistical methods** Multiple logistic regression, independent variables for risk analyses included the following: multiparity, maternal smoking, high social class, preeclampsia, absence of antenatal steroids, multiple birth, gestational age, birth weight, gender, SGA, vaginal delivery, Apgar score <4 at 5 min, university	Multiple linear and logistic regression, independent variables for risk analyses included the following: multiparity, maternal smoking, high social class, preeclampsia, **absence of antenatal steroids**, multiple birth, gestational age, birth weight, gender, SGA, vaginal delivery, Apgar score <4 at 5 min, university hospital area, birth outside a tertiary hospital, **IVH grade 3-4**, **perforated NEC**, **O2 dependency at 36 weeks**, **ROP grades 3-4**. All variables were included stepwise both forward and backward. Therefore, by assumption, no other significant results were found than what are presented.	**Confounding:** moderate risk of bias Not clear which variables are included in the final models. However, wide range of relevant potential confounders were considered overall. **Analysis and reporting:** moderate risk of bias Not clear which variables are included in the final model. Not all results for primary outcomes are reported, presumably only significant findings. **Overall quality:** moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Source of funding The Finnish Pediatric Research Foundation, the Medical Society of Finland, and the Signe and Ane Gyllenberg Foundation.			hospital area, birth outside a tertiary hospital, IVH grade 3-4, perforated NEC, O2 dependency at 36 weeks, ROP grades 3-4. All variables were included stepwise both forward and backward. **Length of follow-up** 5 years.		
Ref Id 411200 **Full citation** Moore, G. S., Kneitel, A. W., Walker, C. K., Gilbert, W. M., Xing, G., Autism risk in small- and large-for-gestational-age infants, American Journal of Obstetrics and Gynecology, 206, 314.e1-314.e9, 2012 **Country/ies where the**	**Sample size** N=21717 **Characteristics** **<u>Gender</u>** Male (n): no autism group: 3040,131; autism group:18011 Female (n): no autism group: 2,917757; autism group: 3706 **<u>Age of mother (n):</u>** ≤20 years: no autism group:960,822; autism group: 1753 21-25 years: no autism group:1,499,201; autism group:4263 26-30 years: no autism group: 1,633, 158; autism group: 6081 30-35 years: no autism group:1,242, 483; autism group:5927 35-40 years: no autism group: 530,653; autism group:3107 ≥41 years: no autism group: 90,664; autism group:683	**Risk factors** Small for gestational age (stratified by gestational age groups: very preterm 23-27 weeks 6 days and 28-31weeks 6 days; midpreterm 32-33 weeks 6 days; late preterm 34-36 weeks 6 days; term 39-41 weeks 6 days; and postdates>42 weeks	**Setting** Data for maternal and infant hospital discharge records obtained from a database for birth records and infant death file published by California Department of Health Services **Method(s) of measurement for risk factor(s)** GA was based on the completed weeks of gestation at the time of birth For each year, the threshold values for male and female birthweight by GA within	**Outcome(s) at age** **Outcomes assessed at 11 years age:** **<u>For the outcome of autism:</u>** **<u>SGA 5-10 % (stratified by gestational age groups)</u>:** Reference: AGA>10 to <90%=1.00 <u>23-31 weeks GA:</u> SGA: OR 1.36 95%CI 0.91-2.02 *reached significance <u>32-33 weeks GA:</u> SGA: OR 1.00 95%CI 0.57-1.78 * reached significance <u>34-36 weeks GA:</u> SGA: OR 1.12 95%CI 0.91-1.38 <u>37-38 weeks GA:</u>	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** Low risk of bias Overall quality: hgh

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
study was carried out United States **Study type** Retrospective cohort study **Aim of the study** To determine whether small for gestational age (SGA) and large for gestational age (LGA) birth weights increase autism risk **Study dates** 11 year birth cohort from January 1991 through December 2001 **Source of funding**	**Maternal race/ethnicity (n):** Non-Hispanic white: no autism group:2,082,149; autism group:8789 African American: no autism group:421,764; autism group:1764 Asian: no autism group:593,146; autism group: 3049 Other race: no autism group:75,398; autism group:206 **Birth weight percentile (n):** <5%: no autism group: 436, 800; autism group:1516 5-10%: no autism group:280,316; autism group:1090 >10to <90%: no autism group: 4,414,624; autism group:15828 90-95%: no autism group:290,242; autism group:1083 >95%: no autism group:275,319; autism group:1130 **Inclusion criteria** Infants who survived to one year of age, without exclusion of children with comorbid congenital or neurodevelopmental abnormalities **Exclusion criteria**		the annual birth cohort (at 5th, 10th, 90th and 95th BW percentiles) was calculated. Each north according to sex and year was identified as SGA (enter <5th or 5-10th percentile), appropriate for GA (>10th to <90th percentile), or LGA (either 90-95th or >95th percentile. **Outcome(s) ascertainment/measures** Cases of autism were identified by: 1. An autistic level of one on any Client Development Evaluation Report or 2. An International Classification of Diseases 9th edition (ICD-9) code of 299.0 (autistic disorder), 299.8 or 299.9 **Statistical methods** Multivariate logistic regression analysis **Length of follow-up**	SGA: OR 1.01 95%CI 0.89-1.15 39-41 weeks GA: SGA: OR 1.03 95%CI 0.95-1.12 ≥42 weeks GA: SGA: OR 1.17 95%CI 0.92-1.48 **SGA <5% (stratified by gestational age groups):** Reference:AGA > 10 to <90%=1.00 23-31 weeks GA: SGA: OR 1.60 95%CI 1.09-2.35 * reached significance 32-33 weeks GA: SGA: OR 1.83 95%CI 1.16-2.87 * reached significance 34-36 weeks GA: SGA: OR 1.07 95%CI 0.86-1.34 37-38 weeks GA: SGA: OR 1.10 95%CI 0.97-1.25 39-41 weeks GA: SGA: OR 1.09 95%CI 1.00-1.18 ≥42 weeks GA: SGA: OR 1.24 95%CI 0.98-1.58 The multivariate analysis was adjusted for maternal age, race, hypertension, preeclampsia, diabetes,	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
National Institutes of Health			11 years	birth order, twin gestation, and months since last live birth. The analysis included infants that survived to 1 year of age Identification of covariates that were associated with SGA was carried out using previously published studies, and confirmed association with autism through univariate analysis using a 95%CI threshold of >1.0 or <1.0 for inclusion	
Ref Id 225763 **Full citation** Natarajan,G., Pappas,A., Shankaran,S., Kendrick,D.E., Das,A., Higgins,R.D., Laptook,A.R., Bell,E.F., Stoll,B.J., Newman,N., Hale,E.C., Bara,R.,	**Sample size** N=963 **Characteristics** Demographic characteristics of ELBW preterm infants with and without BPD, as determined by the physiologic definition	**Risk factors** GA Male gender SGA Maternal education Surgical NEC IVH or PVL Physiologic BPD	**Setting** Children's hospital **Method(s) of measurement for risk factor(s)** For BPD: Infants were classified as having “physiologic BPD” if they fulfilled either of two conditions: a) any form of assisted ventilation or continuous positive airway pressure (CPAP) or supplemental	**Outcome(s) at age** Assessed at 18 to 22 months corrected age: **Cognitive impairment**: Cognitive composite score from the Bayley III exam. Gestational age: OR 0.91 (95%CI 0.76-1.08) Male gender: OR 1.39 (95%CI 0.86-2.24) Small for gestational age: OR 2.60 (95%CI 1.23-5.50) Surgical NEC: OR 3.35 (95%CI 1.42-7.91)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** Moderate risk of bias, the study included those born < 27 weeks gestation and still hospitalised at 36 weeks post-menstrual age. **Attrition:** moderate risk of bias.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Walsh,M.C., Outcomes of extremely low birth weight infants with bronchopulmonary dysplasia: Impact of the physiologic definition, Early Human Development, 88, 509-515, 2012

Country/ies where the study was carried out

United States

Study type

Prospective cohort study

Aim of the study

To compare the growth and neuro-developmental outcomes at 18-22 months corrected age of a recent cohort</td>
<td>
<table>
<tr><th>Characteristic</th><th>BPD, N=603</th><th>No BPD, N=556</th><th>p-value[1]</th></tr>
<tr><td>Birth weight, mean (SD)</td><td>726 (139)</td><td>801 (128)</td><td><.0001</td></tr>
<tr><td>Gestational age, mean (SD)</td><td>25.2 (1.5)</td><td>26.2 (1.8)</td><td><.0001</td></tr>
<tr><td>Male Gender, %</td><td>55.6</td><td>41.6</td><td><.0001</td></tr>
<tr><td>Ethnicity, %</td><td></td><td></td><td></td></tr>
<tr><td>Caucasian</td><td>56.2</td><td>49.7</td><td></td></tr>
<tr><td>Black</td><td>38.8</td><td>46.6</td><td>0.08</td></tr>
<tr><td>Am. Indian/Alaskan native</td><td>0.3</td><td>0.4</td><td></td></tr>
<tr><td>Asian/Pacific Islander</td><td>4.0</td><td>2.9</td><td></td></tr>
<tr><td>More than one race</td><td>0.7</td><td>0.4</td><td></td></tr>
<tr><td>Apgar score at 5 min < 5, %</td><td>17.4</td><td>7.6</td><td><.0001</td></tr>
<tr><td>Small for gestation, %</td><td>11.8</td><td>14.4</td><td>0.22</td></tr>
</table>
</td>
<td></td>
<td>O_2 with an effective FiO_2 > 30% at 36 weeks postmenstrual age or b) O_2 via nasal cannula or hood with effective FiO_2 < 30% and failed the stepwise O_2 reduction challenge in the 36th postmenstrual week, using previously published criteria (O_2saturation 80% to 89% for 5 consecutive minutes or <80% for 15 seconds)

Outcome(s) ascertainment/measures

Results of a structured neurologic examination by trained examiners and language and cognitive scores on Bayley Scales of Infant

Development III at 18-22 months corrected age

Cognitive score < 70 was defined as cognitive impairment</td>
<td>IVH or PVL: OR 3.97 (95%CI 2.40-6.55)
Physiologic BPD: OR 2.41 (95%CI 1.40-4.13)
Antenatal steroids: NS
Sepsis (blood stream infection): NS

Change in odds of the outcome with each additional week of gestational age.

Variables were adjusted for each other in the multivariate regression model, as well as maternal education.

Other risk factors assessed but non-significant association was found:

Blood stream infection;

Antenatal steroids</td>
<td>Prognostic factor measurement: mode rate risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: Moderate risk of bias (study participants characteristics not reported)

Overall quality: Moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
of ELBW (birth weights 401-1000 grams) infants with and without physiologic BPD. **Study dates** 2006-2007 **Source of funding** Not reported	<table><tr><td>Maternal Age, mean (SD)</td><td>26.9 (6.4)</td><td>27.1 (6.6)</td><td>0.47</td></tr><tr><td>Prenatal care, %</td><td>93.7</td><td>92.8</td><td>0.62</td></tr><tr><td>Outborn, %</td><td>6.3</td><td>5.0</td><td>0.42</td></tr><tr><td>Cesarean delivery, %</td><td>66.5</td><td>71.4</td><td>0.08</td></tr><tr><td colspan="4"></td></tr><tr><td>Any Antenatal steroids, %</td><td>81.4</td><td>86.2</td><td>0.03</td></tr><tr><td colspan="4"></td></tr><tr><td>Singleton, %</td><td>76.6</td><td>74.1</td><td>0.35</td></tr></table> **Inclusion criteria** preterm infants with birth weights of 401-1000 grams, born between January 1, 2006 and June 30, 2007, eligible for follow-up (< 27 weeks gestation and inborn, or in an approved study with follow-up), and still hospitalized at 36 weeks postmenstrual age. **Exclusion criteria** Not reported		**Statistical methods** Multivariable logistic regression analysis was used to determine the association between BPD using the physiologic definition and cognitive impairment (cognitive score < 70), after adjusting for confounding variables that have been previously demonstrated to impact developmental outcomes; The other factors examined were small for gestational age status, surgical NEC, severe IVH or cystic PVL, bloodstream infection, and antenatal steroids **Length of follow-up** around 2 years		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Ref Id 316738 **Full citation** Odd,D.E., Lingam,R., Emond,A., Whitelaw,A., Movement outcomes of infants born moderate and late preterm, Acta Paediatrica, 102, 876-882, 2013 **Country/ies where the study was carried out** UK. **Study type** Regional prospective cohort. **Aim of the study** To investigate whether children born between 32	**Sample size** N= 13, 843 **Characteristics** **Inclusion criteria** Children born in the Bristol area, UK Gestational age: 32-36 weeks (preterm) or 37-42 weeks (term) Children with diagnosis of cerebral palsy at age 4 years **Exclusion criteria** Not reported.	**Risk factors** Gestational age	**Setting** The ALSPAC study is an on-going longitudinal study in Bristol in which data on cohort members and their families have been collected from half-day research clinics or retrieved from routine medical or educational records. **Method(s) of measurement for risk factor(s)** Data on gestational age were extracted from clinical notes (based on the last menstrual period), ultrasound or paediatric assessment. If gestational age was <37 weeks, then this was confirmed by a single paediatrician after reviewing the clinical records. Of the last menstrual period was considered unreliable, then the earliest ultrasound measurement was used.	**Outcome(s) at age** Cerebral palsy at 7 years age: Term: reference Preterm group 32-36 weeks: OR 6.38 (2.28-17.76)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** medium risk of bias (6967 children, 50.3%, had no movement data available, and these infants were more likely to have been preterm, were smaller, and they differed on most socioeconomic measures) **Prognostic factor measurement:** low risk of bias **Analysis and Reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
and 36 weeks of gestation have an increased risk of motor co-ordination difficulties or cerebral palsy at age 7 years. **Study dates** April 1991 to December 1992 **Source of funding** None			**Outcome(s) ascertainment/measures** All infants with CP were identified and confirmed by the Standard Recording of Central Motor Deficit **Statistical methods** Data on CP were available for the whole cohort, but only 8878 children had complete data on all confounder variables. Regression models were used to investigate the association between gestational group and outcome measures: logistic or ordered regression models were derived as appropriate. Adjustment for possible confounders was performed by adding the variables in blocks of common variables. Potential selection bias in the multivariate analysis, a multiple imputation data technique was used to impute missing covariate data.		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>All data was presented as odds ratios with their 95% confidence intervals.

Length of follow-up

7 years</td><td></td><td></td></tr>
<tr><td>Ref Id

347988

Full citation

Pappas, A., Kendrick, D. E., Shankaran, S., Stoll, B. J., Bell, E. F., Laptook, A. R., Walsh, M. C., Das, A., Hale, E. C., Newman, N. S., Higgins, R. D., Chorioamnionitis and early childhood outcomes among extremely low-gestational-age neonates, JAMA Pediatrics, 168, 137-147, 2014

Country/ies where the</td><td>Sample size

Overall sample
N = 3082
Eligible for follow up:
N = 2390
Included in follow up:
N = 2235

Characteristics

<table><tr><th>Characteristic</th><th>No chorioamnionitis n = 1014</th><th>Histological chorioamnionitis n = 910</th><th>Histological and clinical chorioamnionitis n = 466</th></tr><tr><td>Maternal age

mean (SD), years</td><td>27.2 (6.48)</td><td>26.9 (6.29)</td><td>27.8 (6.53)</td></tr><tr><td>Ethnicity</td><td></td><td></td><td></td></tr></table></td><td>Risk factors

Histological chorioamnionitis
Histological and clinical chorioamnionitis</td><td>Setting

Multicentre Neonatal Research Network hospitals.

Method(s) of measurement for risk factor(s)

Histological chorioamnionitis was recorded if chorioamnionitis was recorded on the placental pathology report, based on local reports made by individual site pathologists.
Clinical chorioamnionitis (typically characterised by 2 or more of maternal fever, uterine tenderness, malodorous amniotic fluid, maternal or fetal tachycardia or evidence of</td><td>Outcome(s) at age

At age 18-22 months' corrected
<u>Neurodevelopmental impairment</u>
Histological chorioamnionitis
No: Reference
Yes: OR 0.89 (0.56-1.42)†
Histological chorioamnionitis plus clinical chorioamnionitis
No: Reference
Yes: OR 1.51 (0.88-2.59)†

<u>Cerebral palsy</u>
Histological chorioamnionitis
No: Reference
Yes: OR 0.80 (0.42-1.53)‡
Histological chorioamnionitis plus clinical chorioamnionitis</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS
Participants: low risk of bias
Attrition: low risk of bias
87% of eligible participants included in follow up
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: high</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>study was carried out

United States

Study type

Multicentre retrospective cohort study.

Aim of the study

To evaluate whether histological and clinical chorioamnionitis are associated with increased risk of neurodevelopmental impairment at 18-22 months' corrected age among extremely premature neonates of <27 weeks gestation.

Study dates

January 1st 2006 and</td>
<td>
<table>
<tr><td>Black</td><td>35.4 %</td><td>42.2%</td><td>43.2%</td></tr>
<tr><td>White</td><td>39.4%</td><td>34.7%</td><td>29.9%</td></tr>
<tr><td>Hispanic</td><td>20.6%</td><td>18.4%</td><td>20.9%</td></tr>
<tr><td>Other</td><td>4.7%</td><td>4.7%</td><td>6.0%</td></tr>
<tr><td>Education: high school graduate</td><td>72.3%</td><td>75.2%</td><td>76.5%</td></tr>
<tr><td>Antenatal steroids</td><td>75.4%</td><td>75.9%</td><td>74.6%</td></tr>
<tr><td>Birth weight, g</td><td></td><td></td><td></td></tr>
<tr><td>401-500</td><td>14.0%</td><td>11.1%</td><td>13.7%</td></tr>
<tr><td>501-750</td><td>54.6%</td><td>54.4%</td><td>52.4%</td></tr>
<tr><td>751-1000</td><td>31.4%</td><td>34.5%</td><td>33.9%</td></tr>
<tr><td>Gestational age mean (SD), weeks</td><td>24.6 (1.29)</td><td>24.2 (1.36)</td><td>24.1 (1.39)</td></tr>
</table>
</td>
<td></td>
<td>inflammation) was noted if recorded in the mother's medical record by the treating clinicians and confirmed histopathologically. Cases of clinical chorioamnionitis without histopathological confirmation were excluded to avoid misclassification.

Outcome(s) ascertainment/measures

Infants underwent a comprehensive follow up assessment at 18-22 months corrected age. Psychometric testing was perforemd using the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley III). A score of less than 70 represents <2SD below the mean. Children who were so severely developmentally delayed that they could not be assessed were assigned scores (54 for severe cognitive delay and 46 for severe language delay).</td>
<td>No: Reference
Yes: OR 1.39 (0.67-2.87)‡

<u>MDI <70</u>
Histological chorioamnionitis
No: Reference
Yes: OR 1.07 (0.62-1.85)‡
Histological chorioamnionitis plus clinical chorioamnionitis
No: Reference
Yes: OR 2.00 (1.10-3.64)‡

MDI <85
Histological chorioamnionitis
No: Reference
Yes: OR 1.15 (0.82-1.60)†
Histological chorioamnionitis plus clinical chorioamnionitis
No: Reference
Yes: OR 1.50 (0.99-2.28)†

†Adjusted for maternal age, multiple birth, parity, antenatal steroids, maternal hypertension, antepartum haemorrhage, sex, gestational age, SGA</td>
<td></td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>December 31st 2008.

Source of funding

The National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Center for Research Resources and National Center for Advancing Translational Sciences.</td>
<td>
<table>
<tr><td>Male</td><td>53.5%</td><td>49.0%</td><td>51.7%</td></tr>
<tr><td>SGA at birth</td><td>10.9%</td><td>2.0%</td><td>2.2%</td></tr>
</table>
Inclusion criteria

Preterm infants of less than 27 weeks gestational age, born during the study period.

Exclusion criteria

No placental histology data. No follow up at 18-22 months corrected age. Congenital or chromosomal abnormalities.
</td>
<td></td>
<td>Cerebral palsy was defined as a nonprogressive central nervous system disorder with abnormal muscle tone in at least one extremity and abnormal control of movement and posture that interfered with age-appropriate activities. Disabling CP was classified as GMFCS ≥ level 2. Neurodevelopmental impairment was defined by one or more of disabling CP, Bayley scores <70, GMFCS level II or greater, blindness or permanent hearing loss that did not permit the child to understand or communicate despite amplification.

Statistical methods

For outcome exposure measures, 2 exposure groups were compared: no chorioamnionitis, histological chorioamnionitis alone, and histological plus clinical chorioamnionitis. Multivariable logistic and linear regression models were developed to</td>
<td>status, insurance, race and centre.
‡Adjusted by reduced models that contained covariates for centre, sex, antenatal steroids, SGA and hypertension.</td>
<td></td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			assess the primary (death/NDI) and secondary outcomes, adjusting for important confounders available at the time of birth that were selected *a priori* (maternal age, multiple birth, parity, antenatal steroids, maternal hypertension, antepartum haemorrhage, sex, gestational age, SGA status, insurance, race and centre). **Length of follow-up** 18 to 22 months' corrected age		
Ref Id 411392 **Full citation** Payne, A. H., Hintz, S. R., Hibbs, A. M., Walsh, M. C., Vohr, B. R., Bann, C. M., Wilson-Costello, D. E., Neurodevelopmental outcomes	**Sample size** n=2514 infants born <27 weeks with cranial ultrasound data n=202 exluded due to major congenital anomaly, hydrocephalus requiring shunt, meningitis, porencephalic cyst at <28 days n=627 excluded due to death before 18-22 months of age n=178 no follow-up data n=35 incomplete follow-up data **n=1472 included in the study** (n=1021 no PIVH, n=270 PIVH grade 1 or 2, n=181 PIVH grade 3 or 4)	**Risk factors** Periventricular-intraventricular hemorrhage (PIVH). Either none, low grade PIVH (Grade 1 or 2) or severe PIVH (Grade 3 or 4) Antenatal steroids Sepsis Postnatal steroids Bronchopulmonary dysplasia (BPD) Periventricular leucomalasia (PVL)	**Setting** 16 centers of the Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network in US. **Method(s) of measurement for risk factor(s)**	**Outcome(s) at age** **Outcomes at 18-22 months of corrected age:** The covariates in the model were PIVH severity (3 levels), gestational age, sex, race/ethnicity, maternal education, chorioamnionitis, sepsis, antenatal steroid exposure, postnatal steroid exposure, high	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** moderate risk of bias Limited reporting on how was measured.

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
of extremely low-gestational-age neonates with low-grade periventricular-intraventricular hemorrhage, JAMA Pediatrics, 167, 451-459, 2013 **Country/ies where the study was carried out** United States **Study type** Longitudinal observational study **Aim of the study** To compare neurodevelopmental outcomes at 18-22 months corrected age for extremely low gestational age infants with low grade (grade 1 or 2) periventricular-	**Characteristics** <u>Maternal characteristics:</u> Mean age (Y, SD): No PIVH group: 28 (6); Low-grade PIVH group: 27 (7); severe PIVH group: 27 (6) Education (>=high school, n): no PIVH group: 83; Low-grade PIVH group: 81; severe PIVH group: 81 Married (n): no PIVH group:47; Low-grade PIVH group:47; severe PIVH group:44 Prolonged ROM (n): no PIVH group: 28; Low-grade PIVH group: 28; severe PIVH group: 19 Chorioamnionitis (n): no PIVH group: 17; Low-grade PIVH group: 21; severe PIVH group:29 Antenatal corticosteroids (any, n): no PIVH group: 91; low-grade PIVH group:89; severe PIVH group:78 Postnatal corticosteroids (n): no PIVH group: 14; low-grade PIVH group: 14; severe PIVH group: 22 <u>Infant characteristics:</u> Gestational age (mean, SD), wk: no PIVH group: 25.1 (0.9); low grade PIVH group: 25.0 (1); severe PIVH group: 24.7 (1) Birth weight (mean, SD), g: no PIVH group: 769 (154); low grade PIVH group: 769 (151); severe PIVH group: 749 (154) Male sex (n): no PIVH group: 47; low grade PIVH group:61; severe PIVH group: 57 Race (black, n): no PIVH group: 39; low grade PIVH group: 39; severe PIVH group: 35 **Inclusion criteria** Infants born <+ 26 6/7 weeks estimated gestational age within 16 Neonatal Research Network centers between 2006-2008. Infants documented cranial ultrasound within 28 days of life. Infants surviving to 18-22 months corrected age.	Necrotising enterocolotis (NEC)	Periventricular-intraventricular hemorrhage (PIVH): cranial ultrasound done prior to 28 days of life. Other details not reported. Antenatal steroids: maternal receipt of >=1 dose of any corticosteroid for the purpose of accelerating fetal lung maturity. Sepsis: positive blood culture any time during the neonatal admission. Postnatal steroids: any corticosteroids given for prevention or treatment of bronchopulmonary dysplasia. Bronchopulmonary dysplasia (BPD): physiologic definition at 36 weeks postmenstrual age. Periventricular leucomalasia (PVL): evidence of cystic lesions in the periventricular area on any cranial ultrasound during the neonatal admission. Necrotising enterocolotis (NEC): Bell's Staging Criteria >=IIA.	frequency ventilation and patent ductus arteriosus. Other risk factors considered (BPD, PVL, NEC) not included in the final model, presumably not significant in univariate analysis? <u>Any CP</u> No PIVH: Reference Low grade PIVH: aOR 1.00 (0.61-1.64) No PIVH: reference Severe PIVH: aOR 3.43 (2.24-5.27) Low grade PIVH: reference Severe PIVH: aOR 3.44 (1.96-5.98) No antenatal steroids: reference Antenatal steroids: aOR 0.69 (0.42-1.14) No sepsis:reference Sepsis: AOR 1.48 (1.03-2.11) No postnatal steroids: reference Postnatal steroids: AOR 1.44 (0.92-2.26) <u>Cognitive <70</u> No PIVH: reference	**Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** low risk of bias **Overall quality:** moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
intraventricular hemorrhage to infants with either no hemorrhage or severe (grade 3 or 4) hemorrhage on cranial ultrasound. **Study dates** Infants born between 2006-2008 with follow-up at 18-22 months. **Source of funding** National Institutes of Health (Grant 5T32HD060537-01) Rainbow Babies and Children's Foundation Fellowship Research Award Program	**Exclusion criteria** Infants with major congenital anomaly, porencephalic cyst on cranial ultrasound prior to 28 days of life, meninigitis, or hydrocephalus requiring shunt. Infants who died before 18-22 months of corrected age. Infants without documented cranial ultrasound within 28 days of life.		**Outcome(s) ascertainment/measures** **Any cerebral palsy (CP)**, defined as abnormal tone or reflexes in at least one extremity and abnormal control of movement or posture to a degree that interferes with age-appropriate activity assessed with the Amiel-Tison neurologic assessment and Palisano's Gross Motor Function Classification System (GMFCS). **Cognitive impairment**, defined as a score of <70 on the Bayley Scales of Infant Development 3rd edition (Bayley III). **Language impairment**, defined as a score of <70 on the Bayley III. **Composite neurodevelopmental impairment (NDI) <70**, a composite measure of having any one of the following: moderate-severe CP, severe visual impairment, deafness, or cognitive score <70 (-2SD) on the Bayley III. Neurologic and developmental testing	Low grade PIVH: AOR 0.94 (0.54-1.61) No PIVH: reference Severe PIVH: AOR 1.37 (0.79-2.37) Low grade PIVH: reference Severe PIVH: AOR 1.46 (0.74-2.88) No antenatal steroids: reference Antenatal steroids: AOR 0.64 (0.36-1.13) No sepsis: reference Sepsis: AOR 2.28 (1.49-3.48) No postnatal steroids: reference Postnatal steroids: AOR 2.28 (1.41-3.69) <u>Language <70</u> No PIVH: reference Low grade PIVH: AOR 0.76 (0.52-1.13) No PIVH: reference Severe PIVH: AOR 1.57 (1.04-2.37) Low grade PIVH: reference Severe PIVH: AOR 2.05 (1.24-3.39)	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			was performed by annually certified examiners trained to realibility. **Statistical methods** Multivariate mixed effects regression analysis done to study the association between PIVH severity and neurodevelopmental outcomes. The covariates in the model included PIVH severity (3 levels), gestational age, sex, race/ethnicity, maternal education, chorioamnionitis, sepsis, antenatal steroid exposure, postnatal steroid exposure, high frequency ventilation and patent ductus arteriosus. Missing values for predictor variables were imputed as not having the exposure to have as large sample as possible (less than 2% of predictor data imputed). **Length of follow-up** At 18-22 months of corrected age.	No antenatal steroids: reference Antenatal steroids: AOR 0.62 (0.41-0.94) No sepsis: reference Sepsis: AOR 1.76 (1.31-2.37) No postnatal steroids: reference Postnatal steroids: AOR 1.67 (1.13-2.46) <u>Composite NDI <70</u> No IPVH: reference Low grade PIVH: AOR 0.82 (0.51-1.31) No PIVH: reference Severe PIVH: AOR 1.68 (1.06-2.65) Low grade PIVH: reference Severe PIVH: AOR 2.04 (1.15-3.64) No antenatal steroids: reference Antenatal steroids: AOR 0.84 (0.51-1.40) No sepsis: reference Sepsis: AOR 1.99 (1.40-2.83) No postnatal steroids: reference	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				Postnatal steroids: AOR 1.62 (1.06-2.48)	
Ref Id 321787 **Full citation** Perrott,S., Dodds,L., Vincer,M., A population-based study of prognostic factors related to major disability in very preterm survivors, Journal of Perinatology, 23, 111-116, 2003 **Country/ies where the study was carried out** Canada **Study type** Population-based cohort study	**Sample size** n=355 very preterm infants identified n=14 excluded due to lethal anomaly n=341 infants followed n=262 survived to 1 year of age n=9 infants lost to follow-up (no follow-up data) **n=253 infants included in the analyses of risk factors for major disability** **Characteristics** Limited information available. <u>Gestational age at birth for those who survived first year of life (n, %)</u> 22-27 weeks: 92 (56.1); lost to follow up=2 28-30 weeks: 170 (96.1); lost to follow up=7 **Inclusion criteria** All live-born infants among Nova Scotia residents born between 1992 and 1996 who were between 22 and 30 weeks gestation. **Exclusion criteria** Infants with lethal anomaly.	**Risk factors** Cystic PVL IVH grades 1 and 2 IVH grades 3 and 4	**Setting** Nova Scotia **Method(s) of measurement for risk factor(s)** No description, just that the neonatal risk factors were collected from medical records by trained health records personnel. **Outcome(s) ascertainment/measures** **Major disability** defined as possessing at least 1 of the following: mental development index (MDI) <70 on the Bayley Scale of Infant Development; moderate or severe cerebral palsy (moderate: lower limb dysfunction such that the child walks with significant difficulty	**Outcome(s) at age** **Outcomes assessed at 12 and 24 months corrected age (between 1992-1995) and at 18 and 36 months corrected age (since 1996):** <u>Major disability</u> Cystic PVL:OR 31.1 (95% CI 8.8-110.3) No Cystic PVL: reference Covariates in the multiple regression model (i.e. factors that were significant in univariate analysis) were: neonatal indomethacin therapy; severe depression at birth with pallor; neonatal therapy of dexamethasone for BPD; severe RDS, ventilated; moderate BPD without cystic change on X-ray; severe BPD with cystic change on X-ray; IVH grades 3 and 4; clinical	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moderate risk of bias Poor/no description of baseline characteristics. **Attrition:** moderate risk of bias 79 infants out of 341 (23%) died within 1st year of life but only 9 of the ones who survived were lost to follow-up. No description given on the characteristics of the ones lost to follow-up vs the ones included in analysis. **Prognostic factor measurement:** high risk of bias No description of how risk factors are defined or measured.

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Aim of the study To determine the rates of major disability in very preterm survivors born to residents of Nova Scotia, Canada between 1992 and 1996 inclusive and to identify risk factors associated with major disability in these infants. **Study dates** 1992 to 1996 Follow-up at 4, 8, 12, 18, 24 months corrected age and since 1996 also at 36 months corrected age. **Source of funding** IWK Health Centre,			and/or a major upper limb dysfunction, severe: nonambulatory or considered likely to never walk); bilateral visual acuity <20/200; deafness requiring bilateral hearing aids. A detailed physical and neurodevelopmental examination conducted by a neonatologist at each follow-up. A cognitive score using the Bayley Scale of Infant Development was conducted by a psychologist at 12 and 24 months corrected age between 1992-1995 and at 18 and 36 months corrected age in 1996. Hearing assessment conducted by the Nova Scotia Hearing and Speech Program within 1 year of birth. Vision assessment performed by an ophthalmologist within 1 year of birth. **Statistical methods** Multivariate logistic regression model including all risk factors that were significantly	evidence of neonatal seizure; PDA confirmed by echocardiogram; surgery requiring anesthesia; azotemia; late metabolic acidosis; hyperkalemia; hyponatremia; hypocalcemia; hypernatremia; neontal use of sulfactant for hyaline membrane disease; and cystic PVL. IVH Grades 3 and 4 (vs. no IVH Grade 3 and 4 as reference) was significantly associated with major disability in univariate analysis (OR 8.01 95% CI 2.31-27.67) but not in the multivariate analysis (effect estimate not reported). IVH Grades 1 and 2 (vs. no IVH Grades 1 and 2 as reference) not significant in univariate analysis (OR 1.2 95% CI 0.37-3.89). The multivariate model where only factors that potentially are present within the first few days of life, thus, not including cystic PVL which is not apparent	**Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias **Overall quality:** low

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Dalhouse University Faculty of Medicine			associated with major disability in univariate regression. **Length of follow-up** 2 years (up to 1995) and 3 years (since 1996)	until an infant is a few weeks old: IVH Grade 3 and 4: OR 7.3 (95% CI 1.9-27.9) No IVH Grade 3 and 4: reference Covariates in this model were: hypernatremia; and surgery.	
Ref Id 411731 **Full citation** Shah, T. A., Meinzen-Derr, J., Gratton, T., Steichen, J., Donovan, E. F., Yolton, K., Alexander, B., Narendran, V., Schibler, K. R., Hospital and neurodevelopmental outcomes of extremely low-birth-weight infants with necrotizing enterocolitis and spontaneous intestinal perforation, Journal of	**Sample size** n=1722 infants survived >12h n=995 infants who survived NICU discharge and were included in the NICHD NRN high-risk infant follow-up (criteria was changed for infants born 1/1/2006 or later to include only the ones born <27 weeks of gestation). n=20 children died before follow-up n=110 no neurodevelopmental follow-up data available **n=865 included in analysis** n=785 without NEC or SIP n=30 with medical NEC n=32 with surgical NEC n=18 with SIP **Characteristics**	**Risk factors** Necrotising enterocolitis (NEC) defined as Modified Bell's classification stage IIA or greater. Subgroups: NEC with surgical intervention, medical NEC (without surgical intervention)	**Setting** Population-based study in the greater Cincinnati region from 1998 to 2009, utilizing data from the National Institute of Child Health Neonatal Research Network registry and the Cincinnati Collaborative Outreach Program Database. **Method(s) of measurement for risk factor(s)** Modified Bell's classification state IIA or greater. **Outcome(s) ascertainment/measures**	**Outcome(s) at age** **Outcomes assessed at 18 to 22 months:** <u>MDI <70</u> No NEC: reference NEC: OR 2.04 (0.96-4.34) NEC (surgically managed): NS NEC (Medically managed): NS <u>PDI<70</u> No NEC: reference NEC: OR 2.64 (1.18-5.91) <u>Any disability*</u> No NEC: reference NEC: OR 2.59 (1.44-4.66) *Any of the following: MDI score <70, PDI score <70, cerebral	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moderate risk of bias Inclusion and exclusion criteria not very clearly reported. **Attrition:** moderate risk of bias Losses to follow-up not very clearly reported, no information provided if those lost to follow up differed compared to those included in analysis. **Prognostic factor measurement:** moderate risk of bias No description of how NEC was diagnosed.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Perinatology, 32, 552-8, 2012

Country/ies where the study was carried out

United States

Study type

Population-based cohort study

Aim of the study

To determine the incidence of necrotising enterocolitis (NEC) and spontaneous intestinal perforation (SIP) in surviving extremely low-birth-weight (<1000g birth weight) infants and to establish the impact of NEC on outcomes by hospital discharge and at</td>
<td>Characteristics of no NEC, NEC, medical NEC, surgical NEC and SIP groups with NICU outcomes
<table>
<tr><th></th><th>No NEC or SIP, n = 1459</th><th>NEC, n = 208</th><th>Medical NEC, n = 87</th><th>Surgical NEC, n = 121</th><th>NEC vs no NEC or SIP, P-value</th></tr>
<tr><td colspan="6">Perinatal factors</td></tr>
<tr><td>Antenatal antibiotics, n (%)</td><td>792 (54)</td><td>123 (59)</td><td>42 (48)</td><td>81 (67)</td><td>0.18</td></tr>
<tr><td>Antenatal steroids, n (%)</td><td>1173 (80)</td><td>175 (84)</td><td>72 (83)</td><td>103 (85)</td><td>0.16</td></tr>
<tr><td>Multiple, n (%)</td><td>356 (24)</td><td>62 (30)</td><td>22 (25)</td><td>40 (33)</td><td>0.09</td></tr>
<tr><td>ROM >24 h, n (%)</td><td>227 (16)</td><td>38 (18)</td><td>11 (13)</td><td>27 (22)</td><td>0.32</td></tr>
<tr><td colspan="6">Neonatal factors</td></tr>
<tr><td>Birth weight (g), mean (s.d.)</td><td>783 (144)</td><td>759 (145)</td><td>769 (140)</td><td>753 (148)</td><td>0.03</td></tr>
</table>
</td>
<td></td>
<td>Neurological examination was based on the Amiel-Tison assessments.
Gross motor skills examination was developed from the work of Russell and Palisano.
Bayley Scales of Infant Development-II (BSID-II) (for infant born before 2006) and Bayley Scales of Infant Development-III (BSID-III) (for infants born after 1/1/2006) was used to obtain mental development index (MDI) and psychomotor developmental index (PDI).

Impaired mental development defined as a MDI score <70.
Impaired psychomotor development defined as PDI score <70.

"Any disability" defined as a composite variable including any one of the following conditions:
MDI score <70
PDI score <70
Cerebral palsy (CP), defined as a non-progressive central nervous system disorder characterized by abnormal muscle tone in</td>
<td>palsy (CP), hearing impairment, or visual impairment.

No significant differences were detected when comparing outcomes between medical NEC and surgical NEC (effect estimates not reported).</td>
<td>Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: moderate</td>
</tr>
</table>

Study details	Participants						Risk factors	Methods	Outcomes and results	Comments
18 to 22 months adjusted age. **Study dates** 1998 to 2009, follow-up at 18 to 22 months of corrected age. **Source of funding** National Instititute of Child Health and Human Development Eunice Kennedy Shriver Neonatal Research Network (U10 HD 027853).	GA (week), mean (s.d.)	26.2 (2.0)	25.9 (2.0)	26.1 (1.8)	25.7 (2.1)	0.03	0.15	at least 1 extremity and abnormal control of movement and posture. Hearing impairment, defined as any restriction or lack of ability to perform within the range of considered as normal, resulting in impairment, or if there was chronic otitis media associated with delayed speech skills. Visual impairment, defined as need for corrective lenses, blindness with some functional vision or blindness with no functional vision. All neurological assessmented performed by one of two certified, masked developmental specialists over the entire study period. BSID-II was administered by a single, experienced gold standard examiner. **Statistical methods** Regression analysis done to compare the outcome between		
	Race Black, n (%)	823 (56)	136 (65)	60 (69)	76 (63)	0.01	0.36			
	Male, n (%)	674 (46)	107 (51)	45 (52)	62 (51)	0.39	0.95			
	Abbreviations: GA, gestational age; NEC, necrotizing enterocolitis; NICU, newborn intensive care unit; ROM, rupture of membranes; SIP, spontaneous intestinal perforation. **Inclusion criteria** Extremely low-birth-weight (<1000 g). Infants who survived 12 h. **Exclusion criteria** Birth weight >=1000 g. Infants with extremely low-birth-weight who died <12 h of birth.									

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			children without NEC (reference) and children without NEC. The model adjusted for birth weight, race, gender, multiple births, antenatal steroids, surfactant, bronchopulmonary dysplasia, sepsis, and any intraventricular hemorrhage. **Length of follow-up** 18 to 22 months.		
Ref Id 357477 **Full citation** Shankaran, S., Johnson, Y., Langer, J. C., Vohr, B. R., Fanaroff, A. A., Wright, L. L., Poole, W. K., Outcome of extremely-low-birth-weight infants at highest risk: Gestational age <24 weeks, birth weight <750 g, and 1-minute Apgar	**Sample size** N= 246 **Characteristics** Seen at follow-up (n=246) Black race (n):146 Complete steroids (n):70 Maternal age (mean year, SD):26.7 (6.9) Male (n):110 Gestational age (mean week, SD):23.6 (0.7) Grade III-IV ICH (n):79 PVL (n): 21 BPD (n): 157 Steroids for BPD (n):200 Household income <20k (n):135 **Inclusion criteria**	**Risk factors** ICH grades 3 - 4; PVL; Any antenatal steriods; Male; Black; Household income < 20k; BPD;	**Setting** Neonatal Intensive Care Unit (NICU) of the 12 participating centres; **Method(s) of measurement for risk factor(s)** Data are abstracted onto standardized forms from the mothers' and infants' charts by trained research nurses, who use definitions that were developed by the investigators and described in the study manual of operations.	**Outcome(s) at age** **Outcomes assessed at age 18-22 months' corrected age;** **Mental development index score <70: OR (95%CI)** ICH grade 3-4: 1.8 (0.9-3.6) PVL: 3.4 (1.0-10.8) Any antenatal steriods: 0.9 (0.5-1.7) Male: 2.1 (1.1-4.0) Black ethnicity: 1.9 (0.9-3.8) Non-black ethnicity: reference	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** Low risk of bias **Attrition:** moderate risk of bias (n=58 were not seen at follow up) **Prognostic factor measurement:** High risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
<3, American Journal of Obstetrics and Gynecology, 191, 1084-1091, 2004 **Country/ies where the study was carried out** United States **Study type** Prospective study **Aim of the study** To evaluate neuro-developmental outcome in extremely low-birth-wight infants, all of whom had 3 characteristics: gestational age <= 24 weeks, birth weight < 750 g, and 1-minute Apgar score <=3.	Extremely-low-birth-weight infants, all of whom had 3 characteristics: gestational age (GA)≤24 wks, birth weight ≤750g, and 1-minute Apgar score ≤3. **Exclusion criteria** Not reported		**Outcome(s) ascertainment/measures** The assessment consisted of a neurologic examination, a developmental evaluation, and medical and social history. Cerebral palsy was defined as a non-progressive central nervous system disorder characterized by abnormal muscle tone in at least 1 extremity and abnormal control of movement and posture. The Bayley Scales of Infant Development (BSID-II), including the Mental Developmental Index (MDI) and Psychomotor Developmental Index (PDI), was administered by clinical psychologists or psychometricians trained to reliability. Deafness was defined as bilateral impairment requiring hearing aids. Blindness was defined as <20/200 visual acuity; Neurodevelopmental impairment (NDI) was	Household income < 20K: 1.2 (0.5-2.5) BPD: Not signficant (NS) **Psychomotor development index score <70 (PDI): OR (95%CI)** ICH grade 3-4: 1.1 (0.6-2.3) PVL: 3.1 (1.1-9.4) Any antenatal steriods: 0.9 (0.5-1.7) Male: 1.3 (0.7-2.6) Black ethnicity: 1.2 (0.6-2.5) Non-black ethnicity: reference Household income < 20K: 1.5 (0.7-3.2) BPD: Not signficant (NS) **<u>CP: OR (95%CI)</u>** ICH grade 3-4: 1.9 (0.9-4.1) PVL: 4.4 (1.4-13.5)	**Analysis and reporting:** low risk of bias Overall quality: Low

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Study dates 1993-1999 **Source of funding** National Institute of Child Health and Human Development			defined as CP, MDI or PDI < 70, bilateral blindness, or hearing impaired with amplification. **Statistical methods** Multivariate analysis was performed to identify association between risk factors and outcomes of cerebral palsy, developmental disability (MDI <70, PDI <70, or NDI), or death after NICU discharge, and results expressed as odds ratios and 95% confidence intervals. **Length of follow-up** Around 2 years.	Any antenatal steriods: 1.1 (0.6-2.3) Male: 1.2 (0.6-2.4) Black ethnicity: 1.1 (0.5-2.2) Non-black ethnicity: reference Household income < 20K: 1 (0.4-2.4) BPD: Not signficant (NS) **NDI: OR (95%CI)** ICH grade 3-4: 2.5 (1.2-5.2) PVL: 2.4 (0.6-9.5) Any antenatal steriods: 1.4 (0.7-2.6) Male: 1.4 (0.7-2.6) Black ethnicity: 1.1 (0.6-2.2) Non-black ethnicity: reference Household income < 20K: 1.3 (0.6-2.8) BPD: 1.7 (0.9-3.3) **NDI or death: OR (95%CI)**	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				ICH grade 3-4: 2.3 (1.2-4.5) PVL: 2.3 (0.7-10.1) Any antenatal steriods: 1.2 (0.7-2.1) Male: 1.5 (0.9-2.8) Black ethnicity: 1.4 (0.8-2.5) Non-black ethnicity: reference Household income < 20K: 1.3 (0.6-2.8) BPD: 1.5 (0.8-2.8) -risk factors were adjusted for each other, plus surfactant administration, steriods for BPD, Medicaid, No high school degree, 2-parent household;	
Ref Id	**Sample size**	**Risk factors**	**Setting**	**Outcome(s) at age**	**Limitations**

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
411763 **Full citation** Singer, L. T., Hawkins, S., Huang, J., Davillier, M., Baley, J., Developmental outcomes and environmental correlates of very low birthweight, cocaine-exposed infants, Early Human Development, 64, 91-103, 2001 **Country/ies where the study was carried out** United States **Study type** Prospective cohort study **Aim of the study** To assess a cohort of very	Sample recruited - N = 82 very low birthweight infants (41 mothers cocaine-positive + 41 mothers cocaine-negative) Developmental outcomes are reported for 69 very low birthweight infants (31 mothers cocaine-positive + 38 mothers cocaine-negative) **Characteristics** Very low birthweight (VLBW) (<1500 g) infants: with positive findings of maternal cocaine use were compared with an equal number of noncocaine-exposed infants of similar race, social class and age, from the same study population (African–American) receiving public assistance **Inclusion criteria** No details given – see population characteristics **Exclusion criteria** No details given – see population characteristics	**Social/environmental/ maternal** Substance use (Maternal use of cocaine)	Population based study in the US **Method(s) of measurement for risk factor(s)** Cocaine status was determined through prospective urine screening or clinical interview at the time of the infant's birth, or both. Urine samples were obtained immediately before or after labor and delivery in the NICU in which the majority (85%) of infants were recruited. They were analyzed by enzyme immunoassay, using the Syva EMIT method (Syva, Palo Alto, CA), for the presence of cocaine's primary metabolite, benzoylecgonine and for heroin, phencyclidine, methadone, opiates, barbiturates and marijuana. **Outcome(s) ascertainment/measures** The Bayley Scales of Infant Development that	Intellectual disability (developmental delay - Mental Developmental Index [MDI] or a Psychomotor Developmental Index [PDI]) "When the baseline differences […the effects of IVH, the only neonatal neurologic complication which differed between the groups…] were controlled, the effects of cocaine on these developmental outcomes remained significant"	**Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.** **Participants: low risk of bias** **Attrition:** moderate risk of bias (the attrition was higher in the cocaine-exposed cohort) **Prognostic factor measurement: low risk of bias** **Outcome measurement: low risk of bias** **Confounding moderate risk of bias (No sufficient information about the measurement and the definition of confounders measured in the study)** **Analysis and Reporting:** high risk of bias (presentation of data in narrative way for some important outcomes. Potential risk of selective reporting) Overall quality: low

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
low birthweight, cocaine-exposed infants and a comparison group of nonexposed infants who were identified at birth and followed to 3 years of age, assessing 1) developmental outcome measures, 2) early maternal–child interactions, 3) maternal psychological characteristics and environmental factors conceptualized to be important for child outcome **Study dates** Not reported: Period of data collection (patient 'enrolment') – 2001: date of publication 3 years: follow-up assessment			is described as widely used assessment toll of infant development. The Mental Development Index (MDI) is a standard score reflecting memory, learning and problem-solving abilities. The psychomotor index (PDI) measures gross and fine motor control and coordination. The Battelle communication domain subscale provides a standard measure of receptive and expressive language skills. The scales provide a deviation quotient similar to the standard scores of the Bayley scales. **Statistical methods** The $\chi 2$ test for comparisons of categorical data, and Student's *t*-test or ANOVA for continuous data were used. The study hypothesis was that that cocaine-exposed children would have poorer behavioral ratings and developmental outcomes at follow-up, based on		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td>Source of funding

Supported by Grants MCJ-390592 and 390715 from the Maternal and Child Health Program (Title V, Social Security Act) Health Resources and Services Administration, Department of Health and Human Services and from NIH-HL-38193, NIDA 07957.</td><td></td><td></td><td>the outcome assessment at 17 months
Analyses of covariance were used to compare developmental outcomes with control for confounding variables, when necessary.

Length of follow-up

3 years</td><td></td><td></td></tr>
<tr><td>Ref Id

411856

Full citation

Stoll, B. J., Hansen, N. I., Adams-Chapman, I., Fanaroff, A. A., Hintz, S. R., Vohr, B., Higgins, R. D., Neurodevelopm</td><td>Sample size

n=6314

Characteristics

<table><tr><td></td><td>Uninfected (n=2161)</td><td>Clinical infection alone</td><td>Sepsis alone (n=1922)</td><td>Sepsis + NEC (n=279)</td><td>Meningitis with or without sepsis (n=193)</td></tr></table></td><td>Risk factors

Sepsis alone
Sepsis plus NEC
Meningitis with or without sepsis</td><td>Setting

Data obtained from the National Institute of Child Health and Human development (NICHD) Neonatal Research Network registry, participants born in the different centers of the network between 1993-2001.</td><td>Outcome(s) at age

Outcomes assessed at 18-22 months' corrected age:
ORs (95% CI) presented, the logistic regression model adjusted for study center, gestational age, birth weight, sex, race/ethnicity, rupture of membranes >24 h, CS, multiple birth, antenatal antibiotics, antenatal</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
20% of the eligible ones for follow-up were lost to follow-up. Baseline</td></tr>
</table>

Study details	Participants						Risk factors	Methods	Outcomes and results	Comments
ental and growth impairment among extremely low-birth-weight infants with neonatal infection, Journal of the American Medical Association, 292, 2357-2365, 2004 **Country/ies where the study was carried out** United States **Study type** Multicentre cohort study **Aim of the study** To determine if neonatal infections in extremely low birth weight infants are associated with increased risks of adverse			(n=1538)					**Method(s) of measurement for risk factor(s)** Sepsis alone, defined by a positive blood culture and antibiotic therapy for 5 or more days. Sepsis plus necrotizing enterocolitis (NEC), NEC classified according to the system of Bell et al. Meningitis with or without sepsis, meningitis defined by a positive cerebrospinal fluid culture and antibiotic therapy for 5 or more days. **Outcome(s) ascertainment/measures** Mental developemental index (MDI) <70, assessed with Bayley Scales of Infant Development II (BSID-II) Psychomotor developmental index (PDI) <70, assessed with Bayley Scales of Infant Development II (BSID-II) Cerebral palsy (CP), defined as nonprogressive disorder of movement and posture.	steroids, postnatal steroids, surfactant use, respiratory distress syndrome, bronchopulmonary dysplasia, patent ductus arteriosus, intraventricular haemorrhage grade 3-4, periventricular leukomalacia, maternal age at time of delivery, caregiver's level of education. MDI <70 No infection: reference Sepsis alone: 1.3 (1.1-1.6) Sepsis+NEC: 1.6 (1.2-2.2) Meningitis with or without sepsis: 1.6 (1.1-2.3) PDI <70 No infection: reference Sepsis alone; 1.5 (1.2-1.9) Sepsis+NEC: 2.4 (1.7-3.4) Meningitis with or without sepsis: 1.7 (1.1-2.5) CP No infection: reference Sepsis alone: 1.4 (1.1-1.8) Sepsis+NEC: 1.7 (1.2-2.5)	characteristics were not compared but the risk factor of interest (different types or levels of infection) were compared between ones lost to follow-up and ones included. Infants who survived bu did not complete follow-up were more likely to be uninfected and the percentages in each infection group were 1-2% lower for the ones lost to follow-up than the ones included in analysis (p=0.001). **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias **Overall quality:** Moderate
	Maternal age <=19 y, %	16	16	18	18	16				
	ROM >24 h, %	23	25	23	29	25				
	Antenatal antibiotics, %	59	64	67	65	72				
	Antenatal steroids, %	73	72	70	70	74				
	CS, %	65	57	55	56	47				
	Caregiver education: high school graduate, %	75	75	75	74	77				
	Birth weight 401-500 g, %	<1	2	2	2	3				
	Birth weight	23	40	48	46	44				

Study details	Participants						Risk factors	Methods	Outcomes and results	Comments
neurodevelopmental and growth sequelae in early childhood. **Study dates** 1993-2001, follow-up at 18-22 months corrected age. **Source of funding** Grants from the National Institutes of Health.	591-750 g, %							Vision impairment, defined as blindness in one or both eyes or need for corrective lenses. Hearing impairment, defined as hearing aids in one or both ears. Neurodevelopmental impairment (NDI, a composite outcome, defined as one or more of the following: MDI <70, PDI <70, CP, bilateral blindness or bilateral hearing impairment. **Statistical methods** Multiple logistic regression, adjusting for study center, gestational age, birth weight, sex, race/ethnicity, rupture of membranes >24 h, CS, multiple birth, antenatal antibiotics, antenatal steroids, postnatal steroids, surfactant use, respiratory distress syndrome, bronchopulmonary dysplasia, patent ductus arteriosus, intraventricular haemorrhage grade 3-4, periventricular leukomalacia, maternal age at time of delivery,	Meningitis with or without sepsis: 1.6 (1.0-2.5) <u>Vision impairment</u> No infection: reference Sepsis alone: 1.7 (1.3-2.2) Sepsis+NEC: 2.0 (1.3-3.0) Meningitis with or without sepsis: 2.2 (1.4-3.6) <u>Hearing impairment</u> No infection: reference Sepsis alone: 1.8 (1.0-3.1) Sepsis+NEC: 3.4 (1.6-7.3) Meningitis with or without sepsis: 0.8 (0.2-2.8) <u>NDI</u> No infection: reference Sepsis alone: 1.5 (1.2-1.7) Sepsis+NEC: 1.8 (1.4-2.5) Meningitis with or without sepsis: 1.6 (1.1-2.3)	
	Birth weight 751-1000 g, %	77	59	50	52	53				
	GA <25 wk, %	8	22	27	25	25				
	GA 25-28 wk, %	69	69	66	70	73				
	GA 29-32 wk, %	22	9	6	6	3				
	GA >=33 wk, %	1	<1	<1	0	0				
	SGA at birth, %	24	14	14	13	16				
	Male, %	41	51	48	53	41				
	Race/ethnicity black, %	44	46	46	50	50				
	Race/ethnicity white, %	41	39	35	38	34				
	Race/ethnicity	11	13	16	10	15				

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
	hispanic, % Race/ethnicity other, % 3 2 3 3 2 **Inclusion criteria** Surviving infants who weighed 1000 g or less at birth. **Exclusion criteria** Infants with major congenital malformations/syndromes, and those with ventricular shunts. Infants with positive blood cultures but who received antibiotic therapy for less than 5 days (and therefore considered probable contaminants).		caregiver's level of education. **Length of follow-up** 18-22 months' corrected age.		
Ref Id 317149 **Full citation** Tommiska,V., Heinonen,K., Kero,P., Pokela,M.L., Tammela,O., Jarvenpaa,A.L., Salokorpi,T., Virtanen,M.,	**Sample size** N = 208 extremely low birth weight infants. **Characteristics** Characteristic: Gestational age, mean (range), 27.3 (22.3-34.9)	**Risk factors** No antenatal steroid treatment Vaginal delivery	**Setting** Population based cohort. **Method(s) of measurement for risk factor(s)** Data were recorded prospectively through the national follow up program.	**Outcome(s) at age** Risk of cerebral palsy Antenatal steroids: Yes: Reference No: OR 3.6 (1.3-10.0) Sepis: NS NEC (with perforation): NS Brain abnormalities (IVH grade II-IV): NS Vaginal delivery:	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Fellman,V., A national two year follow up study of extremely low birthweight infants born in 1996-1997, Archives of Disease in Childhood Fetal and Neonatal Edition, 88, F29-F35, 2003 **Country/ies where the study was carried out** Finland. **Study type** Prospective cohort study. **Aim of the study** To study neurodevelopmental outcome in extremely low birthweight infants at 18 months of age, including comparisons to	weeks Birthweight, mean (range), grams: 807 (447-995) Male gender, n (%): 97 (47) Multiple pregnancy, n (%): 55 (26) Antenatal steroid treatment, n (%): 164 (79) Vaginal delivery, n (%): 68 (33) Lower social classes 3-4, n (%): 120 (65) Maternal smoking, n (%): 37 (19) Small for gestational age, n (%): 84 (40) IVH grades 2-4, n (%): 24 (12) RDS, n (%): 144 (69) Septicaemia, n (%): 53 (26)		**Outcome(s) ascertainment/measures** A national neurological follow up program included an opthalmologic assessment at 12-18 months (corrected), and examinations by a neurologist, physiotherapist and speech therapist at the corrected age of 18 months. Cerebral palsy was defined as a non-progressive motor impairment with spastic or dystonic muscle tone, brisk tendon reflexes, positive Babinski's sign and persistent primitive reflexes. **Statistical methods** Logistic regression analysis was used to detect risk factors for cerebral palsy. The factors included in the analyses were multiparity, pre-eclampsia, premature rupture of membranes,	No: Reference Yes: OR 4.3 (1.5-12.2) Male (vs female): not an independent predictor on multivariate analysis OR adjusted for variables listed above.	**Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: High

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
term born children, and assessment of risk factors for unfavourable outcome. **Study dates** Recruitment from 1st January 1996 to 31st December 1997. **Source of funding** The Finnish Paediatric Foundation and Signe and Ane Gyllenberg Foundation.	ROP stages 3-5, n (%) — 19 (9) Oxygen dependency at the age equivalent to 36 weeks, n (%) — 81 (39) **Inclusion criteria** All infants with a birth weight below 1000g and gestational age of at least 22 full weeks born in Finland during the study time period. **Exclusion criteria** None reported.		maternal infection, antenatal steroid treatment, hyperstimulation or in vitro fertilisation, maternal age below 20 or above 40, smoking, marital status, social class 1-4, birth in secondary level hospital, catchment area for the different hospitals, vaginal delivery, birth weight (100g groups), intrauterine growth restriction, gestational age, male gender, multiple birth, anomalies, respiratory distress syndrome, septicaemia, necrotising enterocolitis with perforation and intraventricular haemorrhage grades 2-4. **Length of follow-up** 18 months.		
Ref Id 412006 **Full citation** Van Marter, L. J., Kuban, K. C.	**Sample size** n=1047 **Characteristics**	**Risk factors** Bronchopulmonary dysplasia (BPD) with only O2 (no mechanical ventilation) at 36 weeks BPD with mechanical ventilation	**Setting** 14 participating centers within the Extremely Low Gestational Age Newborns ELGAN study in the US during 2002-2004.	**Outcome(s) at age** **Outcomes assessed at 24 months' corrected age:** The model adjusted for early gestational age, CS, race, gender, public	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>K., Allred, E., Bose, C., Dammann, O., O'Shea, M., Laughon, M., Ehrenkranz, R. A., Schreiber, M. D., Karna, P., Leviton, A., Does bronchopulmonary dysplasia contribute to the occurrence of cerebral palsy among infants born before 28 weeks of gestation?, Archives of Disease in Childhood: Fetal and Neonatal Edition, 96, F20-F29, 2011

Country/ies where the study was carried out

United States

Study type

Multicentre cohort study</td>
<td>Antenatal and perinatal variables associated with bronchopulmonary dysplasia (BPD) and cerebral palsy (CP) diagnoses
<table>
<tr><th rowspan="2">Antenatal characteristics</th><th rowspan="2"></th><th rowspan="2">BPD</th><th colspan="3">CP (-paresis)</th><th rowspan="2">GMFCS ≥2</th><th rowspan="2">N</th></tr>
<tr><th>Quadri</th><th>Di</th><th>Hemi</th></tr>
<tr><td rowspan="2">Public insurance</td><td>Yes</td><td>48</td><td>7</td><td>5</td><td>1</td><td>7</td><td>396</td></tr>
<tr><td>No</td><td>52</td><td>6</td><td>3</td><td>2</td><td>4</td><td>631</td></tr>
<tr><td rowspan="3">Race</td><td>White</td><td>53</td><td>7</td><td>3</td><td>1</td><td>6</td><td>624</td></tr>
<tr><td>Black</td><td>51</td><td>6</td><td>5</td><td>3</td><td>6</td><td>280</td></tr>
<tr><td>Other</td><td>40</td><td>2</td><td>2</td><td>2</td><td>2</td><td>127</td></tr>
<tr><td>Latino</td><td>Yes</td><td>48</td><td>6</td><td>2</td><td>2</td><td>5</td><td>123</td></tr>
</table>
</td>
<td></td>
<td>Method(s) of measurement for risk factor(s)

Bronchopulmonary dysplasia (BPD), defined as children who received supplemental oxygen at 36 weeks postmenstrual age, divided into 2 levels:
receiving supplemental O2 without ventilation (BPD)
receiving supplemental O2 with mechanical ventilation (BPD/MV), receiving mechanical ventilation defined as the child being managed on mechanical support that included endotracheal intubation, mechanical ventilation included conventional ventilation inn a variety of modes, as well as high frequency ventilation/ Infants in room air CPAP (n=5) at 36 weeks were classified as having no BPD. At 36 weeks, no infants were receiving mechanical ventilation without supplemental O2.
Necrotising enterocolitis (NEC), classified</td>
<td>insurance (vs private), pulmonary interstitial emphysema, arterial hydrogen ion concentration, methylxanthine.
<u>Cerebral palsy (CP) quadriparesis</u>
No BPD: reference
BPD only: 1.6 (0.8-3.2)

No BPD with mechanical ventilation: reference
BPD with mechanical ventilation: 5.7 (2.5-13)

<u>CP diparesis</u>
No BPD: reference
BPD only: 2.1 (0.8-5.0)

No BPD with mechanical ventilation: reference
BPD with mechanical ventilation: 4.2 (1.3-14)

<u>CP hemiparesis</u>
No BPD: reference
BPD only: 2.7 (0.7-11)

No BPD with mechanical ventilation: reference
BPD with mechanical ventilation: 1.2 (0.1-13)</td>
<td>Participants: low risk of bias
Attrition: low risk of bias
12.0% of the ones who survived to 2 years did not have outcome assessment. 30.5% of the ones originally enrolled were not included in current study, due to death or lack of data.
Prognostic factor measurement: low risk of bias
Outcome measurement: moderate risk of bias
Definition of CP not provided. CP diagnosis done on the basis of neurological examinations performed by people who "received formal instruction and studied a manual, a data collection form an an instructional CD designed to minimise examiner variability", thus, not clear how experienced they are and if they are professionals. The topographic diagnosis</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Aim of the study

To explore the relationship between bronchopulmonary dysplasia (BPD) and cerebral palsy (CP), incluyding CP phenotypes, while considering both potential shared antecedents as well as possible intermediaries in the causal pathway to CP.

Study dates

2002-2004, follow-up at 24 months corrected age.

Source of funding

Supported by a cooperative agreement with the National Institute of Neurological Diseases and</td>
<td>
<table>
<tr><td>ethnicity</td><td>No</td><td>51</td><td>6</td><td>4</td><td>2</td><td>5</td><td>919</td></tr>
<tr><td rowspan="3">Antenatal steroid treatment</td><td>Complete</td><td>49</td><td>7</td><td>4</td><td>2</td><td>5</td><td>674</td></tr>
<tr><td>Incomplete</td><td>56</td><td>4</td><td>3</td><td>3</td><td>4</td><td>259</td></tr>
<tr><td>None</td><td>53</td><td>8</td><td>4</td><td>0</td><td>8</td><td>112</td></tr>
<tr><td rowspan="2">Caesarean section</td><td>Yes</td><td>51</td><td>6</td><td>2</td><td>1</td><td>5</td><td>693</td></tr>
<tr><td>No</td><td>51</td><td>7</td><td>6</td><td>3</td><td>6</td><td>354</td></tr>
<tr><td rowspan="6">Initiator of preterm delivery</td><td>Preterm labour</td><td>49</td><td>6</td><td>4</td><td>3</td><td>5</td><td>469</td></tr>
<tr><td>pPROM</td><td>48</td><td>6</td><td>4</td><td>2</td><td>4</td><td>230</td></tr>
<tr><td>Pre-eclampsia</td><td>62</td><td>5</td><td>1</td><td>1</td><td>7</td><td>137</td></tr>
<tr><td>Abruption</td><td>55</td><td>3</td><td>3</td><td>2</td><td>3</td><td>113</td></tr>
<tr><td>Cx insufficiency</td><td>45</td><td>15</td><td>5</td><td>0</td><td>9</td><td>55</td></tr>
</table>
</td>
<td></td>
<td>according to the modieif Bell staging system. Antenatal glucocorticoid, considered complete if the mother received 2 doses of betamethasone 24 h apart of if she received 4 doses of dexamethasone at 12 h intervals and delivered at least 48 h after the first dose of either medication.

Outcome(s) ascertainment/measures

Cerebral palsy (CP), assessed through a neurological examination and an assessment for the Gross Motor Function Classification System (GMFCS) to assess the severity of the motor disability related to CP. Neurological examination was performed by persons who received formal instruction and studied a manual, a data collection form, and an instructional CD designed to minimise examiner variability. Topographic diagnosis</td>
<td></td>
<td>of CP is not clearly explained.
Confounders: low risk of bias
Analysis and reporting: moderate risk of bias
Reporting of univariate analyses is unclear, no p-values or ORs are given.
The final model was built by starting with the earliest occurring predictors, leaving the ones that were significant and then adding later occurring predictors and so on. However, it is not very clear which variables were included in the early, later, and late postnatal epochs.

Overall quality: moderate</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Stroke and Mental Retardation and Developmental Disabilities Research Center grant from the National Institute of Child Health and Development. Thrasher Research Fund. National Institutes of Heart, Lung, and Blood.</td>
<td>
<table>
<tr><td></td><td>Fetal indicatio n</td><td>58</td><td>9</td><td>2</td><td>0</td><td>9</td><td>43</td></tr>
<tr><td rowspan="3">Gestational age (weeks)</td><td>23–24</td><td>76</td><td>13</td><td>8</td><td>3</td><td>10</td><td>21 1</td></tr>
<tr><td>25–26</td><td>54</td><td>5</td><td>2</td><td>2</td><td>4</td><td>48 4</td></tr>
<tr><td>27</td><td>33</td><td>3</td><td>3</td><td>1</td><td>3</td><td>35 2</td></tr>
<tr><td rowspan="3">Birth weight Z-score</td><td>less than −1</td><td>70</td><td>5</td><td>2</td><td>2</td><td>6</td><td>19 7</td></tr>
<tr><td>−1 to 0</td><td>54</td><td>5</td><td>5</td><td>2</td><td>4</td><td>38 9</td></tr>
<tr><td>≥0</td><td>41</td><td>7</td><td>3</td><td>2</td><td>6</td><td>46 1</td></tr>
<tr><td>Maximum N</td><td></td><td>53 6</td><td>64</td><td>37</td><td>19</td><td>55</td><td>10 47</td></tr>
</table>

These are row percents, calculated separately for CP phenotype and severity (GMFCS).
Cx, cervical; GMFCS, Gross Motor Classification System; pPROM, preterm prelabour rupture of fetal membranes.

</td>
<td></td>
<td>of CP was based on algorithm using these data. CP classifications: quadriparesis diparesis hemiparesis

Statistical methods

Time-oriented multiple logistic regression to study the association between BPD and CP, where risk factors were ordered in a temporal pattern, the earliest occurring predictors were entered first and the ones that were significant, were then included in the later model. This was done because BPD is a postnatal phenomenon and can be influenced by antepartum factors.

Length of follow-up

24 months' corrected age.</td>
<td></td>
<td></td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td>Inclusion criteria

Infants born before 28 weeks of gestation in 1 of the 14 participating centers (within the Extremely Low Gestational Age Newborns ELGAN study) during 2002-2004.
Infants whose respiratory status at 36 weeks postmenstrual age was known and who survived to 24 months post-term equivalent and had a complete neurological exam.

Exclusion criteria

None reported.</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Ref Id

337012

Full citation

Victorian Infant, Collaborative, Postnatal corticosteroids and sensorineural outcome at 5 years of age, Journal of Paediatrics & Child Health, 36, 256-61, 2000

Country/ies where the</td><td>Sample size

n=346 children fitting inclusion criteria
n=298 survived until 5-year follow-up
n=280 with follow-up data (94% of the ones survived)
(n=98 with postnatal corticosteroid exposure, n=200 without postnatal corticosteroid exposure)

Characteristics

<table><tr><td></td><td>Corticosteroids</td><td>No corticosteroids</td><td>p</td></tr><tr><td>gestational age in weeks, mean (SD)</td><td>25.5 (1.3)</td><td>27.3 (1.9)</td><td><0.0001</td></tr></table></td><td>Risk factors

Postnatal exposure to corticosteroids.</td><td>Setting

Four different level-III neonatal units in the state of Victoria, Australia.

Method(s) of measurement for risk factor(s)

Postnatal corticosteroid exposure, dexamethasone was prescribednon-randomly at the discretion of the attending physicians at any of the level-III units in Victoria to treat respiratory insufficiency in ventilator-dependent infants. Occassionally</td><td>Outcome(s) at age

Outcomes assessed at 5 years of corrected age:
ORs (95% CI) for the following outcomes:
<u>Cerebral palsy (CP)</u>
No postnatal corticosteroids: reference
Postnatal corticosteroids: 7.8 (2.9-21.0)
Model adjusted for PVL and grade 3-4 cerebroventricular haemorrhage (the only potential confounders that were significant in univariate analysis).</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: moderate risk of bias
No description of the source population or the baseline sample (only the sample followed-up).
Attrition:
moderate risk of bias
94% of the ones who survived to follow-up time were followed-up. But 80.9% of the ones who fitted the inclusion criteria survived and were</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>study was carried out

Australia

Study type

Cohort study

Aim of the study

To determine the association between corticosteroid therapy given postnatally and sensoneural outcome in childhood.

Study dates

1991-1992, follow-up at 5 years of corrected age.

Source of funding

None reported.</td>
<td>
<table>
<tr><td>Birth weight in grams, mean (SD)</td><td>797 (147)</td><td>932 (149)</td><td><0.0001</td></tr>
<tr><td>Singleton, %</td><td>63.3</td><td>72.5</td><td>ns</td></tr>
<tr><td>Antenatal corticosteroid therapy, %</td><td>74.5</td><td>72.0</td><td>ns</td></tr>
<tr><td>Membrane rupture >24h, %</td><td>23.5</td><td>21.5</td><td>ns</td></tr>
<tr><td>Non-vertex presentation, %</td><td>53.1</td><td>43.5</td><td>ns</td></tr>
<tr><td>CS, %</td><td>25.5</td><td>44.5</td><td><0.01</td></tr>
<tr><td>Male, %</td><td>61.2</td><td>39.5</td><td><0.001</td></tr>
<tr><td>Intermittent positie pressure ventilation, %</td><td>100</td><td>88.5</td><td><0.001</td></tr>
<tr><td>Surfactant therapy, %</td><td>66.3</td><td>27.0</td><td><0.0001</td></tr>
<tr><td>Patent ductus arteriosus, %</td><td>69.4</td><td>44.0</td><td><0.0001</td></tr>
<tr><td>Air leak, %</td><td>53.1</td><td>16.5</td><td><0.0001</td></tr>
</table>
</td>
<td></td>
<td>other corticosteroids, such as hydrocortisone, were given. No predetermined protocols were followed. Dexamethasone was not prescribed postnatally to any infants before the first week of life.

Outcome(s) ascertainment/measures

Asssessed by a pediatrician (CP, blindness, deafness) and a pscyhologist (IQ score) masked for perinatal details including exposure to postnatal corticosteroid exposure.
Cerebral palsy (CP), not defined
Moderate to severe sensineural impairment: Severe sensorineural impairment, composite outcome, defined as having 1 or more of the following:
bilateral blindness
CP with the child unlikely ever to walk
IQ score <-3SD, IQ score assessed by Wechsler Preschool and Primary Scale of Intelligence - Revised</td>
<td><u>Moderate or severe sensorineural impairment</u>
No postnatal corticosteroids: reference
Postnatal corticosteroids: 3.2 (1.6-6.4)
Model adjusted for ruptured membranes >24h, cystic PVL, surgery during the primary hospitalization (only potential confounders that were significant in univariate analysis).</td>
<td>followed up. The possible differences in characteristics of the ones included and the ones lost to follow-up not reported.
Prognostic factor measurement: low risk of bias
The type, dose and timing of postnatal corticosteroid therapy might vary between participants but since the risk factor is postnatal exposure to corticosteroids that should not matter.
Outcome measurement: high risk of bias
For most children IQ score was assessed using WPPSI-R but for some (when WPPSI-R was not available) it was assessed using other psychological test, however, these test were not described or named. Children unable to be assessed by any of these tests were given a stardardized IQ score of-4SD. 12 children (out of 298) were not assessed at</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
	<table><tr><td>BPD, %</td><td>99.0</td><td>39.5</td><td><0.0001</td></tr><tr><td>Grade 3 or 4 cerebroventricular haemorrhage, %</td><td>9.3</td><td>4.5</td><td>ns</td></tr><tr><td>Cystic PVL, %</td><td>10.4</td><td>4.2</td><td>ns</td></tr><tr><td>NEC, %</td><td>10.2</td><td>8.0</td><td>ns</td></tr><tr><td>Surgery in primary hospital, %</td><td>44.9</td><td>16.5</td><td><0.0001</td></tr><tr><td>Assisted ventilation in days, median (IQR)</td><td>43.5 (31-53)</td><td>17 (4-28)</td><td><0.0001</td></tr><tr><td>O2 in days, median (IQR)</td><td>94 (58-118)</td><td>33 (5-64)</td><td><0.0001</td></tr><tr><td>Inspired % of O2 at 28 days, median (IQR)</td><td>37 (30-49)</td><td>25 (21-30)</td><td><0.0001</td></tr></table> **Inclusion criteria** Liveborn infants with either birth weight <1000 g or with gestational age <28 weeks born in the state of Victoria (Australia) during 1991 and 1992 who survived the first week of of life.		(WPPSI-R) or other psychological test when WPPSI-R was unavailable (not specified). Children unable to complete psychological tests because of presumed severe intellectual impairment were assigned a standardised IQ score of -4SD. Moderate sensorineural impairment, composite outcome, defined as having 1 or more of the following: bilateral sensorinerual deafness requiring hearing aids CP in children not walking at 5 years but expected to walk or those alking with difficulty at 5 years IQ score from -3SD to <-2SD, IQ score assessed by Wechsler Preschool and Primary Scale of Intelligence - Revised (WPPSI-R) or other psychological test when WPPSI-R was unavailable (not specified). Children unable to complete psychological tests because of presumed severe intellectual impairment were		5 years, but 11 of them were fully assessed at 2 years and 1 was fully assessed at 7 years, it was assumed that the outcomes would have been similar for the children at 5 years so they were included in the study. **Confounders:** low risk of bias A variety of appropriate potential confounders were considered and added to the final models if significant in univariate analysis. **Analysis and reporting:** moderate risk of bias Statistical methods seem appropriate. However, results for the multiple logistic regression model are not fully reported for all outcomes that they considered. Only results for CP and moderate to severe sensorineural impairment are reported although according to methods, they also looked at blindness, hearing impairment

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
	Exclusion criteria None reported.		assigned a standardised IQ score of -4SD. **Statistical methods** Forward conditional logistic regression for dichotomous variables. Potential confouders tested in univariate analyses (and added to the multiple logistic regression model if significant in univariate analysis): gestational age, birth weight, singleton, antenatal corticosteroid therapy, membrane rupture >24h, non-vertex presentation, caesarean section, male, intermittent positive pressure ventilation, surfactant therapy, patent ductus arteriousus, air leak, BPD, grade 3 and 4 cerebreventricular haemorrhage, cyctic PVL, NEC, surgery in primary hospitalization, assisted ventilation, days of O2, inspired % O2 at 28 days. **Length of follow-up**		and mild, moderate and severe sensorineural impairment (separately). **Overall quality:** moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			5 years of corrected age, apart from 11 children who were assessed at 2 years and 1 who was assessed at 7 years.		
Ref Id 322383 **Full citation** Vincer,M.J., Allen,A.C., Joseph,K.S., Stinson,D.A., Scott,H., Wood,E., Increasing prevalence of cerebral palsy among very preterm infants: a population-based study, Pediatrics, 118, e1621-e1626, 2006 **Country/ies where the study was carried out** Canada **Study type**	**Sample size** n=672 **Characteristics** Not described. **Inclusion criteria** Liveborn very preterm infants who were 24 to 30 weeks' gestational age, including all delivery room deaths, and born to mothers who were resident of Nova Scotia, Canada between 1 Jan 1993 and 31 Dec 2002. **Exclusion criteria** None reported, see inclusion criteria.	**Risk factors** Neonatal risk factors: Antenatal corticosteroids Postnatal dexamethasone use Intraventricular haemorrhage (IVH) grades 3 and 4	**Setting** All liveborn very preterm children in Nova Scotia, data from the Perinatal Follow-up Program database. **Method(s) of measurement for risk factor(s)** Data on the neonatal risk factors were obtained from the Perinatal Follow-up Program database where details about maternal illnesses and procedures, newborn illnesses and procedures, and demographic information were entered. Antenatal corticosteroids Postnatal dexamethasone use Intraventricular haemorrhage (IVH) grades 3 and 4	**Outcome(s) at age** **Outcomes assessed at 0, 4, 8, 12, 18, and 24 months' corrected gestational age:** <u>Cerebral palsy</u> No antenatal corticosteroids: reference Antenatal corticosteroids: AOR 0.53 (95% CI 0.27-1.00) No postantal dexamethasone use: reference Postnatal dexamethasone use: AOR 2.245 (95% CI 1.24-4.06) No IVH grade 3 and 4:reference IVH grade 3 and 4: AOR 7.78 (95% CI 3.43-18.34) The final model included the following variables: gestational age <28 weeks vs >28	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moderate risk of bias The characteristics of the participants are not described. **Attrition:** moderate risk of bias Out of the 672 infants included in the study, there were 111 deaths and 21 were lost to follow-up for other reasons, i.e. follow-rate was 80.4%. The characteristics of the ones lost to follow-up are not described or compared with the ones included. **Prognostic factor measurement:** moderate risk of bias Risk factors were not described in details

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Population-based cohort study. **Aim of the study** To examine and investigate recent temporal changes in the prevalence of cerebral palsy in a population-based cohort of very preterm infant who were 24 to 30 weeks of gestational age. **Study dates** 1993-2002, follow-up at 24 months corrected age. **Source of funding** Peter Lougheed New Investigator award from the Canadian Institutes of			**Outcome(s) ascertainment/measures** Cerebral palsy (CP), to identify CP, all surviving infants were enrolled in the Perinatal Follow-up Program and were evaluated by a neonatologist or developmental paediatrician who performed a general physical and neurodevelopmental examination at 0, 4, 8, 12, 18, and 24 months' corrected gestational age. Children who received a diagnosis of were suspected of having CP were examined by a paediatric neurologist to confirm or exclude the diagnosis. CP was defined as a disorder of control of movement or posture secondary to a nonprogressive brain lesion. **Statistical methods** Logistic regression, adjusting for covariables that were included in the model through a	weeks to 30 weeks; postnatal dexamethasone use; patent ductus artriosus; severe hyaline membrane disease; resuscitation in the delivery room; IVH grades 3 and 4; antenatal corticosteroid use. Other variables that were considered and tested for in the stepwise backward manner were: Maternal age at delivery; maternal substance use; pregnancy-induced hypertension; chlorioamnionitis; funisitis; oligohydramnios; polyhydramnios; multiple birth; major anomaly; hydrops fetalis; SGA; maternal analgesic use; maternal anaesthetics; premature rupture of membranes; birth depression, 5-min Apgar score; cardiopulmonary resuscitation; indomethacin use; hypernatremia, hyponetremia; unconjugated bilirubin; hypoglycemia; gender of the infant.	nor their ways of diagnosis or measurement were described. **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Health Research.			stepwise backward elimination process. **Length of follow-up** Up to 24 months' corrected age.		
Ref Id 412062 **Full citation** Vohr, B. R., Wright, L. L., Dusick, A. M., Mele, L., Verter, J., Steichen, J. J., Simon, N. P., Wilson, D. C., Broyles, S., Bauer, C. R., Delaney-Black, V., Yolton, K. A., Fleisher, B. E., Papile, L. A., Kaplan, M. D., Neurodevelopmental and functional outcomes of extremely low birth weight infants in the National Institute of Child Health and Human	**Sample size** n=1151 **Characteristics** Demographic characteristics of the cohort evluated at 18-22 months corrected age Less than high school graduate (%): 28 Infant not living with biologic mother (%): 13 Not married (%): 49 Age <=19 y (%): 18 Income <$20,000 (%): 57 Meidcaid (%): 65 Race black (%): 51 Race white (%): 35 Race Hispanic (%): 12 Race other (%): 2 Primary language English (%): 88 Primary language Spanish: (%):9 Primary language other (%): 3 **Inclusion criteria** Live-born infant with birth weight 401-1000 g born between Jan 1993 and Dec 1994 who were admitted to level II units in any of the 12 centres of the National	**Risk factors** Neonatal risk factors: Intraventricular haemorrhage (IVH) or periventricular leukomalacia (PVL) grade III-IV Postnatal steroids Chronic lung disease (i.e. bronchopulmonary dysplasia BPD, received oxygen at 36 weeks) Antenatal steroids Early-onset sepsis Late-onset sepsis Necrotizing enterocolitis (NEC) Social/maternal/environmental risk factors: Parent less than high school graduate Biological risk factors: Small for gestational age (SGA) Race, white Sex, boy	**Setting** 12 centres of the National Institute of Child Health and Human Development Neonatal Research Network. **Method(s) of measurement for risk factor(s)** Participating centres collected pregnancy and delivery data. Neonatal outcome data were assessed at 129 days after birth, at discharge from neonatal units or death, whichever came first. All data were abstracted from hospital records by trained study coordinators. Neonatal risk factors: Intraventricular haemorrhage (IVH) or periventricular	**Outcome(s) at age** **Outcomes assessed at 18-22 months' corrected age:** **Logistic regression analysis, maternal and neonatal risk factors that are known to be associated with increased neurodevelopmental outcome were entered into the models but not reported which ones.** **<u>Disorders:</u>** <u>CP</u> Neonatal risk factors: IVH/PVL grade III-IV: OR 3.05 (95% CI 2.03-4.57) NEC: OR 2.01 (95% CI 1.05-3.73) Maternal and neonatal risk factors that are known to be associated with increased	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias Out of 1527 infants who were initially included in the study, 3% died 21% were otherwise lost to follow-up before 18-22 months' corrected age. **Prognostic factor measurement:** moderate risk of bias Not explained how the all risk factors were measured or defined. **Outcome measurement:** moderate risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Development Neonatal Research Network, 1993-1994, Pediatrics, 105, 1216-1226, 2000 **Country/ies where the study was carried out** United States **Study type** Multicentre cohort study **Aim of the study** To report the neurodevelopmental, neurosensory, and functional outcomes of 1551 extremely low birth weight (401-1000 g) survivors cared for in the 12 participating centers of the National Institute of Child Health	Institute of Child Health and Human Development Neonatal Research Network. **Exclusion criteria** Children who died before admission to the nursery units, children who died before follow-up.		leukomalacia (PVL) grade III-IV Postnatal steroids, any doses or courses of steroids for chronic lung disease Chronic lung disease (i.e. bronchopulmonary dysplasia BPD, received oxygen at 36 weeks) Antenatal steroids, indicates beta-methasone (2 doses, 12 and 24 hours apart) or dexamethasone (4 doses, 6 hours apart). Early-onset sepsis, positive blood culture result within the first 72h. Late-onset sepsis, positive blood culture result >72h obtained in the presence of clinical signs of septicaemia. Necrotizing enterocolitis (NEC) Social/maternal/environmental risk factors: Parent less than high school graduate Biological risk factors: Small for gestational age (SGA) Race, white Sex, boy	neurodevelopmental outcome were entered into the model but not reported which ones. <u>MDI <70</u> Neonatal risk factors: IVH/PVL grade III-IV: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 1) Postnatal steroids: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 1) Chronic lung disease (i.e. BPD): Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 1) Antenatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 1) Early-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 1) Late-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 1)	Not clear how problems outcomes (no independent feeding, no independent walking) outcomes were assessed. **Confounders:** high risk of bias They report that the logistic regression models adjusted for different maternal and demographic variables but do not specify which ones. **Analysis and reporting:** moderate risk of bias ORs (95% CI) are not reported numerically, only on forest plots for many outcomes. Overall quality: low

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
and Human Development Neonatal Research Network and to identify medical, social and environmental factors associated with these outcomes. **Study dates** 1993-1994, , follow-up at 18-22 months corrected age. **Source of funding** Grants source not reported			**Outcome(s) ascertainment/measures** Disorders: Cerebral palsy (CP), defined as a nonpregressive central nervous system disorder characterized by abnormal muscle tone in at least 1 extremity and abnormal control of movement and posture. Neurologic examinations based on the Amiel-Tison neurologic assessment performed by crtified, masked developmentalists who had been trained on reliability in the examination procedure in a 2-day, hands-on workshop on neurologic assessment. Mental development index (MDI) <70, assessed by Bayley Scales of Infant Development-II (BSID-II) Psychomotor development index (PDI) <70, assessed by Bayley Scales of Infant Development-II (BSID-II) Problems: No independent feeding, not clear how assessed but they report	NEC: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 1) Biological risk factors: Sex, male (vs female): Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 1) SGA: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 1) Race white (vs. Black??): Significantly decreased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 1) Social/maternal/environmental risk factors: Parent less than high school graduate: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 1) <u>PDI <70</u> Neonatal risk factors: IVH/PVL grade III-IV: Significantly increased odds, OR (95% CI) not	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			that a basic, functional, gross motor skills were assessed derived from the work of Russell et al. and Palisano et al. No independent walking, not clear how assessed but they report that a basic, functional, gross motor skills were assessed derived from the work of Russell et al. and Palisano et al. **Statistical methods** Logistic regressions were used to identify associations among biologic, social, demographic factors and the major neurologic, developmental and functional outcomes. Maternal and neonatal risk factors that are known to be associated with increased neurodevelopmental outcome were entered into the model. **Length of follow-up** 18-22 months corrected age.	reported numerically, only on a forest plot Figure 2) Postnatal steroids: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 2) NEC: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 2) CLD (i.e. BPD): Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Late-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Early-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Antenatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Biological risk factors: sex, male (vs female): Not significant, OR (95% CI) not reported	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				numerically, only on a forest plot Figure 2) SGA: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Race white (vs black??): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) Social/maternal/environmental risk factors: Parent less than high school graduate: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 2) **Problems:** No independent walking Neonatal risk factors: IVH/PVL grade III-IV: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Postnatal steroids: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 3) NEC: Not significant, OR (95% CI) not	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				reported numerically, only on a forest plot Figure 3) CLD (i.e. BPD): Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Late-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Early-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Antenatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) Biological risk factors: sex, male (vs female): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) SGA: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3 Race white (vs black??): Not significant, OR (95% CI) not reported	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				numerically, only on a forest plot Figure 3) Social/maternal/environmental risk factors: Parent less than high school graduate: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 3) <u>No independent feeding</u> Neonatal risk factors: IVH/PVL grade III-IV: Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 4) Postnatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) NEC: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) CLD (i.e. BPD): Significantly increased odds, OR (95% CI) not reported numerically, only on a forest plot Figure 4) Late-onset sepsis: Not significant, OR (95% CI) not reported	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				numerically, only on a forest plot Figure 4) Early-onset sepsis: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) Antenatal steroids: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4)Biological risk factors: Biological risk factors: sex, male (vs female): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) SGA: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) Race white (vs black??): Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4) Social/maternal/environmental risk factors: Parent less than high school graduate: Not significant, OR (95% CI) not reported numerically, only on a forest plot Figure 4)	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr>
<td>Ref Id

317215

Full citation

Vohr,B.R., Wright,L.L., Poole,W.K., McDonald,S.A., Neurodevelopmental outcomes of extremely low birth weight infants <32 weeks' gestation between 1993 and 1998, Pediatrics, 116, 635-643, 2005

Country/ies where the study was carried out

United States

Study type

A multicentre cohort study</td>
<td>Sample size

n=7398 infants fit the inclusion criteria
n=4761 infants survived until discharge or 120 days
n=124 post-discharge deaths
n=858 infants lost to follow-up
n=118 infants with incomplete follow-up data
n=3785 infants included in analysis (51% of the original sample, 79.5% of the ones who survived up to discharge or 120 days)

Characteristics

<table>
<tr><td></td><td colspan="2">1993-94</td><td colspan="2">1995-96</td><td colspan="2">1997-98</td></tr>
<tr><td></td><td>22-26 weeks</td><td>27-32 weeks</td><td>22-26 weeks</td><td>27-32 weeks</td><td>22-26 weeks</td><td>27-32 weeks</td></tr>
<tr><td>Evaluated at 18 mo, n</td><td>665</td><td>444</td><td>716</td><td>538</td><td>910</td><td>512</td></tr>
<tr><td>White, %</td><td>33.8</td><td>35.6</td><td>32.4</td><td>38.3</td><td>37.1</td><td>46.2</td></tr>
<tr><td>Maternal age <19 y, %</td><td>14.6</td><td>10.4</td><td>11.6</td><td>11.7</td><td>11.5</td><td>11.1</td></tr>
</table>
</td>
<td>Risk factors

Periventricular leucomalasia (PVL)
Grade 3-4 IVH
Postnatal steroids
Broncho pulmonary dysplasia (BPD)
Sepsis
Antenatal steroids</td>
<td>Setting

Using data collected from 12 different centers of the National Institute of Child Health and Human Development Neonatal Research Network in the US.

Method(s) of measurement for risk factor(s)

Perinatal data collected prospectively by study nurses using standard registry forms.
Definitions of risk factors or measurements of them are not described in the publication, they refer to other studies which cannot be accessed.
Periventricular leucomalasia (PVL), not described
Grade 3-4 IVH, not described
Postnatal steroids, not described
Broncho pulmonary dysplasia (BPD), O2 requirement at 36 weeks</td>
<td>Outcome(s) at age

Outcomes assessed at 18-22 months of corrected age:
Variables included in the model: epoch; gestational age group; birth weight; gender; small for gestational age; multiple births; surfactant; grades 3 to 4 IVH; PVL; sepsis; oxygen requirement at 36 weeks; white vs. non-white race; outborn vs. inborn status ceasarean section vs. vaginal delivery; maternal education <12 years vs. >=12 years; private health insurance vs. public; conventional ventiolation vs. none; adjusted age at the time of assessment; centre; and the 4 interventions of interest: antenatal steroids (yes, no), high-frequency ventilation vs. none; days to regain birth weight, and postnatal steroids (yes, no).</td>
<td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: moderate risk of bias
No description of baseline sample characteristics (only of the ones who were followed-up).
Attrition: moderate risk of bias
Almost half (49%) of original sample were lost to follow-up, of the ones surviving to discharge 20.5% were lost to follow-up. These infants (the 20.5%) were more often outborn, had had less prenatal care, had received less antenatal steroids, had had less surfactant use, they had higher birth weight, less chronic lung disease, lower percentage of multiple birth, fewer</td>
</tr>
</table>

Study details	Participants							Risk factors	Methods	Outcomes and results	Comments
Aim of the study This study evaluated the impact of changes in perinatal management of neurodevelopmental impairment at 18 to 22 months' corrected age of low gestation (22-26 weeks) and higher gestation (27-32 weeks) extremely low birth weight infants (401-1000 g birth weight) who were cared for in the National Institute of Child Health and HUman Development Neonatal Research Network during 3 epochs (1993-1994, 1995-1996, and 1997-1998). It was hypothesized that outcomes would improvae	Maternal education <12 y, %	34.4	26.6	27.2	23.3	28.7	24.0		Sepsis, not described Antenatal steroids, not described **Outcome(s) ascertainment/measures** Moderate to severe cerebral palsy (CP), defined as a nonprogressive central nervous system disorder characterized by abnormal muscle tone in at least 1 extremity and abnormal control of movement or posture. Moderate to severe CP included children who were nonambulatory or required an assistance device for ambulation. Mental Development Index (MDI) <70, assessed through Bayley Scales of Infant Development II (BSID-II) or a neurologic examination (not defined). Psychomotor Development Index (PDI) <70, assessed through Bayley Scales of Infant Development II (BSID-II) or a gross	**<u>Moderate to severe cerebral palsy (CP)</u>** No PVL: reference PVL: AOR 10.5 (7.2-15.2) No grade 3-4 IVH: reference Grade 3-4 IVH: Significantly increased odds, AOR and 95% CI not reported in numbers, only in a forest plot (Fig 1). No postnatal steroids: reference Postnatal steroids: AOR 2.02 (1.40-2.92) No BPD: reference BPD: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 1). No Sepsis: reference Sepsis: Not significant, AOR and 95% CI not reported, only in a forest plot (Fig 1). No antenatal steroids: reference Antenatal steroids: AOR 0.66 (0.47-0.92) **<u>PDI <70</u>**	days at the hospital, fewer postnatal steroids and fewer days on a ventilator. **Prognostic factor measurement:** moderate risk of bias Poor description of risk factors or their measurements, the publication refers to other publications with more description (cannot be accessed). **Outcome measurement:** high risk of bias MDI and PDI assessed through either BSID-II or "neurologic examination and gross motor assessment", thus, not the same for all the participants. **Analysis and reporting:** moderate risk of bias Statistical methods seem appropriate, however, reporting of exact effect estimates is limited. **Overall quality:** moderate
	Medicaid, %	63.8	63.7	65.3	55.5	58.8	51.6				
	Outborn, %	13.1	11.7	11.6	7.6	9.1	8.6				
	Ceasarean section, %	41.6	68.8	46.0	73.9	50.7	73.0				
	Birth weight, mean g	752.6	858.4	750.4	857.7	744.9	860.2				
	SGA, %	4.1	38.1	3.3	37.2	4.7	35.3				
	Surfactant, %	75.8	62.6	79.9	68.2	84.9	67.8				
	IVH grades 3-4, %	28.0	14.0	28.4	12.9	17.2	9.5				
	PVL, %	7.3	5.2	8.8	7.0	6.2	4.7				
	O2 at 36 weeks, %	47.7	30.2	51.9	33.8	54.3	34.5				

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>over the 3 epochs.

Study dates

1993-1998, follow-up at 18 to 22 months of corrected age.

Source of funding

National Institute of Child Health and Human Development through Cooprative Agreements HD 27904, Brown University; U10 HD27856, Indiana University; U10 HD27853, Cincinnati University; U10 HD27851, Emory University; U10 HD21364, Case Western University; U10 HD21373, University of Texas-Houston; U10</td>
<td>
<table>
<tr><td>Days on ventilator, mean</td><td>36.6</td><td>16.5</td><td>34.7</td><td>15.7</td><td>35.2</td><td>14.5</td></tr>
<tr><td>Sepsis, %</td><td>48.0</td><td>31.1</td><td>45.1</td><td>29.4</td><td>43.4</td><td>28.1</td></tr>
<tr><td>Multiple births, %</td><td>18.3</td><td>20.9</td><td>17.2</td><td>19.1</td><td>24.0</td><td>25.6</td></tr>
<tr><td>Days in hospital, mean</td><td>114.4</td><td>86.0</td><td>109.8</td><td>83.30</td><td>108.7</td><td>77.7</td></tr>
<tr><td>Coorected age, months</td><td>19.4</td><td>19.6</td><td>19.3</td><td>19.4</td><td>19.6</td><td>19.9</td></tr>
</table>
Inclusion criteria

Infants born prematurely at 22-32 weeks of gestation with an extremely low birth weight (401-1000 g) who were being cared for in 1 of the 12 centres of the National Institute of Child Health and Human Development Neonatal Research Network during 1993-1998. Deaths in the delivery room were included.

Exclusion criteria

None reported.
</td>
<td></td>
<td>motor assessment (not defined).
Neurodevelopmental impairment (NDI), defined as the presence of any of the following: moderate to severe CP
hearing loss requiring bilateral amplification
bilateral blindness (not defined)
MDI <70
PDI <70

Statistical methods

Multiple logistic regression.
Variables included in the model: epoch; gestational age group; birth weight; gender; small for gestational age; multiple births; surfactant; grades 3 to 4 IVH; PVL; sepsis; oxygen requirement at 36 weeks; white vs. non-white race; outborn vs. inborn status ceasarean section vs. vaginal delivery; maternal education <12 years vs. >=12 years; private health insurance vs. public; conventional ventiolation vs. none; adjusted age at the time of assessment; centre;</td>
<td>No PVL: reference
PVL: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 2).

No grade 3-4 IVH: reference
Grade 3-4 IVH: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 2).

No postnatal steroids: reference
Postnatal steroids: AOR 1.99 (1.56-2.55)

No BPD: reference
BPD: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 2).

No sepsis: reference
Sepsis: Not significant, AOR and 95% CI not reported, only in a forest plot (Fig 2).

No antenatal steroids: reference</td>
<td></td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
HD21397, Miami University; U10 HD21385, Wayne State University; U10 HD21415, University of Tennessee; U10 HD27880, Stanford University; U10 HD27881, University of New Mexico; U10 HD27871, Yale University, and U01 HD36790, RTI International.			and the 4 interventions of interest: antenatal steroids (yes, no), high-frequency ventilation vs. none; days to regain birth weight, and postnatal steroids (yes, no). **Length of follow-up** 18-22 months' corrected age	Antenatal steroids: AOR 0.66 (0.52-0.84) **MDI <70** No PVL: reference PVL: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 3). No grade 3-4 IVH: reference Grade 3-4 IVH: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 3). No postnatal steroids: reference Postnatal steroids: AOR 1.29 (1.04-1.61) No BPD: reference BPD: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 3). No sepsis: reference Sepsis: Not significant, AOR and 95% CI not reported, only in a forest plot (Fig 3).	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				No antenatal steroids: reference Antenatal steroids: Not significant, AOR and 95% CI not reported, only in a forest plot (Fig 3). **<u>Neurodevelopmental impairment</u>** No PVL: reference PVL: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 4). No grade 3-4 IVH: reference Grade 3-4 IVH: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 4). No postnatal steroids: reference Postnatal steroids: Significantly increased odds, AOR and 95% CI not reported in numbers only in a forest plot (Fig 4). No BPD: reference BPD: significantly increased odds, AOR	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
				and 95% CI not reported in numbers only in a forest plot (Fig 4). No sepsis: reference Sepsis: Not significant, AOR and 95% CI not reported, only in a forest plot (Fig 4). No antenatal steroids: reference Antenatal steroids: Not significant, AOR and 95% CI not reported, only in a forest plot (Fig 4).	
Ref Id 339682 **Full citation** Walsh, M. C., Morris, B. H., Wrage, L. A., Vohr, B. R., Poole, W. K., Tyson, J. E., Wright, L. L., Ehrenkranz, R.	**Sample size** N= 3041 **Characteristics** Neonates were born at a weight of 766 ± 140 g, 25.8 ± 2.2 weeks postemnstrual age; 50.1% male, 43.8% African American. Mean maternal age was 26.6 ±2.2 years, 52.7% of mothers were married, and 69% had received one or more doses of antenatal corticosteriods. 15% of the infants were small for gestational age.	**Risk factors** PVL; Non-White; Male; Severe IVH; Late onset sepsis; SGA; Postnatal steriods; NEC (while on ventilator); NEC (while off ventilator);	**Setting** Retrospective analysis of data prospectively collected at the 15 participating centres of the National Institute of Child Health and Human Development Neonatal Research Network	**Outcome(s) at age** **Outcomes assessed at 18-22 months Postmenstrual age, among children born at 25.8 ±2.23 weeks postmenstrual age.** **Mental developmental index < 70, Physical developmental index < 70, moderate or**	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moderate risk of bias (the study is not a population based study)

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
A., Stoll, B. J., Fanaroff, A. A., National Institutes of Child, Health, Human Development Neonatal Research, Network, Extremely low birthweight neonates with protracted ventilation: mortality and 18-month neurodevelopmental outcomes, Journal of Pediatrics, 146, 798-804, 2005 **Country/ies where the study was carried out** United Kingdom **Study type** Prospective cohort study **Aim of the study**	**Inclusion criteria** Not reported **Exclusion criteria** Not reported	Prenatal steriods;	**Method(s) of measurement for risk factor(s)** **Outcome(s) ascertainment/measures** For the outcome of Neurodevelopmental impairment: The Bayley Scales of Infant Development - II, including the mental scale, psychomotor scale, and the behavior rating scale, were administered by developmental specailists trained. BSID-II scores of 100 ± 15 represent the mean ± 1 standard deviation The neurologic examination is based on the Amiel-Tison neurologic assessment. Infants were scored as normal if no abnormalities were observed in the examination. CP was defined as a nonprogression central nervous system disorder characterized by abnormal muscle tone in	**<u>severe cerebral palsy, blindness in both eyes or deafness: OR (95%CI)</u>** **PVL: 3.72 (2.52-5.50)** **Non-White: 1.75 (1.45-2.11)** **Male gender: 1.62 (1.35-1.93)** **Grade III-IV IVH: 1.30 (1.06-1.69)** **Postnatal steriods: 1.13 (0.91-1.40)** **Antental steriods: 0.81 (0.65-1.00)** **-Risk factors were adjusted for each in the multivariate regression model,** -**SGA; NEC (while on ventilator); NEC (while off ventilator) were not found to be significantly associated with the outcome**	**Attrition:** moderate risk of bias. 20%, those who were followed were slightly smaller and modestly more ill than those infants who were not followed. **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** Moderate risk of bias Overall quality: Moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
To compare duration of ventilation to mortality and adverse neuro-developmental outcomes among extremely low birth weight (ELBW: 501-1000g) infants. **Study dates** 1995-1998 **Source of funding** Not reported			at least on extremity with abnormal control of movement and posture. Deafness was defined as as hearing impairment requiring amplification. Blindness defined as no functional vision on both eyes. In this study, the overall outcome of survival with impairment was defined as survival to 18 to 22 months of age with one or more of the following: **Mental developmental index < 70, Physical developmental index < 70, moderate or severe cerebral palsy, blindness in both eyes or deafness** **Statistical methods** Associations between impairment and days on a ventilator, maternal and neonatal variables, and in-hospital morbidities were explored using a logistic regression. **Length of follow-up** 2 years		

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr>
<td>Ref Id

356965

Full citation

Wong, D., Abdel-Latif, M., Kent, A., Nicus Network, Antenatal steroid exposure and outcomes of very premature infants: a regional cohort study, Archives of Disease in Childhood Fetal & Neonatal Edition, 99, F12-20, 2014

Country/ies where the study was carried out

Australia

Study type

Multicentre retrospective cohort study.</td>
<td>Sample size

n=2,701 infants <29 gestational weeks
n=152 excluded due to major congenital anomalies
n=2,549 infants <29 weeks without major congenital anomalies (study population)
n=1473 followed up at 2-3 years (74.8% follow-up rate)
n=150 infants with no steroid exposure followed up at 2-3 years
n=1323 infants with steroid exposure followed up at 2-3 years

Characteristics
<table><tr><td></td><td>No steroid</td><td>Steroid</td><td>p</td></tr><tr><td>Maternal age in years, median (IQR)</td><td>28.0 (23.0-32.0)</td><td>30.0 (25.0-34.0)</td><td><0.001</td></tr><tr><td>Aboriginal ethnicity, %</td><td>8.8</td><td>5.1</td><td>0.010</td></tr><tr><td>Pregnancy induced hypertension, %</td><td>6.6</td><td>16.1</td><td><0.001</td></tr><tr><td>Vaginal breech, %</td><td>20.7</td><td>10.0</td><td><0.001</td></tr></table></td>
<td>Risk factors

Antenatal steroid exposure.</td>
<td>Setting

Data from 10 neonatal intensive care units in New South Wales and the Australian Capital Territory and an ongoing statewise audit of admitted infants called the Neonatal Intensive care Units Follow-up Data Collection (NICUS).

Method(s) of measurement for risk factor(s)

Antenatal steroid regimen consists of betamethasone 2 doses of 12 mg given i.m. 24h apart, or dexamethasone 4 doses of 6 mg given i.m. 12h apart. Complete course of antenatal steroids defined as all doses received 48 h prior to delivery but <7 days before birth. (However, multiple regression model for complete course of antenatal steroids not reported in the publication.)</td>
<td>Outcome(s) at age

Outcomes assessed at 2-3 years:
<u>Moderate to severe functional disability OR (95% CI)</u>
No steroid; reference
Any steroid: 1.056 (0.785-1.420)
Adjusted for significant and clinically important baseline population characteristics: maternal age, pregnancy-induced hypertension, gestational age, birth weight, gender, outborn status and assisted conception.
For other individual outcomes (developmental delay, CP, blindness, deafness), results for multiple logistic regression model are not reported but are presumably not significant. The results reported on Table 3 of the publication are apparently univariate analysis even though not clearly stated. ORs for all are thus</td>
<td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
25.2% lost to follow-up. The ones lost to follow-up were more likely to be of aboriginal ethnicity and outborn, they had a higher median birth weight and were less likely to require surfactant therapy or mechanical ventiolation, they were less likely to have had proven systemic infection and they were less likely to have received postnatal steroids for treatment of chronic lung disease (all of these with a p-value of <0.001).
Prognostic factor measurement: low risk of bias</td>
</tr>
</table>

Study details	Participants				Risk factors	Methods	Outcomes and results	Comments
Aim of the study To compare mortality, short-term morbidity and long-term neurodevelopmental outcomes of <29 week premature infants with antenatal steroid exposure (none, incomplete, and complete). **Study dates** 1998-2004 **Source of funding** None reported.	CS in labour, %	18.2	23.5	0.043		**Outcome(s) ascertainment/measures** Moderate/severe functional disability, defined as one or more of the following: developmental delay (<2SD below the mean for adjusted age determined by the GMDS or BSID-II) cerebral palsy (unable to walk without aids) bilateral blindness (visual acuity <6/60 in better eye) bilateral deafness (requiring bilateral hearing aids or cochreal implants Developmental delay assessed using Griffiths Mental Development Scale (GMDS) scored by General Quotient (GQ) or the Mental Scale of the Bayley Scales of Infant Development-II (BSID-II) scored by Mental Development Index (MDI). **Statistical methods**	reported for univariate analyses but not for multiple regression analysis.	**Confounders:** low risk of bias **Outcome measurement:** low risk of bias However, developmental delay was assessed using two different tools and scores for different children, but both are, however, validated tools. **Analysis and reporting:** moderate risk of bias The results reported for all neurodevelopmental outcomes and different types of steroid regimens as risk factors on Table 3 of the publication are apparently univariate analysis even though not clearly stated. Multiple logistic regression was done but results are not reported, except for "any steroid exposure" on moderate to severe functional disability. ORs for all individual outcomes (developmental
	Born in non-tertiary centre, %	43.9	5.4	<0.001				
	APGAR <7 at 5 min, %	41.8	23.3	<0.001				
	Male gender, %	55.2	54.6	0.900				
	Gestational age in weeks, median (IQR)	26.0 (25.0-28.0)	27.0 (25.0-28.0)	0.012				
	Birth weight in grams, median (IQR)	895 (730-1090)	917 (733.75-1096)	0.597				
	Surfactant therapy, %	85.6	71.0	<0.001				
	Mechanical ventilation, %	95.6	86.8	<0.001				
	IVH grade 3 or 4, %	18.7	11.8	0.001				
	NEC, %	11.3	7.3	0.018				

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
	Length of intensive care in days, median (IQR) | 73 (11-92) | 73 (56-94) | 0.029 **Inclusion criteria** All infants admitted to 10 NICUs in New South Wales and the Australian Capital Territory between 1 Jan 1998 and 31 Dec 2004 born at <29 gestational weeks. **Exclusion criteria** Infants with major congenital anomalies. Neonates who were not or could not be resuscitated in the delivery room.		Multiple logistic regression model used to determine the differences in neurodevelopmental outcome between those exposed and not exposed to antenatal steroids, including significant and clinically important baseline population characteristics: maternal age, pregnancy-induced hypertension, gestational age, birth weight, gender, outborn status and assisted conception. Cut-off for entry to and removal from a model was set at p<0.05 and p>0.10. **Length of follow-up** 2-3 years		delay, CP, blindness, deafness) are reported for univariate analyses but not for multiple regression analysis (presumably not significant). **Overall quality:** moderate
Ref Id 337051 **Full citation** Wood, N. S., Costeloe, K., Gibson, A. T., Hennessy, E.	**Sample size** Overall sample: N = 811 preterm babies admitted to NICU Long term survivors, eligible for follow up: N = 308 Sample included in follow up: N = 283	**Risk factors** **Biological** Gender Ethnicity **Neonatal** Significantly abnormal ultrasound scan Antenatal steroids Postnatal steroids	**Setting** National population based study. **Method(s) of measurement for risk factor(s)**	**Outcome(s) at age** At 30 months correct age. **Cerebral palsy** *Including antenatal variables* Male No: Reference	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
M., Marlow, N., Wilkinson, A. R., The EPICure study: Associations and entecedents of neurological and developmental disability at the 30 months of age following extremely preterm birth, Archives of Disease in Childhood: Fetal and Neonatal Edition, 90, F134-F140, 2005 **Country/ies where the study was carried out** United Kingdom and Ireland. **Study type** Population based prospective cohort study.	**Characteristics** Not reported in this article. **Inclusion criteria** All babies born between 20 weeks and 25+6 weeks during the study period. **Exclusion criteria** Death before follow up.	ROP **Social/Maternal/Environmental** Chorioamnionitis	Information was recorded prospectively from all maternity units. Significantly abnormal ultrasound was classified as parenchymal pathology and/or ventriculomegaly on final cranial ultrasound scan. **Outcome(s) ascertainment/measures** At a corrected age of 30 months an assessment of neurological and developmental functioning was performed. The comprised a structured neurological examination and an assessment of development using the second edition of Bayley Scales of infant development. Mental development index (MDI) and psychomotor development index (PDI) scores were used as a continuous variable. Cerebral palsy was classified retrospectively, being defined as a non-progressive disorder of movement and posture.	Yes: OR 2.27 (1.21 to 4.23) <u>Chorioamnionitis</u> No: Reference Yes: OR 0.39 (0.16 to 0.96) *Including perinatal variables* <u>Male</u> No: Reference Yes: OR 2.32 (1.24 to 4.33) *Including day 1 postnatal variables* <u>Male</u> No: Reference Yes: OR 2.06 (1.09 to 3.91) *Including all variables until discharge* <u>Male</u> No: Reference Yes: OR 2.34 (1.16 to 4.75) <u>> 8 weeks systemic steroids</u> No: Reference Yes: OR 4.90 (1.54 to 15.61) <u>Significantly abnormal USS</u> No: Reference Yes: OR 4.95 (2.25 to 10.85)	**Attrition:** low risk of bias **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** moderate risk of bias OR are stated to be adjusted, but the factors adjusted for are not described. **Analysis and reporting:** low risk of bias Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Aim of the study To describe perinatal factors associated with later morbidity among extremely preterm children at 30 months of age. **Study dates** March to December 1995. **Source of funding** Serono Laboratories UK Ltd and BLISS.			**Statistical methods** Logistic regression and multiple linear regression analysis was used to identify significant independent predictors of cerebral palsy or PDI-MDI scores. A forward stepwise procedure was used to establish independent factors associated with neurological and developmental outcomes. OR are stated to be adjusted. Factors adjusted for are not stated in the text. OR are calculated separately for four different time points. Initially, variables present before pregnancy and antenatally were included. Then those present at birth were included. Then those measured on the first postnatal day were included. Finally those present at discharge were included. Some OR which are present and significantly associated with an adverse outcome at birth are subsequently not found to be significantly associated,	<u>Antenatal steroids</u> Not significant on univariate analysis <u>Afro-Caribbean ethnicity</u> Not significant on univariate analysis <u>Treatment for ROP</u> Not significant on univariate analysis **Effect of total steroid use in hospital** **Cerebral palsy** <u>Steroid treatment (days)</u> None: Reference 1-14: OR 0.92 (0.30 to 2.82) 15-28: OR 1.06 (0.40 to 2.84) 29-42: OR 1.09 (0.35 to 3.40) 43-56: OR 0.68 (0.13 to 3.40) 57 or more: OR 4.77 (1.29 to 17.56)	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			after adjustment for later variables. **Length of follow-up** 30 months corrected age.		
Ref Id 412808 **Full citation** Kent, A. L., Wright, I. M., Abdel-Latif, M. E., New South, Wales, Australian Capital Territory Neonatal Intensive Care Units Audit, Group, Mortality and adverse neurologic outcomes are greater in preterm male infants, Pediatrics, 129, 124-31, 2012 **Country/ies where the**	**Sample size** N=2701 Followed up at 2-3 years: n=1473 **Characteristics** Male (n=1394); female (n=1155) Maternal age (male/female, years ,SD): 29.1 (6.1)/29.4 (6.1) Gestational age (male/female, weeks, SD): 26.3 (1.5)/26.3 (1.5) Birth weight (male/female, g, SD): 952.9 (246.2)/886.9 (230.0) Birth weight <10th percentile (male/female, SD): 141 (10.1)/131 (11.3) **Inclusion criteria** Very premature babies of <29 weeks gestation **Exclusion criteria** Babies with major malformations or known syndromes with developmental implications	**Risk factors** Male gender SGA Gestational age	**Setting** Very premature babies were admitted to any of the 10 neonatal intensive are units (NICU) in New South Wales (NSW) and the Australian Capital Territory (ACT) in Australia. NICU follow-up data was an on-going prospective state-wide audit at 2 to 3 years age, admitted to a NSW or ACT NICU **Method(s) of measurement for risk factor(s)** Small for gestational age was measured as < 10th percentile Gestational age: <29 weeks	**Outcome(s) at age** **<u>Moderate to severe disability among male and female infants at 2 to 3 years corrected age</u>** <u>Gender:</u> Female: reference Male: OR 1.877 (1.398-2.521) <u>SGA:</u> AGA: reference SGA: OR 2.077 (1.376-3.136) <u>Gestational age:</u> 27-28 weeks GA: reference 22-26 weeks GA: OR 2.444 (1.831-3.263)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. Participants: low risk of bias (there is an adequate description of population of interest and of the inclusion/exclusion criteria) Attrition: low risk of bias (there is a an adequate description of loss to follow up shown in the flow diagram and also in the text) Prognostic factor measurement: low risk of bias Outcome measurement: low risk of bias Confounding: low risk of bias

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
study was carried out Australia **Study type** Population based longitudinal cohort study **Aim of the study** To determine whether male gender has an effect on survival, early neonatal morbidity, and developmental outcome in extremely premature neonates born in a geographically discrete population **Study dates** January 1998 to December 2004			**Outcome(s) ascertainment/measures** Assessment of outcome involved examination of 4 domains: developmental, neurologic, vision, and hearing Developmental assessment used the Griffiths Mental Developmental Scales or Bayley Scales of Infant Development II Neurologic assessment included evaluation of muscle tone, primitive reflexes, automatic reactions, and volitional movement Cerebral palsy was diagnosed if the child had non-progressive motor impairment characterised by abnormal muscle tone and a decreased range or decreased control of movements, accompanied by neurologic signs Moderate to severe functional disability was defined as one or more of the following: developmental delay (<2SD below the mean for adjusted age		Analysis and Reporting: low risk of bias Overall quality: high

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Source of funding None			determined by the Griffiths Mental Developmental Scales or BSID-II, cerebral palsy (unable to walk without aids), bilateral blindness (visual acuity <6/60 in better eye), or bilateral deafness (requiring bilateral hearing aids or cochlear implants) **Statistical methods** Adjusted differences between male and female genders in neurodevelopmental outcome were estimated by using multiple regression Criteria for entry and removal of factors were a P value <0.05 and P>0.10 The level of statistical significance for all analyses was set at) <0.05 (2 tailed comparisons) The significance level was not changed when multiple comparisons were performed **Length of follow-up**		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			2 to 3 years age corrected for prematurity		
Ref Id 412882 **Full citation** Laughon, M., O'Shea, M. T., Allred, E. N., Bose, C., Kuban, K., Van Marter, L. J., Ehrenkranz, R. A., Leviton, A., Chronic lung disease and developmental delay at 2 years of age in children born before 28 weeks' gestation, Pediatrics, 124, 637-648, 2009 **Country/ies where the study was carried out** United States **Study type**	**Sample size** Sample recruited - N = 1506 Sample eligible for assessment - N = 1190 Sample analysed after exclusions - N = 915 **Characteristics** No details given **Inclusion criteria** Children included in the extremely low gestational age newborns (ELGANs) study sample Children who were assessed at 24 months of age with the BSID-II or the Vineland Adaptive Behavior Scales (VABS) Children who were able to walk independently (Gross Motor Function Classification System [GMFCS] < 1) **Exclusion criteria** Children who were not able to walk independently (GMFCS ≥1) at the 24-month follow-up assessment	**Risk factors** Necrotizing enterocolitis –NEC (stage II or worse) Sepsis (Pneumothorax; Late bacteremia) BDP- bronco pulmonary dysplasia (chronic lung disease [CLD] at 36 weeks	**Setting** The Extremely low gestational age newborn (ELGAN) study identified characteristics and exposures that increase the risk of structural and functional neurologic disorders in ELGANs newborns. During the years 2002-2004, women delivering before 28 weeks' gestation at 1 of 14 participating institutions were asked to enrol in the study. **Method(s) of measurement for risk factor(s)** Necrotizing enterocolitis (NEC) was classified according to the modified Bell staging system The diagnosis of CLD was made at 36 weeks' postmenstrual age (PMA). If an infant was receiving supplemental oxygen, the infant was classified as having CLD.	**Outcome(s) at age** Intellectual disability (developmental delay - Mental Developmental Index [MDI] or a Psychomotor Developmental Index [PDI]) <u>Mental Developmental Index [MDI] -OR (95% CI) Referent group is not reported</u> Sepsis (Late bacteremia): 1.8 (1.3–2.5) NEC ≥ stage II: 2.1 (1.2–3.7) BPD (CLD without mechanical ventilation [MV]): 1.1 (0.8–1.4) BPD (CLD with MV): 1.2 (0.7–2.3) <u>Psychomotor Developmental Index [PDI] -OR (95% CI) Referent group is not reported</u> CLD without mechanical ventilation [MV]: 1.1 (0.6–2.0) CLD with MV: 1.9 (0.97–3.9)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. Participants: low risk of bias Attrition: low risk of bias Prognostic factor measurement: low risk of bias Outcome measurement: low risk of bias Confounding: moderate risk of bias (No sufficient information about the measurement and the definition of all measured confounders) Analysis and Reporting: low risk of bias Overall: moderate quality

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Prospective cohort study **Aim of the study** To explore to what extent chronic lung disease (CLD) and its antecedents influence the risk of developmental delays at 24-months adjusted age, as assessed with the Bayley Scales of Infant Development-2nd Edition (BSID-II), among infants without gross motor function impairments. **Study dates** 2002-2004: Period of data collection (patient enrolment)			Late bacteremia was defined as recovery of an organism from blood drawn during postnatal weeks 2, 3, or 4. No information about the measurement of Pneumothorax are reported. **Outcome(s) ascertainment/measures** The assessment of developmental delays (determined by cognitive impairment Mental Development Index [MDI] or sychomotor Developmental Index (PDI) at 24-months adjusted age at 24-months included the Bayley Scales of Infant Development-2nd Edition (BSID-II), a neurologic examination, an assessment of gross motor function by using the Gross Motor Function Classification System and, when necessary, a parent-reported assessment of adaptive development by using the Vineland Adaptive Behavior Scales (VABS).		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
24 month: follow-up Assessment **Source of funding** Grant Support 5U01NS040069-04/NS/NINDS NIH HHS/United States; U01 NS040069-04/NS/NINDS NIH HHS/United States Financial Disclosure: The authors have indicated they have no financial relationships relevant to this article to disclose			**Statistical methods** Data analysis focused to test the hypothesis that antecedents of CLD, and not CLD itself, contribute to suboptimal performance on the BSID-II. We assessed associations between antecedents (antenatal and postnatal variables and CLD) and low MDIs and PDIs. Relationships between risk factors and low MDIs and PDIs were assessed with Pearson's $\chi 2$, and variables associated with both CLD and a low BSID-II at a P value of ≤.30 were considered for logistic regression analyses. Risk factors in logistic regression models were ordered in a temporal pattern. **Length of follow-up** 2 years		
Ref Id	**Sample size**	**Risk factors**	**Setting**	**Outcome(s) at age**	**Limitations**
436810	n=215 early preterm/extremely low birth weight infants n=157 normal birth weight (>2499 g) controls	Extremely preterm (<28 weeks of gestation) or	Geographic cohort of children born in the state	**Outcomes assessed at 18 years:**	Based on the NICE manual 2014

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Full citation

Burnett, A., Davey, C. G., Wood, S. J., Wilson-Ching, M., Molloy, C., Cheong, J. L. Y., Doyle, L. W., Anderson, P. J., Extremely preterm birth and adolescent mental health in a geographical cohort born in the 1990s, Psychological medicine, 44, 1533-44, 2014

Country/ies where the study was carried out

Australia

Study type

Prospective geographical cohort study

Aim of the study</td>
<td>n=372 in total

Characteristics
<table>
<tr><td></td><td colspan="2">Extremely premature/extremely low birth weight</td><td colspan="2">Control (normal birth weight)</td></tr>
<tr><td></td><td>Followed up (n=215)</td><td>Lost to follow-up (n=83)</td><td>Followed up (n=157)</td><td>Lost to follow-up (n=105</td></tr>
<tr><td>GA in weeks, mean (SD)</td><td>26.6 (2.0)</td><td>26.9 (1.7)</td><td>39.2 (1.5)</td><td>39.2 (1.4)</td></tr>
<tr><td>Birth weight in grams, mean (SD)</td><td>889 (159)</td><td>885 (166)</td><td>3408 (460)</td><td>3341 (409)</td></tr>
<tr><td>Female, %</td><td>55</td><td>49</td><td>59</td><td>42</td></tr>
<tr><td>Singleton, %</td><td>68</td><td>73</td><td>99</td><td>94</td></tr>
<tr><td>Major neonatal brain injury, %</td><td>10</td><td>12</td><td>0</td><td>0</td></tr>
<tr><td>SGA, %</td><td>16</td><td>14</td><td>0.6</td><td>0</td></tr>
</table>
</td>
<td>extremely low birth weight (<1000 g) (vs. normal birth weight >2499 g controls).
Note that the study also looked at different biological, neonatal and maternal/social/environmental risk factors but these analyses were univariate (not adjusted), thus, not included here.</td>
<td>of Victoria in Australia 1991-1992, all participants recruited at birth.

Method(s) of measurement for risk factor(s)

Extremely preterm (<28 weeks of gestation) or extremely low birth weight (<1000 g) (vs. normal birth weight >2499 g controls), measured at birth.

Outcome(s) ascertainment/measures

Standardized face-to-face clinical interview and questionnaires were used to assess the mental health status in late adolescence:
ADHD, any type (All ADHD types assessed with the ADHD module of the Children's Interview for Psychiatric Syndromes (ChIPS))
ADHD, combined type
ADHD, inattentive type</td>
<td>Multiple logistic regression adjusting for sex, parental education and childhood SES, ORs (95% CI) presented.
<u>ADHD, any type</u>
Normal BW: reference
EP/ELBW: 2.67 (1.08-6.58)

<u>ADHD, combined type</u>
Normal BW: Reference
EP/ELBW: 4.9 (0.56-43.24)

<u>ADHD, inattentive type</u>
Normal BW: Reference
EP/ELBW: 2.09 (0.78-5.63)

<u>ADHD, hyperactive/impulsive type</u>
Normal BW: Reference
EP/ELBW: NR (0 cases in the control group)

<u>Any SCID-I/NP diagnosis</u>
Normal BW: Reference
EP/ELBW: 1.16 (0.67-2.04)

<u>Any anxiety or mood disorder</u>
Normal BW: Reference
EP/ELBW: 1.08 (0.61-1.91)</td>
<td>checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: high risk of bias
72% of the participants and 60% of the controls were followed-up at 18 years of age. Baseline characteristics of those lost to follow-up in both groups were compared with the ones included. Among both the EP/ELBW group and the control group, the ones lost to follow-up had less often mothers and fathers who had graduated high school than the ones included (EP/ELBW group: 50% vs 41% for mothers' education and 44% vs 33% for fathers' education; control group: 69% vs 44 % for mothers education and 68 % vs 46% for fathers' education). The ones lost to follow up in both groups were less often with high SES</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>To aim to characterize mental health and personlity traits in a prospective geographical cohort if adolescents born extremely preterm or extremely low birth weight in Victoria, Australia in 1991 and 1992.

Study dates

Children born in 1991-1992 and followed up at 18 years.

Source of funding

Victorian Government's Operational Infrastructure Support Program Australian National health and Medical Research Council</td>
<td>
<table>
<tr><td>Postnatal steroids, %</td><td>31</td><td>37</td><td>0</td><td>0</td></tr>
<tr><td>Neonatal surgery, %</td><td>26</td><td>27</td><td>0</td><td>0</td></tr>
<tr><td>Maternal age in years, mean (SD)</td><td>28.9 (6.0)</td><td>27.7 (5.3)</td><td>29.9 (4.9)</td><td>28.0 (5.5)</td></tr>
<tr><td>Mother completed high school, %</td><td>50</td><td>41</td><td>69</td><td>44</td></tr>
<tr><td>Father completed high school, %</td><td>44</td><td>33</td><td>68</td><td>46</td></tr>
<tr><td>Major disability at age 8 years, %</td><td>13</td><td>32</td><td>2</td><td>8</td></tr>
<tr><td>Higher SES at age 8 years, %</td><td>60</td><td>45</td><td>72</td><td>66</td></tr>
<tr><td>Age at current assessment in years, mean (SD)</td><td>17.9 (0.9)</td><td>NA</td><td>18.1 (0.8)</td><td>NA</td></tr>
</table>
</td>
<td></td>
<td>ADHD, hyperactive/impulsive type
Any anxiety or mood disorder (All DSM-IV Axis I disorders (mood, anxiety, substance use, psychotic, eating and adjustment disorders) assessed with the Structured Clinical Interview dor DSM-IV Disorders, Axis 1 Non-Patient version (SCIP-I/NP), administered by 5 interviewers blinded to group. Experienced consultant psychiatrists, also blinded by group, were consulted extensively and consensus diagnoses were reached for all participants. These assessments were supplemented by questionnaires examining recent anxiety and depression symptoms: the Beck Anxiety Inventory (BAI) and the Center for Epidemiologic Studies Depression Scale - Revised (CESD-R).)
Any mood disorder
Any anxiety disorder
Co-morbid anxiety and mood disorder</td>
<td><u>Any mood disorder</u>
Normal BW: Reference
EP/ELBW: 0.96 (0.51-1.84)

<u>Any anxiety disorder</u>
Normal BW: Reference
EP/ELBW: 1.11 (0.53-2.33)

<u>Co-moprbid anxiety and mood disorder</u>
Normal BW: Reference
EP/ELBW: 0.90 (0.34-2.41)</td>
<td>(EP/ELBW group: 60% vs 45%, control group: 72 % vs 66%). In the EP/ELBW group, the ones lost to follow-up more often had a major disability at year 8 follow-up (13% vs 32%). The participants vs the ones lost to follow-up had older mothers (p=0.004) and better childhood emotional/behavioural functioning (p-values 0.002-0.05, depending on the domain).
Prognostic factor measurement: low risk of bias
Outcome measurement: mode rate risk of bias
It is not quite clear how the anxiety and mood disorders were measured. SCID-I/NP was used but they also used the Beck Anxiety Inventory (BAI) and the Center for Epidemiologic Studies Depression Scale - Revised (CESD-R), not clear with whom or with all?</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
	Inclusion criteria Participants: infants born extremely preterm (<28 weeks gestation) or extremely low birth weight (<1000 g) in Victoria, Australia during 1991 and 1992 and surviving. Controls: normal birth weight infants (>2499 g) matched at the group level for mother's country of origin (English-speaking or not), mother's health insurance status and sex of the child. **Exclusion criteria** None reported.		**Statistical methods** Logistic regression model adjusting for sex, parental education and childhood SES. **Length of follow-up** 18 years		**Confounders:** moder ate risk of bias They did adjust for sex, parental education and childhood SES but not for example for gestational age and some other potentially important confounding factors. **Analysis and reporting:** low risk of bias For the risk factors and outcomes considered for this review, analysis and reporting was adequate. However, for other risk factors (neonatal, biological etc.) unfortunately they only conducted univariable logistic regression, thus, these results are not considered in this review. Overall quality: low
Ref Id 436815 **Full citation** Wolke, D., Samara, M.,	**Sample size** n=308 children born <=25 gestational weeks n=241 children survived to follow-up n=160 full-term born children as comparison group, matched by age and sex	**Risk factors** Gestational age, <=25 weeks of gestation (vs. full-term born)	**Setting** National cohort of extremely preterm children in the UK and Ireland born between March and Dec 1995.	**Outcome(s) at age** **Outcomes assessed at median age of 6 years and 4 months:** Serious impairment in language abilities Total score:	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Bracewell, M., Marlow, N., E. PICure Study Group, Specific language difficulties and school achievement in children born at 25 weeks of gestation or less, Journal of Pediatrics, 152, 256-62, 2008 **Country/ies where the study was carried out** UK and Ireland **Study type** National cohort study **Aim of the study** To determine whether language and educational problems are specific or due to general cognitive deficits in	**Characteristics** Not reported. **Inclusion criteria** All surviving children born 25 weeks, 6 days gestational age or less between March and December 1995 in the UK and Ireland. **Exclusion criteria** None reported.		**Method(s) of measurement for risk factor(s)** How GA was estimated is not reported. **Outcome(s) ascertainment/measures** Serious impairment in receptive and expressive language ability, evaluated using the Preschool Language Scale-3 (UK) (PLS-3) which comprises Auditory Comprehension and Expressive Communication scales. Total score Auditory comprehension Expressive communication Articulation screener Outcome were dichotomized a priori using a cutoff of 2 SD or the 10th/90th percentiles as appropriate (not specified which one was used for this outcome).	Full-term: reference Extremely preterm: 1.3 (0.3-5.3) Auditory comprehension: Full-term: reference Extremely preterm: 1.6 (0.3-9.8) Expressive communication: Full-term: reference Extremely preterm: 1.2 (0.2-6.5) Articulation screener: Full-term: reference Extremely preterm: 1.1 (0.3-4) Model adjusted for cognitive impairment score (MPC score).	**Participants:** high risk of bias Study population not described. **Attrition:** high risk of bias Only 241 out of 308 were followed-up (78%). **Prognostic factor measurement:** low risk of bias **Outcome measurement:** mode rate risk of bias Not clear which cutoff was used to define "serious impairment", either -2SD or 10th/90th percentile. **Confounders:** high risk of bias Analysis for language impairment adjust for only cognitive score, thus, other important confounders (GA, sex) were not considered. **Analysis and reporting:** high risk of bias The study also looked at cognitive outcome but only unadjusted results were presented. Even the analysis for language impairment adjust for only cognitive score,

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
children born at 25 weeks' gestation or less. **Study dates** March-December 1995, follow-up at the median age of 6 years 4 months. **Source of funding** BLISS, PPP Foundation and WellBeing.			**Statistical methods** Logistic regression, adjusting for MPC score (cognitive ability). **Length of follow-up** Median follow-up age 6 years and 4 months.		thus, other important confounders (GA, sex) were not considered. Overall quality: low
Ref Id 433327 **Full citation** Miyazaki, K., Furuhashi, M., Ishikawa, K., Tamakoshi, K., Hayashi, K., Kai, A., Ishikawa, H., Murabayashi, N., Ikeda, T., Kono, Y., Kusuda, S., Fujimura, M., Impact of chorioamnionitis	**Sample size** Study population N=5849 Sample (population with pathological examination of the placenta done) at baseline N=4078 Sample evaluated at 3 years N=2201 **Characteristics** The group with histological chorioamnionitis (HCA) (compared to no-HCA), significantly younger mothers (30.8 versus 31.2 years), higher parity (0.7 versus 0.6), less pre-eclampsia (6.2% versus 26.1%), more premature rupture of membranes (53.1% versus 24.8%), less non-reassuring fetal status (25.0% versus 29.4%), more antenatal steroids (51.3% versus 37.1%), lower gestational age at birth (26.5 weeks	**Risk factors** Chorioamnionitis (histological)	**Setting** Cohort of preterm born neonates born in Japan that were included in the Neonatal Research Network Database, which collects data for >50% of very low birth weight infants born in Japan. **Method(s) of measurement for risk factor(s)**	**Outcome(s) at age** At 3 years (chronological age) **CP** Non-HCA: Reference HCA: aOR 0.91 (95% CI 0.75-1.30) **DQ <70** Non-HCA: Reference HCA: aOR 1.27 (95% CI 0.90-1.79) **Severe hearing impairment (incl. hearing aids)** Non-HCA: Reference HCA: aOR 1.28 (95% CI 0.49-3.32)	**Limitations** Based on NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moderate risk Multiple births excluded even though prevalence population group among preterms. **Attrition:** high risk of bias 54% of the children lost to follow-up.

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
on short- and long-term outcomes in very low birth weight preterm infants: the Neonatal Research Network Japan, Journal of Maternal-Fetal & Neonatal Medicine, 29, 331-7, 2016 **Country/ies where the study was carried out** Japan **Study type** A population-based cohort study **Aim of the study** To evaluate the impact of histological chorioamnionitis (HCA) on short- and long-term outcomes in very low birth weight	versus 28.1 weeks, mean), lower birth weight (921 g versus 995 g, mean), less SGA (9.0% versus 27.5%). **Inclusion criteria** Added to the neonatal register between 2003 and 2007; birth weight <1500 g; gestational age 22+0 to 33+6; singleton; born alive (deaths in delivery room included). **Exclusion criteria** Multiple pregnancies; major congenital malformation; born outside of participating centres; no data on presence or absence of chorioamnionitis (from pathological examination of the placenta); death before follow-up at 3 years.		Histological examination of the placenta, presence and severity of HCA were examined on the basic of Blanc's criteria. **Outcome(s) ascertainment/measures** At 3 years chronological age, the children were evaluated and assessed at the participating centres. Cerebral palsy (CP), neurological examination. CP was defined as a non-progressive central nervous system disorder characterised by abnormal muscle tone in at least one extremity and abnormal control of movement and posture. Visual impairment, defined as unilateral or bilateral blindness diagnosed by an ophthalmologist. Severe hearing impairment including need for hearing aids. Cognitive function was assessed using the Kyoto Scale of Psychological Development (KSPD) test by psychologists.	**Visual impairment (unilateral or bilateral blindness)** Non-HCA: Reference HCA: aOR 1.08 (95% CI 0.65-1.78) Adjusted for maternal age, parity, maternal diabetes, premature rupture of membranes, preeclampsia, non-reassuring fetal status, mode of birth, administration of antenatal steroids, gestational age at birth, birth weight, SGA and sex.	**Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias Overall quality: low

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
infants, a very high-risk group among preterm infants, by analysing cases from a large database (the Neonatal Research Network Database) in Japan. **Study dates** Children born 2003-2007, follow-up at 3 years (chronological age). **Source of funding** Ministry of Health, Labor and Welfare, Japan			When development quotient (DQ) was <70, the child was considered to have cognitive delay, according to the protocol of the Society for Follow-up Study of High-risk Infants. **Statistical methods** Multiple variable logistic regression analyses were performed to assess the effect of HCA on morbidity. Odds ratios (OR) were calculated wioth 95% confidence intervals (CI) and adjustments were made for maternal age, parity, maternal diabetes, premature rupture of membranes, preeclampsia, non-reassuring fetal status, mode of birth, administration of antenatal steroids, gestational age at birth, birth weight, SGA and sex. **Length of follow-up** 3 years chronological age (36-42 months)		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Ref Id 410768 **Full citation** Johnson, S., Hollis, C., Kochhar, P., Hennessy, E., Wolke, D., Marlow, N., Psychiatric Disorders in Extremely Preterm Children: Longitudinal Finding at Age 11 Years in the EPICure Study, Journal of the American Academy of Child and Adolescent Psychiatry, 49, 453-463.e1, 2010 **Country/ies where the study was carried out** UK and Ireland.	**Sample size** Sample recruited n = 811 preterm children recruited at birth, reduced to 307 surviving at 11 years of age n = 153 full term controls Sample analysed after exclusions n = 219 preterm children at 11 years of age n = 152 full term controls (selected from classmates of those children attending mainstream education). **Characteristics** Not described fully in this article. Authors report "there were no significant differences in age, sex and ethnicity between extremely preterm children and classmates". **Inclusion criteria** Babies born at <26 weeks gestation during the study recruitment period, surviving to the age of 11 years. **Exclusion criteria** Participant moved abroad before follow up period, parents did not provide consent for follow up. Death before the age of 11.	**Risk factors** Gestational age NEC	**Setting** Population based study in UK and Ireland. **Method(s) of measurement for risk factor(s)** Prospective collection of data on neonatal course and perinatal variables for study participants. **Outcome(s) ascertainment/measures** The Development and Well Being Assessment (DAWBA) was administered to parents via a telephone interview (92%) or parents participated in an online version (8%). This is a structured psychiatric evaluation regarding development and behaviour. Supplemental information was obtained from teachers, who completed a corresponding questionnaire based version of the DAWBA.	**Outcome(s) at age** **Full cohort** Risk of any psychiatric disorder at the age of 11 years: Term babies: Reference Preterm babies: OR 3.2 (1.7-6.2) Risk of any ADHD: Term babies: Reference Preterm babies: OR 4.3 (1.5-13.0) Risk of ADHD innattentive subtype: Term babies: Reference Preterm babies: OR 10.5 (1.4-81.1) Risk of ADHD combined type: Term babies: Reference Preterm babies: OR 2.1 (0.5-7.9) Risk of major depression: Term babies: Reference Preterm babies: OR 2.2 (0.2-21.0) Risk of conduct disorder: Term babies: Reference	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** moder ate risk of bias OR are presented as unadjusted, although the authors state that adjustment for socioeconomic status and sex did not significantly affect the results. **Analysis and Reporting:** low risk of bias Overall quality: Moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Study type Prospective cohort study. **Aim of the study** To investigate the prevalence, correlates and precursors of psychiatric disorders in a population of extremely preterm children at 11 years of age. **Study dates** Cohort identified as babies born at <26 weeks from March until December 1995. Follow up at the age of 11 years. **Source of funding** Medical Research Council.			Potential cases were identified using computer generated scoring algorithms, and summary sheets and clinical transcripts were then reviewed by two child and adolescent psychiatrists who assigned DSM-IV and ICD-10 consensus diagnoses. Psychiatric disorders assessed included: attention deficit hyperactivity disorder, emotional disorders (separation anxiety, specific phobia, social phobia, post-traumatic stress disorder, generalized anxiety disorder, childhood emotional disorder not otherwise specified, major depression, autism spectrum disorder, conduct disorder (including oppositional defiant disorder) and tic disorder. **Statistical methods** Rates of psychiatric diagnoses were compared between extremely preterm	Preterm babies: OR 0.9 (0.4-2.2) <u>Risk of oppositional defiant disorder:</u> Term babies: Reference Preterm babies: OR 1.0 (0.4-2.4) **Excluding preterm children with neurosensory impairment** <u>Risk of any ADHD:</u> Term babies: Reference Preterm babies: OR 4.4 (1.5-13.4) <u>Risk of ADHD innattentive subtype:</u> Term babies: Reference Preterm babies: OR 10.5 (1.3-82.7) <u>Risk of ADHD combined type:</u> Term babies: Reference Preterm babies: OR 2.1 (0.5-8.5) <u>Risk of major depression:</u> Term babies: Reference Preterm babies: OR 1.7 (0.2-18.8) <u>Risk of conduct disorder:</u> Term babies: Reference	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			children and classmates. Results are reported as odds ratios (OR) with 95% confidence intervals. For comparison of term versus preterm babies: Adjusted OR were investigated with gender and socioeconomic status as covariates using logistic regression, but adjustment for these variables had no significant effects therefore unadjusted OR are reported. For multivariate regression analysis of preterm babies: OR were adjusted for fetal heart rate >100 beats per minute at 5 minutes, need for oxygen at 36 weeks, gestational age, male gender, prolonged rupture of membranes, maternal age, externalizing behaviour problems at 2.5 years, internalizing behaviour problems at 2.5 years, pervasive attentional problems (at 6 years), serious functional disability (at 6 years)and pervasive conduct problems (at 6 years).	Preterm babies: OR 0.9 (0.4-2.3) Risk of oppositional defiant disorder: Term babies: Reference Preterm babies: 0.9 (0.3-2.5) **Excluding preterm children with neurosensory and cognitive impairment** Risk of any ADHD: Term babies: Reference Preterm babies: OR 2.1 (0.6-7.5) Risk of ADHD innattentive subtype: Term babies: Reference Preterm babies: OR 4.1 (0.4-39.9) Risk of ADHD combined type: Term babies: Reference Preterm babies: OR 1.3 (0.3-6.8) Risk of major depression: Term babies: Reference Preterm babies: OR 1.3 (0.1-20.4) Risk of conduct disorder: Term babies: Reference	

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
			Length of follow-up 11 years.	Preterm babies: OR 0.4 (0.1-1.5) <u>Risk of oppositional defiant disorder:</u> Term babies: Reference Preterm babies: 0.5 (0.1-1.7) **Within preterm group** <u>Risk of any psychiatric disorder at the age of 11 years:</u> <u>NEC</u> No: Reference Yes: adjusted OR 7.15 (1.00-51) n.b. the authors state that adjusted OR were investigated with sex and socioeconomic status as covariates (for term versus preterm comparisons), and that no significant effects were noted, therefore unadjusted OR were used.	
Ref Id 397352 **Full citation** Johnson, S., Wolke, D.,	**Sample size** Sample recruited: n = 811 preterm children, reduced to 307 survivors at 11 years of age n = 153 full term controls	**Risk factors** Gestational age.	**Setting** Population based cohort study.	**Outcome(s) at age** At age 11 years. <u>Risk of learning impairment (reading composite)</u> Term: Reference	**Limitations** Based on the NICE manual 2014 checklist for prognositc studies and QUIPS.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Hennessy, E., Marlow, N., Educational outcomes in extremely preterm children: neuropsychological correlates and predictors of attainment, Developmental Neuropsychology, 36, 74-95, 2011

Country/ies where the study was carried out

UK.

Study type

Population based prospective cohort study (EPICure).

Aim of the study

To investigate educational outcomes at 11 years of age in extremely</td>
<td>Sample analysed after exclusions
n = 219 preterm children
n = 153 full term classmates

Characteristics
<table>
<tr><th>Characteristics</th><th>Preterm < 26 weeks n = 219</th><th>Term controls n = 153</th></tr>
<tr><td>Male, n (%)</td><td>101 (46.1)</td><td>64 (41.8)</td></tr>
<tr><td>Maternal education</td><td></td><td></td></tr>
<tr><td>Up to 16 years, n (%)</td><td>152 (76)</td><td>97 (65.1)</td></tr>
<tr><td>Post 16 years, n (%)</td><td>48 (24)</td><td>52 (34.9)</td></tr>
<tr><td>Socioeconomic status</td><td></td><td></td></tr>
<tr><td>High, n (%)</td><td>79 (43.9)</td><td>77 (57.0)</td></tr>
<tr><td>Medium, n (%)</td><td>44 (24.4)</td><td>21 (15.6)</td></tr>
<tr><td>Low, n (%)</td><td>57 (31.7)</td><td>37 (27.4)</td></tr>
</table>
</td>
<td></td>
<td>Method(s) of measurement for risk factor(s)

Data on gestational age was recorded prospectively.

Outcome(s) ascertainment/measures

Academic achievement was assessed using the Wechsler Individual Achievement Test-II from which standardised scores (mean=100, SD=15) were obtained for Word Reading, Reading Comprehensions, Pseudo-word Decoding, Numerical Operations, Mathematical Reasoning and the composite scales of Reading and Mathematics. Learning impairment was classifed as scores < 2SD below the mean of the comparison group of classmates on each scale.
For children in whom severe cognitive deficits precluded testing (n=18) a score 1 point below the basal score for the</td>
<td>Preterm: OR 21.6 (6.6 to 70.4)
<u>Risk of learning impairment (mathematics composite)</u>
Term: Reference
Preterm: OR 58.7 (14.2 to 242.9)

Excluding children with serious neuro-cognitive impairment:
<u>Risk of learning impairment (reading composite)</u>
Term: Reference
Preterm: OR 5.5 (1.5 to 20.1)
<u>Risk of learning impairment (mathematics composite)</u>
Term: Reference
Preterm: OR 15.1 (3.4 to 65.8)

<u>Risk of special educational needs (full cohort)</u>
Term: Reference
Preterm: OR 13.1 (7.4 to 23.3)

<u>Risk of special educational needs provision (full cohort)</u>
Term: Reference
Preterm: OR 12.6 (7.1 to 22.4)</td>
<td>Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: moderate risk of bias
OR are presented as unadjusted. However, the authors describe that adjustment for maternal education and socioeconomic status made only minor impact on the results.
Analysis and reporting: low risk of bias

Overall quality: moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
premature children. **Study dates** Recruitment for preterm children took place between March and December 1995. At age 6 and 11 years, a group of full term controls were assessed. **Source of funding** Not reported.	<table><tr><td>Age at test, mean (SD)</td><td>10.9y (0.38y)</td><td>10.9y (0.55y)</td></tr></table> **Inclusion criteria** Preterm group: all infants born at < 26 weeks during the recruitment period in UK and Ireland. Term controls: a comparison group of classmates was selected when participants were aged 6 and 11, born at term and matched for age, sex and ethnicity. **Exclusion criteria** Death before the age of 11.		reading and mathematics composite scales were substituted. Teachers completed a questionnaire to elicit information detailing whether special educational needs (SEN) provision was utilised by the child and, if so, what type of SEN services were utilised. **Statistical methods** Rates of impairment were cross tabulated and the risks of adverse outcomes are presented as OR with 95% confidence intervals. As adjustment for socioeconomic status and maternal education reduced group differences by 1 mental processing composite point or less for all comparisons, and there was more missing data for these variables than other predictors, OR are presented as unadjusted. **Length of follow-up** 11 years.	OR are unadjusted, as adjustment for socioeconomic status and maternal education made only minor impact on the results.	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr>
<td>Ref Id

410891

Full citation

Kuzniewicz, M. W., Wi, S., Qian, Y., Walsh, E. M., Armstrong, M. A., Croen, L. A., Prevalence and neonatal factors associated with autism spectrum disorders in preterm infants, Journal of Pediatrics, 164, 20-25, 2014

Country/ies where the study was carried out

USA

Study type

Retrospective cohort study using population registry data.</td>
<td>Sample size

Sample recruited
N = 235,198

Sample analysed after exclusions
N = 195021

Data from 454 participants, who had symptoms suggestive of ASD but no definitive diagnosis, was not included in this review.

Characteristics

<table>
<tr><td>Characteristic</td><td>ASD n = 2462</td><td>No ASD n = 192105</td></tr>
<tr><td>Gestational age</td><td></td><td></td></tr>
<tr><td>24-26 week, n (%)</td><td>12 (3.8)</td><td>306 (96.2)</td></tr>
<tr><td>27-33 week, n (%)</td><td>68 (2.0)</td><td>3407 (97.7)</td></tr>
<tr><td>34-36 week</td><td>200 (1.7)</td><td>11703 (98.0)</td></tr>
<tr><td>37-41 week</td><td>2152 (1.2)</td><td>174588 (98.6)</td></tr>
</table>
</td>
<td>Risk factors

Gestational age
Small for gestational age
Bacteraemia
ICH
Cystic PVL</td>
<td>Setting

Population based study of infants born in one of the 11 Kaiser Permanente Northern California Hospitals. Membership is representative of the total population in the region, except for the highest and lowest income earners.

Method(s) of measurement for risk factor(s)

Gestational age was determined from the maternal record. Gender, Maternal age, birth weight, maternal ethnicity, multiple gestation and 5 minute Apgar score were obtained from the Kaiser Permanente administrative databases. Small for gestational age was obtained by plotting the infants weight and gestational age on the Fenton curves, using 5th percentile as a cut off for small for gestational age,</td>
<td>Outcome(s) at age

Diagnosis of ASD (follow up 2-11 years)
Gestational age
37-41 weeks: Reference
34-36 weeks: HR 1.3 (1.1-1.4)
27-33 weeks: HR 1.4 (1.1-1.8)
24-26 weeks: HR 2.7 (1.5-5.0)
HR adjusted for gender, maternal age, maternal education, Caesarean delivery and SGA.

<u>Small for gestational age</u>
No: Reference
Yes: HR 3.0 (1.4-6.3)

<u>Bacteraemia</u>
No: Reference
Yes: HR 1.6 (0.8-3.4)

<u>Intracranial haemorrhage (ICH)</u>
No (or USS not done): Reference
Grade 1/2: HR 1.9 (1.1-3.4)
Grade 3/4: HR 3.4 (1.4-8.6)</td>
<td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS:
Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: high</td>
</tr>
</table>

Study details	Participants			Risk factors	Methods	Outcomes and results	Comments
Aim of the study To assess the prevalence of autistic spectrum disorders (ASD) at different gestational ages of birth and identify potential risk factors in the neonatal intensive care unit. **Study dates** Infants born between January 1st 2000 and December 31st 2007 were included. All ASD diagnoses made until January 31st 2011 were retrieved. **Source of funding** Kaiser Permanente Northern California	≥42 weeks	30 (1.4)	2201 (98.2)		and 95th percentile for large for gestational age. Chorioamnionitis, preeclampsia and hypoglycaemia were determined from ICD-9 codes. Maternal education was from the infants birth certificate. All infants delivered at < 34 weeks were admitted to NICU, and detailed information on complications and interventions occurring during the NICU admission was obtained from the KPNC minimum data set, captured by medical record abstractors and through electronic data collection. **Outcome(s) ascertainment/measures** The birth cohort was linked to the Kaiser Permanente (KP) Autism Registry. This contains the location, provider, provider speciality and date of any ASD diagnosis recorded in the KP outpatient databases. Children with a diagnosis of austism,	<u>Cystic periventricular leucomalacia</u> No: Reference Yes: HR 1.7 (0.2-12.4) <u>NEC</u> Not reported (0% of the ones with outcome had NEC) HR adjusted for gestational age, gender, maternal age, maternal education and SGA.	
	Male, n (%)	2003 (2.0)	97719 (97.7)				
	Female, n (%)	459 (0.5)	94386 (99.4)				
	Small for GA, n (%)	60 (1.6)	3586 (97.9)				
	Ethnicity						
	Asian, n (%)	555 (1.4)	39919 (98.4)				
	Black, n (%)	167 (1.2)	13402 (98.6)				
	Hispanic, n (%)	497 (1.1)	46921 (98.8)				
	White, n (%)	1075 (1.3)	80429 (98.5)				
	Other, n (%)	178 (1.5)	11434 (98.1)				
	Maternal age						
	≤14 yrs, n (%)	0 (0)	72 (100)				

Study details	Participants			Risk factors	Methods	Outcomes and results	Comments
Community Benefit Program.	15-19 yrs, n (%)*	74 (0.8)	72 (100)		Asperger syndrome or pervasive developmental disorder not otherwise specified were identified. The minimum age of children in the cohort was 3 years of age at the time the registry was assessed. ASD cases were defined as children with at least 1 diagnosis of ASD made at an ASD evaluation centre, or by a clinical specialist (psychiatrist, psychologist or developmental paediatrician) outside of the evaluation centre, or by a general paediatrician. **Statistical methods** Cox proportional hazards regression models were used to evaluate the association between gestational age and ASD, as there was differential follow up time among the cohort (from 2 to > 11 years). The censoring date was the date of first ASD diagnosis, or the date of last membership in the health plan. The		
	20-24 yrs, n (%)	285 (0.9)	8693 (99.0)				
	25-29 yrs, n (%)	625 (1.2)	30234 (98.6)				
	30-34 yrs, n (%)	793 (1.3)	58043 (98.4)				
	35-39 yrs, n (%)	533 (1.6)	33066 (98.1)				
	40-44 yrs n, (%)	141 (1.8)	7768 (98.0)				
	≥45 yrs, n (%)	11 (2.2)	477 (97.0)				
	Maternal education						
	< High school, n (%)	136 (0.7)	18777 (99.1)				
	High school, n (%)	524 (1.1)	45968 (98.6)				
	College, n (%)	1284 (1.4)	90308 (98.4)				

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
	<table><tr><td>Post graduate, n (%)</td><td>425 (1.5)</td><td>28807 (98.3)</td></tr><tr><td>Unknown, n (%)</td><td>93 (1.1)</td><td>8245 (98.7)</td></tr></table> * data reported as in paper, however note inconsistency with percentage values for this row. Suggest typographical error in paper. **Inclusion criteria** All infants born alive at a gestation of ≥24 weeks from January 1st 2000 to December 31st 2007, and who survived to discharge. **Exclusion criteria** Infants with data missing on gestational age, gender, maternal age or who transferred out of the Kaiser Permanente Northern California Hospitals during their birth hospitalisation. Children who did not remain within the health plan at the age of 2 years.		baseline model included gestational age, sex, maternal age, maternal education. Additional variables were tested in the baseline model and included in the final model if p<0.05. **Length of follow-up** 2 to 11 years.		
Ref Id 410915 **Full citation** Larroque, B., Ancel, P. Y., Marret, S., Marchand, L., Andre, M., Arnaud, C.,	**Sample size** Sample recruited n = 2901 preterm children (24-32 weeks) n = 667 term controls (39-40 weeks) Sample analysed after exclusions n = 1534 preterm infants n = 320 term infants	**Risk factors** Gestational age.	**Setting** Population based prospective cohort. **Method(s) of measurement for risk factor(s)** Gestational age was recorded prospectively	**Outcome(s) at age** **At age 5 years** **Cognitive impairment (MPC score 55-69)** Term: Reference Preterm: OR 3.4 (1.8-6.4) OR for more severe cognitive impairment (MPC<55) are not	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS: **Participants:** low risk of bias **Attrition:** low risk of bias

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Pierrat, V., Roze, J. C., Messer, J., Thiriez, G., Burguet, A., Picaud, J. C., Breart, G., Kaminski, M., Epipage Study group, Neurodevelopmental disabilities and special care of 5-year-old children born before 33 weeks of gestation (the EPIPAGE study): a longitudinal cohort study, Lancet, 371, 813-20, 2008

Country/ies where the study was carried out

France.

Study type

Prospective population based cohort study (EPIPAGE).</td>
<td>Characteristics

<table>
<tr><td>Characteristic</td><td>Preterm children n = 2901</td><td>Term children n = 667</td></tr>
<tr><td>Male sex, n (%)</td><td>940 (52)</td><td>206 (52)</td></tr>
<tr><td>Multiple pregnancy, n (%)</td><td>566 (32)</td><td>6 (2)</td></tr>
<tr><td>Maternal age < 25 years, n (%)</td><td>384 (21)</td><td>63 (16)</td></tr>
<tr><td>Maternal age ≥ 35 years, n (%)</td><td>285 (16)</td><td>51 (13)</td></tr>
<tr><td>Maternal education</td><td></td><td></td></tr>
<tr><td>University, n (%)</td><td>551 (32)</td><td>155 (39)</td></tr>
<tr><td>Secondary school, 2nd part, n (%)</td><td>383 (21)</td><td>85 (22)</td></tr>
<tr><td>Secondary school, 1st part, n (%)</td><td>735 (41)</td><td>143 (36)</td></tr>
<tr><td>Primary school or no school, n (%)</td><td>96 (6)</td><td>11 (3)</td></tr>
<tr><td>Socioeconomic status</td><td></td><td></td></tr>
</table>
</td>
<td></td>
<td>based on the date of the last menstrual period and an early prenatal ultrasound.

Outcome(s) ascertainment/measures

The European Cerebral Palsy Network definition of cerebral palsy was used, and questionnaires for children with abnormal findings from neurological examinations were checked by a group of paediatricians to validate the diagnosis. Functional severity was classified into three subtypes: walking with no aid, walking with aid or unable to walk. CP was classified into three subtypes: bilateral spastic CP (including diplegia and tetraplegia), hemiplegia or monoplegia, and ataxic or dyskinetic CP. Vision was assessed, without correction, with the Rossano test, and visual deficiency was classified as severe (<3/10 for both eyes),</td>
<td>presented as there were no cases in the reference category (0%), but there were 36 cases in the very preterm group (2%).</td>
<td>Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounders: low risk of bias
Analysis and Reporting: low risk of bias

Overall quality: high</td>
</tr>
</table>

Study details	Participants			Risk factors	Methods	Outcomes and results	Comments
Aim of the study To investigate neurodevelopmental outcome and use of special health care at 5 years of age in preterm children. **Study dates** Recruitment between 1 January and 31 December 1997. **Source of funding** National Institute of Health and Medical Research, the Directorate General for Health of the Ministry for Social Affairs, Merck-Sharp and Dohme-Chibret, Medical Research Foundation and	Professional, n (%)	274 (16)	91 (23)		moderate (<3/10 for one eye) or none/mild (≥3/10 both eyes). Severe auditory deficit was defined as a hearing loss of more than 70dB for one or both ears, or the use of a hearing aid. The mental processing composite (MPC) of the Kaufman assessment battery for children (K-ABC) was used to assess cognitive function. The scale is standardised to a mean score of 100 (SD 15). For some children with severe neurosensory deficiency the team undertaking the 5-year assessment did not administer the K-ABC because of the extent of their disability. The composite outcome of moderate-severe disability was defined as non-ambulatory cerebral palsy or cerebral palsy requiring aids to walk, an MPC score of less than 69 (<2SD below the mean), severe hearing deficiency or severe visual deficiency. **Statistical methods**		
	Intermediate, n (%)	461 (25)	123 (31)				
	Administrative/public service self-employed, student, n (%)	425 (23)	87 (22)				
	Shop assistant, service worker, n (%)	271 (15)	38 (10)				
	Manual worker or unemployed, n (%)	377 (21)	57 (14)				
	Inclusion criteria Preterm group: All births between 22 and 32 completed weeks of gestation from 1 Jan to 31 Dec 1997. Term group: one in every four births at 39-40 weeks during one week in 1997. **Exclusion criteria** Death before follow up. Follow up data not available (physician report, cerebral palsy information or K-ABC score).						

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
"Hospital Program for Clinical Research 2001 n°AOM01117" of the French Department of Health.			Odds ratios were estimated with multinomial models. Multiple linear regression analysis was used to adjust for potentially confounding variables for K-ABC scales to compare both very preterm and reference groups. Adjustment was made for maternal age, parity, maternal education, maternal birthplace and socioeconomic status. **Length of follow-up** 5 years.		
Ref Id 321792 **Full citation** Petrini,J.R., Dias,T., McCormick,M.C., Massolo,M.L., Green,N.S., Escobar,G.J., Increased risk of adverse neurological development for late preterm	**Sample size** Complete sample: N = 142735 children born at ≥ 30 weeks. Sample analysed after exclusions: N = 141321 **Characteristics** Characteristic / Preterm 30-33 weeks n = 1921 / Preterm 34-36 weeks n = 8341 / Term 37-41 weeks n = 128955	**Risk factors** Gestational age.	**Setting** Northern California medical program of 12 hospitals. **Method(s) of measurement for risk factor(s)** All pregnancies were dated using ultrasound scanning between 12 and 24 weeks, and gestational age was recorded in the data	**Outcome(s) at age** Risk of cerebral palsy during follow up time **Gestational age** Term: Reference 34-36 weeks: HR 3.39 (2.54-4.52) 30-33 weeks: HR 7.87 (5.38-11.51) Risk of developmental delay/mental retardation during follow up time **Gestational age** Term: Reference	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** low risk of bias **Outcome measurement:** moderate risk of bias

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>infants, Journal of Pediatrics, 154, 169-176, 2009

Country/ies where the study was carried out

USA.

Study type

Retrospective cohort study using registry data.

Aim of the study

To assess the risks of moderate prematurity for cerebral palsy and developmental delay.

Study dates

Cohort identified as born between 1st January 2000 and 30th</td>
<td>
<table>
<tr><td>Maternal ethnicity</td><td></td><td></td><td></td></tr>
<tr><td>Hispanic, n (%)</td><td>386 (20.1)</td><td>1845 (22.1)</td><td>31828 (24.7)</td></tr>
<tr><td>Black, n (%)</td><td>195 (10.2)</td><td>744 (8.9)</td><td>9232 (7.2)</td></tr>
<tr><td>Asian, n (%)</td><td>334 (17.4)</td><td>1529 (18.3)</td><td>23598 (18.3)</td></tr>
<tr><td>White, n (%)</td><td>785 (40.9)</td><td>3397 (40.7)</td><td>53484 (41.5)</td></tr>
<tr><td>Other/unknown, n (%)</td><td>221 (11.5)</td><td>826 (9.9)</td><td>10813 (8.4)</td></tr>
<tr><td>Maternal age, years</td><td></td><td></td><td></td></tr>
<tr><td>< 20, n (%)</td><td>115 (6.0)</td><td>515 (6.2)</td><td>7643 (5.9)</td></tr>
<tr><td>≥ 40, n (%)</td><td>126 (6.6)</td><td>488 (5.9)</td><td>4716 (3.7)</td></tr>
<tr><td>Caesarean delivery, n (%)</td><td>1051 (54.7)</td><td>2776 (33.3)</td><td>26775 (20.8)</td></tr>
<tr><td>Male, n (%)</td><td>1032 (53.7)</td><td>4535 (54.4)</td><td>65585 (50.9)</td></tr>
</table>
</td>
<td></td>
<td>system as completed weeks.

Outcome(s) ascertainment/measures

Neurological diagnoses were made on the basis of ICD-9 codes from patient encounter data. A hierarchical method was used to avoid double counting (due to overlap between diagnoses). Initially, codes relating to cerebral palsy were retrieved. Infants identified were then removed from the pool eligible for the next step. Of the remaining infants, those with codes related to developmental delay/mental retardation were identified when ≥ 2 coded encounters were recorded at least 6 months apart. A further step was used to identify children with seizure disorders (not relevant for this review).

Statistical methods</td>
<td>34-36 weeks: HR 1.25 (1.01-1.54)
30-33 weeks: HR 1.90 (1.34-2.71)

HR adjusted according to variables listed above.</td>
<td>ICD-9 codes were used to identify children with cerebral palsy and developmental delay/mental retardation. These diagnoses will not be subject to rigorous validation/strict criteria, therefore there is a risk of error.
Confounders: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: Moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
June 2004. Follow up until 30 June 2005. **Source of funding** The March of Dimes, The Permanente Medical Group Inc. and Kaiser Foundation Hospitals Inc.	<table><tr><td>Multiple gestation, n (%)</td><td>533 (27.7)</td><td>1412 (16.9)</td><td>1843 (1.4)</td></tr><tr><td>SGA (10th percentile), n (%)</td><td>171 (8.9)</td><td>508 (6.1)</td><td>3209 (2.5)</td></tr></table> **Inclusion criteria** Children born alive at one of the 12 Kaiser Permanente Medical Care Program birth facilities between Jan 1 2000 and Jun 30 2004 with a gestational age of at least 30 weeks. **Exclusion criteria** Death before discharge from hospital, leaving the Kaiser foundation Health Plan < 1 day after discharge from the birth hospitalisation.		Cox proportional hazard models were used to account for varying length of follow up. Separate models for CP and developmental delay/mental retardation were generated. Crude hazard ratios were adjusted for maternal ethnicity, sex, multiple pregnancy and size for gestational age. **Length of follow-up** Between 1 day and 5.5 years.		
Ref Id 411492 **Full citation** Rabie, N. Z., Bird, T. M., Magann, E. F., Hall, R. W., McKelvey, S. S., ADHD and developmental speech/languag	**Sample size** Original sample N = 82862 Sample analysed after exclusions: N = 38802 For the purposes of this review data from the "early term" group (n = 11527) were not included. **Characteristics**	**Risk factors** Gestational age	**Setting** South Carolina Medicaid claims. **Method(s) of measurement for risk factor(s)** Medicaid claims files and birth certificate data was used to ascertain gestational age.	**Outcome(s) at age** Outcomes reported at age 3-5 years. Risk of attention deficit hyperactivity disorder **Gestational age** Term (39-41^{+6} weeks): Reference Late preterm (34-36^{+6}): HR 1.21 (0.98-1.49)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moderate risk of bias Data came exclusively from Medicaid patients who the authors state "are associated with a

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>e disorders in late preterm, early term and term infants, Journal of Perinatology, 35, 660-664, 2015

Country/ies where the study was carried out

USA.

Study type

Retrospective cohort study using population registry data.

Aim of the study

To compare the long term neurodevelopmental outcomes for late preterm, early term and term infants.

Study dates

Cohort identified as babies born</td>
<td>
<table>
<tr><td>Characteristics</td><td>Late preterm n = 3270</td><td>Term n = 24005</td></tr>
<tr><td>Male, %</td><td>51.4</td><td>51.1</td></tr>
<tr><td>Ethnicity, %</td><td></td><td></td></tr>
<tr><td>White</td><td>38.5</td><td>40.2</td></tr>
<tr><td>Black</td><td>57.3</td><td>52.4</td></tr>
<tr><td>Hispanic</td><td>3.2</td><td>6.2</td></tr>
<tr><td>Other/unknown</td><td>1.0</td><td>1.2</td></tr>
<tr><td>SGA, %</td><td>7.0</td><td>9.9</td></tr>
</table>
Inclusion criteria

All infants born within the study dates between 34 and 41^{+6} weeks gestation.

Exclusion criteria

Birth weight < 1500g or > 4500g, congenital anomaly or multiple gestations.
Enrollement in Medicaid program for at least 36 months (to allow time for outcome ascertainment).
</td>
<td></td>
<td>Outcome(s) ascertainment/measures

Outcome measures were also derived from Medicaid files and based on the presence of at least one ICD-9 code for the specific conditions: attention deficit hyperactivity disorders and developmental speech or language disorders.

Statistical methods

A multivariable Cox proportional hazard model was used to account for the different follow up times of participants. Hazard ratios were adjusted for birth weight, SGA and LGA, gender, ethnicity, hospital characteristics and maternal medical comorbidities (diabetes, hypertension, anaemia, chronic lung disease, herpes, neurologic disorder, coagulation disorder, obesity, depression).</td>
<td><u>Risk of developmental speech and/or language delay</u>
Gestational age
Term (39-41^{+6} weeks): Reference
Late preterm (34-36^{+6}): HR 1.36 (1.23-1.50)

Adjusted for factors as reported above.</td>
<td>lower socioeconomic status and traditionally have poorer obstetric outcomes".
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: moderate risk of bias
A diagnostic coding system was used for the identification of affected individuals, therefore the diagnoses may not have been verified appropriately.
Confounders: low risk of bias
Analysis and Reporting: low risk of bias.

Overall quality: low</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
between 1st January 2000 and 31st December 2003. Follow up until 5 years of age. **Source of funding** The Arkansas Children's Hospital Research Institute and the Translational Research Institute of the University of Arkansas.			**Length of follow-up** Until the age of 5 years, or until Medicaid eligibility was discontinued.		
Ref Id 411596 **Full citation** Rogers, C. E., Lenze, S. N., Luby, J. L., Late preterm birth, maternal depression, and risk of preschool psychiatric disorders, Journal of the American	**Sample size** Sample recruited N = 306 Sample analysed after exclusions: N = 271 n = 39 late preterm (34-36 weeks) n = 78 early term (37-39 weeks) n = 154 full term (40-41 weeks) For the purposes of these results, the relevant comparisons were all between full term and late preterm groups.	**Risk factors** Gestational age.	**Setting** Not described. **Method(s) of measurement for risk factor(s)** Gestational age at birth (completed weeks) was reported by the child's primary caregiver.	**Outcome(s) at age** At the age of 3-6 years Risk of any psychiatric diagnosis **Gestational age** Term: Reference Late preterm: OR 3.18 (1.40-7.27) Risk of major depressive disorder **Gestational age** Term: Reference Late preterm: OR 1.16 (0.49-2.74)	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS. **Participants:** moderate risk of bias Individuals known to have depressive or disruptive symptoms were specifically oversampled for this study, therefore the population will not

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Academy of Child and Adolescent Psychiatry, 52, 309-318, 2013 **Country/ies where the study was carried out** USA **Study type** Cross sectional survey. **Aim of the study** To assess the role of preterm birth in the development of preschool psychiatric disorders. **Study dates** Not described. **Source of funding**	**Characteristics** Characteristic / Late preterm (34-36 weeks) n = 39 / Full term (40-41 weeks) n = 154 Male, % / 53.8 / 50.6 Ethnicity, % / / White / 66.7 / 46.8 Black / 30.8 / 37.0 Other / 2.6 / 16.2 **Inclusion criteria** Preschool children between 3 and 6 years of age. Those with depressive or disruptive symptoms were oversampled to address key aims of interest of a larger longitudinal study. Those with low or no symptoms were also included to provide a reference group. **Exclusion criteria** Children born before 34 weeks or after 41 weeks. Children with chronic medical or neurological problems, mental retardation or autistic spectrum disorders. Missing data from the Preschool Age Psychiatric Assessment.		**Outcome(s) ascertainment/measures** The Preschool Age Psychiatric Assessment (PAPA) was used to establish DSM-IV Axis 1 diagnoses. This is an interviewer based tool designed for use with caregivers of children aged 2-6 years. It was administered by bachelor's or master's level clinicians and final diagnoses were derived using computerised algorithms. All interviews were audiotaped for quality control and group calibration. 20% of each interviewers tapes were reviewed by a master coder and, when discrepancies arose, they were recoded in consultation with a senior child psychiatrist. **Statistical methods** The relationship between gestational age and development of any psychiatric disorder was assessed using logistic regression with gender,	Risk of ADHD **Gestational age** Term: Reference Late preterm: OR 0.81 (0.29-2.29) Risk of ADHD-inattentive **Gestational age** Term: Reference Late preterm: OR 1.21 (0.11-13.22) Risk of Oppositional Defiant Disorder **Gestational age** Term: Reference Late preterm: OR 2.30 (0.98-5.40) Risk of Conduct Disorder **Gestational age** Term: Reference Late preterm: OR 1.60 (0.55-4.66) Risk of any anxiety diagnosis **Gestational age** Term: Reference Late preterm: OR 3.74 (1.59-8.78) Risk of Generalized Anxiety Disorder **Gestational age** Term: Reference Late preterm: OR 3.50 (1.03-11.94)	reflect that of the general population. **Attrition:** low risk of bias Not relevant (cross sectional data) **Prognostic factor measurement:** mode rate risk of bias Gestational age was retrospectively reported by the caregiver, therefore a risk of recall bias. **Outcome measurement:** low risk of bias. **Confounders:** moderate risk of bias Limited neonatal data was obtained, therefore adjustment was not performed for any neonatal factors. **Analysis and Reporting:** low risk of bias. Overall quality: low

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td>The National Institute of Mental Health, the National Institute on Alcohol Abuse and Alcoholism, the National Center for Research Resources/National Center for Advancing Translational Sciences.</td><td></td><td></td><td>family income, IQ and ethnicity as covariates.

Length of follow-up

3-6 years</td><td><u>Risk of Separation Anxiety Disorder</u>
Gestational age
Term: Reference
Late preterm: OR 3.04 (1.21-7.63)</td><td></td></tr>
<tr><td>Ref Id

340289

Full citation

Serenius, F., Kallen, K., Blennow, M., Ewald, U., Fellman, V., Holmstrom, G., Lindberg, E., Lundqvist, P., Marsal, K., Norman, M., Olhager, E., Stigson, L., Stjernqvist, K., Vollmer, B., Stromberg, B., Express Group, Neurodevelopm</td><td>Sample size

Sample recruited:
n = 707 liveborn preterm infants
n = 701 term controls

Sample analysed after exclusions:
n = 456 preterm infants
n = 701 full term controls

Characteristics

<table><tr><td>Characteristic</td><td>Preterm < 27 weeks n=456</td><td>Term 37-41 weeks n=701</td></tr><tr><td>Maternal age, n (%)</td><td></td><td></td></tr></table></td><td>Risk factors

Gestational age.</td><td>Setting

National study conducted throughout Sweden.

Method(s) of measurement for risk factor(s)

Perinatal and neonatal data were collected prospectively. Gestational age was based on ultrasound dating in 95% of the pregnancies.</td><td>Outcome(s) at age

<u>Risk of mild cognitive impairment</u>
Gestational age
Term: Reference
Preterm: OR 4.3 (2.3-7.9)

<u>Risk of mild language impairment</u>
Gestational age
Term: Reference
Preterm: OR 3.5 (1.9-6.4)

<u>Risk of moderate language impairment</u>
Gestational age
Term: Reference
Preterm: OR 5.1 (1.9-13.8)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: moderate risk of bias 41 (9%) preterm infants were assessed through chart review alone, without formal follow</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>ental outcome in extremely preterm infants at 2.5 years after active perinatal care in Sweden, JAMA, 309, 1810-20, 2013

Country/ies where the study was carried out

Sweden.

Study type

Population based prospective cohort study.

Aim of the study

To determine the neurodevelopmental outcome in extremely preterm children compared to term controls at 2.5 years of age.</td>
<td>
<table>
<tr><td>< 20 years</td><td>14 (3.1)</td><td>9 (1.3)</td></tr>
<tr><td>≥ 35 years</td><td>136 (29.8)</td><td>162 (23.1)</td></tr>
<tr><td>Maternal education,

n (%)</td><td></td><td></td></tr>
<tr><td>≤ 9 years</td><td>46 (14.1)</td><td>28 (4.5)</td></tr>
<tr><td>≥ 17 years</td><td>32 (9.8)</td><td>87 (14.1)</td></tr>
<tr><td>Gestational age, wks

mean (SD)</td><td>25.4 (1.1)</td><td>39.9 (1.1)</td></tr>
<tr><td>Birth weight, grams

mean (SD)</td><td>783 (172.3)</td><td>3610 (475.5)</td></tr>
<tr><td>Male, n (%)</td><td>248 (54.4)</td><td>387 (55.2)</td></tr>
<tr><td>SGA, n (%)</td><td>73 (16.0)</td><td>7 (1.0)</td></tr>
</table>
Inclusion criteria
</td>
<td></td>
<td>Outcome(s) ascertainment/measures

At 2.5 years of corrected age, certified psychologists assessed cognitive, language and motor development with the Bayley Scales of Infant and Toddler Development. 41 preterm infants were assessed through chart review, with information from local paediatricians, low-vision centres and rehabilitation centres that provided information which the authors regarded as sufficient to allow assessment of developmental and neurosensory outcome. Cognitive, language and motor development was considered normal if the composite score on the respective Bayley-III scale was within 1 SD of the norm, mildly impaired if the score was between 1 and 2SD below the norm, moderately impaired if the score was between 2 and 3 SD below the norm, and severely impaired if the score was < 3SD below the norm.</td>
<td><u>Risk of mild mental developmental delay</u>
Gestational age
Term: Reference
Preterm: OR 3.0 (1.8-5.0)

<u>Risk of moderate mental developmental delay</u>
Gestational age
Term: Reference
Preterm: OR 6.4 (2.4-17.1)

OR adjusted as described above.
Note: data are reported for more severe cognitive/language impairment and developmental delay, but due to small numbers or no affected individuals in the control group adjusted OR are not able to be reported.
Note: possible overlap in these outcomes with developmental problems review.</td>
<td>up. This may lead to a discrepancy in outcome reporting.
Confounders: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: Moderate</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Study dates Recruitment took place between April 1st 2004 and March 31st 2007. Follow up continued until February 2010. **Source of funding** Swedish Research Council, the Uppsala-Örebro Regional Research Council, the Research Council South East Region of Sweden and grants to Researchers in the Public Health Care from the Swedish government, Financial support was also provided through a regional agreement between the Univeristy of Umeå and Västerbotten	Preterm infants: all infants born at < 27 weeks within the study time period throughout Sweden. Controls: Singleton, term infants with a five minute Apgar score greater than 3, with matching of control participants for place of living, sex, day of birth and maternal country of birth. **Exclusion criteria** Death before follow up period. Declined follow up. Mother had protected identity, family moved abroad or error on identification number at birth.		Mental developmental delay was also included as an outcome and classified as follows: Mild: a score of between 1 and 2 SD below the norm on either the cognitive or the language composite score. Moderate: a score of between 2 and 3 SD below the norm on either the cognitive or language composite score. Severe: a score of less than 3 SD below the norm on either the cognitive of language composite score. **Statistical methods** Odds ratios were estimated using multiple logistic regression analysis, adjusting for maternal country of birth Nordic/non-Nordic, maternal and paternal educational level. **Length of follow-up** 2.5 years		

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
County Council, and through a regional agreement on medical training and clinical research between Stockholm County Council and Karolinska Institute. The study also received support from The "Lilla Barnets Fond" Children's fund, the Evy and Gunnar Sandberg and the Birgit and Håkan Ohlsson Foundations and the Marie Curie Individual Intra-European Fellowship.					
Ref Id 411765 **Full citation** Singh, G. K., Kenney, M. K., Ghandour, R. M., Kogan, M. D., Lu, M. C.,	**Sample size** N= 85,535 children aged 2-17 years **Characteristics**	**Risk factors** **Gestational ages (GAs):** pre-maturity (delivery before 37 completed wks of gestation): **Biological risk factors:**	**Setting** National survey **Method(s) of measurement for risk factor(s)** Parents' self-reported gestational ages	**Outcome(s) at age** Among children aged between 2 to 17 (exact assessment time not reported): **<u>Depression, AOR (95%CI):</u>** Term: Reference	**Limitations** Based on the NICE manual 2014 checklist for prognostic studies and QUIPS **Participants:** low risk of bias

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Mental Health Outcomes in US Children and Adolescents Born Prematurely or with Low Birthweight, Depression Research and Treatment, 2013, 570743, 2013

Country/ies where the study was carried out

USA

Study type

Cross sectional survey.

Aim of the study

To examine whether : 1) mental health outcomes associated with prematurity and LBW vary by child’s sex and age; 2) whether</td>
<td>
<table>
<tr><th>Sociodemographic characteristics</th><th>Unweighted number in sample</th><th>Weighted percent in sample</th></tr>
<tr><td colspan="3"></td></tr>
<tr><td>Child born prematurely (<37 weeks of gestation)</td><td></td><td></td></tr>
<tr><td>Premature</td><td>9,590</td><td>11.45</td></tr>
<tr><td>Not premature</td><td>75,095</td><td>88.55</td></tr>
<tr><td>Child’s sex</td><td></td><td></td></tr>
<tr><td>Male</td><td>44,178</td><td>51.22</td></tr>
<tr><td>Female</td><td>41,357</td><td>48.78</td></tr>
<tr><td>Race/ethnicity</td><td></td><td></td></tr>
<tr><td>Hispanic</td><td>11,136</td><td>22.55</td></tr>
<tr><td>Non-Hispanic white</td><td>55,235</td><td>51.58</td></tr>
<tr><td>Non-Hispanic black</td><td>8,073</td><td>13.43</td></tr>
<tr><td>Non-Hispanic mixed race</td><td>4,649</td><td>4.68</td></tr>
</table>
</td>
<td>Child's age:
sex:
Race/Ethnicity:</td>
<td>Outcome(s) ascertainment/measures

Self-reported development problems; For the outcome of behavioral/emotional problems, it was measured as a composite, global mental health indicator which include depression, anxiety, or behavioral or conduct problems in the child.
For disorders, parents were asked whether they were told by a doctor that their child had a disorder between age 2 to 17 years;

Statistical methods

Logistic regressions controlling for household composition, place of residence, highest household/parental education

Length of follow-up</td>
<td>GA <37 weeks:1.33 (1.01-1.74)
<u>Anxiety, AOR (95%CI):</u>
Term: Reference
GA <37 weeks: 1.58 (1.31-1.91)
<u>Oppositional defiant or conduct disorder, AOR (95%CI):</u>
Term: Reference
GA <37 weeks: 1.50 (1.21-1.86)
<u>Autism spectrum disorder, AOR (95%CI):</u>
Term: Reference
GA <37 weeks: 2.26 (1.69-3.03)
Male: 4.49 (3.48-5.8)
Ethnicity (non-Hispanic white (ref) vs Hispanic: 0.85 (0.53-1.36)
Ethnicity (non-Hispanic white (ref) vs non-Hispanic black): 0.61 (0.41-0.92)
Ethnicity (non-Hispanic white (ref) vs non-Hispanic mixed): 1.07 (0.75-1.55)
Ethnicity (non-Hispanic white (ref) vs other): 0.6 (0.4-0.89)
<u>ADD/ADHD, AOR (95%CI):</u>
Term: Reference
GA <37 weeks: 1.49 (1.29-1.73)
Male: 2.43 (2.15-2.75)</td>
<td>Attrition: low risk of bias
Prognostic factor measurement: mode rate risk of bias
Parents reported the gestational age at delivery of children, although this was dichotomised as premature (<37 weeks) or not premature, therefore may be more accurately remembered than specific weeks of gestation.
Outcome measurement: moderate risk of bias
Parents' self-reported developmental disorders based on whether this was diagnosed by doctor, clear definitions of developmental disorders or diagnosis criteria not reported;
Confounders: low risk of bias
Analysis and reporting: low risk of bias

Overall quality: low</td>
</tr>
</table>

Study details	Participants			Risk factors	Methods	Outcomes and results	Comments
social factors are significant predictors of mental health problems in both preterm/LBW and general child populations, and (3) the extent to which neurodevelopmental conditions such as autism/ASD, ADHD, and developmental delay might account for the relationship between perinatal conditions and common emotional/behavioral disorders of depression, anxiety, and conduct problems. **Study dates** 2011-2012 **Source of funding**	Other (Asians/Pacific Islanders and American Indians)	6,442	7.76		Cross sectional survey, children in the survey aged between 2 to 17 years; Gestational ages and prematurity were self-reported by parents;	Ethnicity (non-Hispanic white (ref) vs Hispanic: 0.42 (0.33-0.54) Ethnicity (non-Hispanic white (ref) vs non-Hispanic black): 0.64 (0.53-1.11) Ethnicity (non-Hispanic white (ref) vs non-Hispanic mixed): 0.91 (0.74-1.11) Ethnicity (non-Hispanic white (ref) vs other): 0.33 (0.25-0.43) **Developmental delay, AOR (95%CI):** Term: Reference GA <37 weeks: 2.92 (2.44-3.49) **Learning disability, AOR (95%CI):** ***(this outcome belongs to development problems, just for information here)*** Term: Reference GA <37 weeks: 2.13 (1.84-2.46) **Intellectual disability/mental retardation, AOR (95%CI):** Term: Reference GA <37 weeks: 2.74 (2.02-3.73) Male: 1.7 (1.25-2.31) The effects of prematurity and birthweight were	
	Household composition						
	Two-parent biological	58,306	63.08				
	Two-parent stepfamily	6,517	9.64				
	Single mother	13,708	19.19				
	Other family type	7,004	8.10				
	Place of residence						
	Metropolitan	62,845	84.35				
	Nonmetropolitan	21,486	15.65				
	Highest household or parental education level (years)						
	<12	4,893	11.64				

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Maternal and Health Bureau, US</td>
<td>
<table>
<tr><td>12</td><td>12,771</td><td>19.91</td></tr>
<tr><td>13–15</td><td>21,500</td><td>24.66</td></tr>
<tr><td>16+</td><td>44,186</td><td>43.79</td></tr>
<tr><td>Household poverty status (ratio of family income to poverty threshold)</td><td></td><td></td></tr>
<tr><td>Below 100%</td><td>12,882</td><td>21.95</td></tr>
<tr><td>100–199%</td><td>15,347</td><td>21.72</td></tr>
<tr><td>200–399%</td><td>26,139</td><td>28.44</td></tr>
<tr><td>At or above 400%</td><td>31,167</td><td>27.90</td></tr>
</table>
Inclusion criteria

Not reported

Exclusion criteria

Not reported
</td>
<td></td>
<td></td>
<td>estimated by separate logistic regression models that controlled for age, sex, race/ethnicity, household composition, place of residence, and household education and income levels.</td>
<td></td>
</tr>
<tr>
<td>Ref Id

339221</td>
<td>Sample size

N = 6,145,357 total
n = 8397 children with cerebral palsy</td>
<td>Risk factors

Gestational age</td>
<td>Setting

Population based registry data study, conducted in California.</td>
<td>Outcome(s) at age

Outcome at between 5 and 15 years of age
<u>Risk of cerebral palsy</u></td>
<td>Limitations

Based on the NICE manual 2014 checklist for</td>
</tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Full citation Sukhov, A., Wu, Y., Xing, G., Smith, L. H., Gilbert, W. M., Risk factors associated with cerebral palsy in preterm infants, Journal of Maternal-Fetal & Neonatal Medicine, 25, 53-7, 2012 **Country/ies where the study was carried out** USA. **Study type** Retrospective population based cohort study. **Aim of the study** To assess risk factors associated with the development of cerebral palsy	**Characteristics** For infants with cerebral palsy (n = 8397): Cerebral palsy type Spasticity 60.5% Ataxia 5.6% Dyskinesis 2.7% Hypotonia 14.4% Other 16.9% Limb involvement Diplegia/paraplegia 20.1% Hemiplegia 14.4% Monoplegia 2.0% Triplegia/quadriplegia 52.2% Other 11.3% Severity of motor impairment Mild 17.7% Moderate 43.9% Severe 34.7% Suspected* 3.7% * Condition present but level of impairment undetermined. **Inclusion criteria** All births within time frame of the study. **Exclusion criteria** CP not related to birth events (e.g. related to near drowning, automobile accidents, other accidents and child abuse).		**Method(s) of measurement for risk factor(s)** Ascertainment from records in state databases, including the Office of Statewide Health Planning and Development Patient Discharge Database (recording all patient hospital discharges), the Linked Vital Statistics Birth File (a separate file of all births within California). These databases include information on maternal and neonatal demographics, antenatal, intrapartum and postnatal complications, maternal and infant diagnoses and other outcomes. **Outcome(s) ascertainment/measures** The California Department of Developmental Services database was used to identify cases of cerebral palsy (CP). This includes	Gestational age 37+ weeks: Reference 32-36 weeks: OR 2.20 (2.05-2.36) 28-31 weeks: OR 8.83 (8.04-9.70) < 28 weeks: OR 18.21 (16.70-19.86)	prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** low risk of bias **Prognostic factor measurement:** Low risk of bias **Outcome measurement:** moderate risk of bias Information on CP rates was obtained through an administrative database collecting information from non-profit organisations caring for people with CP. This is stated to include "the vast majority of children in California with developmental disabilities" but is at risk of being incomplete. **Confounding:** low risk of bias **Analysis and reporting:** low risk of bias. Overall quality: moderate Risk factors and outcomes were identified through

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
in preterm infants. **Study dates** January 1st 1991 to December 31st 2001. **Source of funding** NIH grant.			information from 21 nonprofit regional centres which provide therapy services to people with developmental disorders, including CP. **Statistical methods** Data were analysed by determining odds ratios (OR) and 95% confidence intervals (CI) for cerebral palsy. OR were adjusted for maternal age, parity, maternal education, payer-source, ethnicity, timing of initiation of prenatal care, number of prenatal visits, gestational age, birthweight, multiple pregnancy, gender, placental abruption, fetal distress, mild to severe birth asphyxia, birth defects, birth trauma, meningitis and cord prolapse. **Length of follow-up** 5 to 15 years. Cases with CP were identified as of 30th November 2006.		population databases, which may be incomplete. This may lead to under-reporting of CP rates, but may also lead to under-reporting of the identified risk factors.

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td>Participants were delivered between January 1st 1991 and December 31st 2001.</td><td></td><td></td></tr>
<tr><td>Ref Id

322175

Full citation

Toome,L., Varendi,H., Mannamaa,M., Vals,M.A., Tanavsuu,T., Kolk,A., Follow-up study of 2-year-olds born at very low gestational age in Estonia, Acta Paediatrica, 102, 300-307, 2013

Country/ies where the study was carried out

Estonia.

Study type

Prospective population based cohort.</td><td>Sample size

Sample recruited:
n = 187 very low gestational age infants
n = 153 full term controls

Sample analysed after exclusions
n = 155 very low gestational age infants
n = 153 full term controls

Characteristics
<table><tr><td></td><td>VLGA infants</td><td>Full term infants</td></tr><tr><td>Gestational age, mean (95% CI), weeks</td><td>28.8 (28.4-29.1)</td><td>39.6 (39.4-39.7)</td></tr><tr><td>Birthweight, mean (95% CI), grams</td><td>1314 (1252-1377)</td><td>3611 (3536-3685)</td></tr><tr><td>Male, %</td><td>57</td><td>57</td></tr><tr><td>Multiple birth, %</td><td>25</td><td>1</td></tr></table></td><td>Risk factors

Gestational age
Male gender
Severe cerebral lesions (including IVH grade III/IV and/or PVL grade 2-4)</td><td>Setting

Population based cohort.

Method(s) of measurement for risk factor(s)

Perinatal data were collected prospectively in the national neonatal research register.

Outcome(s) ascertainment/measures

Families were invited for a physical assessment by a paediatrician, neurological examination by a child neurologist and an assessment of development by a child psychologist.
Cerebral palsy was defined according to the guidelines of the Surveillance of Cerebral Palsy in Europe collaborative group, and the Gross Motor</td><td>Outcome(s) at age

At age 2 years.
Model includes data from preterm children only.

Risk of neurodevelopmental impairment
According to GA (per week): OR 0.7 (0.6-0.9)
SGA and Male gender were not independent predictors on mulitvariate analysis
<u>Severe cerebral lesions</u>
No: Reference
Yes: OR 33.4 (8.6-129.9)

Risk of language composite score <-2SD
<u>Male gender</u>
No: Reference
Yes: OR 4.9 (1.1-21.8)

<u>Severe cerebral lesions</u>
No: Reference
Yes: OR 19.0 (4.8-75.1)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: low risk of bias
Prognostic factor measurement: low risk of bias
Outcome measurement: low risk of bias
Confounding: low risk of bias
Analysis and reporting: low risk of bias.

Overall quality: high</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Aim of the study To assess the growth, neurosensory and developmental impairment of very low gestational age (VLGA) infants at the age of two years, and to identify risk factors associated with unfavourable outcomes in VLGA infants. **Study dates** 1997 -1999. Cohort identified from 1st January 1997 to 31st December 1997. Follow up at a corrected age of 2 years. **Source of funding**	<table><tr><td>Small for gestational age, %</td><td>10</td><td>7</td></tr><tr><td>Maternal age, mean (95% CI), years</td><td>31.4 (30.3-32.5)</td><td>30.5 (29.7-31.3)</td></tr><tr><td>Maternal higher education, %</td><td>27</td><td>50</td></tr></table> **Inclusion criteria** Preterm infants: all infants born at a gestational age of 22^{+0} to 31^{+6} in Estonia, during the study dates. Full term controls: born at term with a gestational age of ≥37 weeks, no requirement for medical care during the first week of life, born in the same area of the country, and the same gender and nationality as the preterm infant, born shortly after the expected date of the preterm infant. **Exclusion criteria** Death before the follow up examination. Moved abroad before follow up.		Function Classification System (GMFCS) was used to quantify motor function in infants with CP. The Bayley Scales of Infant and Toddler Development were used to generate composite scores for cognitive, language and motor skills, with a mean (SD) score of 100 (±15). Results are presented according to the number of participants with scores <2SD below the mean for cognitive and language composite scores. A composite outcome measure of neurodevelopmental impairment was also used. This includes any one (or more) of the following criteria: CP with GMFCS level 2,3,4 or 5; cognitive and/or language composite scores of ≤-2SD below the norm; hearing loss corrected with hearing aids or deafness; vision moderately reduced or blindness. **Statistical methods**	**Risk of cognitive composite score <-2SD** <u>Severe cerebral lesions</u> No: Reference Yes: OR 9.8 (1.9-49.5) SGA and Male gender were not independent predictors on mulitvariate analysis <u>NEC grade 2-3</u> No: Reference Yes: OR 7.4 (1.5-37.2) **Risk of cerebral palsy** <u>Severe cerebral lesions</u> No: Reference Yes: OR 43.2 (8.2-226.5) SGA and Male gender were not independent predictors on mulitvariate analysis OR are stated as adjusted for all variables (antenatal steroids, multiple births, gestational age, birthweight, small for gestational age, male gender, surfactant, postnatal steroids, IVH grade 3-4 and/or PVL grade 2-4, BPD, ROP stage 3-5 with laser therapy, positive blood culture sepsis, NEC stage 2-3, weight<10th percentile at discharge,	

<table>
<tr><th>Study details</th><th>Participants</th><th>Risk factors</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td>Tallinn Children's Hospital Foundation and the Estonian Science Foundation.</td><td></td><td></td><td>Multivariate logistic regression was used to select statistically significant explanatory variables for each of the unfavourable outcome variables.

Length of follow-up

2 years.</td><td>maternal age, maternal higher education, single mother, paternal age, paternal higher education and low income of the family).</td><td></td></tr>
<tr><td>Ref Id

412158

Full citation

Woythaler, M. A., McCormick, M. C., Smith, V. C., Late preterm infants have worse 24-month neurodevelopmental outcomes than term infants, Pediatrics, 127, e622-9, 2011

Country/ies where the study was carried out

USA.</td><td>Sample size

Sample recruited:
N = 9050

Sample analysed after exclusions
n = 1200 late preterm babies
n = 6300 term babies

N.B. Article states that "all unweighted sample sizes included in this analysis were rounded to the nearest 50 to protect the confidentiality of respondents as specified in the restricted data license agreement".

Characteristics

<table><tr><td>Characteristics</td><td>Late preterm</td><td>Term</td></tr><tr><td>Maternal age, years,

mean (SD)</td><td>27.5 (6.9)</td><td>27.3 (7.9)</td></tr></table></td><td>Risk factors

Gestational age</td><td>Setting

The Early Childhood Longitudinal Study-Birth Cohort, a prospective national longitudinal study assessing the early health care and developmentally influential experiences of children born in 2001 and their families.

Method(s) of measurement for risk factor(s)

Maternal and infant descriptive characteristics were obtained from birth certificates and maternal surveys.</td><td>Outcome(s) at age

<u>Risk of severe developmental delay (MDI score <70)</u>
Gestational age
Term: Reference
Late preterm: OR 1.51 (1.26-1.82)

<u>Risk of mild developmental delay (MDI score 70-84)</u>
Gestational age
Term: Reference
Late preterm: OR 1.43 (1.22-1.67)

<u>Risk of severe psychomotor developmental delay (PDI score <70)</u>
Gestational age
Term: Reference
Late preterm: OR 1.56 (1.29-1.88)</td><td>Limitations

Based on the NICE manual 2014 checklist for prognostic studies and QUIPS.
Participants: low risk of bias
Attrition: moderate risk of bias
17% of participants were lost to follow up. The authors report that these participants were significantly more likely to have a high school education, be impoverished and have less prenatal care than those who remained in the study.</td></tr>
</table>

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Study type Prospective national cohort study. **Aim of the study** To compare the neurodevelopmental outcomes of late preterm to term infants. **Study dates** Cohort established during 2001. Follow up at 24 months chronological age. **Source of funding** The US Department of Education's National Center for Education Statistics in the Institute of	<table><tr><td>Ethnicity, %</td><td></td><td></td></tr><tr><td>White</td><td>75.1</td><td>81.4</td></tr><tr><td>Black</td><td>14.8</td><td>20.4</td></tr><tr><td>Other</td><td>4.5</td><td>4.3</td></tr><tr><td>Male infants, %</td><td>52.6</td><td>51.4</td></tr><tr><td>SGA, %</td><td>8.9</td><td>10.1</td></tr><tr><td>Multiple births, %</td><td>14.7</td><td>1.5</td></tr></table> **Inclusion criteria** Infants with >34 weeks completed gestation who had complete developmental assessments at 24 months. **Exclusion criteria** Infants who were not assessed, or who were unable to be adequately assessed because of a major congenital anomaly or blindness.		**Outcome(s) ascertainment/measures** The primary outcome measures were the mental development index (MDI) and the psychomotor development index (PDI) using the Bayley Short Form Research edition (BSF-R). This was administered in the child's home by trained personnel. Each administrator's testing and scoring were validate through in person quality control visits and videotaped interviews. **Statistical methods** For multivariable analysis, generalized estimating equation models were used to generate odds ratios and 95% confidence intervals. These account for clustering of data in siblings. OR were adjusted for gestational age, plurality, maternal race, education, marital status, depression, prenatal care, primary	Risk of mild psychomotor developmental delay (PDI score 70-84) **Gestational age** Term: Reference Late preterm: OR 1.58 (1.37-1.83)	**Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounders:** low risk of bias **Analysis and reporting:** low risk of bias. Overall quality: moderate

Study details	Participants	Risk factors	Methods	Outcomes and results	Comments
Education Sciences.			language, infant gender, poverty level, delivery type, fetal growth and any breast milk feeding. **Length of follow-up** 24 months of chronological age.		

Developmental follow up of pre-term babies

Prevalence of developmental problems

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Ref Id 409707 **Full citation** Agerholm, H., Rosthoj, S., Ebbesen, F., Developmental problems in very prematurely born children, Danish	**Setting** A regional cohort of all live births in the catchment area of Aalborg hospital in the County of North Jutland in Denmark. **Inclusion criteria** All livebirths with gestational age >=24 and <32 weeks in the County of North Jutland, Denmark within the catchment area of Aalborg hospital during the period from 1 January 1996 t0 31 December 2000.	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Motor problem (MABC 5th to 15 th percentile) Preschool skills (MAP)	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 5 years of age Motor function Uncertain motor function (M-ABC >5th to ≤15th percentile total score) 24-31 wks GA: 31/168, 18.5% (12.9-25.2%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Medical Bulletin, 58, A4283, 2011

Study type

Regional birth cohort study

Aim of the study

To describe the developmental outcome of routine follow-up assessments at the age of five years in a regional cohort of children born at a gestational age <32 weeks and to investigate neonatal risk factors associated with developmental problems.

Study dates

Children born 1996-2000, follow-up at 5 years of age.

Country/ies where the study was carried out</td>
<td>Exclusion criteria

None reported.

Sample size

N=237 live born children with 24-31 weeks GA in the geographical area
N=204 children survived
N=175 children followed-up at 5 years of age (86% of the ones who survived)
N=168 children included in analysis (7 children with CP could not be assessed)

Characteristics

<table>
<tr><th></th><th>Normal development n=70</th><th>Developmental problems n=105</th></tr>
<tr><td>GA <28 wks, %</td><td>13</td><td>27</td></tr>
<tr><td>Singleton, %</td><td>64</td><td>74</td></tr>
<tr><td>SGA, %</td><td>21</td><td>22</td></tr>
<tr><td>Male, %</td><td>40</td><td>68</td></tr>
<tr><td>Asphyxia (Apgar score <=7 at 5 min), %</td><td>7</td><td>11</td></tr>
<tr><td>Septicaemia, %</td><td>9</td><td>24</td></tr>
</table>
</td>
<td>Outcome ascertainment/measures

At 5 years of age, the children were assessed at the outpatient clinic of Aalborg hospital; according to the routine follow-up assessment program for very premature born children. Assessment was carried out by experiences physiotherapists and occupational therapists who are trained in the use of test manuals available for even and precise assessment. After all the children in the birth cohort for a given year had been assessed at five years of age, they were categorised by the same physiotherapist or occupational therapist according to their developmental</td>
<td><u>Motor function problem (M-ABC ≤15th percentile total score)</u>
24-31 wks GA: 61/168, 36.3% (29.0-44.1%)

Preschool skills
<u>Cognitive verbal skills (Uncertain preschool skills, MAP, yellow)</u>
24-31 wks GA: 23/168, 13.7% (8.9-19.8%)

<u>Cognitive verbal skills (Deficit in preschool skills, MAP, red)</u>
24-31 wks GA: 18/168, 10.7% (6.5-16.4%)

<u>Cognitive non-verbal skills (Uncertain preschool skills, MAP, yellow)</u>
24-31 wks GA: 11/168, 6.6% (3.3-11.4%)

<u>Cognitive non-verbal skills (Deficit in preschool skills, MAP, red)</u>
24-31 wks GA: 6/168, 3.6% (1.3-7.6%)

<u>Combined cognitive and motor skills (Uncertain preschool skills, MAP, yellow)</u>
24-31 wks GA: 21/168, 12.5% (7.9-18.5%)</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No.
Low precision, wide confidence intervals, due to relatively small sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear. 86% of the survived children were followed up.

6. Were objective, standard criteria used for the</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Denmark

Source of funding

None reported.</td>
<td>
<table>
<tr><td>Respiratory distress syndrome, %</td><td>37</td><td>39</td></tr>
<tr><td>BPD, %</td><td>3</td><td>16</td></tr>
<tr><td>Abnormal cerebral ultrasound, %</td><td>3</td><td>12</td></tr>
<tr><td>Persistent ductus arteriosus, %</td><td>1</td><td>16</td></tr>
<tr><td>Social class group 1 (lowest), %</td><td>6</td><td>24</td></tr>
</table>
</td>
<td>outcome within the following areas: gross motor function, fine motor function, perception, cognition and behaviour. They were divided into three categories: category 1 contained children with a normal developmental outcome corresponding to their age; category 2 contained children under observational for developmental deficiencies i.e. children with slight deficiencies in 1-3 areas compared with a normal developmental outcome and who needed suggestions for stimulation, but otherwise had no further need for supportive measures; category 3 contained children with developmental deficiencies i.e. moderate to severe developmental deficiencies in more</td>
<td><u>Combined cognitive and motor skills (Deficit in preschool skills, MAP, red)</u>
24-31 wks GA: 12/168, 7.1% (3.8-12.1%)

Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.
Confidence intervals of prevalence estimates not provided.

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		than two areas compared with a normal developmental outcome and in need of extra or extensive supportive measures. Motor function was examined using the Movement Assessment Battery for Children (M-ABC), it measures three items in the area of manual dexterity, two items in the area of ball skills and three items in the area of balance. The items were scored from 0 to 5, where 0 was the optimum score. The test is standardised and the scores are presented in relation to the 5th and the 15th percentile in the reference group. A score above the 15th percentile show normal motor skills. A score between the 5th and 15th percentile indicates need for observation for motor function deficit, and a score under 5th		

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		percentile indicates motor function deficit. Preschool skills were assessed using the cognitive parts of the Miller Assessment for Preschoolers (MAP) with four items in the cognitive verbal area, fice items in the cognitive non-verbal area and four items in the combined motor and cognitive area. MAP is standardised and the scores are presented in relation to two different percentiles within the three area and administered by colours according to the manual: green shows normal preschool skills, yellow indicates observation for deficit in preschool skills and red indicates deficit in preschool skills. **Age at assessment** 5 years		

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Ref Id

434849

Full citation

Anderson, P., Doyle, L. W., Neurobehavioral Outcomes of School-age Children Born Extremely Low Birth Weight or Very Preterm in the 1990s, Journal of the American Medical Association, 289, 3264-3272, 2003

Study type

Prospective regional cohort study (Victorian Infant Collaborative Study Group)

Aim of the study

To determine the cognitive, educational, and behavioural outcome of ELBW or very preterm infants born in the 1990s compared with normal birth weight controls.</td>
<td>Setting

Cohort of very preterm children in the region of Victoria, Australia (Victorian Infant Collaborative Study Group).

Inclusion criteria

All surviving children with birth weights <1000g or with gestational ages younger than 28 completed weeks in Victoria, Australia between 1991-1992.

Exclusion criteria

Children who were not able to complete the psychological assessment due to significant neurosensory impairments.

Sample size

N=568 consecutive live births of neonates with BW <1000g or <28 weeks GA.
n=298 infants survived to 2, and 5 years assessment.
n=275 children assessed at 8 years age.

Characteristics

<table>
<tr><td>Small for gestational age (<-2SD)(n,%)</td><td>38 (13.8)</td></tr>
<tr><td>Male (n, %)</td><td>128 (46.5)</td></tr>
<tr><td>Married mother (n, %)</td><td>180/271 (66.4)</td></tr>
<tr><td>Low SES (n, %)</td><td>132 (48.0)</td></tr>
</table>
</td>
<td>Gestational age ascertainment

Not reported.

Outcomes of interest in this study

Behavioural problems

Outcome ascertainment/measures

The behaviour assessment system (BASC; parent and teacher rating scales) were used to assess children's adaptive and problem behaviours at home (parent) or at school (teacher). Both scales provide composite indexes for externalising problems, internalising problems, adaptive skills, and overall behavioural problems. For behavioural problems, T scores of 70 + are considered clinically</td>
<td>Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)

At 8 years age
Behavioural problems- at risk (parent reported)
<28 wks GA: 41/275, 15% (95%CI 11.0-19.7)
Behavioural problems- clinically significant (parent reported)
<28 wks GA: 19/275, 7% (95%CI 4.2-10.6)

http://statpages.info/confint.html</td>
<td>Overall quality

Low

1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

The participants were recruited consecutively.

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Study dates

Infants born 1991-1992, assessed at 8 years age.

Country/ies where the study was carried out

Australia.

Source of funding

Health and Community Services, Australia. National Health and Medical Research Council, Australia.</td>
<td>
<table>
<tr><td>Maternal education (≥12 years schooling)</td><td>129/269 (48.0)</td></tr>
<tr><td>Maternal ethnicity (born in English-speaking country)</td><td>220/274 (80.3)</td></tr>
<tr><td>Maternal ethnicity (black)</td><td>3/274 (1.1)</td></tr>
</table>
</td>
<td>significant, whereas T scores of 60-69 represent at risk range. For adaptive index, a T score of 30 or below is clinically significant, whereas a T score of 31-40 represents at risk range.

Age at assessment

8 years age.</td>
<td></td>
<td>coverage of the identified sample?

Unclear. The follow up rate was 92.3%, of which some of the group were lost to follow up or refused to participate, or were living in another country. The children who were not assessed at 8 years age, tended to be from lower social class

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals for prevalence estimates were not provided.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				9. Are all important confounding factors/subgroups/differences identified and accounted for? N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 409756 **Full citation** Anderson, P. J., De Luca, C. R., Hutchinson, E., Spencer-Smith, M. M., Roberts, G., Doyle, L. W., Attention problems in a representative sample of extremely preterm/extremely low birth weight children, Developmental	**Setting** All surviving children born extremely preterm (<28 weeks) or extremely low birth weight (<1000 g) in the state of Victoria, Australia. **Inclusion criteria** All surviving children born with a gestational age 22-27 weeks and/or birth weight <1000 g in the state of Victoria, Australia between January 1 and December 31, 1997. **Exclusion criteria** None reported.	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** Problems: selective attention; sustained attention; attention encoding; executive attention; ADHD symptoms	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 8 years (corrected) Selective attention (TEA-Ch Sky Search, <-1SD) 22-27 wks GA/BW 1000 g: 58/171, 33.9% (26.9-41.5%)* Sustained attention (TEA-Ch Score!, <-1SD) 22-27 wks GA/BW 1000 g: 52/173, 30.1% (23.3-37.5%)* Attention Encoding (TEA-Ch Forward digit span, <-1SD) 22-27 wks GA/BW 1000 g: 71/178, 39.9% (32.6-47.5%)*	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Neuropsychology, 36, 57-73, 2011

Study type

Population-based cohort study

Aim of the study

To examine attention in large, representative, contemporary cohort of children born extremely preterm and/or extremely low birth weight.

Study dates

Children born 1997, follow-up at 8 years of corrected age.

Country/ies where the study was carried out

Australia

Source of funding</td>
<td>Sample size

n=201 children survived to 8 years
n=189 assessed at 8 years (94%)

Characteristics

<table>
<tr><td></td><td>n=189</td></tr>
<tr><td>Gestational age in weeks, mean (SD)</td><td></td></tr>
<tr><td>Gestational age <26 wks, %</td><td></td></tr>
<tr><td>Birth weight in grams, mean (SD)</td><td></td></tr>
<tr><td>Birth weight <750 g, %</td><td></td></tr>
<tr><td>Male, %</td><td></td></tr>
<tr><td>Multiple birth, %</td><td></td></tr>
<tr><td>Antenatal cortisocsteroids, %</td><td></td></tr>
<tr><td>NEC, %</td><td></td></tr>
<tr><td>ROP, %</td><td></td></tr>
<tr><td>BPD, %</td><td></td></tr>
<tr><td>Postnatal corticosteroids, %</td><td></td></tr>
</table>
</td>
<td>Outcome ascertainment/measures

The children were assessed at 8 years (corrected) by psychologists blind to perinatal details, predominantly in specialised follow-up clinics, although a few were tested at school or home if they could not attend the clinics.

Selective attention was assessed with the Sky Search subtest from the Test of Everyday Attention for Children (TEA-Ch).
Sustained attention was assessed with the Score! subtest from the TEA-Ch.
Attention encoding was assessed with the forward digit span from the Wechsler Intelligence Scale for Children (WISC-IV).
Executive attention was categorised into 1) inhibitory control, which</td>
<td><u>Executive attention</u>
<u>1) Inhibitory control:</u>
a) Opposite Worlds (<-1SD)
22-27 wks GA/BW 1000 g: 10/167, 6.0% (2.9-10.7%)*
b) BRIEF-Inhibit (T score >60)
22-27 wks GA/BW 1000 g: 28/187 15.0% (10.2-20.9%)*
<u>2) Shifting attention:</u>
a) Creature counting (<-1SD)
22-27 wks GA/BW 1000 g: 46/170, 27.1% (20.5-34.4%)*
b) BRIEF-Shift (T score >60)
22-27 wks GA/BW 1000 g: 35/184, 19.0% (13.6-25.5%)*
<u>3) Divided attention:</u>
Sky Search Dual Task (<1SD)
22-27 wks GA/BW 1000 g: 62/168, 36.9% (29.6-44.7%)*

<u>ADHD symptoms</u>
<u>CADS-P Inattentive symptoms (T score >60)</u>
22-27 wks GA/BW 1000 g: 18/56, 32.1% (20.3-46.0%)*
<u>CADS-P Hyperactive-Impulsive symptoms (T score >60)</u>
22-27 wks GA/BW 1000 g: 23/55, 41.8% (28.7-55.9%)*</td>
<td>3. Was the sample size adequate?

No.
Low precision (wide confidence intervals) due to relatively small sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Australia's National Health and Medican Research Council, and Senior Research Fellowship, and the University of Melbourne.s CR Roper Fellowship.	IVH grade 3-4, % Cystic PVL, % Intact family, % Mother's education, tertiary degree, % English spoken at home, % Age at 8 year follow-up, mean (SD)	was assessed with the Opposite Worlds from the TEA-Ch, and the Inhibit scale from the parent form of the Behavioral Rating Inventory of Executive Function (BRIEF), 2) shifting attention, which was assessed with Creature Counting from the TEA-Ch, and the Sgift scale from BRIEF, 3) divided attention, which was assessed with the Sky Search Dual Task from the TEA-Ch. Attention deficit hyperactivity disorder (ADHD) was assessed with the Conner's ADHD/DSM-IV Scales (CADS-P). The CADS-P consists of 26 items. For this study three scales were used: ADHD Index (items that best distinguish ADHD children from nonclinical children), DSM-IV Inattentive (items directly related to the DSM-IV symptoms of	ADHD Index (CADS-P T score >60) 22-27 wks GA/BW 1000 g: 24/55, 43.6% (30.3-57.7%)* *Only number of cases and the prevalence (as percentage) given, the denominator was calculated by the NGA technical team. Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**8. Was there appropriate statistical analysis?** No. Denominators for the prevalence estimates not provided. Confidence intervals for the prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		inattention), and DSM-IV Hyperactive-Impulsive (items directly related to DSM-IV symptoms of hyperactivity-impulsivity). Impairment was defined as scores more than 1 SD below the mean of the control group (term/normal birth weight peers) for the attention tasks and T scores >60 for the BRIEF and the CADS-P. **Age at assessment** 8 years (corrected)		
Ref Id 433049 **Full citation** Anderson, P. J., Doyle, L. W., Executive functioning in school-aged children who were born very preterm or with extremely low birth	**Setting** Geographical cohort of extremely low birth weight or very preterm children. **Inclusion criteria** Live births with birth weight <1000 g or gestational age <28 weeks in Victoria, Australia between January 1991 and December 1992.	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** Executive function (BRIEF)	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 8 years (corrected) Global executive composite (BRIEF, >=1.5SD above normative mean) <28 wks GA/BW <1000 g: 32/245, 13.1% (9.1-17.9%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>weight in the 1990s, Pediatrics, 114, 50-57, 2004

Study type

A geographically determined cohort study (Victoria, Australia)

Aim of the study

To determine the frequency, nature and severity of executive dysfunction at 8 years of age in extremely low birth weight/ very preterm infants who were born in the 1990s, compared with normal birth weight control subjects.

Study dates

Children born 1991-1992, follow-up at 8 years of age (corrected).</td>
<td>Exclusion criteria

Children who did not survive to 2 years of age,

Sample size

N=275 final sample

Characteristics
<table>
<tr><th></th><th>ELBW/Very preterm</th><th>NBW</th></tr>
<tr><td>Male, %</td><td>46.5</td><td>46.6</td></tr>
<tr><td>Maternal ethnicity:</td><td></td><td></td></tr>
<tr><td>Born in English-speaking country, %</td><td>80.3</td><td>84.3</td></tr>
<tr><td>Aboriginal, %</td><td>1.5</td><td>0</td></tr>
<tr><td>Black, %</td><td>1.1</td><td>0.4</td></tr>
<tr><td>English only spoken at home, %</td><td>82.1</td><td>86.1</td></tr>
<tr><td>Intact family structure, %</td><td>70.2</td><td>77.3</td></tr>
<tr><td>Married mother, %</td><td>66.4</td><td>77.2</td></tr>
<tr><td>Low social class, %</td><td>48.0</td><td>42.8</td></tr>
<tr><td>Maternal education >=12 y of schooling, %</td><td>48.0</td><td>60.8</td></tr>
</table>
</td>
<td>Outcome ascertainment/measures

Behaviour Rating Inventory of Executive Function (BRIEF) is a questionnaire that assesses behavioural manifestations of executive function. In this study the parent version was administered. Composite score (global executive composite) is derived from 8 clinical scales (inhibit, shift, emotional control, initiate, working memory, plan/organize, organization of materials and monitor) and 2 indices (metacognitive and behavioural regulation). Score >065 (>=1.5 SD above normative mean) is considered abnormal.</td>
<td>Confidence interval calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No.
Low precision, wide confidence interval due to relatively low sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear.
Out of 298 survivors, 245 had BRIEF composite score (82%)

6. Were objective, standard criteria used for the</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Country/ies where the study was carried out Australia **Source of funding** Health and Community Services, Victoria; National Health and Medical Research Council, Australia	Paternal education >=12 y of schooling, % | 41.1 | 61.3	**Age at assessment** 8 years (corrected)		**measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Ref Id

409787

Full citation

Arnaud, C., Daubisse-Marliac, L., White-Koning, M., Pierrat, V., Larroque, B., Grandjean, H., Alberge, C., Marret, S., Burguet, A., Ancel, P. Y., Supernant, K., Kaminski, M., Prevalence and associated factors of minor neuromotor dysfunctions at age 5 years in prematurely born children: The EPIPAGE study, Archives of Pediatrics and Adolescent Medicine, 161, 1053-1061, 2007

Study type

Prospective population-based cohort study

Aim of the study</td>
<td>Setting

All maternity wards in 9 regions of France.

Inclusion criteria

Children born before 33 weeks completed gestation
Children born at 33 to 34 weeks completed gestation

Exclusion criteria

In 2 regions, half of the infants born at 32 weeks were randomly excluded from the follow-up to reduce the workload

Sample size

n=1662 children born before 33 weesk GA, examined at 5 years
n=246, children born at 33 and 34 weeks GA, examined at 5 years

Characteristics
<table>
<tr><td>Characteristics of children born preterm</td><td>≤32 weeks GA</td><td>33-34 weeks GA</td></tr>
<tr><td>Follow-up offered at birth (n)</td><td>2382</td><td>427</td></tr>
<tr><td>Follow-up accepted at birth (n)</td><td>2276</td><td>386</td></tr>
</table>
</td>
<td>Gestational age ascertainment

Not reported

Outcomes of interest in this study

Minor neuromotor dysfunction

Outcome ascertainment/measures

The short version of Touwen examination was used to assess at 5 years age, a 16 item assessment grouped into 4 subsets for posture and muscle tone, reflexes, coordination and balance, and motor and behaviour of the face and eyes. Each of the subsets was rated as optimal or nonoptimal. The children were then classified as healthy</td>
<td>Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)

Assessment at 5 years age
<u>Minor neuromotor dysfunction ((mild, MND-1, one or two items affected), Touwen assessment)</u>
≤27 wks GA: 93/178, 52.3% (95%CI 44.6-60.0)
28-30 wks GA: 177/440, 40.2% (95%CI 35.6-45.0)
31 wks GA: 107/263, 40.7% (95%CI 34.7-47.0)
32 wks GA: 138/356, 38.8% (95%CI 33.7-44.0)
33-34 wks GA: 60/195, 30.8% (95%CI 24.4-37.8)
28-31 wks GA: 284/703, 40.4% (95%CI 36.8-44.1)
32-34 wks GA: 198/551, 36.0% (95%CI 32.0-40.1)
<u>Minor neuromotor dysfunction ((moderate, MND-2, >2 items affected), Touwen assessment)</u>
≤27 wks GA: 9/178, 5.1% (95%CI 2.3-9.4)
28-30 wks GA: 16/440, 3.6% (95%CI 2.1-5.8)
31 wks GA: 6/263, 2.3% (95%CI 0.8-5.0)
32 wks GA: 7/356, 2.0% (95%CI 0.8-4.0)</td>
<td>Overall quality

Low

1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>To assess the frequency of minor neuromotor dysfunctions (MNDs) at age 5 years according to gestational age, to test their association with behavioral and learning difficulties, and to find determining neonatal factors

Study dates

Children born in 1997, assessed at 5 years age

Country/ies where the study was carried out

France

Source of funding

Institut National de la Sante´ et de la Recherche Me´dicale (French National Institute of Health and Medical Research), Merck-Sharp,</td>
<td>
<table>
<tr><td>Children still alive at 5 years (n)</td><td>2251</td><td>383</td></tr>
<tr><td>Children seen at 5 years (n)</td><td>1846</td><td>278</td></tr>
<tr><td>Children examined by paediatrician at 5 years (n)</td><td>1662</td><td>246</td></tr>
<tr><td>CP (n)</td><td>135</td><td>4</td></tr>
<tr><td>Severe intellectual impairment (IQ<50) (n)</td><td>10</td><td>0</td></tr>
<tr><td>Severe bilateral sensory impairment (n)</td><td>5</td><td>0</td></tr>
</table>
</td>
<td>(MND-0), mild (MND-1) or moderate (MND-2) neuromotor dysfunctional signs. The test was designed to detect minor abnormalities.

Age at assessment

5 years age</td>
<td>33-34 wks GA: 1/195, 0.5% (95%CI 0.01-2.8)
28-31 wks GA: 22/703, 3.1% (95%CI 2.0-4.7)
32-34 wks GA: 8/551, 1.5% (95%CI 0.63-2.8)
<u>Postural/muscle tone regulation (consistent mild deviation in posture (≥2 items) and/or in muscle tone (≥1 item)</u>
≤27 wks GA: 36/178, 20.2% (95%CI 14.6-29.0)
28-30 wks GA: 63/440, 14.3% (95%CI 11.2-18.0)
31 wks GA: 14/263, 5.3% (95%CI 2.9-8.8)
32 wks GA: 20/356, 5.6% (95%CI 3.5-8.5)
33-34 wks GA: 4.1% (95%CI 1.8-7.9)
28-31 wks GA: 77/703, 11.0% (95%CI 8.7-13.5)
32-34 wks GA: 28/551, 5.1% (95%CI 3.4-7.3)
<u>Reflex abnormalities (abnormal intensity and/or threshold or asymmetry in ≥1 item)</u>
≤27 wks GA: 26/178, 14.6% (95%CI 9.8-20.7)37.1
28-30 wks GA: 41/440, 9.3% (95%CI 6.8-12.4)
31 wks GA: 29/263, 11.0% (95%CI 7.5-15.5)</td>
<td>coverage of the identified sample?

No. 69.9% were followed up. 30.1% Children had an incomplete Touwen assessment at 5 years age due to lack of cooperation, or refusal to participate, intellectual impairment, learning difficulty, behavioural problems.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals were not provided in the study</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Dohme-Chibret, Medical Research Foundation, Directorate General for Health of the French Ministry for Social Affairs, French Hospital Program of Clinical Research			32 wks GA: 29/356, 8.2% (95%CI 5.5-11.5) 33-34 wks GA: 9/195 4.6% (95%CI 2.1-8.6) 28-31 wks GA: 70/703, 10.0% (95%CI 7.8-12.4) 32-34 wks GA: 38/551, 6.9% (95%CI 4.9-9.3) Coordination and balance (presence of age-inadequate performance on ≥2 tests) ≤27 wks GA: 66/178, 37.1% (95%CI 30.0-44.6) 28-30 wks GA: 121/440, 27.5% (95%CI 23.4-32.0) 31 wks GA:74 /263, 28.1% (95%CI 22.8-34.0) 32 wks GA: 90/356, 25.3% (95%CI 21.0-30.1) 33-34 wks GA: 41/195, 21.0% (95%CI 15.5-27.4) 28-31 wks GA: 195/703, 27.7% (95%CI 24.5-31.2) 32-34 wks GA: 131/551, 23.8% (95%CI 20.3-27.6) Motor behaviour of face and eyes (≥1 abnormal item) ≤27 wks GA: 28/178, 15.7% (95%CI 10.7-22.0) 28-30 wks GA: 53/440, 12.1% (95%CI 9.2-15.5) 31 wks GA: 36/263, 13.7% (95%CI 9.8-18.4) 32 wks GA: 57/356, 16.0% (95%CI 12.4-20.2)	**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
			33-34 wks GA: 20/195, 10.3% (95%CI 6.4-15.4) 28-31 wks GA: 89/703, 12.7% (95%CI 10.3-15.4) 32-34 wks GA: 77/551, 14.0% (95%CI 11.2-17.2) http://statpages.info/confint.html	
Ref Id 410048 **Full citation** Chan, E., Quigley, M. A., School performance at age 7 years in late preterm and early term birth: a cohort study, Archives of Disease in Childhood Fetal & Neonatal Edition, 99, F451-7, 2014 **Study type** Prospective Cohort Study **Aim of the study** To investigate the effect of gestational age,	**Setting** The Millennium Cohort Study (MCS) is a UK nationally representative longitudinal study of 18 818 children born in 2000–2001. This study included MCS families who responded at 9 months and 7 years of age with known gestational age. **Inclusion criteria** Children and born and attending school in England, UK Families included in the Millennium Cohort Study (MSC) who responded at 9 months and 7 years of age with known gestational age **Exclusion criteria** Children were excluded if: the mother was not the main respondent, gestational age was unknown, implausible for birth weight or below 23 weeks or above 42 weeks **Sample size**	**Gestational age ascertainment** Gestational age was derived from the mother's report of the expected due date in weeks taken at the 9-month survey, which has been shown to have high agreement with routine hospital records except for >42 weeks gestation. **Outcomes of interest in this study** School performance. **Outcome ascertainment/measures**	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 7 years The study reports weighted percentages, however, in order to calculate confidence intervals, the NGA technical team used the absolute numbers of cases and total sample in each GA group, therefore, the percentages reported here and in the study paper might differ. Not achieving level 2 (expected) or above in reading, writing or mathematics (KS1) <32 wks GA: 29/69, 42.0% (30.2-54.5%) 32-33 wks GA: 18/67, 26.9% (16.8-39.1%) 34-36 wks GA: 84/360, 23.3% (19.1-28.1%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision, wide confidence intervals, due to small sample size,

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>particularly late preterm birth (34–36 weeks gestation) and early term birth (37–38 weeks gestation) on school performance at age 7 years.

Study dates

2000/2001: Period of data collection (patient enrolment)
7 years: follow-up assessment

Country/ies where the study was carried out

UK

Source of funding

No details given</td>
<td>Sample recruited - N = 18818
Sample eligible for assessment - N = 13543
Sample analysed after exclusions - N = 6031
n=69 - Very preterm (<32 weeks)
n=67 - Moderately preterm (32–33 weeks)
n=360 - Late preterm (34–36 weeks)
n=1258 - Early term (37–38 weeks)
n=4277 - Full term (39–41 weeks) Reference

Characteristics

<table>
<tr><th></th><th><32 wks n=69</th><th>32-33 wks n=67</th><th>34-36 wk n=360</th></tr>
<tr><td>Maternal characteristics: (%)</td><td></td><td></td><td></td></tr>
<tr><td>UK born</td><td>84</td><td>89</td><td>88</td></tr>
<tr><td>Single mother</td><td>18</td><td>12</td><td>13</td></tr>
<tr><td>Higher education level</td><td>29</td><td>29</td><td>29</td></tr>
<tr><td>Medium education level</td><td>5</td><td>13</td><td>13</td></tr>
<tr><td>Lower education level</td><td>39</td><td>50</td><td>46</td></tr>
</table>
</td>
<td>School performance was investigated using the statutory Key Stage 1 (KS1) teacher assessments performed in the third school year in England. At KS1, children generally perform between level 1 (below expected level) to level 3 (considerably above the expected level), with adequate performance categorised as achieving level 2 or above.
KS1 results were obtained from the Department of Education's National Pupil Database.

Age at assessment

7 years</td>
<td>Not achieving level 2 (expected) or above in reading (KS1)
<32 wks GA: 18/69, 26.1% (16.3-38.1%)
32-33 wks GA: 13/67, 19.4% (10.8-30.9%)
34-36 wks GA: 65/360, 18.1% (14.2-22.4%)

Not achieving level 2 (expected) or above in writing (KS1)
<32 wks GA: 27/69, 39.1% (27.6-51.6%)
32-33 wks GA: 16/67, 23.9% (14.3-35.9%)
34-36 wks GA: 74/360, 20.6% (16.5-25.1%)

Not achieving level 2 (expected) or above in speaking and listening (KS1)
<32 wks GA: 20/69, 29.0% (18.7-41.2%)
32-33 wks GA: 11/67, 16.4% (8.5-27.5%)
34-36 wks GA: 47/360, 13.1% (9.8-17.0%)

Not achieving level 2 (expected) or above in mathematics (KS1)
<32 wks GA: -</td>
<td>especially in some GA subgroups.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear.
22% of children in the population did not have KS1 results.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td></td>
<td>
<table>
<tr><td>No formal education</td><td>27</td><td>9</td><td>12</td></tr>
<tr><td>White ethnicity</td><td>80</td><td>88</td><td>86</td></tr>
<tr><td>Only English spoken at home</td><td>90</td><td>95</td><td>92</td></tr>
<tr><td>Pregnancy and perinatal characteristics:</td><td></td><td></td><td></td></tr>
<tr><td>Maternal age in years, mean</td><td>28.7</td><td>29.1</td><td>29.2</td></tr>
<tr><td>Male, %</td><td>50</td><td>65</td><td>51</td></tr>
<tr><td>First born child, %</td><td>53</td><td>40</td><td>59</td></tr>
<tr><td>CS, %</td><td>64</td><td>60</td><td>32</td></tr>
<tr><td>Admission to NICU, %</td><td>94</td><td>82</td><td>38</td></tr>
<tr><td>Birth weight in kilograms, mean</td><td>1.26</td><td>2.03</td><td>2.57</td></tr>
</table>
</td>
<td></td>
<td>32-33 wks GA: -
34-36 wks GA: 31/360, 8.6% (5.9-12.0%)

No achieving level 2 (expected) or above in science (KS1)
<32 wks GA: 17/69, 24.6% (15.1-36.5%)
32-33 wks GA: 11/67, 16.4% (8.5-27.5%)
34-36 wks GA: 42/360, 11.7% (8.5-15.4%)

Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>8. Was there appropriate statistical analysis?

No.
Confidence intervals for prevalence estimates not provided.

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td>
</tr>
<tr>
<td>Ref Id

410055

Full citation</td>
<td>Setting

Children born in the Nord-Pas de Calais region of France (one of the 9 study areas in the EPIPAGE study).</td>
<td>Gestational age ascertainment

Gestational age referred to completed weeks of amenorrhea and was the best</td>
<td>Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)

At 2 years corrected age</td>
<td>Overall quality

Low</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Charkaluk, M. L., Truffert, P., Fily, A., Ancel, P. Y., Pierrat, V., Neurodevelopment of children born very preterm and free of severe disabilities: The Nord-Pas de Calais Epipage cohort study, Acta Paediatrica, International Journal of Paediatrics, 99, 684-689, 2010

Study type

Population based prospective cohort study (EPIPAGE).

Aim of the study

To describe the development of very preterm children free of cerebral palsy or severe sensory impairment in the domains of gross and fine motor functions, language and sociability at a corrected age of 2 years; to identify factors associated with</td>
<td>Inclusion criteria

Children born alive at a gestational age of <33 weeks.

Exclusion criteria

Children with congenital abnormalities interfering with development.

Sample size

N=634 children born alive at GA <33 weeks.
n=546 surviving children included at follow up.

Characteristics

<table>
<tr><td>Preterm cohort (N=634)</td><td></td></tr>
<tr><td><33 weeks GA (n)</td><td>634</td></tr>
<tr><td>Deaths in delivery room (n)</td><td>37</td></tr>
<tr><td>Deaths in NICU (n)</td><td>49</td></tr>
<tr><td>Down's syndrome (n)</td><td>1</td></tr>
</table>
</td>
<td>obstetric estimate based on the date of last menstrual period and an early prenatal ultrasound scan, which is routine practice in France.

Outcomes of interest in this study

Developmental quotients (DQ).

Outcome ascertainment/measures

Developmental quotients were ascertained by the revised Brunet-Lezine scale, an early childhood psychomotor development scale covering four domains of development: gross motor function, fine motor function, language and sociability.
Four separate DQs could be calculated for</td>
<td>Global DQ/developmental delay <70 (severe) (n=347 very preterm group)
<33 wks GA: 8/347, 2.3% (1.0-4.5%)
Global DQ/developmental delay <85 (moderate) (n=347 very preterm group)
<33 wks GA: 62/347, 17.9% (14.0-22.0%)

Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

The follow up rate was 83%, and differences between children followed-up and those who were lost to follow</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>performances in each domain

Study dates

Children born in 1997, assessed at 2 years corrected age.

Country/ies where the study was carried out

France.

Source of funding

Not reported.</td>
<td>
<table>
<tr><td>Agenesis of corpus callosum (n)</td><td>1</td></tr>
<tr><td>Cerebral palsy (n)</td><td>29 (quadriplegia (15), diplegia (20), hemiplegia (4)</td></tr>
<tr><td>Sensory impairment (n)</td><td>9 (hearing aid (7; one associated with CP), blind (2; both associated with CP))</td></tr>
<tr><td>Loss to follow up (n)</td><td>85</td></tr>
<tr><td>Refusal of test (n)</td><td>69</td></tr>
</table>
</td>
<td>children aged 2-30 months, which can be combined to give a global DQ. (Global DQ cut off not reported in paper; DQ ≤70 is defined as moderate developmental delay; DQ <70 is defined as severe developmental delay)
Children were considered to have an achievement discrepancy if the difference between the global DQ and at least one partial DQ was a value obtained by only 5% of the reference sample.

Age at assessment

At 2 years corrected age.</td>
<td></td>
<td>up or refused to take the test were more frequently boys and small for gestational age. They had a higher CRIB score and were more often diagnosed as having severe ultrasound abnormality. Their parents had a lower educational and occupational level.

6. Were objective, standard criteria used for the measurement of the condition?

The BLR scale (screening tool) was used to identify moderate or severe developmental delay as DQ.

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals for percentage estimates were not provided.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				9. Are all important confounding factors/subgroups/differences identified and accounted for? N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 412440 **Full citation** Chyi, L. J., Lee, H. C., Hintz, S. R., Gould, J. B., Sutcliffe, T. L., School Outcomes of Late Preterm Infants: Special Needs and Challenges for Infants Born at 32 to 36 Weeks Gestation, Journal of Pediatrics, 153, 25-31, 2008	**Setting** The data source was the publicly available ECLS-K dataset from the United States Department of Education. Children were enrolled from public and private schools from Kindergarten to eighth grade. **Inclusion criteria** Children born between 32 and 36 weeks GA and also children born between 32 and 33 weeks GA. **Exclusion criteria** Children in whom anoxia or respiratory distress at birth was reported.	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Special education needs enrollment Individualised education programme **Outcome ascertainment/measures**	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** <u>Individualised education programme</u> <u>Kindergarten stage (3 years age</u>?) 32-33 wks GA: 19/146, 13.0% (95%CI 8.0-19.6) 34-36 wks GA: 46/572, 8.0% (95%CI 6.0-10.6) 32-36 wks GA: 65/718, 9.1% (95%CI 7.1-11.4) <u>First grade (6-7 years age?)</u> 32-33 wks GA: 26/146, 17.8% (95%CI 12.0-25.0) 34-36 wks GA: 61/579, 10.5% (95%CI 8.2-13.3)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Study type

Population based cohort study (Early Childhood Longitudinal Study-Kindergarten Cohort)

Aim of the study

to test the hypothesis that infants born in the United States

at 32 to 36 weeks gestation without significant neonatal complications have greater rates

of learning difficulties compared with FT classmates</td>
<td>Sample size

N= 17,565 (ECLS-K cohort)
n=988 preterms selected
n=970 included in the analysis (after exclusions)

Characteristics

<table>
<tr><td>Characteristics of preterm cohort</td><td>n=970</td></tr>
<tr><td>Gestational age 32-33 weeks (n)</td><td>203</td></tr>
<tr><td>Gestational age 34-36 weeks (n)</td><td>767</td></tr>
<tr><td>Male (n, %)</td><td>524 (54.0)</td></tr>
<tr><td>Multiple birth (n,%)</td><td>100 (10.3)</td></tr>
<tr><td>Maternal age (32-33 wks GA) (mean, SD, yrs)</td><td>32.4+/-7.8</td></tr>
<tr><td>Maternal age (34-36 wks GA) (mean, SD, yrs)</td><td>33.4+/-6.5</td></tr>
<tr><td>Maternal education ≤ high school (n, %)</td><td>391 (40.3)</td></tr>
<tr><td>Paternal education ≤ high school (n, %)</td><td>324 (33.4)</td></tr>
</table>
</td>
<td>Direct child assessment tests were conducted with a trained assessor. This assessment included a battery of tests, including reading and math. Test items were adapted from the Peabody Individual Achievement Test-Revised, Peabody Picture Vocabulary Test-Revised, Primary Test of Cognitive Skills, the Test of Early Reading Ability, the Test of Early Mathematics Ability, and the Woodcock Johnson Tests of Achievement-Revised. Teacher academic ratings were also completed involving teacher evaluations of each student's reading and math ability.</td>
<td>32-36 wks GA: 87/725, 12% (95%CI 9.7-14.6)
<u>Third grade (8-9 years age?)</u>
32-33 wks GA: 26/132, 19.7% (95%CI 13.3-27.5)
34-36 wks GA: 64/528, 12.1% (95%CI 9.5-15.2)
32-36 wks GA: 90/660, 13.6% (95%CI 11.1-16.5)
<u>Fifth grade (10-11 years age?)</u>
32-33 wks GA: 17/94, 18.1% (95%CI 10.9-27.4)
34-36 wks GA: 49/402, 12.2% (95%CI 9.2-15.8)
32-36 wks GA: 66/402, 16.4% (95%CI 12.9-20.4)

<u>Special education enrolment Kindergarten stage (3 years age</u>?)
32-33 wks GA: 16/199, 8.04% (95%CI 4.7-12.7)
34-36 wks GA: 50/751, 6.7% (95%CI 5.0-8.7)
32-36 wks GA: 66/956, 6.9% (95%CI 5.4-8.7)
<u>First grade (6-7 years age?)</u>
32-33 wks GA:23/193, 11.9% (95%CI 7.7-17.3)
34-36 wks GA: 46/734, 6.3% (95%CI 4.6-8.3)
32-36 wks GA: 69/927, 7.4% (95%CI 5.8-9.3)
<u>Third grade (8-9 years age?)</u></td>
<td>3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. There was missing data due to children changing schools, moving out of country, or lost to follow up. In third grade, there was attrition of 14.9% and 19.7% in the late preterm and moderate preterm groups respectively. In the fifth grade, the attrition was 34% in late preterm group, and 38.9% in the moderate preterm group as infants were missing.

6. Were objective, standard criteria used for the</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Study dates 1998-1999 (children recruited at Kindergarten stage) **Country/ies where the study was carried out** USA **Source of funding** Not reported		**Age at assessment** First grade through to fifth grade	32-33 wks GA: 22/153, 14.4% (95%CI 9.2-21.0) 34-36 wks GA: 57/623, 9.2% (95%CI 7.0-11.7) 32-36 wks GA: 79/776, 10.0% (95%CI 8.0-12.3) Fifth grade (10-11 years age?) 32-33 wks GA: 18/124, 14.5% (95%CI 8.8-22.0) 34-36 wks GA: 52/506, 10.3% (95%CI 7.8-13.3) 32-36 wks GA: 70/630, 11.1% (95%CI 8.8-13.8) http://statpages.info/confint.html	**measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not reported in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Ref Id 336268 **Full citation** De Groote, I., Vanhaesebrouck, P., Bruneel, E., Dom, L., Durein, I., Hasaerts, D., Laroche, S., Oostra, A., Ortibus, E., Roeyers, H., Van Mol, C., Outcome at 3 years of age in a population-based cohort of extremely preterm infants, Obstetrics and Gynecology, 110, 855-864, 2007 **Study type** Population-based geographically defined cohort study (EPIBEL) **Aim of the study** To assess health and neurodevelopmental outcome at 3 years of age in neonatal intensive care unit-surviving children who	**Setting** Population-based cohort of all surviving extremely preterm infants in Flanders, Belgium (the Extremely Preterm Infants in Belgium [EPIBEL] Study). **Inclusion criteria** All infants who were born at less than 27 weeks of gestation in one of the perinatal centres of Flanders, Belgium from January 1, 1999 to January 1, 2001, who were admitted to a neonatal intensive care unit and who survived to discharge from the neonatal intensive care unit. **Exclusion criteria** None reported. **Sample size** n=95 children that survived to discharge from NICU n=77 children assessed at 3 years (n=3 died before follow-up, n=12 parents did not give consent, n=3 could not be reached), 81% follow-up rate (84% of the ones who were alive at follow-up). **Characteristics** The mean body weight at 36 months of age was 1.25 (+-1.48) standard deviation below the mean of the specific Flemish population norms. Average head circumference was 0.80 (+-1.30) standard deviation lower. Stature -0.76 (+-1.23) standard	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** Psychomotor Developmental Index (PDI) **Outcome ascertainment/measures** The assessement at 3 years comprised of a detailed clinical examination and full developmental evaluation. The clinical evaluation included collecting the recent medical history and a global health and anthropometric assessment as well as standardised neurologic and sensory examination. The Dutch edition of the second version of the	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 3 years Severe psychomotor developmental delay (PDI <55) <27 wks GA: 21/77, 27.3% (17.7-38.6%) Moderate psychomotor developmental delay (PDI 55-69) <27 wks GA: 16/77, 20.8% (12.4-31.5%) Moderate to severe psychomotor developmental delay (PDI <70)* <27 wks GA: 37/77, 48.1% (36.5-59.7%) *Calculated by the NGA technical team. Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to low sample size. **4. Were the study subjects and the setting described in detail?** No. Limited description of characteristics provided.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
were born at 26 or fewer weeks of gestation in a geographically defined region of Blgium from 1999 through 2000. **Study dates** Children born in 1999-2000, follow-up at 3 years of age. **Country/ies where the study was carried out** Belgium **Source of funding** The Foundation Marguerite Marie Delacroix and the Belgian Ministry of Health	deviation shorter than the corresponding figures in age-matched controls. 54% had one or more somatic difficulties (data available for 87 of the 92 longterm survivors). Recurrent upper (25%) and/or lower (23%) airway disease were most frequently encountered with chronic aerosol treatment in 18% of the children. Chronic intestinal disorders were present in 10%, with two toddlers dependent on gastrostomy feeding. Shunt got hydrocephalus was present in five children (6%). Other background characteristics not provided.	Bayley Scales of Infant Development (BSID-II-NL) was used to assess mental and psychomotor development. The BSID-II-NL is standardised on a mean score of 100 and a SD of 15 points. Moderate impairment is defined as a score of 55-69 and severe impairment as a score of <55. **Age at assessment** 3 years		**5. Was the data analysis conducted with sufficient coverage of the identified sample?** Unclear. 84% of the children still alive at follow-up were followed-up. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				9. Are all important confounding factors/subgroups/differences identified and accounted for? N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 410216 **Full citation** de Kleine, M. J., den Ouden, A. L., Kollee, L. A., Nijhuis-van der Sanden, M. W., Sondaar, M., van Kessel-Feddema, B. J., Knuijt, S., van Baar, A. L., Ilsen, A., Breur-Pieterse, R., Briet, J. M., Brand, R., Verloove-Vanhorick, S. P., Development and evaluation of a follow up assessment of preterm infants at 5	**Setting** Three Dutch neonatal intensive care units. **Inclusion criteria** 5-year old survivors born before 32 weeks of gestation or weighing <1500 g and treated in one of three Dutch neonatal intensive care units in 1/10/1992-15/6/1994 (NICU at the University Medical Centre Nijmegen); 15/11/1992-1/1/1994 (Academic Medical Centre Amsterdam); and 1/1/1993-1/1/1995 (Maxima Mecical Centre Veldhoven. **Exclusion criteria** Children who participated in another study (n=46).~ Children with known severe cerebral palsy, blindness, severe mental retardation, chromosomal abnormalities, or inborn error	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** Behavioural problems (CBCL, score of >=64) **Outcome ascertainment/measures** At 5 years, behavioural problems were assessed with the full Child Behaviour	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 5 years Total behavioural problems (CBCL, score >=65) <32 wks GA/bw <1500 g: 56/407, 56/407, 13.8% (10.6-17.5%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>years of age, Archives of Disease in Childhood, 88, 870-5, 2003

Study type

A prospective cohort study

Aim of the study

To develop and validate an assessment tool that can help paediatricians to identify before 6 years of age which survivors have developmental disturbances that may interfere with normal education and normal life.

Study dates

Children 1992-1995, assessed at 5 years.

Country/ies where the study was carried out

The Netherlands</td>
<td>of metabolism (n=21) because it was obvious they would not be able to perform the assessment tests.

Sample size

n=566 eligible children
n=431 assessed at 5 years (76%)
n=404 assessed for motor functioning (M-ABC)
n=402 assessed for IQ (IQ test)
n=407 assessed for behavioural problems (CBCL)

Characteristics

<table>
<tr><td></td><td>Eligible children n=431</td></tr>
<tr><td>Male, %</td><td>55</td></tr>
<tr><td>Multiple pregnancy, %</td><td>36</td></tr>
<tr><td>GA in weeks, mean? (SD)</td><td>30.2 (2.0)</td></tr>
<tr><td>Birth weight in grams, mean? (SD)</td><td>1276 (332)</td></tr>
</table>
</td>
<td>Checklist (CBCL) by trained child psychologists. Total scores up to and including 59 are considered normal, from 60 up to and including 63 intermediate and from 64 upwards "clinically important" disturbance of behaviour.

Age at assessment

5 years</td>
<td></td>
<td>3. Was the sample size adequate?

Unclear.
Somewhat low precision (somewhat wide confidence intervals) due to relatively low sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
More than 20% of the eligible children were not followed-up. However, the study compares the characteristics of the ones assessed and the ones not assessed. Statistically, the ones followed-up were more often multiple pregnancies, otherwise no big differences between the groups were observed.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Source of funding The Dutch Health Organisations Praeventiefonds and ZorgOnderzoek Nederland (ZON).	CS, % 48 Apgar score <7 at 5 min, % 17 Positive pressure ventilation, % 49 Surfactant administration, % 19 BPD, % 14 IVH grade I-IV, % 19			**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				10. Were subpopulations identified using objective criteria? N/A
Ref Id 410231 **Full citation** Delobel-Ayoub, M., Arnaud, C., White-Koning, M., Casper, C., Pierrat, V., Garel, M., Burguet, A., Roze, J. C., Matis, J., Picaud, J. C., Kaminski, M., Larroque, B., Behavioral problems and cognitive performance at 5 years of age after very preterm birth: The EPIPAGE study, Pediatrics, 123, 1485-1492, 2009 **Study type** Population based prospective cohort study (EPIPAGE).	**Setting** All liveborn very preterm infants in 9 regions in France. **Inclusion criteria** All live born infants born at <33 weeks of gestation in 1997 in 9 French regions. **Exclusion criteria** Death before follow up. Declined follow up. Multiple births. Children with severe sensory impairment (blindness or deafness) or severe neuromotor deficiency. Children aged ≥6 years at the time of assessment. **Sample size** n = 2276 preterm infants born at 22-32 weeks originally recruited n = 1690 children's parent(s) completed questionnaire n = 1102 preterm children included in analysis after exclusions **Characteristics** Not reported in this article.	**Gestational age ascertainment** Gestational age was expressed in completed weeks of amenorrhoea. **Outcomes of interest in this study** Total behavioural difficulties (SDQ) **Outcome ascertainment/measures** The French version of the Strengths and Difficulties Questionnaire (SDQ) was completed by one or both parents' (98%) or another caregiver (2%). Scores from the four symptom scales (hyperactivity/inattentio	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 5 years Total behavioural difficulties (SDQ, 10th percentile) 22-32 wks GA: 240/1095, 21.9% (19.5-24.5%) Hyperactivity (SDQ, 10th perc) 22-32 wks GA: 198/1096, 18.1% (15.8-20.5%) Conduct problem (SDQ, 10th perc) 22-32 wks GA: 123/1097, 11.2% (9.4-13.2%) Emotional symptoms (SDQ, 10th perc) 22-32 wks GA: 228/1096, 20.8% (18.4-23.3%) Peer problems (SDQ, 10th perc) 22-32 wks GA: 220/1097, 20.1% (17.7-22.6%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. Relatively high precision, the confidence intervals are relatively narrow.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Aim of the study To compare the frequency of behavioural problems in very preterm and term children at 5 years of age. **Study dates** Children born 1997, follow-up at 5 years of age. **Country/ies where the study was carried out** France **Source of funding** Institut National de la Santé et de la Recherche Médicale, Marck-Sharp, Dohme-Chibret, la Fondation de la Recherche Médicale and la Direction Générale de la Santé du Ministère des Affaires Sociales, the		n, conduct, emotional and peer problems) are summed to provide a "total difficulties" score, with higher scores indicating poorer mental health. Cut-offs were defined based on the 10th percentile of the observed scores in the control group. **Age at assessment** 5 years	Prosocial behaviour (SDQ, 10th perc) 22-32 wks GA: 169/1095, 15.4% (13.3-17.7%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**4. Were the study subjects and the setting described in detail?** No. Description of population and sample not provided. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. N= 2382 very preterm children born, parents gave consent for follow-up in 96% (n=2276) cases. Follow-up questionnaire was completed by n=1690 (74% of the consented ones), of which 1102 were included in final analysis (65% of the consented ones). **6. Were objective, standard criteria used for the measurement of the condition?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Programme Hospitalier de Recherche Clinique.				**7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 412504	**Setting** All liveborn very preterm infants in 9 regions in France.	**Gestational age ascertainment**	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)**	**Overall quality** 391Low

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Full citation

Delobel-Ayoub, M., Kaminski, M., Marret, S., Burguet, A., Marchand, L., N'Guyen, S., Matis, J., Thiriez, G., Fresson, J., Arnaud, C., Poher, M., Larroque, B., Behavioral outcome at 3 years of age in very preterm infants: The EPIPAGE study, Pediatrics, 117, 1996-2005, 2006

Study type

Population based prospective cohort study (EPIPAGE).

Aim of the study

To compare the prevalence of behavioural problems between very preterm children and term children at 3 years of age and examine the factors associated with behavioural problems in very preterm children.</td>
<td>Inclusion criteria

All live born infants born at <33 weeks of gestation in 1997 in 9 French regions.

Exclusion criteria

Death before follow up. Declined follow up. Multiple births. Children with severe sensory impairment (blindness or deafness or severe cerebral palsy) or severe neuromotor deficiency. Children who were >4 years old when questionnaire was completed.

Sample size

N=2382 very preterm infants originally survived to discharge
N=1880 children's parent(s) completed the questionnaire
N=1228 very preterm singletons included in analysis after exclusions

Characteristics

<table>
<tr><th></th><th>N</th></tr>
<tr><td>Male</td><td>637</td></tr>
<tr><td>Female</td><td>565</td></tr>
<tr><td>Maternal age >25 y</td><td>232</td></tr>
</table>
</td>
<td>Gestational age was expressed in completed weeks of amenorrhoea.

Outcomes of interest in this study

Behavioural difficulties (SDQ)

Outcome ascertainment/measures

The French version of the Strengths and Difficulties Questionnaire (SDQ) for 3- to 4-year-old children was completed by parents. Scores from the four symptom scales (hyperactivity/inattention, conduct, emotional and peer problems) are summed to provide a "total difficulties" score, with higher scores indicating poorer mental health. Cut-offs</td>
<td>At 3 years
<u>Total behavioural difficulties, (SDQ, 10th percentile)</u>
<33 wks GA: 240/1202, 20.0% (17.7-22.3%)
24-28 wks GA: 66/274, 24.1% (19.2-29.6%)
29-30 wks GA: 57/338, 16.9% (13.0-21.3%)
31-32 wks GA: 112/590, 19.0% (15.9-22.4%)
29-32 wks GA: 169/928, 18.2% (15.8-20.9%)

<u>Hyperactivity (SDQ, 10th perc)</u>
<33 wks GA: 241/1205, 20.0% (17.8-22.4%)
24-28 wks GA: 66/274, 24.1% (19.2-29.6%)
29-30 wks GA: 58/339, 17.1% (13.3-21.6%)
31-32 wks GA: 112/592, 18.9% (15.8-22.3%)
29-32 wks GA: 170/931, 18.3% (15.8-20.9%)

<u>Conduct problem (SDQ, 10th perc)</u>
<33 wks GA: 193/1207, 16.0% (14.0-18.2%)
24-28 wks GA: 44/274, 16.1% (11.9-21.0%)</td>
<td>1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No.
Especially in some smaller GA subgroups, the precision is low (confidence intervals are wide) due to relatively small sample.

4. Were the study subjects and the setting described in detail?

Yes</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Study dates Children born 1997, follow-up at 3 years of age. **Country/ies where the study was carried out** France **Source of funding** Institut National de la Santé et de la Recherche Médicale, Marck-Sharp, Dohme-Chibret, la Fondation de la Recherche Médicale and la Direction Générale de la Santé du Ministère des Affaires Sociales, the Programme Hospitalier de Recherche Clinique.	Maternal age 25-34 y: 741 Maternal age >=35 y: 220 Birth order: 1: 622 2 or 3: 452 >=4: 121 Low social class of the family: 508 Middle social class of the family: 369 High social class of the family: 302 Maternal education status low: 862 Maternal education status not low: 309 Mother living alone: 122 Mother not living alone: 1000 Information missing: 80 Mother's nationality French: 981 Mother's nationality other than French: 101 Information missing: 120 SGA: 118 Not SGA: 1078	were defined based on the 10th percentile of the observed scores in the control group. **Age at assessment** 3 years	29-30 wks GA: 54/340, 15.9% (12.2-20.2%) 31-32 wks GA: 89/593, 15.0% (12.2-18.1%) 29-32 wks GA: 143/933, 15.3% (13.1-17.8%) <u>Emotional symptoms (SDQ, 10th perc)</u> <33 wks GA: 181/1207, 15.0% (13.0-17.1%) 24-28 wks GA: 47/274, 17.2% (12.9-22.2%) 29-30 wks GA: 48/340, 14.1% (10.6-18.3%) 31-32 wks GA: 89/593, 15.0% (12.2-18.1%) 29-32 wks GA: 137/933, 14.7% (12.5-17.1%) <u>Peer problems (SDQ, 10th perc)</u> <33 wks GA: 168/1203, 14.0% (12.1-16.1%) 24-28 wks GA: 49/274, 17.9% (13.5-22.9%) 29-30 wks GA: 44/339, 13.0% (9.6-17.0%) 31-32 wks GA: 71/590, 12.0% (9.5-14.9%) 29-32 wks GA: 115/929, 12.4% (10.3-14.7%) <u>Prosocial behaviour (SDQ, 10th perc)</u>	**5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. 52% of the survived children included in final analysis. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Number of cases in each group and confidence intervals for prevalence estimates not provided. **9. Are all important confounding**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	GA 24-28 wks: 274 GA 29-30 wks: 338 GA 31-32 wks: 590 Major cerebral lesions: 29 Moderate cerebral lesions: 166 Minor cerebral lesions: 190 No cerebral lesions: 797		<33 wks GA: 181/1205, 15.0% (13.1-17.2%) 24-28 wks GA: 55/274, 20.1% (15.5-25.3%) 29-30 wks GA: 54/339, 15.9% (12.2-20.3%) 31-32 wks GA: 77/592, 13.0% (10.4-16.0%) 29-32 wks GA: 131/931, 14.1% (11.9-16.5%) The study reported only the denominator and the percentage without decimals, and the NGA technical team calculated the number of cases in each group based on these figures. Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 410382 **Full citation** Faebo Larsen, R., Hvas Mortensen, L., Martinussen, T., Nybo Andersen, A. M., Determinants Of	**Setting** National birth cohort in Denmark. **Inclusion criteria** Children whose mothers had provided interview information early in pregnancy and had participated in the 7-year follow-up during the period when motor development was assessed. Children with no other siblings.	**Gestational age ascertainment** **Outcomes of interest in this study** DCD symptoms	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 7 years of age Indication of, or suspect for DCD 23-31 wks GA: 25/137, 18.3% (12.2-25.8%) 32-36 wks GA: 79/1234, 6.4% (5.1-7.9%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Developmental Coordination Disorder In 7-Year-Old Children: A Study Of Children In The Danish National Birth Cohort, Developmental Medicine and Child Neurology, 55, 1016-1022, 2013

Study type

Danish National Birth Cohort study.

Aim of the study

To investigate early life determinants of developmental coordination disorder (DCD) in 7-year-old children.

Study dates

Children born in 1996-2002, follow-up at 7 years of age.</td>
<td>Exclusion criteria

Children with missing information on at least 1 of the questions in the DCDQ.
Children with missing data on covariates.

Sample size

N=32097 children (including term and preterm children) included in analysis
N=1234 moderately preterm (32-36 wks)
N=137 very preterm (23-31 wks)

Characteristics

Characteristics of the study population before excluding because of missing information on DCDQ or covariates (total N=33354)
<table>
<tr><td></td><td>23-31 wk</td><td>32-36 wk</td><td>37-41 wk</td></tr>
<tr><td>Total number</td><td>141</td><td>1281</td><td>29044</td></tr>
<tr><td>Male, %</td><td>52.5</td><td>54.9</td><td>50.9</td></tr>
<tr><td>SGA, %</td><td>41.8</td><td>17.2</td><td>8.4</td></tr>
<tr><td>Maternal age <25 y, %</td><td>12.8</td><td>13.1</td><td>10.9</td></tr>
<tr><td>Maternal age >=35 y, %</td><td>13.5</td><td>14.2</td><td>12.6</td></tr>
</table>
</td>
<td>Outcome ascertainment/measures

The outcome was based on the Developmental Coordination Disosder Questionnaire (DCDQ) '07 which is a parent questionnare aimed at identifying children with motor problems. It enables classification of children into the categories 'indication possible or suspect for DCD' versus 'probably not DCD'. It captures three motor development areas: control during movement, fine motor control/handwriting, and general coordination. It has been demonstrated as a valid instrument in terms od internal consistency, construct validity, and concurrent validity and is regarded as an accurate screening instrument. The Danish version</td>
<td>Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Unclear.
For the larger GA subgroup (32-36 wks) the sample size was adequate (good precision, narrow confidence intervals), however, for the smaller GA subgroup (23-31 wks) the sample was small and showed low precision (wide confidence intervals).

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Country/ies where the study was carried out

Denmark

Source of funding

None reported.</td>
<td>
<table>
<tr><td>Maternal occupation:</td><td></td><td></td><td></td></tr>
<tr><td>High grade professionals, %</td><td>11.4</td><td>7.6</td><td>10.1</td></tr>
<tr><td>Lower grade professionals, %</td><td>22.7</td><td>29.7</td><td>29.9</td></tr>
<tr><td>Skilled workers, %</td><td>14.2</td><td>18.6</td><td>18.4</td></tr>
<tr><td>Unskilled workers, %</td><td>32.6</td><td>25.5</td><td>23.0</td></tr>
<tr><td>Students, %</td><td>12.8</td><td>12.2</td><td>13.0</td></tr>
<tr><td>Economically inactive, %</td><td>5.0</td><td>5.4</td><td>4.7</td></tr>
<tr><td>Unclassified, %</td><td>1.4</td><td>1.1</td><td>0.9</td></tr>
</table>
</td>
<td>was, after translation from English and back-translation from Danish to English by an independent translator, approved by Dr Brenda Wilson, who developed and tested the original questionnaire.

Age at assessment

7 years of age</td>
<td></td>
<td>Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.
Confidence intervals for prevalence estimates not provided.

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				10. Were subpopulations identified using objective criteria? N/A
Ref Id 434950 **Full citation** Farooqi, A., Hagglof, B., Sedin, G., Gothefors, L., Serenius, F., Mental health and social competencies of 10- to 12-year-old children born at 23 to 25 weeks of gestation in the 1990s: a Swedish national prospective follow-up study, Pediatrics, 120, 118-33, 2007 **Study type** Nationally-representative population-based cohort study **Aim of the study**	**Setting** National cohort in Sweden. **Inclusion criteria** Survivors of a national cohort of 247 consecutive, live-born, extremely immature (<26 weeks of gestation) infants born during the period from April 1990 through March 1992 in the whole of Sweden. **Exclusion criteria** None reported. **Sample size** Total sample: n=169 Extremely immature (EI) children born before 26 completed weeks of gestation (n=————————————————83) Controls (n=————————————————86) children with normal birth weight born at term at the same hospital, of the same gender and nearest in birth date (7 days) to the extremely immature child.	**Gestational age ascertainment** Not reported how GA was measured/estimated. **Outcomes of interest in this study** Behavioural problems (CBCL and TRF) Children self report of depression scale Special schooling School difficulties **Outcome ascertainment/measures** For assessment of the parents' and teachers' perceptions of the children's behavior, the parents completed the Child Behavior Checklist (CBCL) for	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 11 years **Parents' report** Total behavioural problems (CBCL, 90th perc) <26 wks GA: 24/83, 28.9% (19.5-39.9%) Anxious/depressed (CBCL, 90th perc) <26 wks GA: 22/83, 26.5% (17.4-37.4%) Withdrawn (CBCL, 90th perc) <26 wks GA: 30/83, 36.1% (25.9-47.4%) Somatic complaints (CBCL, 90th perc) <26 wks GA: 11/83, 13.3% (6.8-22.5%) Social problems (CBCL, 90th perc) <26 wks GA: 21/83, 25.3% (16.4-36.0%)) Thought problems (CBCL, 90th perc) <26 wks GA: 16/83, 19.3% (11.4-29.4%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to small sample size.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
To investigate a national cohort of extremely immature children with respect to behavioral and emotional problems and social competencies, from the perspectives of parents, teachers, and children themselves. **Study dates** Children born between 1990 and 1992, assessed at 11 years. **Country/ies where the study was carried out** Sweden **Source of funding** The study was supported by the Oskarfonden Foundation and the Sven-Jerrings Fond Foundation.	**Characteristics** At 11 years of age, 13 EI children (15%) had neurosensory impairments, which included 1 of the following conditions: CP for 5, severe visual impairment (including unilateral or bilateral blindness) for 10, and sensorineural disability requiring a hearing aid for 5. In the control group, the corresponding rate was 2% (n ——————————— 2; 1 child had CP, and 1 had severe visual impairment).25 Of the 86 EI children, 73 (85%) were in mainstream schools and 13 (15%) were receiving full-time special education. The corresponding rates for the control group were 82 (95%) and 4 (5%). The overall prevalence of 1 major disability was 21% for the EI children and 6% for the control participants (——————————— 2 ——————————— 7.03; P ——————————— .006).25 There were no statistically significant differences between the EI and control participants regarding family structure, maternal education, maternal mental health risk index, SES, and family function.	ages 4 to 18 years and the teachers completed the analogous Teacher Report Form (TRF). Both forms include 118 items for scoring particular behavior/emotional problems, plus 2 open-ended problem items. The list contains 118 items on difficult behaviors, all scored 0 (not true), 1 (somewhat or sometimes true), or 2 (very true or often true). Principal-component analyses reveal 8 sets of behaviors: **withdrawn, somatic complaints, anxious or depressed, social problems, thought problems, attention problems, delinquent behavior, and aggressive behavior.** Principal-factor analyses of the 8 categories produce 2 broad groupings, namely, **internalizing**, derived from the sum of the items in the first	Attention problems (CBCL, 90th perc) <26 wks GA: 25/83, 30.1% (20.5-41.2%) Aggressive behaviour (CBCL, 90th perc) <26 wks GA: 11/83, 13.3% (6.8-22.5%) Delinquent behaviour (CBCL, 90th perc) <26 wks GA: 9/83, 10.8% (5.1-19.6%) Internalising (CBCL, 90th perc) <26 wks GA: 27/83, 32.5% (22.7-43.7%) Externalising (CBCL, 90th perc) <26 wks GA: 8/83, 9.6% (4.3-18.1%) **Teachers' report** Total behavioural problems (TRF, 90th perc) <26 wks GA: 20/83, 24.1% (15.4-34.7%) Anxious/depressed (TRF, 90th perc) <26 wks GA: 19/83, 22.9% (14.4-33.4%) Withdrawn (TRF, 90th perc) <26 wks GA: 19/83, 22.9% (14.4-33.4%) Somatic complaints (TRF, 90th perc)	**4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes (out of 89 children alive at 11 years, 83 were followed up) **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		3 sets, and **externalizing**, derived from the last 2 (delinquent behavior and aggressive behavior). The remaining 3 categories (social, thought, and attention problems) represent problems that fit either broad grouping. Respondents were asked to base their answers on the preceding 6 months. For all TRF and CBCL problem subscales, scores above the 90th percentile for the control subjects of the same gender were classified as being in the abnormal range. The percentile distribution of the total CBCL problem scores for our control group was similar to that for a Swedish reference population. Children completed a self-report with a **depression** self-rating scale (DSRS).32 The DSRS is an 18-item	<26 wks GA: 17/83, 20.5% (12.4-30.8%) Social problems (TRF, 90th perc) <26 wks GA: 17/83, 20.5% (12.4-30.8%) Thought problems (TRF, 90th perc) <26 wks GA: 25/83, 30.1% (20.5-41.2%) Attention problems (TRF, 90th perc) <26 wks GA: 20/83, 24.1% (15.4-34.7%) Aggressive behaviour (TRF, 90th perc) <26 wks GA: 17/83, 20.5% (12.4-30.8%) Delinquent behaviour (TRF, 90th perc) <26 wks GA: 19/83, 22.9% (14.4-33.4%) Internalising (TRF, 90th perc) <26 wks GA: 21/83, 25.3% (16.4-36.0%) Externalising (TRF, 90th perc) <26 wks GA: 15/83, 18.1% (10.5-28.1%) Children's self-reported depression scale abrnormal score (DSRS) <26 wks GA: 10/83, 12.1% (5.9-21.0%)	Confidence intervals for prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		self-report questionnaire composed of a psychiatric symptom checklist that measures anxiety and depression. The child is asked to rate his or her own situation during the past month, on a 3-point scale. Scores of 2, 1, and 0 refer to most of the time, sometimes, and never, respectively. For the DSRS, scores above the 90th percentile for the control subjects of the same gender were classified as being in the abnormal range. School difficulties was defined as the child repeating a grade and/or using special educational resources (full-time or part-time). Attending special class or special school means attending a special school or training school for the physically disabled and severely mentally	<u>Special class or special school</u> <26 wks GA: 13/86, 15.1% (8.3-24.5%) <u>Grade repetition</u> <26 wks GA: 13/83, 15.7% (8.6-25.3%) <u>School difficulties (repeated year or special educational resources)</u> <26 wks GA: 51/86, 59.3% (48.2-69.8%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		retarded or receiving full-time special education attached to the mainstream school. **Age at assessment** 11 years		
Ref Id 410443 **Full citation** Foix-L'Helias, L., Marchand, L., Theret, B., Larroque, B., Ancel, P. Y., Blondel, B., Garel, M., Maillard, F., Missy, P., Sehili, F., Supernant, K., Durand, M., Matis, J., Messer, J., Treisser, A., Burguet, A., Abraham-Lerat, L., Menget, A., Roth, P., Schaal, J. P., Thiriez, G., Leveque, C., Marret, S., Marpeau, L., Boulot, P., Picaud, J. C., Donadio, A. M., Ledesert, B., Andre, M., Fresson, J., Hascoet, J. M., Arnaud, C., Bourdet-Loubere,	**Setting** All maternity units in nine regions of France, EPIPAGE study. **Inclusion criteria** For this analysis, any birth between 24^{+0} and 32^{+6} weeks of gestation in all maternity units of nine French regions in 1997. **Exclusion criteria** Missing data on antenatal steroid use. For the purpose of this analysis children who died before 5 years were excluded. The protocol included the option of not following up one of every two infants born at 32 weeks (to reduce the workload). 2 regions exercised this option leading to the exclusion of 68 infants. **Sample size** Disorders: n=1781 children with data on CP (77% of n=2300 survivors up to follow-up)	**Gestational age ascertainment** Gestational age was determined from the last menstrual period and findings from early prenatal ultrasound scans and calculated in completed weeks. **Outcomes of interest in this study** Total behavioural difficulties (SDQ) **Outcome ascertainment/measures** Follow up was at 5 years of age, and involved a medical and	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 5 years Total behavioural difficulties (SDQ, 10th percentile) 24-32 wks GA: 348/1645, 21.2% (19.2-23.2%) 24-27 wks GA: 52/234, 22.2% (17.1-28.1%) 28-32 wks GA: 296/1411, 21.0% (18.9-23.2%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Moderate. **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. Presicion is somewhat low (relatively wide confidence intervals) due to relatively

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
S., Grandjean, H., Rolland, M., Leignel, C., Lequien, P., Pierrat, V., Puech, F., Subtil, D., Truffert, P., Boog, G., Rouger-Bureau, V., Roze, J. C., Ancel, P. Y., Breart, G., Kaminski, M., Du Mazaubrun, C., Dehan, M., Zupan-Simunek, V., Vodovar, M., Voyer, M., Impact of the use of antenatal corticosteroids on mortality, cerebral lesions and 5-year neurodevelopmental outcomes of very preterm infants: The EPIPAGE cohort study, BJOG: An International Journal of Obstetrics and Gynaecology, 115, 275-282, 2008 **Study type** Prospective population based cohort study (EPIPAGE). **Aim of the study**	n=1508 children with data on cognition (66% of the n=2300 survivors up to follow-up) Problems: n=1645 children with data on behavioural difficulties (72% of the n=2300 survivors up to follow-up) **Characteristics** Baseline characteristics not described in this publication.	neuropsychological assessment. Total behavioural difficulties were assessed using the French version of the Strengths and Difficulties Questionnaire (SDQ) completed by parents. This questionnaire includes 25 items structured into five scales which assess hyperactivity-inattention, conduct problems, emotional symptoms, peer problems and prosocial behaviour. Scores for the first four symptom scales are summed to provide an overall difficulties score with a range of 0-40. The cut-offs were defined such that about 10% of the children in contemporaneous reference group of children born at term (born between 39 and 40 weeks of GA) were considered at high risk of having a behavioural problem.		small sample size, especially in 24-27 weeks of GA group. **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. Around 30% lost to follow-up. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
To assess the impact of antenatal steroids on neurodevelopmental outcome of infants born at 24-27 weeks and 28-32 weeks gestation. **Study dates** Recruitment took place in 1997. Follow up was at 5 years. **Country/ies where the study was carried out** France **Source of funding** INSERM (National Institute of Health and Medical Research), Directorate General for Health of the Ministry for Social Affairs, Merck-Sharp and Dohme-Chibret, Medical Research Foundation, HAS (French National Authority for Health) and "Hospital Program		**Age at assessment** 5 years.		**8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
for Clinical Research 2001 n° AOMO1117" of the French Department of Health.				
Ref Id 322030 **Full citation** Germa,A., Marret,S., Thiriez,G., Rousseau,S., Hascoet,J.M., Paulsson-Bjornsson,L., Soderfeldt,B., Ancel,P.Y., Larroque,B., Kaminski,M., Nabet,C., Neonatal factors associated with alteration of palatal morphology in very preterm children: the EPIPAGE cohort study, Early Human Development, 88, 413-420, 2012 **Study type** Prospective population-based cohort (EPICURE)	**Setting** All births between 22 and 32 completed weeks of gestation in all maternity units in 9 French regions in 1997 **Inclusion criteria** Children born at 22-33 completed weeks of gestation whose parents agreed to participate in the follow up, or lack of information on palatal morphology **Exclusion criteria** Children with cranial, facial or neck malformation **Sample size** N=2901 born in 1997 N=247 born in 1998 n=2349 children born very preterm and followed n=1882 children followed because they attended the medical examination n=1711 children born followed who did not have head malformation and who underwent the medical examination at 5 years age were included	**Gestational age ascertainment** Gestational age (GA) recorded was the best obstetric estimate based on the date of the last menstrual period and an early prenatal ultrasound, which is routine practice in France **Outcomes of interest in this study** Palatal morphology **Outcome ascertainment/measures** Palatal morphology was assessed by simple visual inspection as altered or not by the physicians,	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 5 years age Altered palatal morphology 22-33 wks GA: 63/1711, 3.7% (95%CI 2.9-4.7) http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Aim of the study

To explore the role of neonatal characteristics and neuromotor dysfunction in alteration of palatal morphology at 5 years of age in very preterm children

Study dates

1997-1998, assessed at 5 years age

Country/ies where the study was carried out

France

Source of funding

INSERM(French National Institute of Health and Medical Research), the Directorate General for Health of the Ministry for Social Affairs, Merck-Sharp and</td>
<td>Characteristics

<table>
<tr><td>Characteristics of the study population</td><td>n=1711</td></tr>
<tr><td>Boys (n, (%))</td><td>880 (51.4)</td></tr>
<tr><td>23-26 GA (weeks) (n, (%))</td><td>200 (11.7)</td></tr>
<tr><td>27-29 GA (weeks) (n, (%))</td><td>456 (26.7)</td></tr>
<tr><td>30-32 GA (weeks) (n, (%))</td><td>1055 (61.7)</td></tr>
<tr><td>Small for gestational age (n, (%))</td><td>321 (18.8)</td></tr>
<tr><td>Maternal country of birth France (n, (%))</td><td>1434 (85.0)</td></tr>
</table>
</td>
<td>without any further indication. The assessment criteria for altered palatal morphology were left to the physicians' judgement.

Age at assessment

5 years age</td>
<td></td>
<td>5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

No. As palatal morphology was not among the main outomes of the cohort followed up, the physicians were not specifically standardised for this assessment.

8. Was there appropriate statistical analysis?

Yes</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Dohme-Chibret, Medical Research Foundation, and the Hospital Program for Clinical Research of the French Department of Health				**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 357437 **Full citation** Guellec, I., Lapillonne, A., Renolleau, S., Charlaluk, M. L., Roze, J. C., Marret, S., Vieux, R., Monique, K., Ancel, P. Y., Neurologic outcomes at school age in very preterm infants born with severe or mild growth restriction, Pediatrics, 127, e883-e891, 2011 **Study type**	**Setting** Cohort of preterm children in 9 regions in France (EPIPAGE). **Inclusion criteria** All children born at <33 completed weeks of gestation in all maternity units of 9 regions of France in 1997 who survived to discharge. In addition, all children born at 32 weeks of gestation were included in 7 of the regions and in 2 regions, every other child born at 32 weeks were included. **Exclusion criteria** Children who died before discharge from the hospital. Children whose neurologic status was unknown at follow-up due to artificial respiration (n=4).	**Gestational age ascertainment** Gestational age referred to completed weeks of amenorrhoea, which was the best obstetric estimate and combined last menstrual period and early prenatal ultrasound and clinical assessments, which is routine practice in France. **Outcomes of interest in this study**	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 5 years age <u>Inattention-hyperactivity symptoms (SDQ, 10th perc)</u> *SGA children (bw <10th percentile)* 24-28 wks GA: 4/21, 19% (5.5-42.0%) 29-32 wks GA: 27/115, 23.5% (16.0-32.3%) *MGA children (bw 10th-19th percentile)* 24-28 wks GA: 7/33, 21.2% (9.0-38.9%) 29-32 wks GA: 19/121, 15.7% (9.7-23.4%) *AGA (bw >=20th percentile)*	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Population based prospective cohort study (EPIPGAGE study)

Aim of the study

To determine whether mild and severe growth restriction at birth among preterm infants is associated with neonatal mortality and cerebral palsy and cognitive performance at 5 years of age and school performance at 8 years age.

Study dates

Children born 1997, assessed at 5 years (at 8 years for school difficulties).

Country/ies where the study was carried out

France.</td>
<td>Sample size

N=2855 live births at 24-32 weeks GA.
n=2357 infants eligible for follow-up

Characteristics

<table>
<tr><td>Live births 24-32 weeks GA =2864)</td><td></td></tr>
<tr><td>24-28 wks GA (SGA)</td><td>8.6%</td></tr>
<tr><td>29-32 wks GA (SGA)</td><td>9.5%</td></tr>
<tr><td>Singleton (SGA) at 24-28 wks GA</td><td>9.5%</td></tr>
<tr><td>Singleton (SGA) at 29-32 wks GA</td><td>10.2%</td></tr>
<tr><td>Maternal age <25 yrs (24-28 wks GA, SGA)</td><td>7.9%</td></tr>
<tr><td>Maternal age <25 yrs (29-32 wks GA, SGA)</td><td>10.7%</td></tr>
</table>
</td>
<td>Inattention-hyperactivity symptoms
Total behavioural difficulties
School difficulties

Outcome ascertainment/measures

Inattention-hyperactivity symptoms, assessed with the French version of the Strength and Difficulties Questionnaire completed by the parents.Total behavioural difficulties, including a sum score of scales on hyperactivity-inattention, conduct, emotional and peer problems, assessed with the French version of the Strength and Difficulties Questionnaire completed by the parents. The cutoffs were defined so that 10% of the term control</td>
<td>24-28 wks GA: 75/346, 21.7% (17.5-26.4%)
29-32 wks GA: 156/1041, 15.0% (12.9-17.3%)

<u>Total behavioural difficulties (SDQ, 10th perc)</u>
SGA children (bw <10th percentile)
24-28 wks GA: 7/21, 33.3% (14.6-57%)
29-32 wks GA: 22/115, 19.1% (12.4-27.5%)
MGA children (bw 10th-19th percentile)
24-28 wks GA: 9/33, 27.3% (13.3-45.5%)
29-32 wks GA: 32/121, 26.5% (18.8-35.2%)
AGA (bw >=20th percentile)
24-28 wks GA: 82/346, 23.7% (19.3-28.5%)
29-32 wks GA: 201/1037, 19.4% (17.0-21.9%)

At 8 years
<u>School difficulties</u>
SGA children (bw <10th percentile)
24-28 wks GA: 6/17, 35.3% (14.2-61.7%)
29-32 wks GA: 30/107, 28.0% (19.8-37.6%)</td>
<td>3. Was the sample size adequate?

No.
Low precision (wide confidence intervals) due to low sample size in GA subgroups.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear.
Follow up rate was 83%. Differences between children followed up and lost to follow up were not reported.

6. Were objective, standard criteria used for the measurement of the condition?

Yes</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Source of funding Not reported.		group was considered to have a behavioural problem. School difficulties were defined by special schooling (institution or special school, special class in mainstream school, mainstream class) or low grades. This was asked through a questionnaire sent to the parents when the child was 8 years old. **Age at assessment** Age 5 years	*MGA children (bw 10th-19th percentile)* 24-28 wks GA: 13/29, 44.8% (26.5-64.3%) 29-32 wks GA: 24/104, 23.1% (15.4-32.4%) *AGA (bw >=20th percentile)* 24-28 wks GA: 98/295, 33.2% (27.9-38.9%) 29-32 wks GA: 163/887, 18.4% (15.9-21.1%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for proportion estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 397279	**Setting** Geographical region of the East Midlands (LAMBS)	**Gestational age ascertainment** Not reported	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)**	**Overall quality** Low

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Full citation Guy, A., Seaton, S. E., Boyle, E. M., Draper, E. S., Field, D. J., Manktelow, B. N., Marlow, N., Smith, L. K., Johnson, S., Infants born late/moderately preterm are at increased risk for a positive autism screen at 2 years of age, Journal of Pediatrics, 166, 269-75.e3, 2015 **Study type** Population-based prospective cohort (Late and Moderate Preterm Birth Study) **Aim of the study** To assess prevalence of positive screens using the modified checklist for autism in toddlers (MCHAT) **Study dates**	**Inclusion criteria** Babies born at 32-36 weeks gestational age **Exclusion criteria** Babies with major congenital anomalies were recruited but excluded from the study Those with missing MCHAT questionnaires **Sample size** n=1130 late and moderately preterm infants recruited n=634 late and moderately preterm infants in the final sample **Characteristics** Late and moderately preterm infants: Moderately preterm: (32-33 weeks GA): 86 (14%) Late preterm: (34-36 weeks GA): 548 (86%)	**Outcomes of interest in this study** ASD behaviour (M-CHAT) **Outcome ascertainment/measures** <u>ASD/behaviour</u> The MCHAT 23 item parent questionnaire was used to identify early behaviours associated with ASD. Infants failing ≥2 of 6 critical items or ≥3 items overall screen positive for the risk of ASD. The interview took 5-15 minutes after which the MCHAT was re-scored and children with positive screens after follow-up were classified as true positives.	At 2 years age <u>ASD behaviour positive screen (MCHAT)</u> 32-33 wks GA: 8/86, 9.3% (95%CI 4.1-17.5) 34-36 wks GA: 84/548, 15.3% (95%CI 12.4-18.6) 32-26 wks GA: 92/634, 14.5% (95%CI 12.0-17.5) Confidence interval calculated by the NGA technical team using http://statpages.info/confint.html	**1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
September 2009 to December 2010, assessed at 2 years age **Country/ies where the study was carried out** United Kingdom **Source of funding** National Institute for Health Research		**Age at assessment** 2 years		No. Only 56% of the preterm group was analysed in the study **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				10. Were subpopulations identified using objective criteria? N/A
Ref Id 433220 **Full citation** Hutchinson, E. A., De Luca, C. R., Doyle, L. W., Roberts, G., Anderson, P. J., Victorian Infant Collaborative Study, Group, School-age outcomes of extremely preterm or extremely low birth weight children.[Erratum appears in Pediatrics. 2013 Oct;132(4):780], Pediatrics, 131, e1053-61, 2013 **Study type** Prospective cohort study (Victorian Infant Collaborative Study Group)	**Setting** Cohort of preterm children born in the state of Victoria, Australia (at four neonatal intensive care units in the state). **Inclusion criteria** All children with a gestational age <28 weeks or birth weight <1000g born in the state of Victoria, Australia in 1997 (63,4% survived to 2 years age). **Exclusion criteria** Not reported. **Sample size** n=189 preterm/low birth weight cohort (94% eligible for follow-up; 12 children were not seen, but 10/12 were assessed at 2 years corrected age).	**Gestational age ascertainment** Ascertainment of gestational age not reported. **Outcomes of interest in this study** Behavioural problems (SDQ) **Outcome ascertainment/measures** Behavioural outcomes were assessed by using Strengths and Difficulties Questionnaire (SDQ). This 25-item parent-rated questionnaire has 5 scales: emotional symptoms,	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 8 years age Abnormal total behavioural difficulties score (SDQ, 90th percentile, SDQ norms as reference) <28 wks GA/BW <1000 g: 34/189, 18.0% (12.8-24.2%) Confidence interval calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (confidence intervals were wide) due to low sample size.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Aim of the study

To examine cognitive, academic and behavioural outcomes at age 8 years in a regional cohort of extremely preterm (EP) or birth weight <1000g (ELBW)

Study dates

Children born in 1997, assessed at 8 years age.

Country/ies where the study was carried out

Australia.

Source of funding

National Medical Research Council Senior Research Fellowship (part funding) and Victorian Government's Operational</td>
<td>Characteristics
<table>
<tr><th></th><th>EP/ELBW (n=189)</th><th>T/NBW (n=173)</th></tr>
<tr><td>Male (n)</td><td>100</td><td>92</td></tr>
<tr><td>Female (n)</td><td>89</td><td>81</td></tr>
<tr><td>GA, mean±SD, completed wk</td><td>26.5±2.0</td><td>39.9±1.1</td></tr>
<tr><td>Birth weight, mean±SD, g</td><td>833±164</td><td>3506±1455</td></tr>
<tr><td>Birth weight <-2SDs (n)</td><td>34</td><td>0</td></tr>
<tr><td>Age at evaluation, mean±SD, y</td><td>8.45±0.41</td><td>8.50±0.39</td></tr>
<tr><td>Antenatal corticosteroids (n)</td><td>166</td><td>2</td></tr>
<tr><td>Surfactant (n)</td><td>154</td><td>1</td></tr>
<tr><td>Postnatal corticosteroids (n)</td><td>70</td><td>0</td></tr>
<tr><td>O2 dependency at 36 wks (n)</td><td>72</td><td>0</td></tr>
</table>
</td>
<td>conduct problems, hyperactivity/inattention, peers relationship problems and prosocial behaviour. Twenty of the items are combined to generate a "total difficulties" score. Normative data for children from the SDQ website was used to determine those in the clinical range. Children with scores above 90th percentile were classified as being in the "abnormal" range, those between the 80th and 90th percentile were classified as "bordeline" and those below 80th percentile were classified as "normal".

Age at assessment

At 8 years age.</td>
<td></td>
<td>4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes.
Follow-up rate was 94%.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals for percentage estimates were not provided.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Infrastructure Support Programme.	<table><tr><td>Grade 3/4 intraventricular haemorrhage (n)</td><td>7</td><td>0</td></tr><tr><td>Cystic periventricular leukomalacia (n)</td><td>6</td><td>0</td></tr></table>			**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 410767 **Full citation** Johnson, S., Evans, T. A., Draper, E. S., Field, D. J., Manktelow, B. N., Marlow, N., Matthews, R., Petrou, S., Seaton, S. E., Smith, L. K., Boyle, E. M., Neurodevelopmental outcomes following late and moderate prematurity: A population-based cohort study, Archives	**Setting** All children born 32-36 weeks of gestation in one of four maternity centres, a midwifery-led birthing unit and home births in the East Midlands during the study period (LAMBS). **Inclusion criteria** Preterm babies: All babies born from 32 to 36+6 weeks of gestation within a geographically defined region of the East Midlands. Term babies: a random sample of term babies born during the same time period and in the same geographical region, including all term born multiples. **Exclusion criteria**	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** Cognitive impairment (using screening tool PARCA-R) **Outcome ascertainment/measures**	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 2 years of corrected age Cognitive impairment (PARCA-R , <2.5 percentile) 32-36 wks GA: 40/638, 6.3% (4.5-8.4%) Confidence interval calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>of Disease in Childhood: Fetal and Neonatal Edition, 100, F301-F308, 2015

Study type

Prospective cohort study (LAMBS)

Aim of the study

To assess neurodevelopmental outcomes at 2 years of age following late and moderate prematurity.

Study dates

Children born September 2009 to December 2010, follow-up at 2 years of corrected age.

Country/ies where the study was carried out

UK</td>
<td>Infants with congenital abnormalities.
No completed questionnaire data received.

Sample size

n = 1130 late/moderately preterm infants recruited
n = 638 late/moderately preterm infants included in analysis

Characteristics
<table>
<tr><th>Characteristic</th><th>Term infants (n = 765)</th><th>Late/moderatepreterm infants (n = 638)</th></tr>
<tr><td>Gestational age</td><td></td><td></td></tr>
<tr><td>32-33 weeks , n (%)</td><td></td><td>87 (13.6)</td></tr>
<tr><td>34-36 weeks, n (%)</td><td></td><td>551 (86.4)</td></tr>
<tr><td>37-38 weeks, n (%)</td><td>241 (31.5)</td><td></td></tr>
<tr><td>39-40 weeks, n (%)</td><td>357 (46.7)</td><td></td></tr>
<tr><td>41-42 weeks, n (%)</td><td>167 (21.8)</td><td></td></tr>
<tr><td>Multiple births, n (%)</td><td>151 (19.7)</td><td>107 (16.8)</td></tr>
<tr><td>Birth weight, g, mean (SD)</td><td>3322 (535)</td><td>2435 (502)</td></tr>
</table>
</td>
<td>At 2 years corrected age, cognitive impairment was assessed using the Parent Report of Children's Abilities-Revised (PARCA-R). Scores for non-verbal cognition and expressive language were combined to give a total parent report composite. These scores are strongly correlated with scores on gold standard developmental tests. Moderate/severe cognitive impairment was identified as a score corresponding to with PRC scores < 2.5th percentile in the term reference group.

Age at assessment

2 years corrected age.</td>
<td></td>
<td>3. Was the sample size adequate?

No.
Low precision, wide confidence interval due to relatively low sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
For 1130 recruited children, only 638 were included in analysis (57%).

6. Were objective, standard criteria used for the measurement of the condition?

Yes</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Source of funding

National Institute for Health Research.</td>
<td>
<table>
<tr><td>SGA, n (%)</td><td>48 (6.3)</td><td>67 (10.5)</td></tr>
<tr><td>Male, n (%)</td><td>384 (50.2)</td><td>343 (53.8)</td></tr>
<tr><td>Maternal age < 20, n (%)</td><td>16 (2.3)</td><td>19 (3.2)</td></tr>
<tr><td>Maternal age ≥ 35, n (%)</td><td>188 (27.3)</td><td>114 (19.5)</td></tr>
<tr><td>Ethnicity</td><td></td><td></td></tr>
<tr><td>White, n (%)</td><td>569 (82.5)</td><td>461 (78.5)</td></tr>
<tr><td>Mixed, n (%)</td><td>7 (1.0)</td><td>12 (2.0)</td></tr>
<tr><td>Asian, n (%)</td><td>77 (11.2)</td><td>86 (14.7)</td></tr>
<tr><td>Black, n (%)</td><td>30 (4.4)</td><td>21 (3.6)</td></tr>
<tr><td>Chinese or other, n (%)</td><td>7 (1.0)</td><td>6 (1.0)</td></tr>
<tr><td>Unknown, n (%)</td><td>0 (0)</td><td>1 (0.2)</td></tr>
<tr><td>Socioeconomic status</td><td></td><td></td></tr>
<tr><td>Low risk, n (%)</td><td>339 (49.1)</td><td>256 (43.6)</td></tr>
<tr><td>Medium risk, n (%)</td><td>209 (30.3)</td><td>184 (31.4)</td></tr>
<tr><td>High risk, n (%)</td><td>142 (20.6)</td><td>147 (25.0)</td></tr>
</table>
</td>
<td></td>
<td></td>
<td>7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.
Confidence interval for prevalence estimate not provided.

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td>
</tr>
<tr>
<td>Ref Id

433234</td>
<td>Setting

All children born late and moderately preterm in the geographically defined region of the East Midlands of England,</td>
<td>Gestational age ascertainment

Not reported.</td>
<td>Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)</td>
<td>Overall quality

Low</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Full citation

Johnson, S., Matthews, R., Draper, E. S., Field, D. J., Manktelow, B. N., Marlow, N., Smith, L. K., Boyle, E. M., Early Emergence of Delayed Social Competence in Infants Born Late and Moderately Preterm, Journal of Developmental & Behavioral Pediatrics, 36, 690-9, 2015

Study type

A prospective geographical population-based study (LAMBS)

Aim of the study

To assess behavioural outcomes and social competence at 2 years of age in infants born late and moderately preterm.

Study dates</td>
<td>births derived from four large maternity hospitals in the region,a midwifery-led birthing unit, and home births.

Inclusion criteria

Mothers of all children born late to moderately preterm (32+0 - 36+6 weeks of gestation) from September 1, 2009 to December 31, 2010 within a geographically defined area of the East Midlands of England were invited to participate.

Exclusion criteria

Infants with major structural or chromosomal congenital anomalies.

Sample size

N=625 with completed BITSEA data (56% of originally recruited ones)

Characteristics

<table>
<tr><td></td><td>Late and moderately preterm children</td></tr>
<tr><td>Multiple birth, %</td><td>16.8</td></tr>
<tr><td>Birth weight in grams, mean (SD)</td><td>2435.0 (502.1)</td></tr>
<tr><td>SGA, %</td><td>10.5</td></tr>
</table>
</td>
<td>Outcomes of interest in this study

Behaviour problems (BITSEA),
delayed social competence (BITSEA)

Outcome ascertainment/measures

To assess behavioural outcome, parents completed the Brief infant Toddler Social Emotional Assessment (BITSEA). This 42-item questionnaire comprises 2 scales to assess behaviour problems and social competence and has previously been shown to have excellent test-retest reliability, interrater reliabiloty and predictive validity for psychiatric disorders at school age in both term and preterm populations.</td>
<td>At 2 years of corrected age
<u>Behaviour problems (BITSEA, >25th percentile)</u>
32-36 wks GA: 131/625, 21.0% (17.8-24.4%)
32-33 wks GA: 17/84, 20.2% (12.3-30.4%)
34-36 wks GA: 114/541, 21.1% (17.7-24.8%)

<u>Delayed social competence (BITSEA, <15th percentile)</u>
32-36 wks GA: 165/625, 26.4% (23.0-30.0%)
32-33 wks GA: 23/84, 27.4% (18.2-38.2%)
34-36 wks GA: 142/541, 26.3% (22.6-30.2%)

Behaviour problem or delayed social competence (BITSEA)
32-36 wks GA: 233/625, 37.3% (33.5-41.2%)
32-33 wks GA: 34/84, 40.5% (29.9-51.8%)
34-36 wks GA: 199/541, 36.8% (32.7-41.0%)

Behaviour problem and delayed social comptence (BITSEA)
32-36 wks GA: 63/625, 10.1% (7.8-12.7%)</td>
<td>1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Unclear.
In the whole sample of late and moderate preterms the precision was quite high (relatively narrow confidence intervals) but in the GA subgroups, the precision was low (wide confidence intervals).

4. Were the study subjects and the setting described in detail?

Yes</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Children were born between 1 Sept 2009 and December 31 2010. Follow-up at 2 years of age (corrected).

Country/ies where the study was carried out

UK

Source of funding

National Institute for Health Research (NIHR) under its Programme grants for Applied Research Programme. One author received funding from the Department of Health's NIHR Biomedical Research Centres funding scheme at UCLH/UCL.</td>
<td>
<table>
<tr><td>Male, %</td><td>53.8</td></tr>
<tr><td>Maternal age in years, mean (SD)</td><td>30.3 (5.5)</td></tr>
<tr><td>Maternal ethnicity white, %</td><td>78.6</td></tr>
<tr><td>Maternal ethnicity mixed, %</td><td>2.0</td></tr>
<tr><td>Maternal ethnicity Asian or Asian British, %</td><td>14.7</td></tr>
<tr><td>Maternal ethnicity Black or Black British, %</td><td>3.6</td></tr>
<tr><td>Maternal ethnicity Chinese or other, %</td><td>1.0</td></tr>
<tr><td>Mother's first language not English, %</td><td>14.0</td></tr>
<tr><td>Mother's SES-index low risk, %</td><td>43.6</td></tr>
<tr><td>Mother's SES-index moderate risk, %</td><td>31.4</td></tr>
</table>
</td>
<td>The BITSEA "problem scale" comprises of 31 items that assess behaviour problems in the areas of externalising problems, internalising difficulties, dysregulation, maladaptive behaviours, and atypical behaviours. Individual item scores are summed indicating greater problems. Using the published age- and sex-specfici norm-references cutoffs, infants were identified as having behaviour problems if they scores >25th percentile of the BITSEA standardisation sample.
The BITSEA "competence scale" comprises of 11 items that assess areas of attention, compliance, mastery motivation, prosocial peer relations, empathy, imitation/play skills, and social relatedness</td>
<td>32-33 wks GA: 6/84, 7.1% (2.7-14.9%)
34-36 wks GA: 57/541, 10.5% (8.1-13.4%)

Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
Only 57% of originally recruited were included in the follow-up analysis.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.
Confidence intervals of the prevalence estimates not provided.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	Mother's SES-index high risk, %: 25.0	and is designed to identify children who have delays or deficits in the acquisition of social-emotional competencies (irrespective if behaviour problems are present). Individual item scores were summed to provide a total competence score with lower scores indicating poorer social competence. Infants were identified as having delayed social competence if their total competence score was <15th percentile of children of the same age and sex in the BITSEA standardisation sample. **Age at assessment** 2 years corrected age		**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 397352	**Setting** Population-based national cohort of all children born extremely preterm (<26 weeks) in the UK and Ireland between March and December 1995.	**Gestational age ascertainment** Not reported.	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 11 years	**Overall quality** Low

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Full citation

Johnson, S., Wolke, D., Hennessy, E., Marlow, N., Educational outcomes in extremely preterm children: neuropsychological correlates and predictors of attainment, Developmental Neuropsychology, 36, 74-95, 2011

Study type

National population-based cohort study (EPICure)

Aim of the study

First, to investigate educational outcomes at 11 years of age in children born extremely preterm compared with term-born classmates in order to quantify the effect of extremely preterm birth on school performance in middle school. Second, using</td>
<td>Inclusion criteria

All children born at <26 weeks of gestation and admitted for neonatal intensive care in the UK and Ireland between March and December 1995 and who survived to discharge.

Exclusion criteria

None reported.

Sample size

n=219 children assessed at 11 years (data missing for some individuals in the outcomes of interest)
(of n=307 survivors at 11 years, 71%)

Characteristics

<table>
<tr><td></td><td>n=219</td></tr>
<tr><td>GA <=23 wks, n (%)</td><td>23 (10.5)</td></tr>
<tr><td>GA 24 wks, (%)</td><td>70 (32.0)</td></tr>
<tr><td>GA 25 wks, (%)</td><td>126 (57.5)</td></tr>
<tr><td>Birthweight in grams, median (IQR)</td><td>740 (660-840)</td></tr>
<tr><td>Male, %</td><td>46.1</td></tr>
<tr><td>White maternal ethnicity, %</td><td>82.1</td></tr>
<tr><td>Mother's education:</td><td></td></tr>
</table>
</td>
<td>Outcomes of interest in this study

Special educational needs (SEN)

Outcome ascertainment/measures

Teachers completed a questionnaire to elicit information detailing whether SEN provision was utilised by the child.

Age at assessment

11 years</td>
<td><u>Identified SEN</u>
<26 wks GA: 134/215, 62.3% (55.5-68.8%)
<u>SEN provision</u>
<26 wks GA: 132/215, 61.4% (54.5-67.9%)

Children in mainsteam schools only:
<u>Identified SEN</u>
<26 wks GA: 105/186, 56.5% (49.0-63.7%)
<u>SEN provision</u>
<26 wks GA: 103/186, 55.4% (47.9-62.7%)*
*In the paper, the number of cases is reported as 105 but the percentage is reported as 55.4% (out of 186), therefore, presumably, there is a mistake in the number of cases and it should say 103 instead.

Confidence intervals for the prevalence estimates were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No.
Low precision (wide confidence intervals) due to relatively small sample.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
outcome data obtained at 6 years, investigate social and neuropsychological antecedents of attainment in reading and mathematics at 11 years and examine the relative impact of these antecedents between children born extremely preterm and at term. Finally, to examine neonatal variables and early neurodevelopmental outcomes at 30 months of age as predictors of attainment in reading and mathematics and the need for SEN provision in children born extremely preterm at 11 years of age. **Study dates** Children born between March and December 1995, follow-up at 11 years of age.	Up to 16 years of age, % 76.0 Post-16 years of age, % 24.0 SES at 11 years: High, % 43.9 Medium, % 24.4 Low, % 31.7 Age at assessment, mean (SD) 10.9y (0.38y))			71% of the children alive at 11 years were assessed. **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Teachers filled in a questionnaire, not clear how standardized the questionnaire is. **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differen**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Country/ies where the study was carried out UK and Ireland **Source of funding** None reported.				**ces identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 409051 **Full citation** Kan, E., Roberts, G., Anderson, P. J., Doyle, L. W., Victorian Infant Collaborative Study, Group, The association of growth impairment with neurodevelopmental outcome at eight years of age in very preterm children, Early Human Development, 84, 409-16, 2008 **Study type** Regional cohort study	**Setting** Paediatric and psychological assessment at 8 years of age at one of the three level-III perinatal centres in the state **Inclusion criteria** All preterm infants born at 23-27 weeks GA, surviving to 8 years age, and free of neurosensory impairment **Exclusion criteria** Those children with neurosensory impairment **Sample size** N=401 consecutive very preterm infants n=225 surviving to age 8 years n=210 assessed at age 8 years n=179 very preterm infants assessed in study	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Motor performance **Outcome ascertainment/measures** Assessment of motor function, using the Movement Assessment Battery for Children (Movement ABC), which yields a percentile score composed of	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At age 8 years Motor performance (MABC, <15th percentile) 23-27 wks GA: 26/179, 14.5% (95%CI 9.7-20.6) Confidence interval calculated by the NGA technical team using http://statpages.org/confint.html	**Overall quality** Very low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** No. The children were enrolled consecutively. **3. Was the sample size adequate?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Aim of the study

To determine the associations between weight and head circumference, at birth and postnatally, with cognitive, academic and motor outcomes at age 8 years for very preterm children free of neurosensory impairment.

Study dates

1991 and 1992, assessed at 8 years age

Country/ies where the study was carried out

State of Victoria, Australia

Source of funding</td>
<td>Characteristics

<table>
<tr><td>Biological characteristics</td><td>n=179 preterm group</td></tr>
<tr><td>Male (n, (%))</td><td>84 (46.9)</td></tr>
<tr><td>Gestational age (weeks), mean (SD)</td><td>25.9 (1.0)</td></tr>
<tr><td>Grade 3 or 4 intraventricular haemorrhage (n, (%))</td><td>10 (5.6)</td></tr>
<tr><td>Cystic periventricular leucomalacia (n, (%))</td><td>5 (2.8)</td></tr>
<tr><td>Postnatal corticosteroids (n,(%))</td><td>63 (35.2)</td></tr>
<tr><td>Surgery in newborn period (n, (%))</td><td>43 (24.0)</td></tr>
</table>
</td>
<td>cumulative scoring of manual dexterity, ball skills and balance tasks. Children with a percentile ranking <15 were considered to have poor motor performance</td>
<td></td>
<td>No. Low precision (confidence intervals wide)

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. 85% of 210 children were assessed at follow up 8 years. Four declined participation, 7 were lost to follow up, and 4 were inaccessible. 31 children were excluded from the analysis as they had neurosensory impairment at 8 years (including CP, blindness and deafness). Only those children without neurosensory impairment were included in the analysis.

6. Were objective, standard criteria used for the</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
National Health and Medical Research Council of Australia		**Age at assessment** 8 years age (corrected for prematurity)		**measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Ref Id 410819 **Full citation** Kerstjens, J. M., de Winter, A. F., Bocca-Tjeertes, I. F., ten Vergert, E. M., Reijneveld, S. A., Bos, A. F., Developmental delay in moderately preterm-born children at school entry, Journal of Pediatrics, 159, 92-8, 2011 **Study type** Population based prospective cohort study (Lollypop). **Aim of the study** To determine the prevalence and nature of developmental delay at preschool age in infants born moderately preterm.	**Setting** Multicentre and community based prospective cohort study. **Inclusion criteria** From a community based preventive child healthcare (PCHC) cohort of 45455 children born in 2002 and 2003 all children with a gestational age of <36 weeks were sampled. For every second preterm child, then next term born child from the cohort was selected as a comparison. The cohort was expanded with very preterm children (<32 weeks) born in 2003 who had been admitted to any of five tertiary neonatal intensive care units. Children were recruited during a routine visit to their local PCHC centre at the age of 43 to 49 months Completed ASQ within the timeframe 43-49 months. **Exclusion criteria** Major congenital malformations, syndromes and congenital infections. **Sample size** Sample recruited: n = 698 gestation < 32 weeks n = 1145 gestation 32-35 weeks Sample analysed after exclusions: n = 512 gestation < 32 weeks n = 927 gestation 32-35 weeks	**Gestational age ascertainment** Gestational age obtained from medical records held by the preventive child healthcare centres, confirmed by early ultrasound measurements in >95% of cases. **Outcomes of interest in this study** Developmental delay (ASQ total score) **Outcome ascertainment/measures** The Dutch version of the age 48 month form of the Ages and Stages questionnaire was used to assess development. The ASQ covers five domains: communication, fine motor function, gross motor	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 4 years Developmental delay (ASQ total score <-2 SD) <32 wks GA: 76/512, 14.9% (11.9-18.2%) 32-35 wks GA: 77/927, 8.3% (6.6-10.3%) Number of cases not reported, only percentage and the overall denominator for GA subgroups, the number of cases calculated by the NGA technical team. Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. Relatively low precision (relatively wide confidence intervals). **4. Were the study subjects and the setting described in detail?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Study dates

Study recruitment during 2005-2007, follow-up at 43-49 months of age.

Country/ies where the study was carried out

The Netherlands

Source of funding

The research foundation of Beatrix Children's Hospital, the Cornelia Foundation for the Handicapped Child, the A. Bulk Preventive Child Health Care Research Fund, the Dutch Brain Foundation, and an unrestricted research grant from FrieslandCampina, Friso Infant Nutrition, Abbott and Pfizer Europe.</td>
<td>Characteristics

<table>
<tr><td>Characteristics</td><td>Early preterm< 32 weeks n = 512</td><td>Moderate preterm 32-35+6 weeks n = 927</td><td>Full term 38-41+6 weeks n = 544</td></tr>
<tr><td>Male, n (%)</td><td>263 (51.4)</td><td>532 (57.4)</td><td>270 (49.6)</td></tr>
<tr><td>Multiple pregnancy, n (%)</td><td>178 (34.8)</td><td>259 (27.9)</td><td>6 (1.1)</td></tr>
<tr><td>SGA <10th percentilen (%)</td><td>97 (19.1)</td><td>85 (9.2)</td><td>45 (8.4)</td></tr>
<tr><td>Maternal age</td><td></td><td></td><td></td></tr>
<tr><td>< 20 yrs, n (%)</td><td>5 (1)</td><td>11 (1.2)</td><td>3 (0.6)</td></tr>
<tr><td>36-46 yrs, n (%)</td><td>66 (12.9</td><td>119 (12.9)</td><td>87 (16.0)</td></tr>
<tr><td>Maternal education</td><td></td><td></td><td></td></tr>
<tr><td>17+ years, n (%)</td><td>154 (30.2)</td><td>247 (26.8)</td><td>165 (30.4)</td></tr>
<tr><td>13-16 years, n (%)</td><td>204 (41.0)</td><td>307 (34.6)</td><td>201 (38.0)</td></tr>
<tr><td><12 years, n (%)</td><td>142 (27.8)</td><td>314 (35.4)</td><td>151 (28.5)</td></tr>
</table>
</td>
<td>function,personal-social functioning and problem solving. The total score was calculated by adding all the domain scores and dividing by five. The individual domain scores, and the total score were dichotomized at 2SD below the mean score of the Dutch reference group as normal/abnormal.

Age at assessment

43-49 months (approximately 4 years)</td>
<td></td>
<td>5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
N=1983 children (all GA groups, including term children) out of the N=3194 originally eligible children included in analysis (62%). Out of the 2517 children originally recruited for the study (not all eligible children were recruited) 79% were included in the analysis.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				No confidence intervals provided, no number of cases provided. The relevant results reported in text only. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 412875 **Full citation** Larroque, B., Ancel, P. Y., Marchand-Martin, L., Cambonie, G., Fresson, J., Pierrat, V., Roze, J. C., Marpeau, L., Thiriez, G., Alberge, C., Breart, G., Kaminski, M., Marret, S., Epipage Study,	**Setting** Population based cohort study in 9 regions in France. **Inclusion criteria** All preterm children born between 22 and 32 weeks in one of nine regions of France during the study dates. **Exclusion criteria**	**Gestational age ascertainment** Gestational age refers to the number of completed weeks of amenorrhoea. **Outcomes of interest in this study** Behavioural difficulties School difficulties, special schooling	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 8 years Total behavioural difficulties (SDQ, 10th perc) 24-32 wks GA: 292/1387, 21.1% (18.9-23.3%) 24-28 wks GA: 93/335, 27.8% (23.0-32.9%) 29-30 wks GA: 65/378, 17.2% (13.5-21.4%) 31-32 wks GA: 134/674, 19.9% (16.9-23.1%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
group, Special care and school difficulties in 8-year-old very preterm children: the Epipage cohort study, PLoS ONE [Electronic Resource], 6, e21361, 2011 **Study type** Population based prospective cohort. **Aim of the study** To investigate school difficulties, special care and behavioural problems in 8 year old very preterm children. **Study dates** Children born 1997, follow-up at 8 years. **Country/ies where the study was carried out** France	Death before follow up or declined follow up. Severe motor deficiencies (cerebral palsy, unable to walk without aid), or severe sensory deficiencies (visual acuity <3/10 for both eyes or severe auditory deficiency). **Sample size** Original sample: n = 2901 very preterm children (22-32 weeks) Included in follow up: n = 1439 preterm children **Characteristics** Not reported in this article.	**Outcome ascertainment/measures** A postal questionnaire investigating school outcome, special care and behavioural problems was sent to parents in the first trimester of 2006, when the children would have been in the third grade of primary school. Schooling outcomes included whether the child attended an institution or special school, whether they were in a special class within mainstream schooling and whether they had repeated a school year. Support at school was defined according to whether the child was enrolled at a particular institution, special school or class, or a mainstream class with support at school (extra teacher in or	29-32 wks GA: 199/1052, 18.9% (16.6-21.4%) <u>Hyperactivity (SDQ, 10th perc)</u> 24-32 wks GA: 239/1387, 17.2% (15.3-19.3%) 24-28 wks GA: 62/335, 18.5% (14.5-23.1%) 29-30 wks GA: 57/378, 15.1% (11.6-19.1%) 31-32 wks GA: 120/674, 17.8% (15.0-20.9%) 29-32 wks GA:177/1052, 16.8% (14.6-19.2%) <u>Conduct problems (SDQ, 10th perc)</u> 24-32 wks GA: 131/1387, 9.4% (8.0-11.1%) 24-28 wks GA: 30/335, 9.0% (6.1-12.5%) 29-30 wks GA: 32/378, 8.5% (5.9-11.7%) 31-32 wks GA: 69/674, 10.2% (8.1-12.8%) 29-32 wks GA: 101/1052, 9.6% (7.9-11.5%) <u>Emotional problems (SDQ, 10th perc)</u> 24-32 wks GA: 238/1387, 17.2% (15.2-19.3%) 24-28 wks GA: 68/335, 20.3% (16.1-25.0%)	**2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Especially in smaller GA subgroup, the precision is low (confidence intervals are wide) due to relatively small sample. **4. Were the study subjects and the setting described in detail?** No. No description of background characteristics given. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. 50% of the originally recruited were included in the analysis at 8 years.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Source of funding INSERM, the Directorate General for Health at the Ministry for Social Affairs, Merck-Sharp and Dohme-Chibret, Medical Research Foundation, and "Hospital Program for Clinical Research 2001 n°AOM01117" of the French Department of Health. The eight year follow up was supported by the "Hospital Program for Clinical REsearch 2004/054/HP" at the French Department of Health and the Wyeth Foundation for Children and Adolescents.		outside of the class room, extra teaching hours at school, intervention of a psychologists or other person at school). Parents filled in the French version of the Strengths and Difficulties Questionnaire (SDQ) to assess behavioural difficulties. It includes four scales that assess hyperactivity-inattention, conduct, emotional and peer problems, which are summed in a score of "total difficulties" and an additional scale assessing prosocial behaviour. Cut-offs were defined based on the 90th percentiles of the observed scores in the reference group (term children). **Age at assessment** 8 years	29-30 wks GA: 54/378, 14.3% (10.9-18.2%) 31-32 wks GA: 116/674, 17.2% (14.4-20.3%) 29-32 wks GA: 170/1052, 16.2% (14.0-18.5%) <u>Peer problems (SDQ, 10th perc)</u> 24-32 wks GA: 241/1387, 17.4% (15.4-19.5%) 24-28 wks GA: 65/335, 19.4% (15.3-24.1%) 29-30 wks GA: 72/378, 19.1% (15.2-23.4%) 31-32 wks GA: 104/674, 15.4% (12.8-18.4%) 29-32 wks GA: 176/1052, 16.7% (14.5-19.1%) <u>Prosocial behaviour (SDQ, 10th perc)</u> 24-32 wks GA: 189/1387, 13.6% (11.9-15.6%) 24-28 wks GA: 46/335, 13.7% (10.2-17.9%) 29-30 wks GA: 36/378, 9.5% (6.8-12.9%) 31-32 wks GA: 98/674, 14.5% (12.0-17.4%) 29-32 wks GA: 134/1052, 12.7% (10.8-14.9%) Schooling and special support:	**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
			Institution or special school or special class 24-32 wks GA: 75/1435, 5.2% (4.1-6.5%) 24-28 wks GA: 32/340, 9.4% (6.5-13.0%) 29-30 wks GA: 20/387, 5.2% (3.2-7.9%) 31-32 wks GA: 23/708, 3.3% (2.1-4.8%) 29-32 wks GA: 43/1095, 3.9% (2.9-5.3%) Support at school in mainstream class 24-32 wks GA: 221/1435, 15.4% (13.6-17.4%) 24-28 wks GA: 77/340, 22.7% (18.3-27.5%) 29-30 wks GA: 40/387, 10.3% (7.5-13.8%) 31-32 wks GA: 104/708, 14.7% (12.2-17.5%) 29-32 wks GA: 144/1095, 13.2% (11.2-15.3%) Special care since the age of 5 years (at least one of orthoptic, speech therapy, physical therapy, occupational therapy, psychologist/psychiatric therapy) 24-32 wks GA: 794/1436, 55.3% (52.7-57.9%)	**10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
			24-28 wks GA: 223/341, 65.4% (60.1-70.4%) 29-30 wks GA: 202/389, 51.9% (46.8-57.0%) 31-32 wks GA: 369/706, 52.3% (48.5-56.0%) 29-32 wks GA: 571/1095, 52.2% (49.1-55.1%) Special care since 5 years (see above) or support at school 24-32 wks GA: 841/1438, 58.5% (55.9-61.1%) 24-28 wks GA: 239/343, 69.7% (64.5-74.5%) 29-30 wks GA: 208/388, 53.6% (48.5-58.7%) 31-32 wks GA: 394/707, 55.7% (52.0-59.4%) 29-32 wks GA: 602/1095, 55.0% (52.0-58.0%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	
Ref Id 433298 **Full citation**	**Setting** All schools in Scotland covered by the school census. Information was collected by head teachers of each school and submitted to education authority. The response rate among schools was 99.8%. 19/32 local education authorities agreed to provide data from the 2005 school	**Gestational age ascertainment** Data on gestational age were collected from the Scottish Morbidity Record	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Assessed at 5-18 years Sensory SEN according to gestational age	**Overall quality** Low

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Mackay, D. F., Smith, G. C., Dobbie, R., Cooper, S. A., Pell, J. P., Obstetric factors and different causes of special educational need: retrospective cohort study of 407,503 schoolchildren, BJOG: An International Journal of Obstetrics & Gynaecology, 120, 297-307; discussion 307-8, 2013 **Study type** Retrospective study using national registry data. **Aim of the study** To determine whether relationships with gestational age and birth weight centile vary between specific causes of special educational need **Study dates**	census. The participating authorities covered a total population of 3.8 million. **Inclusion criteria** Primary and secondary school children included in the 2005 school census in Scotland **Exclusion criteria** Unable to link school census data to obstetrics record (n = 93340). Age <4 years or >19 years at the time of the census. Births where the maternal height was measured as <100cm or >200cm, birth weight recorded as <400g or >5000g, or the gestation was recorded as <24 weeks or >43 weeks. Multiple births **Sample size** Overall sample: N = 407503 Relevant sample included for this analysis N = 237894 n = 215935 full term (40-41 weeks) n = 18035 preterm (33-36 weeks) n = 3449 preterm (28-32 weeks) n = 475 preterm (24-27 weeks) **Characteristics**	(SMR2), which collects data on all women discharged from maternity hospitals, including maternal and infant characteristics, clinical management and obstetric complications. Gestational age is defined as completed weeks of gestation on the basis of the estimated date of delivery in the woman's clinical record. **Outcomes of interest in this study** SEN: Sensory Physical or motor Language Social, emotional or behavioural Specific learning difficulties Intellectual ASD Unspecified	24-27 wks GA: 14/475, 3.0% (95%CI 1.6-4.9) 28-32 wks GA: 17/3449, 0.49% (95% CI 0.29-0.79) 33-36 wks GA: 40/18035, 0.2% (95%CI 0.16-0.3) Physical or motor SEN according to gestational age 24-27 wks GA: 29/475, 6.1% (95%CI 4.1-8.7) 28-32 wks GA: 98/3449, 2.8% (95%CI 2.3-3.5) 33-36 wks GA: 84/18035, 0.47% (95%CI 0.37-0.58) Language SEN according to gestational age 24-27 wks GA: 3/475, 0.63% (95%CI 0.13-1.83) 28-32 wks GA: 13/3449, 0.38% (95%CI 0.2-0.6) 33-36 wks GA: 42/18035, 0.2% (95%CI 0.2-0.3) Social, emotional or behavioural SEN according to gestational age 24-27 wks GA: 6/475, 1.3% (95%CI 0.5-2.7) 28-32 wks GA: 32/3449, 0.9% (95%CI 0.6-1.3) 33-36 wks GA: 169/18035, 0.9% (95%CI 0.8-1.1) Specific learning difficulties SEN according to gestational age	**1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** >20% of potentially eligible participants were excluded due to missing data

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>School census data from 2005.

Country/ies where the study was carried out

UK

Source of funding

No external funding source</td>
<td>Characteristics
<table>
<tr><th>Type of SEN</th><th>Preterm 24-27 wks n = 475</th><th>Preterm 28-32 wks n = 3449</th><th>Preterm 33-36 wks n = 18035</th></tr>
<tr><td>No SEN</td><td>335</td><td>3006</td><td>16754</td></tr>
<tr><td>Sensory</td><td>14</td><td>17</td><td>40</td></tr>
<tr><td>Physical or motor</td><td>29</td><td>98</td><td>84</td></tr>
<tr><td>Language</td><td>3</td><td>13</td><td>42</td></tr>
<tr><td>Social, emotional or behavioural</td><td>6</td><td>32</td><td>169</td></tr>
<tr><td>Specific learning difficulties</td><td>10</td><td>49</td><td>235</td></tr>
<tr><td>Intellectual</td><td>67</td><td>165</td><td>521</td></tr>
<tr><td>Autism Spectrum Disorder (ASD)</td><td>5</td><td>34</td><td>75</td></tr>
<tr><td>Unspecified</td><td>6</td><td>35</td><td>115</td></tr>
</table>
</td>
<td>Outcome ascertainment/measures

Data on SEN were identified through the 2005 school census. SEN includes: language impairments; specific learning difficulties (such as dyslexia or dyscalculia); intellectual disabilities; other developmental disorders that impair learning (including autism, Asperger's syndrome and attention deficit hyperactivity disorder); social, emotional or behavioural problems that impair learning; and physical disabilities that impact on learning (including some sensory impairments, or physical or motor disabilities). In the database, the groups are mutually exclusive. Children with more than one cause of SEN</td>
<td>24-27 wks GA: 10/475, 2.1% (95%CI 1.0-3.8)
28-32 wks GA: 49/3449, 1.4% (95%CI 1.1-1.9)
33-36 wks GA: 235/18035, 1.3% (95%CI 1.1-1.5)
<u>Intellectual SEN according to gestational age</u>
24-27 wks GA: 67/475, 14.1% (95%CI 11.1-17.6)
28-32 wks GA: 165/3449, 4.8% (95%CI 4.1-5.6)
33-36 wks GA: 521/18035, 3.0% (95%CI 2.7-3.1)
<u>ASD SEN according to gestational age</u>
24-27 wks GA: 5/475, 1.1% (95%CI 0.3-2.4)
28-32 wks GA: 34/3449, 1.0% (95%CI 0.7-1.4)
33-36 wks GA: 75/18035, 0.4% (95%CI 0.3-0.5)
<u>Unspecified SEN according to gestational age</u>
24-27 wks GA: 6/475, 1.3% (95%CI 0.5-2.7)
28-32 wks GA: 35/3449, 1.0% (95%CI 0.7-1.4)
33-36 wks GA: 115/18035, 0.6% (95%CI 0.5-0.8)

Confidence intervals calculated by the NGA technical team using</td>
<td>6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals were not provided in the study

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		are classified on the basis of their main impairment. For the purposes of this study the intellectual disability groups (moderate, severe and profound intellectual disabilties, with or without additional complex needs) were aggregated into one group. **Age at assessment** At 5-18 years of age	http://statpages.info/confint.html	**10. Were subpopulations identified using objective criteria?** N/A
Ref Id 412942 **Full citation** MacKay, D. F., Smith, G. C., Dobbie, R., Pell, J. P., Gestational age at delivery and special educational need: retrospective cohort study of 407,503 schoolchildren, PLoS Medicine / Public	**Setting** All schools in Scotland covered by the school census. Information was collected by head teachers of each school and submitted to education authority. The response rate among schools was 99.8%. 19/32 local education authorities agreed to provide data from the 2005 school census. The participating authorities covered a total population of 3.8 million. **Inclusion criteria** Primary and secondary school children included in the 2005 school census in Scotland.	**Gestational age ascertainment** Data on gestational age were collected from the Scottish Morbidity Record (SMR2), which collects data on all women discharged from maternity hospitals, including maternal and infant characteristics, clinical management and obstetric	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Assessed at age 5 to 18 years SEN according to gestational age 24-27 wks GA: 140/475, 29.5% (95%CI 25.4-33.8) 28-32 wks GA: 443/3449, 12.8% (95%CI 11.7-14.0) 33-36 wks GA: 1281/18035, 7.1% (95%CI 6.7-7.5)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Library of Science, 7, e1000289, 2010

Study type

Retrospective study using national registry data.

Aim of the study

To investigate the risk of special educational needs across the whole spectrum of gestational age at delivery.

Study dates

Data from the 2005 school census.

Country/ies where the study was carried out

UK

Source of funding

NHS Health Scotland.</td>
<td>Exclusion criteria

Unable to link school census data to obstetrics record (n = 93340). Age <4 years or >19 years at the time of the census. Births were the maternal height was measured as <100cm or >200cm, birth weight recorded as <400g or >5000g, or the gestation was recorded as <24 weeks or >43 weeks. Multiple births.

Sample size

Overall sample:
N = 407503

Relevant sample included for this analysis
N = 152757

n = 18035 preterm (33-36 weeks)
n = 3449 preterm (28-32 weeks)
n = 475 preterm (24-27 weeks)

Characteristics

<table>
<tr><td>Characteristic</td><td>Special educational need
n = 19821</td></tr>
<tr><td>Gestation at delivery
n (%)</td><td></td></tr>
<tr><td>24-27 weeks</td><td>140 (0.7)</td></tr>
</table>
</td>
<td>complications. Gestational age is defined as completed weeks of gestation on the basis of the estimated date of delivery in the woman's clinical record.

Outcomes of interest in this study

SEN

Outcome ascertainment/measures

Special educational need (SEN) was identified through the school census data. This includes information on children with learning disabilities (including dyslexia, dyspraxia, autism, Asperger's syndrome and attention deficit hyperactivity disorder) as well as children with physical disabilities</td>
<td>Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

>20% of potentially eligible participants were excluded due to missing data

6. Were objective, standard criteria used for the measurement of the condition?

Yes</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr><td></td><td><table>
<tr><td>28-32 weeks</td><td>443 (2.2)</td></tr>
<tr><td>33-36</td><td>1281 (6.5)</td></tr>
<tr><td>Male gender n (%)</td><td>13887 (70.1)</td></tr>
<tr><td>Birth weight centile n (%)</td><td></td></tr>
<tr><td>1-3</td><td>1084 (5.5)</td></tr>
<tr><td>4-10</td><td>1865 (9.4)</td></tr>
<tr><td>Median maternal age y (IQR)</td><td>28 (24-31)</td></tr>
</table></td><td>that impact on learning (including some children with hearing, motor and visual inmpairment).

Age at assessment

5 to 18 years age</td><td></td><td>7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals were not provided in the study

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td></tr>
<tr><td>Ref Id

411078</td><td>Setting</td><td>Gestational age ascertainment

Not reported</td><td>Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)

At 2.5 years age</td><td>Overall quality

Low</td></tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Full citation Mansson, J., Stjernqvist, K., Children born extremely preterm show significant lower cognitive, language and motor function levels compared with children born at term, as measured by the Bayley-III at 2.5 years, Acta Paediatrica, 103, 504-11, 2014 **Study type** Population based cohort study (EXPRESS) **Aim of the study** To assess developmental outcomes of children aged 2.5 years born extremely preterm	Extensive perinatal data on all infants with a gestational age <27 weeks were collected at 7 Swedish perinatal centres (Stockholm, Uppsala, Linkoping, Lund, Gothenburg, Orebro and Umea) **Inclusion criteria** All surviving infants with a gestational age <27 weeks **Exclusion criteria** Mothers of children having protected identity, families moving abroad, mismatching preliminary identity number given at birth	**Outcomes of interest in this study** Motor/language/developmental delay **Outcome ascertainment/measures** <u>Bayley III PDI:</u> Psychomotor Development Index. Bayley-III was used to assess five subtests: Cognition, Receptive Communication, Expressive Communication, Fine Motor, and Gross Motor. Test scores were evaluated on the basis of the means and standard deviations of the controls. Function level was regarded as	<u>Receptive communication (BSID III mild -1SD to 2SD)</u> <27 wks GA:98/394, 24.9% (95%CI 20.7-30.0) <u>Receptive communication (BSID III moderate -2SD to 3SD)</u> <27 wks GA: 36/394, 9.1% (95%CI 6.5-12.4) <u>Receptive communication (BSID III moderate to severe -3SD)</u> <27 wks GA: 23/394, 5.8% (95%CI 3.7-8.6) <u>Expressive communication (BSID III mild -1 SD to 2SD)</u> <27 wks GA: 123/393, 31.3% (95%CI 26.7-36.1) <u>Expressive communication (BSID III moderate -2SD to 3SD)</u> <27 wks GA: 32/393, 8.1% (95%CI 5.6-11.3) <u>Expressive communication (BSID III moderate to severe -3SD)</u> <27 wks GA: 25/393, 6.4% (95%CI 4.2-9.3) <u>Fine motor (BSID III mild -1SD to 2 SD)</u> <27 wks GA: 133/395, 33.7% (95%CI 29.0-39.0) <u>Fine motor (BSID III moderate -2SD to 3SD)</u>	**1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. 87% were followed up with assessment as there were exclusions due to declining of participation

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Study dates

Between April 1, 2004, and March 31, 2007, assessed at 2.5 years

Country/ies where the study was carried out

Sweden

Source of funding

Swedish Research Council,

The Crafoord Foundation,

The Linnea och Josef Carlsson's Foundation,</td>
<td>Sample size

N=707
n=461 eligible for follow up
n=399 children born at <27 weeks GA (after exclusions, surviving to age 2.5 years and had BSID III assessment)

Characteristics

<table>
<tr><td>Characteristics of preterm group</td><td>n=399</td></tr>
<tr><td>Gestational age (weeks, mean, SD)</td><td>25.0 (1.0)</td></tr>
<tr><td>Birth weight (g, mean, SD)</td><td>783.5 (167.8)</td></tr>
<tr><td>Small for gestational age (n, %)</td><td>66 (16.5)</td></tr>
<tr><td>Male (n, %)</td><td>218 (54.6)</td></tr>
</table>
</td>
<td>normal if the subtest scaled score was ≤+1 SD and ≥1 SD of the control mean. Mild delay was classed as ≤1SD to ≥2 SD, moderate delay was classed as <2SD to ≥3 SD, and severe delay was classed as <3SD.

Age at assessment

2.5 years age</td>
<td><27 wks GA: 32/395, 8.1% (95%CI 5.6-11.2)
<u>Fine motor (BSID III moderate to severe -3SD)</u>
<27 wks GA: 17/395, 4.3% (95%CI 2.5-6.8)

<u>Gross motor (BSID III mild -1 SD to 2SD)</u>
<27 wks GA: 111/383, 29.0% (95%CI 24.5-33.8)
<u>Gross motor (BSID III moderate -2SD to 3SD)</u>
<27 wks GA: 27/383, 7.0% (95%CI 4.7-10.1)
<u>Gross motor (BSID III moderate to severe -3SD)</u>
<27 wks GA: 0/0
Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>(n=5) and loss to follow up (n=57).

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals for proportions were not provided in the study

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
The 'Nils W Svenningsens Stiftelse For Prematurforskning				**10. Were subpopulations identified using objective criteria?** N/A
Ref Id 397516 **Full citation** Moore, T., Johnson, S., Hennessy, E., Marlow, N., Screening for autism in extremely preterm infants: problems in interpretation, Developmental Medicine & Child Neurology, 54, 514-20, 2012 **Study type** National population based cohort study (EPICURE -2) **Aim of the study**	**Setting** All children born extremely preterm in the UK were assessed, and data collected at discharge **Inclusion criteria** All infants born less than 27 completed weeks of gestation **Exclusion criteria** Not reported **Sample size** n=2035 EPT children born alive n=1031 survived to 2 years age n=559 completed questionnaires n=523 had completed MCHAT questionnaire **Characteristics**	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Behaviour problems to indicate autistic traits **Outcome ascertainment/measures** The 23-item MCHAT was used to assess children at age 16 to 30 months age to highlight behaviour that may indicate autistic traits and completed by the caregiver. If the child fails two or more of six critical items, or three or more items	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At age 2 years Positive screen for autistic traits (MCHAT) <27 wks GA: 216/523, 41% (95%CI 37.0-45.7) 23 wks GA: 17/31, 54.8% (95%CI 36.0-72.7) 24 wks GA: 46/96, 47.9% (95%CI 37.6-58.4) 25wks GA: 67/168, 40.0% (95%CI 32.4-47.7) 26 wks GA: 86/226, 38.1% (95%CI 31.7-44.7) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>To investigate the prevalence of and neurodevelopmental associations with positive M-CHAT screens at 2 years of age

Study dates

2006, assessed at 2 years age

Country/ies where the study was carried out

United Kingdom

Source of funding

Medical Research Council, UK

NIHR Biomedical Research Centres funding scheme</td>
<td>
<table>
<tr><td>Characteristics of EPT cohort</td><td>n=523</td></tr>
<tr><td>Gestational age (per week)</td><td>25.6 (0.94)</td></tr>
<tr><td>Male (n, %)</td><td>266 (51)</td></tr>
<tr><td>Singleton birth (n, %)</td><td>382 (73)</td></tr>
</table>
</td>
<td>overall, he or she screens positive for autism and further investigation is warranted. The ‘critical’ items specifically address deficiencies in joint attention, prodeclarative pointing, and eye contact. These items have been found to predict the presence of autism.

Age at assessment

2 years age</td>
<td></td>
<td>4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Number of cases for gestational age by week were not provided, confidence</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				intervals for proportions not were not provided **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 307507 **Full citation** Odd,D., Evans,D., Emond,A., Preterm Birth, Age at School Entry and Educational Performance, PLoS ONE, 8, -, 2013 **Study type** Regional prospective cohort study	**Setting** The study included children born at <37 weeks gestational age (ALSPAC cohort) and was an on-going study containing data on over 14,000 infants from the Bristol area **Inclusion criteria** Not reported **Exclusion criteria** No primary outcome measure available (reported key stage 1 score or special educational needs, n = 1997)	**Gestational age ascertainment** Data on gestational age were extracted from information routinely recorded in the clinical notes. If the gestation was recorded as <37 weeks (based on last menstrual period, ultrasound or paediatric assessment) then gestational age was confirmed by a single paediatrician	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Assessed at 8 years Low KS1 score <37 wks GA: 227/722, 31.4% (95%CI 28.1-35.0) Special education needs <37 wks GA: 256/722, 35.5% (95%CI 32.0-39.1) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Aim of the study

To investigate if a lack of age correction and year of education might explain some of the school failure seen in ex-preterm infants.

Study dates

Born from April 1991 to December 1992

Country/ies where the study was carried out

UK

Source of funding

None reported</td>
<td>Sample size

n = 722 preterm infants (<37 weeks)

Characteristics

<table>
<tr><th>Characteristics</th><th>Preterm <37 weeks n = 722</th></tr>
<tr><td>Maternal age, yrs, mean (SD)</td><td>27.5 (4.9)</td></tr>
<tr><td>Maternal socioeconomic group</td><td></td></tr>
<tr><td>Professional</td><td>22 (4.0%)</td></tr>
<tr><td>Managerial</td><td>163 (29.6%)</td></tr>
<tr><td>Skilled non-manual</td><td>223 (40.6%)</td></tr>
<tr><td>Skilled manual</td><td>76 (12.8%)</td></tr>
<tr><td>Semi-skilled</td><td>52 (9.5%)</td></tr>
<tr><td>Non-white ethnicity</td><td>60 (8.5%)</td></tr>
<tr><td>Multiple birth</td><td>136 (18.8%)</td></tr>
<tr><td>Male gender</td><td>411 (56.9%)</td></tr>
<tr><td>Birth weight, g, mean (SD)</td><td>2356 (624)</td></tr>
</table>
</td>
<td>after reviewing the clinical records.

Outcomes of interest in this study

SEN

Outcome ascertainment/measures

At the age of 8 years, the child's teacher was sent a questionnaire, which asked the teacher to identify "has this child ever been recognised as having special educational needs?" (SEN)

Age at assessment

8 years age</td>
<td></td>
<td>3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

No. The authors referred to study website for further information

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. There was missing data for 14% of the eligible cohort due to no outcome data

6. Were objective, standard criteria used for the measurement of the condition?

Yes</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				7. Was the condition measured reliably? Yes **8. Was there appropriate statistical analysis?** No. Number of cases were not reported and were calculated. Confidence intervals were also not provided in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 307228	**Setting** Cohort of children born in Bristol are in 1991-1992.	**Gestational age ascertainment** GA was routinely recorded in the clinical	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 8 years	**Overall quality** Very low.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Full citation

Odd,D.E., Emond,A., Whitelaw,A., Long-term cognitive outcomes of infants born moderately and late preterm, Developmental Medicine and Child Neurology, 54, 704-709, 2012

Study type

Population-based longitudinal cohort study (ALSPAC)

Aim of the study

To investigate whether infants born late preterm have poorer cognitive outcomes than term-born infants.

Study dates

Children born in 1991-1992, follow-up at 8 years of age.</td>
<td>Inclusion criteria

Children born in Bristol area, UK, between April 1991 and December 1992.

Exclusion criteria

None reported.

Sample size

N=741 moderate/late preterm children (32-36 wks) in the cohort
N=319 moderate/late preterm children with data on SEN (43%)

Characteristics

<table>
<tr><td></td><td>Moderate/late preterm children in the cohort n=741</td></tr>
<tr><td>Maternal age</td><td>27y8mo</td></tr>
<tr><td>Maternal socio-economic group:</td><td></td></tr>
<tr><td>Professional</td><td>4.6%</td></tr>
</table>
</td>
<td>noted, based on last menstrual period, ultrasounds, or paediatric assessment and confirmed by a single paediatrician after receiving the clinical records.

Outcomes of interest in this study

Special educational needs (SEN)

Outcome ascertainment/measures

At the age of 8 years, the child's teacher was sent a standardized questionnaire which asked "Has this child ever been recognized as having special educational needs?"

Age at assessment

8 years</td>
<td><u>Special educational needs (reported by teacher)</u>
32-36 wks GA: 110/319, 34.5% (29.3-40.0%)

Confidence interval calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>1. Was the sample representative of the target population?

No.
Such high attrition that the sample is not representative.

2. Were the study participants recruited in an appropriate way?

Yes.

3. Was the sample size adequate?

No.
Low precision (wide confidence intervals) due to relatively small sample.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Country/ies where the study was carried out UK **Source of funding** The UK Medican Research Council, the Wellcome Trust, and the University of Bristol.	Managerial 30.2% Skilled non-manula 40.3% Skilled manual 13.5% Semi-skilled 9.0% Unskilled 2.4% Non-white ethnicity 8.9% Male 57% BW in gram, mean (SD) 2495 (489) Multiple birth 18.5%			**coverage of the identified sample?** No. Only 43% of the eligible late preterm children had data on SEN. **6. Were objective, standard criteria used for the measurement of the condition?** No. Teachers were just asked in a single question "Has this child ever been recognized as having special educational needs?". **7. Was the condition measured reliably?** No. "Has this child ever been recognized as having special educational needs?" **8. Was there appropriate statistical analysis?** No.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				Confidence interval of the prevalence estimate not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 411396 **Full citation** Peacock, P. J., Henderson, J., Odd, D., Emond, A., Early school attainment in late-preterm infants, Archives of Disease in	**Setting** Avon Longitudinal Study of Parents and Children (ALSPAC) in Avon, UK in 1991-1992 **Inclusion criteria** Pregnant women due to deliver in 1991 and 1992 were recruited to participate. No other criteria reported **Exclusion criteria**	**Gestational age ascertainment** Gestational age was retrieved from computerised medical records. Children were considered late preterm if they were born at 32-36+6 weeks of gestation. Term (comparison) was defined as 37-41+6 weeks of gestation	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Assessed at 5 to 7 years age KS1 overall assessment among preterm group (below level 2 in reading, writing and mathematics) 32-36+6 wks GA: 173/596, 29% (95%CI 25.4-33.0) KS1 reading assessment among preterm group (below level 2)	**Overall quality** Very low **1. Was the sample representative of the target population?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Childhood, 97, 118-20, 2012 **Study type** Population-based longitudinal study **Aim of the study** To investigate whether infants born late-preterm have poorer school attainment compared to those born at term **Study dates** Children born in 1991-1992, follow-up at 5-7 years. **Country/ies where the study was carried out** UK **Source of funding** The UK Medical Research Council, the	Infants born at <32 and >=42 weeks gestation. **Sample size** N=13,978 infants alive at 1 year n=596 born at 32-36 wks included in analysis at 5 to 7 years age **Characteristics** 15% of the late-preterm born children were born at 32-33 weeks gestation and 85% at 34-36 weeks. The majority of term and late pre-term infants were from a white ethnic background. Late-preterm infants had lower birth weights and lengths and were more likely to be male, were more likely to be from a multiple pregnancy, and born by CS. Mothers of late-preterm infants tended to have less qualifications and lower incomes.	**Outcomes of interest in this study** KS1 overall KS1 reading, writing and mathematics **Outcome ascertainment/measures** Data on Key Stage 1 assessments were obtained from local education authorities. The results for the three assessment domains (reading, writing and mathematics) were dichotomized, with success defined as achieving at least level 2, the expected level of attainment. Overall KS1 score defined as having at least level 2 in all three domains. **Age at assessment** 5 to 7 years age	32-36+6 wks GA: 132/596, 22.2% (95%CI 19.0-25.7 <u>KS1 writing assessment among preterm group (below level 2)</u> 32-36+6 wks GA: 135/596, 22.7% (95%CI 19.4-26.2) <u>KS1 mathematics assessment among preterm group (below level 2)</u> 32-36+6 wks GA: 108/596, 18.1% (95%CI 15.1-21.5) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Unclear, not reported in study **6. Were objective, standard criteria used for the measurement of the condition?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Wellcome Trust, and the University of Bristol provided core support for ALSPAC study, no separate funding was obtained for this analysis. The lead author is supported by a National Institute for Health Research (NIHR) Academic Clinical Fellowship				**7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 435108	**Setting** Department of Neonatology	**Gestational age ascertainment** Estimation of GA was based on ultrasound	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At age 12-60 months	**Overall quality** Very low

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Full citation

Plomgaard, A. M., Hansen, B. M., Greisen, G., Measuring developmental deficit in children born at gestational age less than 26 weeks using a parent-completed developmental questionnaire, Acta Paediatrica, 95, 1488-94, 2006

Study type

National cohort study

Aim of the study

To assess developmental deficit in children born at gestational age (GA)B 26 wk using a parental questionnaire

Study dates

Children born between 1999-2003</td>
<td>Children admitted to Rigshospitalet, Copenhagen University Hospital (CUH-neo) where almost half of the EPT infants born in Denmark are admitted

Inclusion criteria

Surviving Children born at GA <26 wks, admitted to CUH-neo from 1999-2003
Surviving Children born at GA 26-27 wks, admitted to CUH-neo from 1999-2003

Exclusion criteria

Children with missing records, due to parents not being able to complete the questionnaire as Danish was not their first language

Sample size

n=78 in group 1 (<26 wks GA) invited to the study
n=61 in group 1 returned questionnaire
n=78 in group 2 (26-27 wks GA) invited to the study
n=57 in group 2 returned questionnaire

Characteristics

<table>
<tr><td>Characteristics of preterm groups</td><td><26 wks GA (n=61)</td><td>26-27 wks GA (n=57)</td></tr>
</table>
</td>
<td>performed at GA 18-20 wk

Outcomes of interest in this study

Developmental delay

Outcome ascertainment/measures

To assess developmental deficit the Ages and Stages Questionnaire (ASQ) was used addressing the domains of communication, gross motor skills, fine motor skills, problem solving and personal-social skills. The questionnaire was appropriate for the child's age was completed by the parents at home partly from memory and partly after doing short exercises with their child. Severe</td>
<td><u>Developmental delay (ASQ <-3SD) (before correction for parental education)</u>
<26 wks GA: 17/61, 28% (95%CI 17-40)
26-27 wks GA: 8/57, 14% (95%CI 5-23)
<u>Developmental delay (ASQ <-2SD) (before correction for parental education)</u>
<26 wks GA: 27/61, 44% (95%CI 31-57)
26-27 wks GA: 16/57, 28% (95%CI 16-40)
<u>Developmental delay (ASQ <-3SD) (after correction for parental education)</u>
<26 wks GA: 8/58, 14% (95%CI 5-23)
26-27 wks GA: 2/56, 4% (95%CI 0-8)
<u>Developmental delay (ASQ <-2SD) (after correction for parental education)</u>
<26 wks GA:13/58, 22% (95%CI 12-33)
26-27 wks GA: 7/56, 13% (95%CI 4-21)
<u>Developmental delay (ASQ <-3SD) (after exclusion of children with neurosensory deficit)</u>
<26 wks GA: 3/51, 6% (95%CI 0-12)</td>
<td>1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No. Low precision (wide confidence intervals due to small sample size)

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. The response rate was 75% overall. In the analysis,</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Country/ies where the study was carried out

Denmark

Source of funding

Statens Sundshedsvidenskabelige forskningsfond</td>
<td>
<table>
<tr><td>Birth weight (mean,g, SD)</td><td>733±124</td><td>955±219</td></tr>
<tr><td>GA at birth (wk)</td><td>25.0±0.6</td><td>27.0±0.5</td></tr>
<tr><td>Age (months) corrected for preterm birth</td><td>31.5±13.4</td><td>34.2±13.3</td></tr>
<tr><td>Sex (% female)</td><td>44</td><td>47</td></tr>
<tr><td>Parental education (points)*</td><td>7.8±2.3</td><td>7.9±2.1</td></tr>
</table>
*School education was scored on a 6-point scale and vocational training on a 5-point scale. Total score ranged from 2-11 points. A score of 2 was given in the case of <9years of basic schooling and no vocational training.
</td>
<td>developmental deficit was classed as <-3SD, moderate to severe was classed as <-2SD in both preterm groups.
In order to get a normal distribution of the ASQ raw scores, the children were given questionnaires meant for older children. Due to parent delays, a few children were as old as the nominal age of the questionnaire when they were scored.
Statistical analysis: ASQ standard deviation n (ASQ-SD) was used as an estimate of th reference population (term group) and age adjusted ASQ-SDs were calculated for each child in the preterm groups. The corrected age for preterm birth was used to calculate ASQ-SDs in all preterm children. The two preterm groups were compared using the</td>
<td>26-27 wks GA: 2/55, 4% (95%CI 0-9)
<u>Developmental delay (ASQ <-2SD) (after exclusion of children with neurosensory deficit)</u>
<26 wks GA: 7/51, 14% (95%CI 0.5-23)
26-27 wks GA: 7/55, 13% (95%CI 0-22)</td>
<td>results presented for correction of parental education in both preterm groups had missing parental scores in 5 cases. Also, the age of assessment ranged from 12-60 months, thus there was no clear age of assessment.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

Yes

9. Are all important confounding factors/subgroups/differen</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		independent t test. A second comparison of ASQ-SDs between the groups were done after correction for parental education. A third comparison was done after excluding children with parentally reported neurosensory deficit (CP, blindness) to examine significance of isolated developmental deficit. **Age at assessment** 12-60 months		**ces identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 435113 **Full citation** Potijk, M. R., de Winter, A. F., Bos, A. F., Kerstjens, J. M., Reijneveld, S. A., Higher rates of behavioural and emotional problems at preschool age in children born moderately preterm, Archives of Disease in	**Setting** Community-based sample of preterm children recruited from 13 randomly selected preventive child healthcare centres across the Netherlands, covering urban and rural areas. the 13 covered 25% of all children monitored by the Dutch preventive child healthcare centres. In the Netherlands, 90-95% of children are seen regularly and free of charge by the preventive child healthcare centre doctors. **Inclusion criteria** Moderately preterm born children (32+0-35+6 weeks of gestation) born at one of the 13 participating centres between either Jan 2002 and Jan 2003, or June 2002 and June 2003, depending on the centre.	**Gestational age ascertainment** >95% of the cases, GA was calculated by using the last date of menstruation, and confirmed by early ultrasound measurements. **Outcomes of interest in this study** Behavioural problems (CBCL)	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 4 years of age Total behavioural problems (CBCL, 90th perc) 32-35 wks GA: 72/916, 7.9% (6.2-9.8%) Externalising problems (CBCL, 84th perc) 32-35 wks GA: 87/916, 9.5%* (7.7-11.6%) *The paper reports the percentage to be 8.5%, perhaps a mistake because 87/916 is 9.5%.	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Childhood, 97, 112-7, 2012

Study type

Prospective cohort study (Lollipop)

Aim of the study

To compare preschool children born moderately preterm (32-35 weeks' gestation) and children born at term (38-41 weeks' gestation) regarding the occurrence of behavioural and emotional problems, overall, for separate types of problems and by gender.

Study dates

Children born Jan 2002 - Jan 2003 or June 2002 - June 2003, depending on the centre. Follow-up at 4 years.</td>
<td>Exclusion criteria

Children with congenital malformation or syndromes, children whose GA was <32 weeks.

Sample size

N=916 moderately preterm children

Characteristics
<table>
<tr><th></th><th>Moderately preterm children n=916</th></tr>
<tr><td>32 GA weeks, % (n)</td><td>11.5 (105)</td></tr>
<tr><td>33 GA wks, % (n)</td><td>20.1 (184)</td></tr>
<tr><td>34 GA weeks, % (n)</td><td>27.8 (255)</td></tr>
<tr><td>35 GA weeks, % (n)</td><td>40.6 (372)</td></tr>
<tr><td>SGA, %</td><td>9.2</td></tr>
<tr><td>Male, %</td><td>57.2</td></tr>
<tr><td>One-parent family, %</td><td>7.3</td></tr>
</table>
</td>
<td>Outcome ascertainment/measures

Behavioural and emotional problems were measures using the Dutch version of the Child Behaviour Checklist (CBCL) for ages 1.5-5. The CBCL 1.5-5 has good psychometric properties and is widely used in diverse service settings and in research. It consists of 99 problem items and one open-ended item for recording other problems not listed on the form. Each itme can be rated by the parent as follows: 0, not true; 1, somewhat or stometimes true; or 2, very true or often true. We constructed seven syndrome scales by summing the ratings for the items comprising each syndrome.</td>
<td><u>Internalising problems (CBCL, 84th perc)</u>
32-35 wks GA: 89/916, 9.7% (7.9-11.8%)
<u>Emotionally reactive (CBCL, >97th perc)</u>
32-35 wks GA: 34/916, 3.7% (2.6-5.2%)
<u>Anxious/depressed (CBCL, >97th perc)</u>
32-35 wks GA: 11/916, 1.2% (0.6-2.1%)
<u>Somatic complaints (CBCL, >97th perc)</u>
32-35 wks GA: 54/916, 5.9% (4.5-7.6%)
<u>Withdrawn (CBCL, >97th perc)</u>
32-35 wks GA: 21/916, 2.3% (1.4-3.5%)
<u>Sleep problems (CBCL, >97th perc)</u>
32-35 wks GA: 22/916, 2.4% (1.5-3.6%)
<u>Attention problems (CBCL, >97th perc)</u>
32-35 wks GA: 38/916, 4.15% (3.0-5.7%)
<u>Aggressive behaviour (CBCL, >97th perc)</u>
32-35 wks GA: 31/916, 3.4% (2.3-4.8%)</td>
<td>3. Was the sample size adequate?

Unclear.
There is relatively good precision (relatively narrow confidence intervals).

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear.
Parents of 86.9% of the original cohort gave consent for follow-up. Parents of 93.3% of these responded to the CBCL questionnaire.

6. Were objective, standard criteria used for the measurement of the condition?</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Country/ies where the study was carried out The Netherlands **Source of funding** The research foundation of the Beatrix Children's Hospital, the Corelia Foundation for the Handicapped Child, the A. Bulk Preventive Child Health Care Research Fund, the Dutch Brain Foundation, **Friesland-Campina, Hero, Abbott, and Pfizer Europe.**	Maternal age <25y, % 8.5 Maternal age >34y, % 18.0 Low maternal education level, % 30.5 Medium maternal education level, % 43.0 High maternal education level, % 26.5 Maternal ethnicity from Netherlands, % 94.2 Maternal ethnicity outside of Europe, % 4.1	Subsequently, problem scores were subdivided into three categories: normal range (<93rd percentile), subclinical or bordering range (93rd to 97th percentile), and clinical or elevated range (>97th percentile). In addition, the scores for two broad groups (internalising and externalising) and total problems were calculated. For these scores, cut-offs for subclinical and clinical problems were set at 84th and 90th percentile, respectively, following the CBCL manual. Internalising problems consist of syndrome scales for emotionally reactive behaviour, anxious/depressed behaviour, somatic complaints and withdrawn behaviour. Externalising problems consist of syndrome scales for attention	Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals of prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		problems and aggressive behaviour. **Age at assessment** 4 years		
Ref Id 411462 **Full citation** Potijk, M. R., Kerstjens, J. M., Bos, A. F., Reijneveld, S. A., de Winter, A. F., Developmental delay in moderately preterm-born children with low socioeconomic status: risks multiply, Journal of Pediatrics, 163, 1289-95, 2013 **Study type** Prospective cohort study (Lollipop) **Aim of the study** To assess separate and join effects of low	**Setting** Community-based sample of preterm children recruited from 13 randomly selected preventive child healthcare centres across the Netherlands, covering urban and rural areas. the 13 covered 25% of all children monitored by the Dutch preventive child healthcare centres. In the Netherlands, 90-95% of children are seen regularly and free of charge by the preventive child healthcare centre doctors. **Inclusion criteria** Moderately preterm born children (32+0-35+6 weeks of gestation) born at one of the 13 participating centres between either Jan 2002 and Jan 2003, or June 2002 and June 2003, depending on the centre. **Exclusion criteria** Children with congenital malformation or syndromes, children whose GA could not be verified or was beyond the set range, or if families moved between sampling and inclusion. **Sample size**	**Gestational age ascertainment** >95% of the cases, GA was calculated by using the last date of menstruation, and confirmed by early ultrasound measurements. **Outcomes of interest in this study** Developmental delay (ASQ) **Outcome ascertainment/measures** Developmental outcomes were measured using the Dutch version of the 48-month form of the	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 4 years of age Developmental delay (ASQ total score <-2SD) 32-35 wks GA: 74/891, 8.3% (6.6-10.3%) (Reported in other publication.) Fine motor delay (ASQ, <-2SD) 32-35 wks GA: 74/917, 8.1% (6.4-10.0%) Gross motor delay (ASQ, <-2SD) 32-35 wks GA: 52/911, 5.7% (4.3-7.4%) Communication delay (ASQ, <-2SD) 32-35 wks GA: 86/906, 9.5% (7.7-11.6%) Problem-solving problems (ASQ, <-2SD) 32-35 wks GA: 55/908, 6.1% (4.6-7.8%)	**Overall quality** Moderate. **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. Moderate precision (moderately wide confidence intervals).

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>socioeconomic status (SES) and moderate prematurity on preschool developmental delay.

Study dates

Children born Jan 2002 - Jan 2003 or June 2002 - June 2003, depending on the centre. Follow-up at 4 years.

Country/ies where the study was carried out

The Netherlands

Source of funding

The research foundation of the Beatrix Children's Hospital, the Corelia Foundation for the Handicapped Child, the A. Bulk Preventive Child Health Care Research Fund, the Dutch Brain Foundation, Friesland-</td>
<td>N=926 moderately preterm children assessed at 4 years. (N=544 term born controls)

Characteristics

Characteristics of moderately preterm and term-born children according to SES level, N=1470.
<table>
<tr><th></th><th>Low SES</th><th>Intermediate SES</th><th>high SES</th></tr>
<tr><td>Moderately preterm, %</td><td>71.9</td><td>61.5</td><td>59.7</td></tr>
<tr><td>SGA (<10th perc), %</td><td>10.4</td><td>8.3</td><td>9.2</td></tr>
<tr><td>male, %</td><td>58.5</td><td>53.8</td><td>53.1</td></tr>
<tr><td>Two-parent family, %</td><td>87.9</td><td>94.8</td><td>98.5</td></tr>
<tr><td>Age of mother <25y, %</td><td>13.6</td><td>7.8</td><td>1.1</td></tr>
<tr><td>Age of mother >34 y, %</td><td>18.2</td><td>18.2</td><td>26.0</td></tr>
<tr><td>Maternal ethnicity, Netherlands, %</td><td>90.3</td><td>95.3</td><td>96.3</td></tr>
<tr><td>Maternal ethnicity, outside of Europe, %</td><td>9.3</td><td>2.9</td><td>1.5</td></tr>
</table>
</td>
<td>Ages and Stages Questionnaire (ASQ) which is a validated, parent-completed developmental screening instrument. Five developmental domains: fine motor, gross motor, communication, problem-solving, and personal-social skills. Each domain consists of 6 questions on developmental milestones. ASQ total score was computed by taking the mean of the 5 domain scores. For the total score and the domains scores cut-offs for normal and abnormal scores were set at 2 SD below the mean score of the Dutch reference group.

Age at assessment

4 years</td>
<td>Personal-social problems (ASQ, <-2SD)
32-35 wks GA: 52/915, 5.7% (4.3-7.4%)

Confidence caluclated by the NGA technical team using http://statpages.info/confint.html</td>
<td>4. Were the study subjects and the setting described in detail?

Unclear.
The moderately preterm were not described but the whole population (including term-born controls) were described in detail according to SES level.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear.
Response rate of the eligible participants was 81.0% among the moderately preterm group.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Campina, Friso Infant Nutrition, Abbott, and Pfizer Europe.				Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals of the prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 411485 **Full citation**	**Setting** Nationally representative UK longitudinal study of 18818 infants born in the UK.	**Gestational age ascertainment** Gestational age in weeks was calculated using the mother's report of the expected	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 5 years (after first school year)	**Overall quality** Moderate

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Quigley, M. A., Poulsen, G., Boyle, E., Wolke, D., Field, D., Alfirevic, Z., Kurinczuk, J. J., Early term and late preterm birth are associated with poorer school performance at age 5 years: a cohort study, Archives of Disease in Childhood Fetal & Neonatal Edition, 97, F167-73, 2012 **Study type** Population-based cohort (UK Millennium Cohort Study) **Aim of the study** To compare school performance at age 5 years in children born at full term (39-41 weeks of gestation) with those born at early term (37-38 weeks), late preterm (34-36 weeks), moderately preterm (32-33 weeks) and very preterm (<32 weeks).	**Inclusion criteria** A random two-stage sample of all infants born in England and Wales between September 2000 and August 2001, and in Scotland and Northern Ireland between November 2000 and January 2002, who were alive and living in the UK at age 9 months was drawn from Child Benefit registers that cover virtually all children. (Oversampling of ethnic mnirotieis and disadvantaged areas was done). **Exclusion criteria** Children who died within 9-10 months after birth. Children not living in England at the time of follow-up. Children with missing gestational age or gestational age outside of range. Children with implausible birth weight for GA. Children with missing FSP score. Children whose mother was not the main respondent at recruitment at 9 months. **Sample size** N=8728 total number of children in the study (all gestational ages) N=106 very preterm children (23-31 weeks) N=99 moderately preterm children (32-33 weeks) N=537 late preterm children (34-36 weeks) **Characteristics**	due date, which corresponded well with data in routine hospital records. **Outcomes of interest in this study** School performance, education attainment (Foundation Stage Profile) **Outcome ascertainment/measures** The Foundation Stage Profile (FSP) records the child's achievement as measured by their teacher at the end of their first school year, 'foundation stage'. Teachers are trained in how to conduct the assessments, which are based on observations during the whole year. The FSP captures the 'Early Learning Goals' as set of 13 assessment	The paper reported actual numbers with weighted percentages without confidence intervals. In order to calculate confidence intervals, actual percentages (not weighted) are presented here with their 95% confidence intervals. <u>Not good level of overall achievement in FSP</u> 23-31 wks GA: 56/84, 66.7% (55.5-76.6%) 32-33 wks GA: 56/92, 60.9% (50.1-70.9%) 34-36 wks GA: 276/471, 58.6% (54.0-63.1%) 39-41 wks GA: 2853/5407, 52.8% (51.4-54.1%) 32-36 wks GA: 332/563, 59.0 (54.8-63.1%) <u>Not working securely in all three scales of personal, social and emotional development in FSP</u> 23-31 wks GA: 36/84, 42.9% (32.1-54.1%) 32-33 wks GA: 30/92, 32.6% (23.2-43.2%) 34-36 wks GA: 148/471, 31.4% (27.3-35.8%) 39-41 wks GA: 1456/5407, 26.9% (25.8-28.1%)	**1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. Especially in the smaller GA subgroups the precision is somewhat low (relatively wide confidence intervals). **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Study dates

Children born 2000-2001, follow-up at 5 years of age.

Country/ies where the study was carried out

UK

Source of funding

The Bupa Foundation.</td>
<td>
<table>
<tr><td></td><td>23-31 wks</td><td>32-33 wks</td><td>34-36 wks</td></tr>
<tr><td>Maternal education:</td><td></td><td></td><td></td></tr>
<tr><td>Higher, %</td><td>24.5</td><td>3.9</td><td>16.7</td></tr>
<tr><td>Medium, %</td><td>18.5</td><td>0</td><td>13.7</td></tr>
<tr><td>Lower, %</td><td>15.7</td><td>9.6</td><td>9.0</td></tr>
<tr><td>Overseas/other, %</td><td>0</td><td>0</td><td>19.3</td></tr>
<tr><td>No qualifications, %</td><td>14.2</td><td>14.6</td><td>12.4</td></tr>
<tr><td>Language spoken at home:</td><td></td><td></td><td></td></tr>
<tr><td>English only, %</td><td>18.3</td><td>6.8</td><td>12.5</td></tr>
<tr><td>Mostly English, %</td><td>26.3</td><td>13.4</td><td>6.6</td></tr>
<tr><td>English and other, %</td><td>13.4</td><td>0</td><td>16.1</td></tr>
</table>
</td>
<td>scales across six areas of learning. For each scale the teacher gives the child 1-9 point according to the child's progress in achieving the learning goals. Children achieving a scale score of >=6 points are classified as "working securely with the Early Learning Goals" and are classified as having achieved a good level of development. Children who achieve a score of >=78 points across the 13 assessment scales (i.e. an average of 6 points per scale) and a score of >=6 in each of the three 'personal, social, and emotional development' scales and the four 'communication, language, and literacy' scales are classified as "reaching a good level of overall achievement".</td>
<td>32-36 wks GA: 178/563, 31.6% (27.8-35.6%)

<u>Not working securely in all four scales of communication, language and literacy in FSP</u>
23-31 wks GA: 52/84, 61.9% (50.7-72.3%)
32-33 wks GA: 53/92, 57.6% (46.9-67.9%)
34-36 wks GA: 255/471, 54.1% (49.5-58.7%)
39-41 wks GA: 2652/5407, 49.1% (47.7-50.4%)

32-36 wks GA: 308/563, 54.7% (50.5-58.9%)

<u>Not working securely in all three scales of mathematical development in FSP</u>
23-31 wks GA: 46/84, 54.8% (43.5-65.7%)
32-33 wks GA: 37/92, 40.2% (30.1-51.0%)
34-36 wks GA: 174/471, 36.9% (32.6-41.5%)
39-41 wks GA: 1745/5407, 32.3% (31.0-33.5%)

32-36 wks GA: 211/563, 37.5% (33.5-41.6%)</td>
<td>Unclear.
Of all the 18 818 children recruited at 9 months of age, 14 887 (79%) participated at 5 years.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	<table><tr><td>Ethnicity:</td><td></td><td></td><td></td></tr><tr><td>White, %</td><td>20.6</td><td>7.2</td><td>11.8</td></tr><tr><td>Mixed, %</td><td>0</td><td>0</td><td>21.2</td></tr><tr><td>Indian, %</td><td>31.2</td><td>0</td><td>3.9</td></tr><tr><td>Pakistani/Bangladeshi, %</td><td>17.4</td><td>12.9</td><td>16.2</td></tr><tr><td>Black/Black British, %</td><td>4.6</td><td>0</td><td>15.1</td></tr><tr><td>Other, %</td><td>19.0</td><td>0</td><td>0</td></tr></table>	**Age at assessment** 5 years	Not working securely in the "knowledge and understanding of the world" scale in FSP 23-31 wks GA: 26/84, 31.0% (21.3-42.0%) 32-33 wks GA: 23/92, 25.0% (16.6-35.1%) 34-36 wks GA: 126/471, 26.8% (22.8-31.0%) 39-41 wks GA: 1141/5407, 21.1% (20.0-22.2%) 32-36 wks GA: 149/563, 26.5% (22.9-30.3%) Not working securely in the "physical development" scale in FSP 23-31 wks GA: 18/84, 21.4% (13.2-31.7%) 32-33 wks GA: 14/92, 15.2% (8.6-24.2%) 34-36 wks GA: 67/471, 14.2% (11.2-17.7%) 39-41 wks GA: 570/5407, 10.5% (9.7-11.4%) 32-36 wks GA: 81/563, 14.4% (11.6-17.6%) Not working securely in the "creative development" in FSP	**10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
			23-31 wks GA: 32/84, 38.1% (27.7-49.3%) 32-33 wks GA: 24/92, 26.1% (17.5-36.3%) 34-36 wks GA: 117/471, 24.8% (21.0-29.0%) 39-41 wks GA: 1077/5407, 19.9% (18.9-21.0%) 32-36 wks GA: 141/563, 25.0% (21.5-28.8%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	
Ref Id 397631 **Full citation** Rautava, L., Andersson, S., Gissler, M., Hallman, M., Hakkinen, U., Korvenranta, E., Korvenranta, H., Leipala, J., Tammela,	**Setting** All surviving very low birth weight infants (VLBWI) born in Finland, delivered at university hospitals (level IIIB) and 14 central hospitals (IIB hospitals). **Inclusion criteria** Very low birth weight infants: all surviving infants born at <32 weeks or with a birthweight of ≤1500g in Finland during the study period.	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Motor problems Language problems Executive function problems	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Assessed at 5 years age Motor skills problems (FTF) <32 wks GA: 49/588, 8.3% (95%CI 6.2-11.0) Exexutive function problems (FTF) <32 wks GA: 46/588, 7.8% (95%CI 5.8-10.3) Perception problems (FTF)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>O., Lehtonen, L., Development and behaviour of 5-year-old very low birthweight infants, European Child & Adolescent Psychiatry, 19, 669-77, 2010

Study type

Population based prospective cohort study.

Aim of the study

To evaluate the development and behavioural outcome of very low birth weight infants compared with full term controls.

Study dates

2001-2002.

Country/ies where the study was carried out

Finland.</td>
<td>Exclusion criteria

Incomplete personal identification number in the National Medical Birth Register, major disparity between gestational age and birth weight or missing data in either of these variables suggestive of an error in the database, birth at a level 1 hospital or at a hospital with less than 3 deliveries of VLBW infants within the study period, lethal congenital malformations.

Sample size

Original sample size:
n = 924 preterm/very low birth weight infants
Included in follow up:
n = 588 preterm/very low birth weight infants

Characteristics

<table>
<tr><td>Characteristics</td><td>Very low birth weight infants n = 588</td></tr>
<tr><td>Gestational age weeks and days mean (SD)</td><td>29 4/7 (2 3/7)</td></tr>
<tr><td>Birthweight grams, mean (SD)</td><td>1249 (382)</td></tr>
</table>
</td>
<td>Behavioural, social, emotional, attention problems

Outcome ascertainment/measures

Behavioural outcomes were assessed using the Five to Fifteen Questionnaire (FTF), which was completed by the parents. Questions on development and behaviour were rated by the parents as 0="does not describe", 1="describes to some extent" and 2="describes well" the individual child.

Age at assessment

5 years age</td>
<td><32 wks GA: 23/588, 3.9% (95%CI 2.5-5.8)
<u>Memory problems(FTF)</u>
<32 wks GA: 49/588, 8.3% (95%CI 6.2-11.0)
<u>Language problems (FTF)</u>
<32 wks GA: 27/588, 4.6% (95%CI 3.1-6.6)
<u>Social skills problems (FTF)</u>
<32 wks GA: 25/588, 4.3% (95%CI 2.7-6.2)
<u>Emotional and behavioural problems (FTF)</u>
<32 wks GA: 20/588, 3.4% (95%CI 2.1-5.2)

Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. Only 64% of parents of the VLBWI group returned the questionnaire. Mothers in the non-responder group had more previous foetal deaths, more multiple births, and smoked more often during the pregnancy.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Source of funding The Finnish Academy (Research Program on Health Services Research), the South-West Finnish Fund of Neonatal Research, the University Hospital EVO Funds and the Turku University Hospital Foundation.	Female sex (%) 43 Maternal age at delivery mean (SD) 30.7 (5.8) Maternal years of education mean (SD) 14.6 (2.8)			**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. The number of cases for outcomes was not provided and were calculated. Confidence intervals were also not provided in the study. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
				10. Were subpopulations identified using objective criteria? N/A
Ref Id 413212 **Full citation** Raynes-Greenow, C. H., Hadfield, R. M., Cistulli, P. A., Bowen, J., Allen, H., Roberts, C. L., Sleep apnea in early childhood associated with preterm birth but not small for gestational age: a population-based record linkage study, Sleep, 35, 1475-80, 2012 **Study type** Population based linkage study **Aim of the study**	**Setting** This was a longitudinal, population-based study including all live births in New South Wales (NSW) during the period 2000 to 2004. NSW is the most populous state of Australia with a current population of > 7.0 million and > 90,000 births per annum. **Inclusion criteria** All babies born at ≥20 weeks gestation or weighing ≥400g Preterm: <32 weeks and 32-36 weeks gestational age **Exclusion criteria** Babies with birth weight lying > 3 interquartile ranges than 75th percentile or less than 25th percentile; Babies who died in the perinatal period; Infants who died <12 months; Any infant with major congenital anomaly affecting facial appearance, short stature, cleft palate, congenital laryngomalacia, Down syndrome, tracheomalacia, Hirschsprung disease, achondroplasia;	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Functional problems (Sleep apnea) **Outcome ascertainment/measures** Data from births from 2000–2004 were obtained via the NSW Midwives Data Collection, a legislated population-based surveillance system that includes information on all babies born at ≥ 20 weeks gestation or	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Assessed at age 2.5 to 6 years Functional problems (sleep apnea, ICD-10) <32 wks GA:82/3115, 2.6% (95%CI 2.1-3.2) 32-36 wks GA: 286/22,039, 1.3% (95%CI 1.2-1.5) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>To investigate the relationship between gestational age and weight for gestational age and sleep apnea diagnosis in a cohort of children aged up to 6 years

Study dates

Children born between 2000-2004

Country/ies where the study was carried out

Australia

Source of funding

National Health and Medical Research Council</td>
<td>Sample size

Sample recruited N = 429305
Sample analysed after exclusions N = 403106 (n=3115 children born at <32 weeks; n=22039 children born at 32-36 weeks; n=377952 children born at >36 weeks)

Characteristics

<table>
<tr><td>Characteristics of cohort with sleep apnea</td><td>n=4145</td></tr>
<tr><td>Male (n, (%))</td><td>2532 (1.2)</td></tr>
<tr><td>Birth weight (SGA <10th percentile) (n, (%))</td><td>376 (1.0)</td></tr>
<tr><td>Singletons (n, (%))</td><td>3995 (1.0)</td></tr>
<tr><td>Maternal age ≥30 yrs age (n, (%))</td><td>2325 (1.1)</td></tr>
</table>
</td>
<td>weighing ≥ 400 g. No further details reported. The primary outcome was sleep apnea diagnosis in childhood, first diagnosed between 1 and 6 years of age. Children with sleep apnea were identified from those hospital records with the ICD-10 code G47.3: sleep apnea, central or obstructive.

Age at assessment

2.5 to 6 years</td>
<td></td>
<td>4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals were not provided in the study</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	<table><tr><td>Normal vaginal birth (n, (%))</td><td>2377 (0.9)</td></tr></table> The mean length of follow-up was 5.04 years (SD 1.3) for children with sleep apnea. The mean age at first diagnosis for sleep apnea was 44.2 months (SD 13.9). In only those children with ≥ 5 years follow up (n = 2,121), the mean age at first diagnosis was 47.4 months (SD 14.8).			**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 378586 **Full citation** Samara, M., Johnson, S., Lamberts, K., Marlow, N., Wolke, D., Eating problems at age 6 years in a whole population sample of extremely preterm children, Developmental Medicine & Child	**Setting** All children who were born preterm in maternity units in the UK and Ireland, and were admitted to neonatal care. The majority of children at age 6 years were in mainstream school. **Inclusion criteria** All surviving children born at or before 25 weeks and 6 days of gestation. **Exclusion criteria** Not reported.	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Feeding/eating problems	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Assessed at 6 years age <u>Total eating problems</u> **<26 wks GA: 76/218, 34.9% (95%CI 29.0-41.6)** ≤23 wks GA: 9/22, 40.9% (95%CI 20.7-63.7) 24 wks GA: 34/68, 50.0% (95%CI 37.6-62.4) 25 wks GA: 33/128, 25.8% (95%CI 18.5-34.3) <u>Oral motor problems</u>	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Neurology, 52, e16-22, 2010

Study type

National population based cohort study (EPICURE)

Aim of the study

To investigate the prevalence of eating problems and their association with neurological and behavioural disabilities and growth among children born extremely preterm at 6 years

Study dates

Children born March to December 1995, assessed at 6 years age

Country/ies where the study was carried out

UK and Ireland</td>
<td>Sample size

n=308 children alive at 30 months age
n=241 entered study
n=223 completed eating questionnaire

Characteristics

<table>
<tr><td>Characteristics of preterm children</td><td>n=223</td></tr>
<tr><td>Male (n, (%))</td><td>125 (56.1)</td></tr>
<tr><td>Gestational age (mean, (SD))</td><td>24.5 (0.7)</td></tr>
<tr><td>Birth weight (mean, (SD))</td><td>749.1 (116.8)</td></tr>
</table>
</td>
<td>Outcome ascertainment/measures

When the child reached 6 years of age, parents completed a specially developed eating questionnaire. The scale included 19 items, which were grouped into four categories: refusal-faddy eating problems, oral motor problems, oral hypersensitivity problems and behavioural problems around meals. A total eating problems score was also constructed. Higher scores on each scale indicate more problems. To derive clinical categories, each scale was dichotomised into normal versus clinical (scores above the 90th centile or near according to the comparison group).</td>
<td><26 wks GA: 72/215, 33.5% (95%CI 27.2-40.2)
≤23 wks GA: 8/20, 40.0% (95%CI 19.1-64.0)
24 wks GA: 27/66, 40.9% (95%CI 29.0-53.7)
25 wks GA: 37/129, 28.7% (95%CI 21.1-37.3)

<u>Refusal faddy problems</u>
<26 wks GA: 38/223, 17.0% (95%CI 12.4-22.6)
≤23 wks GA: 3/22, 13.6% (95%CI 2.9-34.9)
24 wks GA: 11/68, 16.2% (95%CI 8.4-27.1)
25 wks GA: 24/133, 18.1% (95%CI 11.9-25.7)

<u>Eating behavioural problems</u>
<26 wks GA: 52/219, 23.7% (95%CI 18.3-30.0)
≤23 wks GA: 8/22, 36.4% (95%CI 17.2-59.3)
24 wks GA: 17/67, 25.4% (95%CI 15.5-37.5)
25 wks GA: 27/130, 20.8 (95%CI 14.2-28.8)

<u>Oral hypersensitivity problems</u>
<26 wks GA: 50/213, 23.5% (95%CI 18.0-30.0)
≤23 wks GA: 4/22, 18.2% (95%CI 5.2-40.3)</td>
<td>3. Was the sample size adequate?

No. Low precision of prevalence estimate (wide confidence intervals)

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. Of the surviving children there were 85 who dropped out of the study due to non-white ethnic origin, young mothers, living in overcrowding homes, experienced one serious life event by 30 months, suffered CP at 30 months, lower PDI, more feeding problems, or diagnosed with overall severe disability</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Source of funding BLISS; Health Foundation; Well-Being of Women;		**Age at assessment** 6 years age	24 wks GA: 22/63, 34.9% (95%CI 23.3-48.0) 25 wks GA: 24/128, 18.8% (95%CI 12.4-26.6) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Ref Id 397672 **Full citation** Samara, M., Marlow, N., Wolke, D., E. PICure Study Group, Pervasive behavior problems at 6 years of age in a total-population sample of children born at </= 25 weeks of gestation, Pediatrics, 122, 562-73, 2008 **Study type** A total-population prospective cohort study (EPICure) **Aim of the study** To test whether extremely preterm children have more pervasive behaviour provlems than classroom peers, by using parent and	**Setting** National cohort of all children born at <26 weeks of gestation in 1995 in the UK and Ireland. **Inclusion criteria** All surviving children in the UK and Ireland who were born at <=25 weeks of gestation from March through December 1995. **Exclusion criteria** None reported. **Sample size** N=224 children assessed at 6 years by parent-report N=215 children assessed at 6 years by teacher-report **Characteristics** Compared with children who were assessed, dropouts (maximum: N ——————————— 108) were more likely to be of nonwhite ethnic origin (30.6% of dropouts vs 19% of those assessed; P .05), to have young mothers (21 years of age; 21.3% vs 9.5%; P .01), to live in overcrowded homes (43.5% vs 21.5%; P .001), to have experienced 1 serious life event by 30 months (42.4% vs 23.5%;	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** Behavioural problems **Outcome ascertainment/measures** Teachers and parents completed the respective versions of the Strengths and Difficulties Questionnaire (SDQ). The 25 SDQ items fall into 5 scales (with 5 items each), that is, emotional symptoms, conduct problems, hyperactivity, peer problems, and prosocial behavior. For each scale except prosocialbehavior,	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 6 years **Parents' report** Overall behavioural difficulties (SDQ, 90th perc) <26 wks GA: 85/221, 38.5% (32.0-45.2%) Emotional problems (SDQ, 90th perc) <26 wks GA: 60/222, 27.0% (21.3-33.4%) Conduct problems (SDQ, 90th perc) <26 wks GA: 80/221, 36.2% (29.9-42.9%) Hyperactivity problems (SDQ, 90th perc) <26 wks GA:107/223, 48.0% (41.3-54.8%) Peer problems (SDQ, 90th perc) <26 wks GA: 80/222, 36.0% (29.7-42.7%) Prosocial behaviour (SDQ, 90th perc) <26 wks GA: 40/219, 18.3% (13.4-24.0%) Additional scales Attention problems	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Relatively low precision (wide confidence intervals) due to relatively low sample size. **4. Were the study subjects and the setting described in detail?** Yes.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
teacher consensus reports. Is there an excess of extremely preterm boys with behaviour problems? **Study dates** Children born 1995, assessed at 6 years of age. **Country/ies where the study was carried out** UK and Ireland **Source of funding** BLISS, the premature infant charity, the Health Foundation, Well-Being of Women.	P .001), and to have cerebral palsy (26.4% vs 15.8%; P .05), were less likely to have a family car (76.5% vs 87.9%; P .05), and had a lower Psychomotor Development Index at 30 months of age (mean score: 78.8 vs 85.5; P .01). The distributions of the other 22 variables, including social factors, all neonatal complications, and all parameters on growth or disability up to 30 months of age, were similar in the 2 groups.	higher scores indicate more problems. Additional items were adapted from the Conners Scales, the Child Behavior Checklist, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, and the International Classification of Diseases, 10th Revision, using the same Likert-scale format to assess components of attention-deficit/hyperactivity disorder (attention: teacher, 4 items; parents, 5 items; overactivity: 4 items each; impulsivity: teacher, 4 items; parents, 3 items). The total scores and subscale scores were dichotomized into normal/borderline versus clinical (score of 90th percentile, with respect to the control	<26 wks GA: 106/224, 47.3% (40.6-54.1%) Overactivity/impulsivity problems <26 wks GA: 73/224, 32.6% (26.5-39.2%) School adaptation difficulties <26 wks GA: 69.209, 33.0% (26.7-39.8%) **Teachers' report** Overall behavioural difficulties (SDQ, 90th perc) <26 wks GA: 72/208, 34.6% (29.2-41.5%) Emotional problems (SDQ, 90th perc) <26 wks GA: 63/211, 29.9% (23.8-36.5%) Conduct problems (SDQ, 90th perc) <26 wks GA: 48/209, 23.0% (17.5-29.3%) Hyperactivity problems (SDQ, 90th perc) <26 wks GA:99/213, 46.5% (39.6-53.4%) Peer problems (SDQ, 90th perc) <26 wks GA: 106/210, 50.5% (43.5-57.4%) Prosocial behaviour (SDQ, 90th perc) <26 wks GA:43/209, 20.6% (15.3-26.7%)	**5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. Our of 308 children known to be alive at 30 months of age, 224 participated in the current study. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates not provided.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		group). If the child scored at 90th percentile in both parent and teacher reports, then the behavior was considered normal (no behavior difficulty); mild difficulty refers to classification of the behavior in the clinical range by either parent or teacher, whereas clinical pervasive behavior refers to classification of the behavior in the clinical range by both parent and teacher (severe behavior difficulty). **Age at assessment** 6 years	Additional scales Attention problems <26 wks GA: 116/215, 54.0% (47.0-60.8%) Overactivity/impulsivity problems <26 wks GA: 65/215, 30.2% (24.2-36.9%) School adaptation difficulties <26 wks GA: 82/209, 39.2% (32.6-46.2%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 397686 **Full citation**	**Setting** All VLBW singleton live births in the study population either identified from state birth certificate files or from the delivery room entry logs of five major urban hospitals in Missouri that provide services for inner city residents or for women at high risk during their pregnancies	**Gestational age ascertainment** Not reported	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At adjusted age 15 months (range 9-34 months)	**Overall quality** Low

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Schendel, D. E., Stockbauer, J. W., Hoffman, H. J., Herman, A. A., Berg, C. J., Schramm, W. F., Relation between very low birth weight and developmental delay among preschool children without disabilities, American Journal of Epidemiology, 146, 740-9, 1997

Study type

Regional prospective cohort study.

Aim of the study

To assess the prevalence of developmental delay in a population of young singleton very low birth weight children, and to compare it to control children.

Study dates</td>
<td>Inclusion criteria

VLBW: birth weight <1500g during the study dates.
MLBW: birth weight 1500 - 2499g.

Exclusion criteria

Multiple pregnancy, physical or other limitations (including cerebral palsy, chronic health conditions, Down's syndrome, blindness, brain injury, orthopaedic problems). Loss to follow up.

Sample size

n = 367 very low birth weight children (<1500 g) with Denver II assessment at follow up
n= 553 moderately low birth weight children (1500-2499 g) with Denver II assessment at follow up

Characteristics

<table>
<tr><td>Characteristics</td><td>VLBW
n = 367</td><td>NBW
n = 555</td></tr>
<tr><td>Male, n (%)</td><td>180 (49.1)</td><td>290 (52.2)</td></tr>
<tr><td>Maternal age, n (%)</td><td></td><td></td></tr>
</table>
</td>
<td>Outcomes of interest in this study

Developmental delay

Outcome ascertainment/measures

The Denver II was used to screen for possible developmental delay by comparing the child's performance on various tasks with children of the same adjusted age. 9 outcomes indicating delay were based on four domains: Personal-social, language, fine motor-adaptive skills, and gross motor skills. The 9 outcomes reflected two types of delay:
1. A moderate delay (overall questionable performance + four domain specific outcomes for children who received one or more caution scores in</td>
<td><u>Developmental delay (Overall performance, Denver II)</u>
Questionable (≥2 cautions and/or 1 delay score):
VLBW/28.4 (3.0) wks GA: 64/367, 17.4% (95%CI 13.7-21.7)
MLBW/35.6 (2.8) wks GA: 65/553, 11.8% (95%CI 9.2-14.7)
Abnormal (≥2 delay scores):
VLBW/28.4 (3.0) wks GA: 40/367, 11.0% (95%CI 7.9-14.6)
MLBW/35.6 (2.8) wks GA: 32/553, 5.8% (95%CI 4.0-8.1)
<u>Developmental delay (personal-social, Denver II)</u>
≥1 cautions:
VLBW/28.4 (3.0) wks GA: 64/367, 17.4% (95%CI 13.7-21.7)
MLBW/35.6 (2.8) wks GA: 65/553, 11.8% (95%CI 9.2-14.7)
≥1 delays:
VLBW/28.4 (3.0) wks GA: 26/367, 7.1% (95%CI 4.7-10.2)
MLBW/35.6 (2.8) wks GA: 15/553, 2.7% (95%CI 1.5-4.4)
<u>Developmental delay (language, Denver II)</u></td>
<td>1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Women recruited were at high risk during their pregnancies

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. Of the survivors, there was loss to follow-up due to</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Participants born between December 1989 and March 1991

Country/ies where the study was carried out

USA

Source of funding

The National Institute of Child Health and Human Development, and the Centers for Disease Control and Prevention.</td>
<td>
<table>
<tr><td>< 20 years</td><td>86 (23.4)</td><td>131 (23.6)</td></tr>
<tr><td>20-34 years</td><td>245 (66.8)</td><td>385 (69.4)</td></tr>
<tr><td>≥35 years</td><td>36 (9.8)</td><td>39 (7.0)</td></tr>
<tr><td>Maternal education</td><td></td><td></td></tr>
<tr><td><High school, n (%)</td><td>105 (29)</td><td>148 (26.9)</td></tr>
<tr><td>≥High school, n (%)</td><td>257 (71)</td><td>403 (73.1)</td></tr>
<tr><td>Maternal race</td><td></td><td></td></tr>
<tr><td>Black, n (%)</td><td>130 (36.5)</td><td>221 (40.5)</td></tr>
<tr><td>Nonblack, n (%)</td><td>226 (63.5)</td><td>325 (59.5)</td></tr>
</table>
</td>
<td>a given domain);
2. Severe delay (abnormal overall test performance +the four domain specific outcomes for children who received one or more delay scores in a given domain
The overall performance was based on total number of caution and/or delay scores across all domains and was categorised as: 1. questionable (two or more cautions and/or maximum of one delay score); 2. abnormal (two or more delay scores).

Age at assessment

Median adjusted age 15 months (range 9-34 months)</td>
<td>≥1 cautions:
VLBW/28.4 (3.0) wks GA: 62/367, 17.0% (95%CI 13.2-21.1)
MLBW/35.6 (2.8) wks GA: 66/553, 11.9% (95%CI 9.4-14.9)
≥1 delays:
VLBW/28.4 (3.0) wks GA: 32/367, 8.7% (95%CI 6.0-12.1)
MLBW/35.6 (2.8) wks GA: 32/553, 5.8% (95%CI 4.0-8.1)
<u>Developmental delay (fine motor-adaptive, Denver II)</u>
≥1 cautions:
VLBW/28.4 (3.0) wks GA: 44/367, 12.0% (95%CI 9.0-15.8)
MLBW/35.6 (2.8) wks GA: 48/553, 8.7% (95%CI 6.5-11.3)
≥1 delays:
VLBW/28.4 (3.0) wks GA: 29/367, 7.9% (95%CI 5.4-11.1)
MLBW/35.6 (2.8) wks GA: 29/553, 5.2% (95%CI 3.5-7.5)
<u>Developmental delay (gross motor, Denver II)</u>
≥1 cautions:</td>
<td>no reply/refusal (n=147), adoption (n=3) and physical/other limitation (n=13)

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals were not provided in the study

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
			VLBW/28.4 (3.0) wks GA: 64/367, 17.4% (95%CI 13.7-21.7) MLBW/35.6 (2.8) wks GA: 49/553, 9.0% (95%CI 6.6-11.6) ≥1 delays: VLBW/28.4 (3.0) wks GA: 39/367, 10.6% (95%CI 7.7-14.2) MLBW/35.6 (2.8) wks GA: 22/553, 4.0% (95%CI 2.5-6.0) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**10. Were subpopulations identified using objective criteria?** N/A
Ref Id 322168 **Full citation** Stahlmann,N., Rapp,M., Herting,E., Thyen,U., Outcome of extremely premature infants at early school age: health-related quality of life and neurosensory, cognitive, and	**Setting** Geographically defined cohort of extremely preterm (<27 weeks) children born in one of 8 perinatal centres in Northern Germany between 1997-1999. **Inclusion criteria** All preterm infants with gestational age <27 weeks born between January 1997 and December 1999 in one of eight perinatal centres in Schleswig-Holstein, Northern Germany.	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** behavioural problems (SDQ total difficulties; emotional symptoms; hyperactivity-inattention; conduct	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Abnormal SDQ total difficulties (score 17-40) <27 wks GA: 21/75, 28.0% (18.2-39.6%) Abnormal emotional symptoms (SDQ subscale score 7-10) <27 wks GA: 20/75, 26.7% (17.1-38.1%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>behavioral outcomes in a population-based sample in northern Germany, Neuropediatrics, 40, 112-119, 2009

Study type

A geographically defined cohort study.

Aim of the study

To collect regional data to support and establish evidence-based decision-making. The report focuses on morbidity at early school age regarding neurosensory status, cognitive status, disability status as well as behavioural problems and health-related quality of life among very immature preterm infants.

Study dates</td>
<td>Exclusion criteria

None reported.

Sample size

n=154 infants identified
n=95 survived until discharge to home
n=92 survived until follow-up at 7-9 years
n=75 children were assessed at 7-9 years (81.5% of the surviving children)

Characteristics

<table>
<tr><td>Study group (n=75)</td><td>Drop-outs (n=17)</td><td></td></tr>
<tr><td>Maternal age at birth in years, median (range)</td><td>30 (17-40)</td><td>32.5 (18-45)</td></tr>
<tr><td>Maternal ethnicity non-German, %</td><td>23</td><td>11</td></tr>
<tr><td>Singleton, %</td><td>75</td><td>71</td></tr>
<tr><td>CS, %</td><td>85</td><td>85</td></tr>
</table>
</td>
<td>problems; peer-relationship problems; prosocial behaviour)

Outcome ascertainment/measures

Behavioural problems was assessed the Strengths and Difficulties Questionnaire (SDQ-Deu). Twenty-five items on five scales measure emotional symptoms, hyperactivity-inattention, conduct problems, peer relationship problems, and prosocial behaviour. Added scales scores (excluding prosocial behaviour) generates the total difficulties score. The scoring was classified into normal, borderline and abnormal. Abnormal scores were based on the SDQ website's scoring instructions</td>
<td><u>Abnormal hyperactivity-inattention score (SDQ subscale score 9-10)</u>
<27 wks GA: 28/75, 37.3% (26.4-49.3%)

<u>Abnormal conduct problems score (SDQ subscale score 6-10)</u>
<27 wks GA: 15/75, 20.0% (11.7-30.8%)

<u>Abnormal peer relationship score (SDQ subscale 5-10)</u>
<27 wks GA: 15/75, 20.0% (11.7-30.8%)

<u>Abnormal prosocial behaviour score (SDQ subscale 0-5)</u>
<27 wks GA: 7/75, 9.3% (3.8-18.3%)

Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No.
Low precision (wide confidence intervals) due to relatively low sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear.
81.5% of the children who survived up to follow-up were included.

6. Were objective, standard criteria used for the</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Children born 1997-1999, follow-up at 7-9 years of age.

Country/ies where the study was carried out

Germany

Source of funding

Stiftung fuer das behinderte Kind</td>
<td>
<table>
<tr><td>Male, %</td><td>44</td><td>41</td></tr>
<tr><td>Gestational age in days, median (range)</td><td>182 (164-188)</td><td>181 (167-188)</td></tr>
<tr><td>Birth weight in grams, median (range)</td><td>790 (430-1165)</td><td>905 (620-1290)</td></tr>
<tr><td>IVH grade III-IV/PVL, %</td><td>19</td><td>29</td></tr>
<tr><td>BPD, %</td><td>38</td><td>33</td></tr>
<tr><td>NEC, %</td><td>12</td><td>12</td></tr>
<tr><td>ROP >II or lasertherapy, %</td><td>33</td><td>24</td></tr>
</table>
</td>
<td>(according to the SDQinfo.com, in the total difficulties score, a score of 17-40 points is abnormal; for emotional symptoms, a score of 7-10 is abnormal; for hyperactivity-inattention, a score of 9-10 is abnormal; for conduct problems, a score of 6-10 is abnormal; for peer relationship problems, a score of 5-10 is abnormal; and for prosocial behaviour, a score of 0-5 is abnormal. These are based on a population-based survey.)

Age at assessment

7-9 years of age</td>
<td></td>
<td>measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.
Confidence intervals for the prevalence estimates were not provided.

9. Are all important confounding factors/subgroups/differences identified and accounted for?

Not applicable

10. Were subpopulations identified using objective criteria?

Not applicable</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Ref Id 411840 **Full citation** Stene-Larsen, K., Brandlistuen, R. E., Lang, A. M., Landolt, M. A., Latal, B., Vollrath, M. E., Communication impairments in early term and late preterm children: A prospective cohort study following children to age 36 months, Journal of Pediatrics, 165, 1123-1128, 2014 **Study type** Prospective population-based pregnancy cohort study (Norwegian Motherand Child Cohort Study (MoBa) **Aim of the study**	**Setting** Pregnant women attending more than 50 hospitals across Norway for their first prenatal ultrasound examination **Inclusion criteria** Complete set of questionnaires from gestational week 17,child age 18 months, and child age 36 months **Exclusion criteria** those with severe malformations or syndromes	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Communication problems **Outcome ascertainment/measures** At 18 months, Child communication impairments were measured using selected items from the Ages and Stages Questionnaire (ASQ) which included receptive communication skills, and expressive communication skills. The selection of items	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At age 18 months Communication impairment (ASQ) (≥ 2SD) 34-36 wks GA: 122/1673, 7.3% (95%CI 6.1-8.6) At 36 months Communication impairment (ASQ ≥2SD) 34-36 wks GA: 105/1673, 6.3% (95%CI 5.2-7.6) http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
To investigate the risk of communication impairments at age 18 and 36 months in children born early term (gestational weeks 37-38) and late preterm (gestational weeks 34-36). **Study dates** Between 1999 and 2008 **Country/ies where the study was carried out** Norway **Source of funding**	(n = 1350), severe hearing deficits (n = 148), and cerebral palsy (n = 54). We also excluded children with gestation longer than 41 6/7 weeks or shorter than 33 6/ 7 weeks (n = 4150) **Sample size** questionnaires from gestational week 17 (n = 101 624), child age 18 months (n = 64 970) excluded those with severe malformations or syndromes (n = 1350), severe hearing deficits (n = 148), and cerebral palsy (n = 54)	for the MoBa study was performed a priori by specialists in clinical and developmental psychology. Mothers were asked to find time to observe the child and rate the extent to which the child would typically show mastery of the skill in question, using the response categories “yes” (1), “very often” (2), “not yet” (3), and “I don’t know” (missing). To identify those children at risk for clinically significant communication impairments, a cutoff at 2 SD above the cohort mean was set At 36 months, infants were assessed using 6 items from the ASQ measuring expressive (3 items) and receptive (3 items) communication skills. To identify the children at risk for clinically significant communication		**5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Norwegian Ministry of Health and the

Ministry of Education and Research, the National Institutes

of Health (NIH)/National Institute of Environmental

Health Sciences,

NIH/National Institute of Neurological Disorders and Stroke,

The Norwegian Research Council/FUGE</td>
<td>excluded children with gestation longer than 41 6/7 weeks or shorter than 33 6/7 weeks (n = 4150)

n=39,423 children (1673 born late preterm, 7109 born early preterm)

Characteristics
<table>
<tr><td>Characteristics of preterm cohort</td><td>Late preterm</td></tr>
<tr><td>Gestational age, wk, median (range)</td><td>36 (34-36)</td></tr>
<tr><td>Male sex (%)</td><td>51.3</td></tr>
</table>
</td>
<td>impairments, a cutoff of 2 SD above the cohort mean was set

Age at assessment

18 months
36 months</td>
<td></td>
<td>N/A

10. Were subpopulations identified using objective criteria?

N/A</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	Maternal age, y, median (range) 31 (16-44) 			
Ref Id 413385 **Full citation** Stoelhorst, G. M. S. J., Martens, S. E., Rijken, M., Van Zwieten, P. H. T., Zwinderman, A. H., Wit, J. M., Veen, S., Behaviour at 2 years of age in very preterm infants (gestational age <32 weeks), Acta Paediatrica, International Journal of Paediatrics, 92, 595-601, 2003 **Study type**	**Setting** Regional cohort of all very preterm born children in the Dutch health regions of leiden, The Hague and Delft. **Inclusion criteria** All liveborn infants of less than 32 weeks of gestation from the Dutch health regions of Leiden, The Hague and Delft born in 1996 or 1997. **Exclusion criteria** Incomplete CBCL questionnaires. Down's syndrome. **Sample size** N=158 children with completed CBCL questionnaires (N=266 children included in the cohort originally, N=235 survived)	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** Behavioural problema (CBCL) **Outcome ascertainment/measures** The Child Behaviour Checklist (CBCL) for 2- to 3-y-old children was handed out to the parents during the 2-year check-up at the	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 2 years of corrected age Total behavioural problems (CBCL, 90th perc) <32 wks GA: 14/158, 8.9% (4.9-14.4%) Anxious/depressed (CBCL, 98th perc) <32 wks GA: 1/158, 0.6% (0.02-3.5%) Withdrawn (CBCL, 98th perc) <32 wks GA: 3/158, 1.9% (0.4-5.5%) Sleep problems (CBCL, 98th perc) <32 wks GA: 5/158, 3.2% (1.0-7.2%) Somatic problems (CBCL, 98th perc)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Regional population-based prospective cohort study (The Leiden Follow-Up Project on Prematurity)

Aim of the study

To determine behavioural outcome and risk factors for abnormal behaviour at 2 y corrected age in very premature infants in a regionally defined prospective cohort study.

Study dates

Children born 1996-1997 and assessed at 2 years corrected age.

Country/ies where the study was carried out

The Netherslands

Source of funding

None reported.</td>
<td>Characteristics
<table>
<tr><th></th><th>Total n=266</th><th>Survivors =235</th><th>Study group n=160</th></tr>
<tr><td>antenatal steroids, %</td><td>73</td><td>74</td><td>74</td></tr>
<tr><td>male, %</td><td>55</td><td>57</td><td>57</td></tr>
<tr><td>GA weeks, mean (SD)</td><td>29.2 (2.1)</td><td>29.5 (1.9)</td><td>29.4 (2.0)</td></tr>
<tr><td>24-26 weeks, %</td><td>17</td><td>13</td><td>14</td></tr>
<tr><td>27-28 weeks, %</td><td>23</td><td>23</td><td>22</td></tr>
<tr><td>29-31 weeks, %</td><td>60</td><td>64</td><td>64</td></tr>
</table>
</td>
<td>outpatient clinic and returned by mail. The CBCL had to be completed by one or both parents. This checklist includes 99 problem items and one open-ended item, which allows parents to add other problems not specified elsewhere. The 99 problem items consist of 49 items especially developed for 2 to 3-y-old children, the remaining 50 items are also included in the CBCL for ages 4–18y. The items are checked from 0 to 2; parents are requested to circle a 0 if an item is not true for their child, 1 if it is somewhat or sometimes true and 2 if it is very true or often true. The CBCL for 2 to 3-y-olds includes six syndrome scales: anxious/depressed behaviour, withdrawn behaviour, sleep problems, somatic problems, aggressive</td>
<td><32 wks GA: 3/158, 1.9% (0.4-5.5%)
<u>Aggressive behaviour (CBCL, 98th perc)</u>
<32 wks GA: 3/158, 1.9% (0.4-5.5%)
<u>Destructive behaviour (CBCL, 98th perc)</u>
<32 wks GA: 5/158, 3.2% (1.0-7.2%)

Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>Low precision (wide confidence intervals) due to relatively small sample.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
Of 235 survivors, 158 with completed questionnaires (67%).

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes</td>
</tr>
</table>

Study details	Participants				Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	BW, mean (SD)	1250 (383)	1293 (370)	1281 (383)	behaviour and destructive behaviour. In the six syndrome scales, scores above the 98th percentile are defined as clinically abnormal; scores from the 95th through the 98th percentile as borderline clinical. For the total problem score, the internalizing and externalizing groups, scores above the 90th centile are defined as clinically abnormal, scores from the 85th through the 90th centile as borderline clinical. **Age at assessment** 2 years corrected age		**8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
	SGA (<10th perc), %	13	13	14			
	Dutch origin, %	75	74	83			
	Maternal education level high, %	29	20	22			
	Maternal education level average, %	50	52	55			
	Maternal education level low, %	21	28	22			
	Maternal age at birth in	30.5 (5.6)	30.6 (4.7)	30.3 (4.6)			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	years, mean (SD)			
Ref Id 413386 **Full citation** Stoelhorst, G. M. S. J., Rijken, M., Martens, S. E., Van Zwieten, P. H. T., Feenstra, J., Zwinderman, A. H., Wit, J. M., Veen, S., Developmental outcome at 18 and 24 months of age in very preterm children: A cohort study from 1996 to 1997, Early Human Development, 72, 83-95, 2003 **Study type** Regional population-based prospective cohort study (The Leiden Follow-Up Project on Prematurity, LFUPP)	**Setting** Regional cohort of all very preterm born children in the Dutch health regions of leiden, The Hague and Delft. **Inclusion criteria** All liveborn infants of less than 32 weeks of gestation from the Dutch health regions of Leiden, The Hague and Delft born in 1996 or 1997. **Exclusion criteria** Down's syndrome. **Sample size** N=163 with PDI data at 18 months CA, N=144 with PDI data at 24 months CA (N=266 children included in the cohort originally, N=235 survived) **Characteristics**	**Gestational age ascertainment** Not reported. **Outcomes of interest in this study** Psychomotor developmental index (PDI) **Outcome ascertainment/measures** Mental and psychomotordevelopment were assessed using the Dutch version of the Bayley Scales of Infant Development I (BSID-I). These scales have a population mean of 100 and a SD of 16. An PDI of >=84 was considered normal, PDI 68-84 (-2 to -1 SD)	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 18 months of corrected age Severe psychomotor delay PDI (BSID-I, <-2SD) <32 wks GA: 29/163, 17.8% (12.3-24.5%) (Moderate psychomotor delay PDI (-2 to -1 SD) <32 wks GA: 18/163, 11.0% (6.7-16.9%)) At 24 months of corrected age Severe psychomotor delay PDI (BSID-I, <-2SD) <32 wks GA: 12/144, 8.3% (4.4-14.1%) (Moderate psychomotor delay PDI (-2 to -1 SD) <32 wks GA: 32/144, 22.2% (15.7-29.9%)) The prevalence of normal PDI score remained similar	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to small sample.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Aim of the study To determine the effect of prematurity (GA <32 weeks) on developmental outcome at corrected age of 18 and 24 months in a regionally defined, prospective cohort study. **Study dates** Children born 1996-1997 and assessed at 18 and 24 months corrected age. **Country/ies where the study was carried out** The Netherslands **Source of funding** None reported.	<table><tr><td></td><td>LFUPP cohort n=266</td></tr><tr><td>Antenatal steroids, %</td><td>75</td></tr><tr><td>Male, %</td><td>55</td></tr><tr><td>GA weeks, mean (SD)</td><td>29.2 (2.1)</td></tr><tr><td>24-26 wks GA, %</td><td>17</td></tr><tr><td>27-28 wks GA, %</td><td>23</td></tr><tr><td>29-31 wks GA, %</td><td>60</td></tr><tr><td>BW in g, mean (SD)</td><td>1250 (383)</td></tr><tr><td>SGA (<10thperc), %</td><td>13</td></tr></table>	was considered moderate delay and <68 (<-2SD) was considered severe delay. **Age at assessment** 18 months and 24 months (corrected)	between 18 and 24 months (71% and 70%), whereas the prevalence of moderate delay increased from 11% to 22% and severe delay decreased from 18% to 8%. Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. Out of 235 survivors, only 163 had data on PDI at 18 months CA (69%) and 144 at 24 months CA (61%). **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr><td></td><td><table>
<tr><td>Dutch origin, %</td><td>75</td></tr>
<tr><td>Maternal level of education high, %</td><td>29</td></tr>
<tr><td>Maternal level of education average, %</td><td>50</td></tr>
<tr><td>Maternal level of education low, %</td><td>21</td></tr>
<tr><td>Maternal age at birth in year, mean (SD)</td><td>30.5 (5.6)</td></tr>
</table></td><td></td><td></td><td>No.
Confidence intervals for prevalence estimates not provided.

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td></tr>
<tr><td>Ref Id

412142

Full citation

Wilson-Ching, M., Molloy, C. S., Anderson, V. A., Burnett, A., Roberts, G.,</td><td>Setting

Consecutive survivors born at <28 weeks GA/ELBW were previously evialuated in the Victorian Infant Collaborative Study Group at age 2, 5 and 8 years age

Inclusion criteria

Adolescents born at <287 weeks GA/ELBW <100g</td><td>Gestational age ascertainment

Not reported

Outcomes of interest in this study</td><td>Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)

At 17 years age
<u>Attention problems</u>
<u>Selective attention (<-1.5 SD)</u>
<28 wks GA/ELBW: 71/199, 35.6% (95%CI 29-43)</td><td>Overall quality

Low

1. Was the sample representative of the target population?

Yes</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Cheong, J. L., Doyle, L. W., Anderson, P. J., Attention difficulties in a contemporary geographic cohort of adolescents born extremely preterm/extremely low birth weight, Journal of the International Neuropsychological Society, 19, 1097-108, 2013

Study type

Geographical cohort study

Aim of the study

To evaluate attention difficulties in a contemporary geographic cohort of adolescents born extremely preterm (EP, 28 weeks' gestation) or extremely low birth weight (ELBW, birth weight, 1000g)</td>
<td>Exclusion criteria

Not reported

Sample size

n=298 consecutive survivors

Characteristics

<table>
<tr><td>Characteristics of preterm/ELBW cohort</td><td>n=298</td></tr>
<tr><td>Gestational age (weeks, mean, SD)</td><td>26.6 (2)</td></tr>
<tr><td>Birth weight (g, mean, SD)</td><td>884 (161)</td></tr>
<tr><td>Birth weight <750g (n, %)</td><td>43 (19)</td></tr>
<tr><td>Male (n, %)</td><td>99 (43)</td></tr>
<tr><td>Multiple births (n, %)</td><td>75 (33)</td></tr>
</table>
</td>
<td>Behavioural, social, emotional, attention problems:
Selective attention
Sustained attention
Shifting attention
Divided attention
Inattentive
Hyperactive
ADHD
Shift
Inhibit

Outcome ascertainment/measures

Attention problems (<-1.5 SD)
Selective attention:

The Telephone Search task of the Test of Everyday Attention was used. Participants were required to search simulated telephone directory for pairs of shapes that looked the same. Participants were encouraged to identify the target shapes that looked the</td>
<td><u>Sustained attention (<-1.5 SD)</u>
<28 wks GA/ELBW, 16/174, 9.2% (95%CI 5.3-14.5)
<u>Shifting attention (<-1.5 SD)</u>
<28 wks GA/ELBW, 86/209, 41.1% (95%CI 34.4-48.2)
<u>Divided attention (<-1.5 SD)</u>
<28 wks GA/ELBW, 30/196, 15.3% (95%CI 10.6-21.1)

<u>Behavioural attention problems</u>
<u>Inattentive (CADS parent report) (<-1.5 SD)</u>
<28 wks GA/ELBW: 32/193, 16.6% (95%CI 11.6-22.6)
<u>Hyperactive (CADS parent report) (<-1.5 SD)</u>
<28 wks GA/ELBW: 28/193, 14.5% (95%CI 9.9-20.1)
<u>ADHD DSM-IV (parent report) (<-1.5 SD)</u>
<28 wks GA/ELBW: 34/193, 17.6% (95%CI 12.5-23.7)
<u>Shift (BRIEF parent report) (<-1.5 SD)</u>
<28 wks GA/ELBW: 38/201, 19% (95%CI 13.7-25.0)
<u>Inhibit (BRIEF parent report) (<-1.5 SD)</u>
<28 wks GA/ELBW: 35/201, 17.4% (95%CI 12.4-23.4)</td>
<td>2. Were the study participants recruited in an appropriate way?

Consecutively selected adolescents

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Limited information about setting

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. The follow up rate was 76.5% who completed the neurological assessment (n=38 refused, n=15 lost to follow up, n=3 lived in other states or countries, n=14 other reasons)</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Study dates 1991-1992, assessed at 17 years age **Country/ies where the study was carried out** Victoria, Australia **Source of funding** NHMRC	CP (n,%) 21 (9) IVH grage 3 or 4 (n, %) 16 (7) BPD (n,%) 81 (36) Postnatal steroids (n, %) 73 (32)	same both accurately and quickly. The number of targets detected (maximum-=20) and the time taken to complete the task were recorded. The Elevator with Distraction task, also from the Test of Everyday Attention, was used as a second measure with a maximum of 7 correct trials recorded. Sustained attention: The Test of Variables of Attention (TOVA) was used to measure how quickly the participants could see a target presented on the computer. The response time, for correct responses, response time variability, number of omission errors (targets not responded to) and number of commission errors	Inattentive (CADS self report) (<-1.5 SD) <28 wks GA/ELBW: 17/192, 8.9% (95%CI 5.2-13.8) Hyperactive CADS (self report) (<-1.5 SD) <28 wks GA/ELBW: 11/192, 5.7% (95%CI 3.0-10.0) ADHD DSM IV (self report) (<-1.5 SD) <28 wks GA/ELBW:10/192, 5.2% (95%CI 2.5-9.4) Shift (BRIEF self report) (<-1.5 SD) <28 wks GA/ELBW: 10/180, 5.6% (95%CI 2.7-10.0) Inhibit (BRIEF self report) (<-1.5 SD) <28 wks GA/ELBW: 17/180, 9.4% (95%CI 5.6-14.7) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Unclear. The cutoffs for assessments was not clearly reported in the methods **8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		(responses to non-targets) were recorded. Age standard scores were analyzed for these variables, which were evaluated for the entire task as well as the 1st, 2nd, 3rd, and 4th quarters of the task. Shifting attention: The Contingency Naming Test (CNT) was used to assess individuals by showning a page of coloured shapes embedded in a smaller shape and were instructed to respond by naming either the colour or shape of each figure. An efficiency score, which represents a ratio of the time taken to complete the task and the number of errors, was the variable of interest		**10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		Divided attention: The Telephone Search while counting task on the Test of Everyday Attention was used. Participants were required to listen to and count a series of tones while completing the Telephone Search task (where they were required to select and circle specific targets). A divided attention score was calculated by multiplying the proportion of correct targets found by the proportion of correct series of tones counted times 10, with a score of 10 signifying a perfect score Behavioural attention: The CADS-P consists of 26 items and the CADS-A of 30 items, and both provide 3 agestandardized scales (inattentive		

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		behaviors, hyperactive behaviors, DSM-IV ADHD index) each with a mean of 50 and SD of 10 Behaviour rating inventory of executive function (BRIEF): Parent or self reported behaviors related to executive functioning were assessed by evaluating specific behaviors relating to executive attention skills including "shift" and "inhibit" scales. Ability to flexibly move from a given activity or aspect of a problem to another as the situation demanded was evaluated. T scores were recorded for		

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		each of these scales (M=50; SD=10) **Age at assessment** 17 years age		
Ref Id 412200 **Full citation** Zhu, J. L., Olsen, J., Olesen, A. W., Risk for developmental coordination disorder correlates with gestational age at birth, Paediatric and Perinatal	**Setting** The cohort resulted from the linkage between the prenatal interview data and the 7-year follow-up data within the Danish National Birth Cohort. About 60% of the women, who were invited by about 50% of the general practitioners in Denmark, participated in the national cohort. When the children reached 7 years of age, a follow-up questionnaire on child health and development was filled out	**Gestational age ascertainment** GA was based on last menstrual period and ultrasound measurements in early pregnancy, giving first priority to ultrasound data in case of disparity	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 7 year follow up DCD ≤31 wks GA: 14/99, 14.1% (95%CI 8.0-22.6) 32 wks GA: 6/46, 13.0% (95%CI 5.0-26.3) 33 wks GA: 7/77, 11.7$ (95%CI 3.7-17.8)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Epidemiology, 26, 572-577, 2012

Study type

National Birth Cohort

Aim of the study

To examine the relation between the larger spectrum of gestational age at birth and the risk of DCD

Study dates

February 2007 and March 2009

Country/ies where the study was carried out

Denmark

Source of funding

Danish Medical Research Council;</td>
<td>by the primary caregivers, usually mothers, either online or on paper.

Inclusion criteria

Children born between gestational age at birth ranging from 25-44 weeks.

Exclusion criteria

Twins and triplets
Singletons without data for the first interview
Missing or incomplete information on infertility status
Missing or wrong information on gestational age from the Medical Birth Register

Sample size

n=22, 898 children with data included in the analysis

Characteristics

<table><tr><td>Characteristics of preterm group born at <37 weeks GA</td><td>n=943/22898</td></tr></table></td>
<td>Outcomes of interest in this study

DCD

Outcome ascertainment/measures

The DCDQ, a 15-item parent questionnaire designed to screen for coordination disorders in children aged 5–15 years, including playing ball (throwing, catching, hitting), writing (fast, legibly, with proper effort) was used.

Parents were asked to provide their responses on a five-point Likert scale when comparing the motor performance between their child and his/her peers. A high score suggests no DCD. In the study, DCD total score of 46 or below defined</td>
<td>34 wks GA: 14/125, 11.2% (95%CI 6.3-18.1)
35 wks GA: 10/185, 5.4% (95%CI 2.6-9.7)
36 wks GA: 18/411, 4.4% (95%CI 2.6-6.8)

32-36 wks GA: 55/844, 6.5% (5.0-8.4%)

Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Danish National Birth Cohort;
Pharmacy Foundation;
The Egmont Foundation;
The March of Dimes Birth Defects Foundation;
The Augustinus Foundation and the Health Foundation</td>
<td>
<table>
<tr><td>Male (n, (%))</td><td>515 (54.6)</td></tr>
<tr><td>GA (weeks) (median, range)</td><td>35 (25-36)</td></tr>
<tr><td>Birth weight (g) (median, range)</td><td>2640 (590-5320)</td></tr>
<tr><td>IUGR (n, (%))</td><td>100 (10.6)</td></tr>
<tr><td>DCD score (median, range)</td><td>68 (15-75)</td></tr>
<tr><td>Maternal age 25-29 years (n, (%))</td><td>385 (40.2)</td></tr>
</table>
</td>
<td>children having probable DCD.

Age at assessment

7 year follow-up</td>
<td></td>
<td>7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals were not provided in the study

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td>
</tr>
<tr>
<td>Ref Id

451626</td>
<td>Setting

A population-based cohort of preterm babies born in the Netherlands in 2002 and 2003.</td>
<td>Gestational age ascertainment

Gestational age on >95% of the cases was</td>
<td>Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)

At 4 and 5 years of age</td>
<td>Overall quality

Low</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Full citation

Hornman, J, de Winter, AF, Kerstjens, JM, Bos, AF, Reijneveld, SA, Emotional and Behavioral Problems of Preterm and Full-Term Children at School Entry, Pediatrics, 137, 2016

Study type

Population-based cohort study (LOLLIPOP)

Aim of the study

To assess individual stability of emotional and behavioural problems in preterm compared with term children first before school entry and again 1 year after school entry, and variation in stability within the preterm group.

Study dates</td>
<td>Inclusion criteria

Children born at <36 weeks of gestation in 2002 and 2003.

Exclusion criteria

Children with major congenital malformations, congenital infections, or syndromes, children with unclear or missing GA, children lost to follow-up or other reasons.

Sample size

n=1054 preterm children
(n=653 moderately preterm children [32-35 weeks]
n=401 early preterm children [25-31 weeks])
n=389 term children as comparisons

Characteristics

<table>
<tr><td></td><td>Preterm (n=1054)</td><td>Term (n=389)</td></tr>
<tr><td>GA, median (IQR)</td><td>33 (30-35)</td><td>40 (39-40)</td></tr>
<tr><td>Boy, %</td><td>54.6</td><td>47.6</td></tr>
</table>
</td>
<td>based on early ultrasound measurements and measured in completed weeks. In the remaining cases, only clinical estimates based on last menstrual date were available, these were checked against clinical estimates of GA after birth.

Outcomes of interest in this study

Behavioural problems (CBCL)

Outcome ascertainment/measures

Emotional and behavioural problems were assessed with the validated Dutch version of the Child Behaviour Checklist (CBCL), applicable for ages 1.5-5 years. The CBCL consists of 99 problem</td>
<td><u>Emerging total behavioural problems (CBCL >=84th percentile) (normal score at 4 years, abnormal score at 5 years)</u>
25-35 wks GA: 45/1054, 4.3% (3.1-5.7%)
25-31 wks GA: 21/401, 5.2% (3.3-7.9%)
32-35 wks GA: 24/653, 3.7% (2.4-5.4%)

<u>Resolving total behavioural problems (CBCL >=84th percentile) (abnormal score at 4 years, normal score at 5 years)</u>
25-35 wks GA: 79/1054, 7.5% (6.0-9.3%)
25-31 wks GA: 22/401, 5.5% (3.5-8.2%)
32-35 wks GA: 57/653, 8.7% (6.7-11.2%)

<u>Persistent total behavioural problems (CBCL >=84th percentile) (abnormal score at 4 and 5 years)</u>
25-35 wks GA: 76/1054, 7.2% (5.7-8.9%)
25-31 wks GA: 33/401, 8.2% (5.7-11.4%)
32-35 wks GA: 43/653, 6.6% (4.8-8.8%)</td>
<td>1. Was the sample representative of the target population?

Unclear.
High attrition, thus, it is unclear whether the final sample represents the population.

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Unclear.
In the smaller subgroup (children born at 25-31 weeks of gestation), precision was somewhat low (wide confidence intervals).

4. Were the study subjects and the setting described in detail?

Yes</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Children in 2002-2003, follow-up at ages 4 and 5 years.

Country/ies where the study was carried out

The Netherlands

Source of funding

The research foundation of Beatrix Children's Hospital, the Cornelia Foundation for the Handicapped Child, The A. Bulk Preventive Child Health Care Research Fund, the Dutch Brain Foundation, and an unrestricted research grant from FrieslandCampina, Friso Infant Nutrition, Abbvie, and Pfizer Europe.</td>
<td>
<table>
<tr><td>SGA, %</td><td>14.2</td><td>6.7</td></tr>
<tr><td>Smoking during pregnancy, %</td><td>19.3</td><td>11.9</td></tr>
<tr><td>Twin, %</td><td>27.4</td><td>1.3</td></tr>
<tr><td>Multiparity, %</td><td>29.9</td><td>62.9</td></tr>
<tr><td>1-parent family, %</td><td>6.3</td><td>2.1</td></tr>
<tr><td>Low education level of both parents, %</td><td>16.1</td><td>11.9</td></tr>
<tr><td>Low education level mother, %</td><td>25.5</td><td>22.2</td></tr>
</table>
</td>
<td>items, each item can be rated by the parents as not true (0), somewhat/sometimes true (1), or very/often true (2). From these ratings, the total, internalising, and externalising problem scales were constructed. >=84th percentile of the scale was considered subclinical or clinical. The dichotomised CBCL outcomes at ages 4 and 5 years were combined, resulting in 4 categories: consistently normal (normal score at both 4 and 5 years), emerging problems (normal score at 4 years, abnormal score at 5 years), resolving problems (abnormal score at 4 years, normal score at 5 years), and persistent problems (abnormal score at both 4 and 5 years).</td>
<td><u>Emerging internalising problems (CBCL >=84th percentile) (normal score at 4 years, abnormal score at 5 years)</u>
25-35 wks GA: 76/1054, 7.2% (5.7-8.9%)
25-31 wks GA: 32/401, 8.0% (5.5-11.1%)
32-35 wks GA: 44/653, 6.7% (4.9-8.9%)

<u>Resolving internalising problems (CBCL >=84th percentile) (abnormal score at 4 years, normal score at 5 years)</u>
25-35 wks GA: 78/1054, 7.4% (5.9-9.2%)
25-31 wks GA: 29/401, 7.2% (4.9-10.2%)
32-35 wks GA: 49/653, 7.5% (5.6-9.8%)

<u>Persistent internalising problems (CBCL >=84th percentile) (abnormal score at 4 and 5 years)</u>
25-35 wks GA: 113/1054, 10.7% (8.9-12.8%)
25-31 wks GA: 47/401, 11.7% (8.7-15.3%)
32-35 wks GA: 66/653, 10.1% (7.9-12.7%)</td>
<td>5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
High attrition, the preterm sample included 1443 children, out of the 3300+ original sample (less than half).

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.
Confidence intervals of the prevalence estimates were not provided.</td>
</tr>
</table>

Study details	Participants			Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	Low education level father, %	29.2	25.3	**Age at assessment** 4 and 5 years	<u>Emerging externalising problems (CBCL >=84th percentile) (normal score at 4 years, abnormal score at 5 years)</u> 25-35 wks GA: 56/1054, 5.3% (4.0-6.8%) 25-31 wks GA: 21/401, 5.2% (3.3-7.9%) 32-35 wks GA: 35/653, 5.4% (3.8-7.4%) <u>Resolving externalising problems (CBCL >=84th percentile) (abnormal score at 4 years, normal score at 5 years)</u> 25-35 wks GA: 76/1054, 7.2% (5.7-8.9%) 25-31 wks GA: 21/401, 5.2% (3.3-7.9%) 32-35 wks GA: 55/653, 8.4% (6.4-10.8%) <u>Persistent externalising problems (CBCL >=84th percentile) (abnormal score at 4 and 5 years)</u> 25-35 wks GA: 88/1054, 8.4% (6.8-10.2%) 25-31 wks GA: 33/401, 8.2% (5.7-11.4%)	**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
	Non-Dutch birth country of parent or child, %	8.3	4.7			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
			32-35 wks GA: 55/653, 8.4% (6.4-10.8%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	
Ref Id 443759 **Full citation** Higa Diez, M., Yorifuji, T., Kado, Y., Sanada, S., Doi, H., Preterm birth and behavioural outcomes at 8 years of age: a nationwide survey in Japan, Archives of Disease in Childhood, 101, 338-43, 2016 **Study type** Prospective cohort design	**Setting** Longitudinal Survey of Babies in the 21st Century in Japan, nationally representative data. **Inclusion criteria** Neonates born in Japan in 2001 between 10 and 17 January and between 10 and 17 July. **Exclusion criteria** Participants with missing information on gestational age, or those who were born after 41 weeks. Participants who were lost to follow-up or those without information on behavioural outcomes at 8 years of age. **Sample size**	**Gestational age ascertainment** GA was calculated in weeks and obtained from birth records. **Outcomes of interest in this study** Attention problems and delinquent behaviour (based on CBCL) **Outcome ascertainment/measures** Some questions of the standardised and	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 8 years **Attentional problems** Interrupting people (CBCL) <34 wks GA: 149/356, 41.9% (36.7-47.2%) 34-36 wks GA: 519/1287, 40.3% (37.6-43.1%) 39-41 wks GA (term): 8718/22635, 38.5% (37.9-39.2%) Inability to wait his/her turn <34 wks GA: 45/356, 12.6% (9.4-16.6%) 34-36 wks GA: 117/1287, 9.1% (7.6-10.8%) 39-41 wks GA (term): 1359/22635, 6.0% (5.7-6.3%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr>
<td>Aim of the study

To analyse the effect of different preterm birth categories on behavioural outcomes.

Study dates

Children born in 2001, assessed at 8 years.

Country/ies where the study was carried out

Japan

Source of funding

Supported by Health and Labour Sciences Research Grants on Health Research on Children, Youth and Families grant and by Efficient Operation of the University grant.</td>
<td>n=34163 neonates born in Japan in 2001
of which
n=356 born at <34 weeks
n=1287 born at 34-36 weeks
n=9885 born at 37-38 weeks
n=22635 born at 39-41 weeks (reference population)

Characteristics

<table>
<tr><th></th><th><34 wks (n=356)</th><th>34-36 wks (n=1287)</th><th>39-41 wks (n=22635)</th></tr>
<tr><td>Male, %</td><td>56.5</td><td>60.1</td><td>49.7</td></tr>
<tr><td>Multiple birth, %</td><td>21.1</td><td>20.3</td><td>0.2</td></tr>
<tr><td>Multiparity, %</td><td>59</td><td>56.2</td><td>47.8</td></tr>
<tr><td>Mean maternal age at</td><td>21.2</td><td>30.7</td><td>30.1</td></tr>
</table>
</td>
<td>validated version of the Child Behaviour Checklist 9CBCL) 4-18 for Japan was used. A total of 7 behavioural outcomes were used, three related to attention problems: 1) interrupting people, 2) inability for the child to wait his/her turn during play, and 3) failure to pay attention to the surrounding area when crossing a street; and four related to delinquent/aggressive behaviour: 1) lying, 2) destroying toys or books, 3) hurting other people, and 4) causing disturbances in public. Binary outcomes for each were used. Combined outcome for both attention and delinquent/aggressive behaviour was also used, defined as participants who present adverse for all attention or delinquent/aggressive behaviours.</td>
<td><u>Failure to pay attention crossing street</u>
<34 wks GA: 81/356, 22.8% (18.5-27.5%)
34-36 wks GA: 265/1287, 20.6% (18.4-22.9%)
39-41 wks GA (term): 4306/22635, 19.0% (18.5-19.5%)
<u>Adverse outcomes for all attentional problems</u>
<34 wks GA: 17/181, 9.4% (5.6-14.6%)
34-36 wks GA: 38/683, 5.6% (4.0-7.6%)
39-41 wks GA (term): 367/12119, 3.0% (2.7-3.4%)
Delinquent/aggressive behaviours
<u>Lying</u>
<34 wks GA: 100/356, 28.1% (23.5-33.1%)
34-36 wks GA: 347/1287, 27.0% (24.6-29.5%)
39-41 wks GA (term): 5621/22635, 24.8% (24.3-25.4%)
<u>Destroying toys/books</u>
<34 wks GA: 54/356, 15.2% (11.6-19.3%)
34-36 wks GA: 162/1287, 12.6% (10.8-14.5%)
39-41 wks GA (term): 2088/22635, 9.2% (8.9-9.6%)</td>
<td>Unclear.
For the smaller gestational age subgroup (<34 weeks), the precision is low (wide confidence intervals) due to relatively low sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
Of the initial total sample (n=47015), 72.7% were included in the analysis (n=34163). This included all gestational ages. Of children born at <34 weeks, 68.3% were included in analysis and children born at 34-36 weeks 69.2% were included in analysis.

6. Were objective, standard criteria used for the</td>
</tr>
</table>

Study details	Participants				Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	delivery, y				**Age at assessment** 8 years.	Hurting other people <34 wks GA: 51/356, 14.3% (10.9-18.4%) 34-36 wks GA: 164/1287, 12.7% (11.0-14.7%) 39-41 wks GA (term): 2381/22635, 10.5% (10.1-10.9%) Disturbance in public <34 wks GA: 88/356, 24.7% (20.3-29.5%) 34-36 wks GA: 327/1287, 25.4% (23.1-27.9%) 39-41 wks GA (term): 4417/22635, 19.5% (19.0-20.0%) Adverse outcomes for all delinquent/aggressive behaviours <34 wks GA: 11/194, 5.7% (2.9-9.9%) 34-36 wks GA: 24/714, 3.4% (2.2-5.0%) 39-41 wks GA (term): 273/13472, 2.0% (1.8-2.3%) Percentages and confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
	Maternal education university or higher, %	11.8	13.3	15.1			
	Maternal education junior college, &	40.7	42	42.6			
	Maternal education <= high school, %	45.2	42.2	40.6			
	Paternal educatio	34.3	37.5	37.5			

Study details	Participants				Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	n university or higher, %						
	Paternal education junior college, %	15.2	14.4	15.8			
	Paternal education <= high school, %	47.8	44.5	44.1			
	Mother smoking, %	13.5	14.9	13.7			
	Mother working, %	53.9	53.2	55.8			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Ref Id 433537 **Full citation** Johnson, S., Matthews, R., Draper, E. S., Field, D. J., Manktelow, B. N., Marlow, N., Smith, L. K., Boyle, E. M., Eating difficulties in children born late and moderately preterm at 2 y of age: a prospective population-based cohort study, American Journal of Clinical Nutrition, 103, 406-14, 2016 **Study type** Prospective population-based cohort study (LAMBS) **Aim of the study** The aims were to assess the prevalence	**Setting** The Late and Moderately Preterm Birth Study (LAMBS) study took place in a geographically defined region of the East Midlands of England from September 2009 through December 2010. This comprised infants delivered at 4 large maternity centers, a midwifery-led birthing unit, and at home. **Inclusion criteria** All infants born LMPT (32+0–36+6 wk) to mothers resident in a geographically defined region of the East Midlands of England from September 2009 through December 2010 were invited to participate in the Late and Moderately Preterm Birth Study. **Exclusion criteria** Infants with major structural or chromosomal congenital anomalies, including cardiovascular malformations, and neurosensory impairment were excluded from the analyses. **Sample size** N=628 late and moderately preterm (LMPT) children (32-36 weeks) **Characteristics**	**Gestational age ascertainment** No description provided. **Outcomes of interest in this study** Eating difficulties **Outcome ascertainment/measures** At 2 y corrected age, parents were asked to complete a questionnaire comprising measures to assess infants' eating behavior, cognitive development, behavior and emotional problems, and neurosensory impairment. A validated eating behavior questionnaire (4) was used to assess	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 2 years of corrected age Total eating difficulties 32-36 wks GA: 69/726, 9.5% (7.5-11.9%) Refusal picky eating 32-36 wks GA: 48/744, 6.5% (4.8-8.5%) Oral motor problems 32-36 wks GA: 41/749, 5.5% (4.0-7.4%) Oral hypersensitivity 32-36 wks GA: 32/756, 4.2% (2.9-5.9%) Eating behaviour problems 32-36 wks GA: 45/738, 6.1% (4.5-8.1%) The percentages reported in the paper are weighted, but in order to calculate confidence intervals, the absolute numbers of cases and total sample are reported here. Confidence intervals calculated by the NGA technical team using	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. Relatively high precision (narrow confidence intervals). **4. Were the study subjects and the setting described in detail?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
of eating difficulties in infants born LMPT at 2 y corrected age and to explore the impact of neonatal and neurodevelopmental factors. **Study dates** Children born between September 2009 and December 2010, follow-up at 2 years corrected age. **Country/ies where the study was carried out** UK **Source of funding** Supported by the National Institute for Health Research under its Programme Grants for Applied Research (PGfAR) program (grant RP-PG-040710029).	LMPT infants were significantly more likely to be born SGA than were termborn controls (10.7% compared with 4.0%) and to have received mechanical ventilation (8.8% compared with 0.7%) and nasogastric feeding (31.8% compared with 1.5%). At 2 y of age, LMPT infants were also at increased risk of cognitive impairment (5.4% compared with 2.6%), behavioral problems (20.4% compared with 17.2%), and delayed social competence (25.6% compared with 17.9%). There were no significant differences between mothers of infants born LMPTand those of infants born at term.	the presence of eating difficulties in the 4 domains of refusal/picky eating (e.g., poor appetite, food refusal, selective eating), oral motor problems (e.g., problems biting, chewing, or swallowing; gagging; or choking on food), oral hypersensitivity (e.g., aversion to being touched around the mouth or having things put in the mouth), and eating behavior problems (e.g., has tantrums or makes a mess during meals). For each of 17 items, parents were asked to state whether their child exhibited the problem behavior never, occasionally, or often. Each item was scored 0, 1, or 2, respectively, from which a total eating difficulties score was computed (range: 0–34) and 4 subscale scores for refusal/picky	http://statpages.info/confint.html	**5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. High attrition, more than 40% of the eligible children were lost to follow-up. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates not provided.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		eating (7 items; range: 0–14), oral motor problems (5 items; range: 0–10), oral hypersensitivity (2 items; range: 0–4), and eating behavior problems (3 items; range: 0–6); for all scales, higher scores indicate greater problems. >90th percentile of the term control group were used to identify children with clinically significant eating difficulties. **Age at assessment** Two years corrected age.		**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 221453 **Full citation** Johnson,S., Hollis,C., Kochhar,P., Hennessy,E., Wolke,D.,	**Setting** All children who were born preterm in maternity units in the UK and Ireland, and were admitted to neonatal care **Inclusion criteria** All surviving babies born at <26 weeks of gestation	**Gestational age ascertainment** Not reported **Outcomes of interest in this study**	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** Assessed at 11 years age Autism spectrum symptoms (SCQ ≥15) <26 wks GA: 29/183, 15.8% (95%CI 10.9-22.0%)	**Overall quality** Low **1. Was the sample representative of the target population?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Marlow,N., Autism spectrum disorders in extremely preterm children, Journal of Pediatrics, 156, 525-531, 2010 **Study type** Population based cohort study (EPICURE) **Aim of the study** To investigate the prevalence, correlates, and antecedents of autism spectrum disorders (ASD) in extremely preterm children **Study dates** Children born from March to December 1995, assessed at 11 years age	**Exclusion criteria** Not reported **Sample size** N=307 survivors at 11 years age n=219 assessed at median age 10 years 11 months n=189 extremely preterm children (SCQ questionnaires returned) **Characteristics**	Autism spectrum symptoms **Outcome ascertainment/measures** Autism spectrum symptoms were assessed by using the Social Communication Questionnaire (SCQ, parent reported). Subscales for social interaction (range 0-16), communication (range, 0-13), and repetitive/steroetyped behaviour (range 0-8) and total SCQ score (range 0-39). HIgher scores indicated higher frequency of symptoms. Total scores are used to screen for autistic disorder (≥22) and ASD (≥15).		Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision, wide confidence intervals, due to relatively small sample size **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** 86% of questionnaires were returned from the extremely preterm group

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Country/ies where the study was carried out UK/Ireland **Source of funding** Medical Research Council, London, UK		**Age at assessment** 11 years age		**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Ref Id 461027 **Full citation** Odd, D., Evans, D., Emond, A., Preterm Birth, Age at School Entry and Long Term Educational Achievement, PLoS ONE [Electronic Resource], 11, e0155157, 2016 **Study type** A cohort study (ALSPAC) **Aim of the study** To investigate if the detrimental impact of year of entering education in preterm infants persists into adolescence.	**Setting** ALSPAC longitudinal cohort study from Bristol, UK. **Inclusion criteria** Not reported in this publication. **Exclusion criteria** Not reported. **Sample size** N=12 586 total sample including term and preterm N=775 children born at <37 weeks of gestation **Characteristics** Compared to the term born infants, the preterm infants were more likely to be male and need resuscitation after birth, had lower Apgar scores, they were more likely to be born as multiple births and less likely to be born through spontaneous cephalic birth and more likely to be born through emergency caesarean section. The mothers of preterm born children were more likely be of non-white ethnicity and have maternal hypertension.	**Gestational age ascertainment** Derived from clinical notes and if under 37 weeks was confirmed by reviewing the clinical records. **Outcomes of interest in this study** Educational attainment (Key Stage, KS) and special educational needs (SEN). More specifically low KS1 score, low KS2 score, low KS3 score. For KS4, <5 GCSE passes at A* to C level, and special educational needs (SEN) at KS4 stage. **Outcome ascertainment/measures** Mandatory UK educational	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 5-7 years <u>Low score at KS1</u> <37 wks GA: 210/662, 31.7% (28.2-35.4%) At 7-11 years <u>Low score at KS2</u> <37 wks GA: 239/675, 35.4% (31.8-39.2%) At 11-14 years <u>Low score at KS3</u> <37 wks GA: 251/631, 39.8% (35.9-43.7%) At 14-16 years <u>Low score at KS4</u> <37 wks GA: 276/701, 39.4% (35.7-43.1%) At 14-16 years <u>SEN</u> <37 wks GA: 166/683, 24.3% (21.1-27.7%) Only number of cases and the prevalence (as percentage) given, the	**Overall quality** Moderate. **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. Relatively good precision (relatively narrow confidence intervals) due to relatively high sample size. (This study only considered all children born preterm, did not stratify by gestational age within the preterm population.)

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Study dates Children born April 1991 to December 1992, follow-up at 5-7 years, 7-11 years, 11-14 years and 14-16 years. **Country/ies where the study was carried out** UK **Source of funding** North Bristol NHS Trust Springboard Fund		assessments done at 4 stages, the stages are Key Stage (KS) 1 at 5-7 years, KS2 at 7-11 years, KS3 at 11-14 years, and KS4 at 14-16 years. The test is done at the end of each stage. Governmental standards set the minimum standard expected at each stage of the first 3 stages and this was used as the cut-off for a low score. At the end of KS4 children take their school exams and an a-priori cut-off of 5 General Certificates of Secondary Education (GCSE) or equivalent at A* to C level was used to define a normal score at this age. At KS4, <5 passes at A* to C level was considered as poor/low attainment at KS4. Children identified as having special educational needs (SEN) in KS4 were	denominator was calculated by the NGA technical team. Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html **Risk of problems:** At 5-7 years Low score at KS1 Matched for date of birth Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.44 (95% CI 1.17-1.77) At 7-11 years Low score at KS2 Matched for date of birth Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.20 (95% CI 0.99-1.46) At 11-14 years Low score at KS3 Matched for date of birth Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.11 (95% CI 0.91-1.35) At 14-16 years Low score at KS4 Matched for date of birth Term (37-42 wks): Reference	**4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No Denominators or confidence intervals were not provided

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		identified from the Pupil Level Annual School Census (PLASC). **Age at assessment** 7 years (KS1), 11 years (KS2), 14 years (KS3) and 16 years (KS4 and SEN).	Preterm (<37 wks): aOR 1.10 (95% CI 0.91-1.34) At 14-16 years SEN Matched for date of birth Term (37-42 wks): Reference Preterm (<37 wks): aOR 1.39 (95% CI 1.14-1.68) Adjusted for ethnicity, maternal education, socio-economic group, age, gender, maternal parity, weight at birth, length and birth, head circumference at birth, mode of birth, maternal hypertension.	and had to be calculated by the NGA technical team. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 346014 **Full citation** Downey,L.C., O'Shea,T.M., Allred,E.N., Kuban,K., McElrath,T.F., Warner,D.D., Ware,J., Hecht,J.L., Onderdonk,A., Leviton,A., Antenatal and early postnatal	**Setting** Children born at 12 of the 14 study sites **Inclusion criteria** Women delivering before 28 weeks' gestation **Exclusion criteria** Not reported	**Gestational age ascertainment** Not reported **Outcomes of interest in this study** Attention problems	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)** At 24 months adjusted age Attention problems (assessed using CBCL =>93rd percentile) <28 wks GA: 88/826, 10.7% (95%CI 8.6-13.0) Confidence intervals calculated by NGA:	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
antecedents of parent-reported attention problems at 2 years of age, Journal of Pediatrics, 166, 20-25, 2015 **Study type** Population based cohort study (ELGAN) **Aim of the study** To assess antenatal and early postnatal antecendents of attention problems identified by the Child Behaviour Checklist in extremely preterm children **Study dates** 2002-2004 **Country/ies where the study was carried out** USA	**Sample size** N=826 children born preterm **Characteristics** <u>Maternal characteristics (N=826; with attention problem=88, without attention problem=738)</u> Race (%) White: 48% (with attention problem); 61% (without attention problem) Black: 34% (with attention problem); 29% (without attention problem) Other: 17% (with attention problem); 10% (without attention problem) Maternal age <21 y (%): 18% (with attention problem); 13% (without attention problem) Maternal education, high school or less (%): 67% (with attention problem); 41% (without attention problem) <u>Newborn characteristics</u> Male (%): 55% (with attention problem); 49% (without attention problem) Gestational age wk (%): 23-24: 15% (with attention problem); 18% (without attention problem) 25-26: 56% (with attention problem); 47% (without attention problem) Birth weight <=750g (%): 38% (with attention problem); 34% (without attention problem)	**Outcome ascertainment/measures** At 24 months adjusted age, a parent/caregiver completed the CBCL for child behaviour problems. Five of the items on the CBCL are included in the attention problem scale (can't concentrate, can't sit still, clumsy, quickly shifts, wanders away). Scores between the 93rd and 97th percentile correspond to the borderline/subclinical range and are considered worthy of concern, and scores above the 97th percentile warrant definite concern. For this report, a child was considered to have an attention problem if his/her score was at or greater than the 93rd percentile.	http://statpages.info/confint.html	**2. Were the study participants recruited in an appropriate way?** Not reported **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** No. The setting was not reported in detail **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Source of funding National Institute of Neurological Disorders and Stroke National Institute of Child Health and Human Development		**Age at assessment** 24 months adjusted age		**7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not reported **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 512287	**Setting**	**Gestational age ascertainment**	**Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)**	**Overall quality** Moderate

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
Full citation Joseph, R. M., O'Shea, T. M., Allred, E. N., Heeren, T., Hirtz, D., Paneth, N., Leviton, A., Kuban, K. C. K., Prevalence and associated features of autism spectrum disorder in extremely low gestational age newborns at age 10 years, Autism Research., 2016 **Study type** Multicentre observational study (ELGAN study) **Aim of the study** To estimate the prevalence of autism spectrum disorder (ASD) in children born extremely preterm at the age of 10 years **Study dates**	Women were enrolled in the ELGAN study at 14 sites in 11 cities in 5 states (Connecticut, Illinois, Massachusetts, Michigan, North Carolina) **Inclusion criteria** Women delivering before 28 weeks gestation **Exclusion criteria** Not reported **Sample size** N=1198 preterm infants surviving to 10 years n=966 children recruited for follow-up n=889 mothers of infants who agreed to participate **Characteristics** Maternal characteristics at birth (n=1198) Age (years, n): <21: 170 21-35: 802 >35: 226 Education (years, n): <=12 years: 506 >12 and <16 years: 270 >=16 years: 376 Single marital status (n): 513	Not reported (reference to O'Shea study 2009) **Outcomes of interest in this study** ASD symptoms **Outcome ascertainment/measures** Participants were screened for ASD symptoms with the Social Communication Questionnaire (SCQ), the SCQ includes 39 ratings for children with simple sentence speech, and 33 ratings for those without simple sentence speech. To increase screener sensitivity, a score 11, recommended by the authors for individuals at higher-than-normal risk for ASD was used instead of the standard criterion of 15.	**At 10 years** ASD symptoms (assessed by SCQ): <27 wks GA: 106/857, 12.4% (95% CI 10.2-14.8%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
2002–2004 **Country/ies where the study was carried out** USA **Source of funding** National Institute of Neurological Disorders and Stroke National Institute of Child Health and Human Development	Ethnicity (n): White: 706 Black: 322 Other: 151 Newborn characteristics (n=1198) Male sex (n): 621 Gestational age, weeks (n): 23-24 wks: 245 25-26 wks: 553 27 wks: 400 Birth weight (g, n): <=750:436 751-1000: 520 >1000: 242	**Age at assessment** 10 years		**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not reported in the study **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)</th></tr>
<tr><td></td><td></td><td></td><td></td><td>N/A</td></tr>
<tr>
<td>Ref Id

539165

Full citation

Joseph, R. M., O'Shea, T. M., Allred, E. N., Heeren, T., Hirtz, D., Jara, H., Leviton, A., Kuban, K. C., Elgan Study Investigators, Neurocognitive and Academic Outcomes at Age 10 Years of Extremely Preterm Newborns, Pediatrics, 137, 2016

Study type

Prospective cohort study (ELGAN)

Aim of the study

To assess the rate of neurocognitive impairment in a contemporary US cohort of 873 children</td>
<td>Setting

11 cities in 5 states in the USA

Inclusion criteria

Women delivering before 28 weeks' gestation

Exclusion criteria

Not reported

Sample size

N=1506 infants
n=1198 survived to age 10 years

Characteristics
<table>
<tr><td>Maternal characteristics</td><td>23-24 wks GA (n)</td><td>25-26 wks GA (n)</td><td>27 wks GA (n)</td></tr>
<tr><td>Age (y)</td><td></td><td></td><td></td></tr>
</table>
</td>
<td>Gestational age ascertainment

Not reported

Outcomes of interest in this study

Language ability
Executive function
Visual-motor function

Outcome ascertainment/measures

Language ability: Expressive and receptive language skills were evaluated with the Oral and Written Language Scales, 30 which assess semantic, morphologic, syntactic, and pragmatic production and comprehension of elaborated sentences.</td>
<td>Prevalence n/N and % (with 95%CI) (incl.GA at birth and age at assessment)

At 10 years age
Language (<28 weeks GA; <=-2SD)
OWLS Listening Comprehension: 166/873, 19% (95%CI 16.5-21.8)
OWLS Oral Expression: 166/873, 19% (95%CI 16.5-21.8)
Executive function (<28 weeks GA; <=-2SD)
DAS-II Working Memory: 157/873, 18% (95%CI 15.5-20.7)
NEPSY-II Auditory Attention: 201/873, 23% (95%CI 20.3-26.0)
NEPSY-II Auditory Response Set: 175/873, 20% (95%CI 17.4-23)
NEPSY-II Inhibition Inhibition: 297/873, 34% (95%CI 31-37)
NEPSY-II Inhibition Switching: 236/979, 27% (95%CI 24.1-30.1)
Processing speed (<28 weeks GA; <=-2SD)</td>
<td>Overall quality

Low

1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

No. Measurement of gestational age was not reported</td>
</tr>
</table>

Study details	Participants				Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
aged 10 years who were born <28 Weeks' gestation **Study dates** 2002 to 2004 **Country/ies where the study was carried out** USA **Source of funding** National Institute of Neurologic Disorders and Stroke National Institute of Child Health and Human Development National Institutes of Health	<21 25 21-35 >35	25 21 18	47 46 43	28 34 38	Executive function: Attention and executive functions were assessed with the DAS-II and the Developmental NEuroPSYchological Assessment-II (NEPSY-II).31 DAS-II Recall of Digits Backward and Recall of Sequential Order measured verbal working memory. The NEPSY-II Auditory Attention and Auditory Response Set evaluated auditory attention, set switching, and inhibition. NEPSY-III Inhibition Inhibition and Inhibition Switching assessed simple inhibition and inhibition in the context of set shifting, respectively. The NEPSY-II Animal Sorting measured concept generation and mental flexibility. Speed of processing: Speed of processing was assessed with NEPSY-II Inhibition	NEPSY-II Inhibition Naming: 270/873, 31% (95%CI 28-34) Visual perception (<28 weeks GA; <=-2SD) NEPSY-II Arrows: 227/873, 26% (95%CI 23-29) NEPSY-II Geometric Puzzles: 148/873, 17.0% (95%CI 14.5-19.6) Confidence intervals calculated by NGA using: http://statpages.info/confint.html	**5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. number of participants and confidence intervals were not calculated. **9. Are all important confounding factors/subgroups/differen**
	Education (y) ≤12 years (high school) >12 and <16 years ≥16 years (college or higher)	 22 36 16	 48 37 46	 30 198 38			
	Racial identity White Black Other	 21 22 17	 43 51 44	 37 27 39			
	Single marital status Yes No	 21 20	 45 45	 34 34			
	Newborn characteristics						
	Gender Male Female	 23 18	 45 46	 32 36			
	Birth weight (g) ≤750 751–1000 >1000	 50 5 0	 37 61 24	 13 33 76			

Study details	Participants				Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
	Necrotising enterocolitis (Bell stage 3b) Yes No	33 20	57 45	10 35	Naming, a baseline measure of processing speed with no inhibitory component. Visual perception: NEPSY-II Arrows, which measures perception of line orientation, and Geometric Puzzles, a measure of mental rotation of complex visual spatial figures. Visual motor function: Visual fine motor function was measured with NEPSY-II Visuomotor Precision. Distribution of neurocognitive test scores were compared to expected normal distribution: 2.3% of ELGAN children would be expected to have z scores ≤ -2,		**ces identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
	Bronchopulmonary dysplasia (oxygen at 36 weeks) Yes No	32 9	46 44	22 47			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE 2014 guideline manual and the Joanna Briggs Institute Prevalence Critical Appraisal Tool)
		13.7% to have *z* scores >−2 and ≤ −1, 68.2% to have *z* scores > −1 and ≤1, and 15.8% to have *z* scores >1 **Age at assessment** 10 years age		

1

2 Developmental follow up of pre-term babies

1 Prevalence of developmental disorders

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 336084 **Full citation** Ancel, P. Y., Livinec, F., Larroque, B., Marret, S., Arnaud, C., Pierrat, V., Dehan, M., N'Guyen, S., Escande, B., Burguet, A., Thiriez, G., Picaud, J. C., Andre, M., Breart, G., Kaminski, M., Cerebral palsy among very preterm children in relation to gestational age and neonatal ultrasound abnormalities: The EPIPAGE cohort study, Pediatrics, 117, 828-835, 2006	**Setting** Cohort of preterm children in 9 regions in France (EPIPAGE). **Inclusion criteria** All children born at <32 weeks of gestation in all maternity units in nine regions in France in 1997 that survived to discharge. Additionally, all children born at 32 weeks of gestation were included in 7 of the regions and in 2 regions, every other child born at 32 weeks were included. **Exclusion criteria** Children who died before discharge from the hospital. Children whose neurologic status was unknown at follow-up due to artificial respiration (n=4). **Sample size** n=1954 (83% of the eligible ones for the follow-up) (The follow-up questionnaire was filled in for n=1960 children but 4 were excluded because of unknown neurologic status due to ongoing artificial respiration.) **Characteristics**	**Gestational age ascertainment** Gestational age refers to completed weeks of amenorrhaea and was the best obstetric estimate based on the date of the last menstrual period and an early ultrasound scan, which is routine practice in France. **Outcome(s) of interest in this study** Cerebral palsy (CP) **Outcome(s) ascertainment/measures** Each child was subjected to a detailed physical and neurologic examination assessing tone, reflexes, posture, and movements. A precoded standardised questionnaire, completed by each treating physician was designed to minimise the risk of ambiguous answers and trained paediatricians	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 2 years (not reported if corrected or not) CP 24-25 wks GA: 12/64, 19.4% (10.4-31.4%) 26 wks GA: 18/82, 22.0% (13.6-32.5%) 27 wks GA: 18/146, 12.3% (7.5-18.8%) 28 wks GA: 21/191, 11.0% (6.9-16.3%) 29 wks GA: 16/196, 8.2% (4.7-12.9%) 30 wks GA: 26/315, 8.3% (5.5-11.9%) 31 wks GA: 29/424, 6.8% (4.6-9.7%) 32 wks GA: 24/538, 4.4% (2.9-6.6%) The following GA groups were calculated by the NGA technical team using the above data: <28 wks GA: 48/290, 16.6% (12.5-21.3%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to relatively low sample size, especially in GA subgroups. **4. Were the study subjects and the setting described in detail?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Study type Prospective population-based cohort study (EPIPAGE). **Aim of the study** To estimate the prevalence of cerebral palsy at 2 years of age among children born very preterm, according to gestational age, infant gender, plurality, and neonatal cranial ultrasound abnormalities. **Study dates** Children born 1997, assessed at 2 years.	n=1960 GA at birth in weeks 24-26: 7.1% 27-28: 16.5% 29-30: 24.9% 21-32: 51.5% Females: 47.7% Singleton: 68.2% Maternal age 14-19 y: 3.3% 20-29 y: 53.0%	reviewed questionnaires for infants with abnormal neurologic examination results. The definition of CP proposed by the European Cerebral Palsy Network was used. **Age at assessment** 2 years (not reported if corrected or not)	28-31 wks GA: 92/1126, 8.2% (6.6-9.9%) The number of cases were calculated by the NGA technical team using the proportion percentage and total number of participants in each subgroup. Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Unclear. Follow-up rate was 83% and differences between the ones followed-up and lost to follow-up were reported. The ones lost to follow-up were less often from the youngest GA groups, they were more often singletons, they had younger mothers, parity of the mother was >=3 more often, more likely to be not married or single, were more likely to have lower educational status. **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. The definition of CP was standards but the measurement

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out France **Source of funding** INSERM (French National Institute of Health and Medical Research), Merck-Sharp, Dohme-Chibret, la Fondation de la Recherche Medicale (Medical Research Foundation), la Direction Generale de la Sante du Ministere des Affaires Sociales (Directorate General for Health of the French Ministry for Social Affairs).	30-34 y 27.7% >=35 y 16.0% Parity 0 53.7% 1-2 36.2% >=3 10.1%			methods/tools were not described. **7. Was the condition measured reliably?** Unclear. The method of assessment of CP was not described. **8. Was there appropriate statistical analysis?** No. Number of cases were not provided. Confidence intervals for prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				10. Were subpopulations identified using objective criteria? Not applicable.
Ref Id 340342 **Full citation** Andersen, G. L., Romundstad, P., Cruz, J. D. L., Himmelmann, K., Sellier, E., Cans, C., Kurinczuk, J. J., Vik, T., Cerebral palsy among children born moderately preterm or at moderately low birthweight between 1980 and 1998: A European register-based study, Developmental Medicine and	**Setting** Population-based cerebral palsy registers in different areas in different European countries. Denominator (live births) were obtained from the same register that had collected the total umber of live births. **Inclusion criteria** All children born moderately preterm (32-36 weeks of gestation) or with a birth weight of 1500 g to 2499 g who had been identified as having CP and thus included in the Surveillance of Cerebral Palsy in Europe database (including 11 areas in 8 countries in Europe). All children were at least 4 years old at the time of inclusion to the register. Also children over 2 years old who had died but had been identied as having CP were included. The denominator was all live births in the same region. **Exclusion criteria** Children who had a postneonatal cause of CP (i.e. linked to a specific aetiological evenr or episode occurring more than 28 days after birth) (n=67).	**Gestational age ascertainment** Not described but the authors discuss that "it is reasonable to assume that gestational age was more likely to be assessed by fetal ultrasound examination towards the end of the study period than at the beginning and since gestational age based upon the last menstrual period tends to overestimate gestational age compared with ultrasound assessment, this might theoretically have introduced a bias whereby the study population towards the end of the period was more mature than at the beginning". **Outcome(s) of interest in this study** Cerebral palsy (CP)	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** Age at assessment not reported but children were included in the register earliest at 4 years of age CP 1990-94 Grenoble, France 32-36 wks GA: 8.2/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) Cork, Ireland 32-36 wks GA: 7.2/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) Göteborg, Sweden	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. The study only reports the total number of cases in the whole time period that each register area collected data,

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Child Neurology, 53, 913-919, 2011 **Study type** Register-based study **Aim of the study** To describe trends in prevalence, subtypes and severity among children with cerebral palsy (CP) born moderately preterm (32-36 weeks of gestation) or at moderately low birth weight (1500-2499 g) in Europe. **Study dates** 1980-1998 (but for this review only data between 1990-1998 is used).	Children whose mothers had lived outside the area of the register at the time of the birth of the child (n=32). **Sample size** n=903 children with CP born moderately preterm **Characteristics** Not described.	**Outcome(s) ascertainment/measures** Children with CP were identified and classified according to the definition and classification tree of the Surveillance of Cerebral Palsy in Europe (SCPE) database. **Age at assessment** Not reported but children were included in the register earliest at 4 years of age.	32-36 wks GA: 6.1/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) Copenhagen, Denmark 32-36 wks GA: 7.2/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) Rome, Italy 32-36 wks GA: 13.0/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) 1995-1998 Grenoble, France 32-36 wks GA: 5.6/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) Cork, Ireland 32-36 wks GA: 7.2/1000 live births (number of cases and the number of live births not reported, thus, not possible	thus, because in the review the population is children born 1990 or after, the number of cases was not known for some areas within the time period of interest. Thus, it was also not possible to calculate the number of general population (denominator), and therefore, it was not possible to calculate confidence intervals for some areas either. For the areas that reported cases born 1990 and after, it was possible to calculate the number of general population (denominator) and the confidence intervals of the prevalence estimates. In these areas, the sample size was generally adequate, there was relatively high precision (narrow confidence intervals). **4. Were the study subjects and the setting described in detail?** No.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out Denmark, France, Ireland, Italy, Norway, Spain, Sweden, UK **Source of funding** The Liaison Committee between the Central Norway Regional Health Authority and the Norwegian University of Science and Technology.			to calculate confidence intervals) Göteborg, Sweden 32-36 wks GA: 6.6/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) Copenhagen, Denmark 32-36 wks GA: 6.1/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) Rome, Italy 32-36 wks GA: 8.6/1000 live births (number of cases and the number of live births not reported, thus, not possible to calculate confidence intervals) 1991-1996 Tonsberg, Norway 32-36 wks GA: 13.8/1000 live births (95% CI 7-25/1000 live births) (number of cases 10, thus, the number of live births calculated to be 725)	This is a register-based study, background characteristics were not described. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** N/A Register-based study. **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. It is not described how CP was diagnosed in each area. It was only reported that the definition and classification of CP was according to the definition and classification tree of the SCPE. **7. Was the condition measured reliably?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			1991-1998 Galway, Ireland 32-36 wks GA: 4.0/1000 live births (95% CI 2-7/1000 live births) (number of cases 11, thus, the number of live births calculated to be 2750) Madrid, Spain 32-36 wks GA: 4.0/1000 live births (95% CI 2-7/1000 live births) (number of cases 14, thus, the number of live births calculated to be 3500) 1992-1998 Bologna, Italy 32-36 wks GA: 8.8/1000 live births (95% CI 5-15/1000 live births) (number of cases 15, thus, the number of live births calculated to be 1705) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	Unclear. It is not described how CP was diagnosed in each area. It was only reported that the definition and classification of CP was according to the definition and classification tree of the SCPE. **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates not reported. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 409756 **Full citation** Anderson, P. J., De Luca, C. R., Hutchinson, E., Spencer-Smith, M. M., Roberts, G., Doyle, L. W., Attention problems in a representative sample of extremely preterm/extremely low birth weight children, Developmental Neuropsychology, 36, 57-73, 2011 **Study type** Population-based cohort study **Aim of the study**	**Setting** All surviving children born extremely preterm (<28 weeks) or extremely low birth weight (<1000 g) in the state of Victoria, Australia. **Inclusion criteria** All surviving children born with a gestational age 22-27 weeks and/or birth weight <1000 g in the state of Victoria, Australia between January 1 and December 31, 1997. **Exclusion criteria** None reported. **Sample size** n=201 children survived to 8 years n=189 assessed at 8 years (94%) **Characteristics** n=189	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Disorders: deafness; blindness; cerebral palsy (CP) Problems: selective attention; sustained attention; attention encoding; executive attention; ADHD symptoms **Outcome(s) ascertainment/measures** The children were assessed at 8 years (corrected) by psychologists blind to perinatal details, predominantly in specialised follow-up clinics, although a few were tested at	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 8 years (corrected) Disorders: Deafness 22-27 wks GA/BW 1000 g: 4/189, 2.1% (0.6-5.3%) Blindness 22-27 wks GA/BW 1000 g: 3/189, 1.6% (0.3-4.6%) Cerebral palsy 22-27 wks GA/BW 1000 g: 22/189, 11.6% (7.4-17.1%) Problems: Selective attention (TEA-Ch Sky Search, <-1SD) 22-27 wks GA/BW 1000 g: 58/171, 33.9% (26.9-41.5%)* Sustained attention (TEA-Ch Score!, <-1SD)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to relatively small sample size. **4. Were the study subjects and the setting described in detail?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
To examine attention in large, representative, contemporary cohort of children born extremely preterm and/or extremely low birth weight. **Study dates** Children born 1997, follow-up at 8 years of corrected age. **Country/ies where the study was carried out** Australia **Source of funding** Australia's National Health and Medican Research Council, and Senior	Gestational age in weeks, mean (SD) Gestational age <26 wks, % Birth weight in grams, mean (SD) Birth weight <750 g, % Male, % Multiple birth, % Antenatal cortisocsteroids, %	school or home if they could not attend the clinics. Deafness was defined as needing hearing aids or worse. Blindness was defined as visual acuity <6/60 for both eyes. CP, deafness and blindness were diagnosed by trained paediatricians who were blind to group membership (the study included a term-born control group). Selective attention was assessed with the Sky Search subtest from the Test of Everyday Attention for Children (TEA-Ch). Sustained attention was assessed with the Score! subtest from the TEA-Ch. Attention encoding was assessed with the forward digit span from the Wechsler Intelligence Scale for Children (WISC-IV). Executive attention was categorised into 1) inhibitory control, which was assessed with the Opposite Worlds from the TEA-Ch, and the Inhibit scale from the parent form of the Behavioral Rating	22-27 wks GA/BW 1000 g: 52/173, 30.1% (23.3-37.5%)* <u>Attention Encoding (TEA-Ch Forward digit span, <-1SD)</u> 22-27 wks GA/BW 1000 g: 71/178, 39.9% (32.6-47.5%)* <u>Executive attention</u> <u>1) Inhibitory control:</u> a) Opposite Worlds (<-1SD) 22-27 wks GA/BW 1000 g: 10/167, 6.0% (2.9-10.7%)* b) BRIEF-Inhibit (T score >60) 22-27 wks GA/BW 1000 g: 28/187 15.0% (10.2-20.9%)* <u>2) Shifting attention:</u> a) Creature counting (<-1SD) 22-27 wks GA/BW 1000 g: 46/170, 27.1% (20.5-34.4%)* b) BRIEF-Shift (T score >60) 22-27 wks GA/BW 1000 g: 35/184, 19.0% (13.6-25.5%)* <u>3) Divided attention:</u> Sky Search Dual Task (<1SD)	Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. For hearing impairment, vision impairment and CP, the definitions and measurements are unclear (they were not the focus of the study). **7. Was the condition measured reliably?** Unclear. For hearing impairment, vision impairment and CP, it is not clear how they were measured and what criteria was used for e.g. CP (these

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Research Fellowship, and the University of Melbourne.s CR Roper Fellowship.	NEC, % ROP, % BPD, % Postnatal corticosteroids, % IVH grade 3-4, % Cystic PVL, % Intact family, % Mother's education, tertiary degree, %	Inventory of Executive Function (BRIEF), 2) shifting attention, which was assessed with Creature Counting from the TEA-Ch, and the Sgift scale from BRIEF, 3) divided attention, which was assessed with the Sky Search Dual Task from the TEA-Ch. Attention deficit hyperactivity disorder (ADHD) was assessed with the Conner's ADHD/DSM-IV Scales (CADS-P). The CADS-P consists of 26 items. For this study three scales were used: ADHD Index (items that best distinguish ADHD children from nonclinical children), DSM-IV Inattentive (items directly related to the DSM-IV symptoms of inattention), and DSM-IV Hyperactive-Impulsive (items directly related to DSM-IV symptoms of hyperactivity-impulsivity). Impairment was defined as scores more than 1 SD below the mean of the control group (term/normal birth weight peers) for the attention tasks and T scores >60 for the BRIEF and the CADS-P.	22-27 wks GA/BW 1000 g: 62/168, 36.9% (29.6-44.7%)* ADHD symptoms CADS-P Inattentive symptoms (T score >60) 22-27 wks GA/BW 1000 g: 18/56, 32.1% (20.3-46.0%)* CADS-P Hyperactive-Impulsive symptoms (T score >60) 22-27 wks GA/BW 1000 g: 23/55, 41.8% (28.7-55.9%)* ADHD Index (CADS-P T score >60) 22-27 wks GA/BW 1000 g: 24/55, 43.6% (30.3-57.7%)* *Only number of cases and the prevalence (as percentage) given, the denominator was calculated by the NGA technical team. Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	outcomes were not the focus of the study). **8. Was there appropriate statistical analysis?** No. Denominators for the prevalence estimates not provided. Confidence intervals for the prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	English spoken at home, % Age at 8 year follow-up, mean (SD)	**Age at assessment** 8 years (corrected)		
Ref Id 347034 **Full citation** Andrews, W. W., Cliver, S. P., Biasini, F., Peralta-Carcelen, A. M., Rector, R., Alriksson-Schmidt, A. I., Faye-Petersen, O., Carlo, W., Goldenberg, R., Hauth, J. C., Early preterm birth: association between in utero exposure to acute inflammation and severe	**Setting** Follow-up of a precious cohort study of mother-child dyads in Alabama, US. **Inclusion criteria** The study included a cohort of 424 consecutive single pregnancies delivered between 23 and <32 weeks during the interval from December 5, 1996 to December 31, 1999. **Exclusion criteria** Not reported **Sample size** n=259 (around 70% of the 375 eligible and alive for the follow-up) with data on IQ n=257 with data on CP	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Cognitive impairment (IQ <70); cerebral palsy (CP) **Outcome(s) ascertainment/measures** Each child was given a battery of tests assessing a wide range of psychometric measures (requiring approximately 3 hours to complete) including the	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 6 years IQ <70 (WISC-IV or DAS) 23-32 wks GA: 41/259, 15.8% (11.6-20.9%) CP 23-32 wks GA: 11/257, 4.3% (2.2-7.5%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Unclear **2. Were the study participants recruited in an appropriate way?** Unclear. Details are not provided. **3. Was the sample size adequate?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>neurodevelopmental disability at 6 years of age, American Journal of Obstetrics & Gynecology, 198, 466.e1-466.e11, 2008

Study type

Prospective cohort study

Aim of the study

To determine the association between in utero exposure to acute inflammation and long-term major neurodevelopmental disability at age 6 years among children born prior to 32 weeks' gestation.

Study dates

1996-1999</td>
<td>Characteristics

Frequency of the neurodevelopmental outcomes according to demographic and
other characteristics of the study cohort (n=261).

<table>
<tr><th>Characteristics</th><th>IQ<70 [*] (%)</th><th>P value</th><th>CP (%)</th><th>P Value</th><th>Major [*] ND (%)</th><th>P Value</th></tr>
<tr><td colspan="7">Race</td></tr>
<tr><td>AA</td><td>19.0</td><td>0.082</td><td>1.3</td><td>0.004</td><td>20.3</td><td>0.930</td></tr>
<tr><td>Non-AA</td><td>10.9</td><td></td><td>9.0</td><td></td><td>19.8</td><td></td></tr>
<tr><td colspan="7">Maternal Age (years)</td></tr>
<tr><td><20</td><td>12.7</td><td>0.184</td><td>3.2</td><td>1.000</td><td>19.1</td><td>0.202</td></tr>
<tr><td>20–30</td><td>19.2</td><td></td><td>4.7</td><td></td><td>23.2</td><td></td></tr>
</table>
</td>
<td>Wechsler Intelligence Scale for Children-IV (WISC-IV) or the Differential Ability Scales (DAS, for children who were not yet six-years-old or were unable to complete the WISC-IV) used to assess IQ. The IQ score <70 on the WISC-IV or DAS was considered a cognitive impairment.

CP was assessed with a complete physical and neurological examination including assessment of gross and fine motor function performed by certified nurse practitioner under the supervision of a developmental pediatrician. CP was defined as abnormal muscle tone in at least 1 extremity and abnormal control of movement and posture.

Age at assessment</td>
<td></td>
<td>Unclear.
Due to relatively low sample size, precision is low (confidence intervals are wide).

4. Were the study subjects and the setting described in detail?

No.
Limited description of study sample. Characteristics reported by outcome, not overall.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
Around 30% of the surviving and eligible children were lost to follow-up. No details of the characteristics are given.

6. Were objective, standard criteria used for</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out US **Source of funding** Not reported	<table><tr><td>>30</td><td>8.9</td><td></td><td>4.4</td><td></td><td>11.1</td><td></td></tr><tr><td colspan="7">Maternal Education (years)</td></tr><tr><td>≤12</td><td>19.3</td><td>0.084</td><td>4.2</td><td>1.000</td><td>24.1</td><td>0.066</td></tr><tr><td>>12</td><td>11.4</td><td></td><td>4.4</td><td></td><td>14.9</td><td></td></tr><tr><td colspan="7">Income</td></tr><tr><td><$1600/month</td><td>15.9</td><td>0.914</td><td>1.6</td><td>0.060</td><td>20.6</td><td>0.779</td></tr><tr><td>>$1600/month</td><td>15.4</td><td></td><td>7.0</td><td></td><td>19.2</td><td></td></tr><tr><td colspan="7">Maternal smoking/pregnancy</td></tr></table>	6 years		**the measurement of the condition?** No. IQ was assessed with either one of two different tools (WISC-IV or DAS), thus, not all children were assessed in a similar way. No description of the examination used to assess CP. **7. Was the condition measured reliably?** Unclear. CP was assessed by a nurse practitioner under a supervision of a developmental pediatrician, not clear how valid the used assessment is. The examination used not described. **8. Was there appropriate statistical analysis?** Unclear. Confidence intervals not provided. Also, prevalence (%) of outcomes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	Yes 9.1 0.365 10.0 0.207 18.2 1.000 No 16.5 3.8 20.3 **Marital status at delivery** Married 10.6 0.066 8.7 0.008 17.3 0.386 Single 19.1 1.3 21.7 **Maternal BMI** <19.8 16.7 0.924 16.7 0.121 16.7 0.896 19.8–<26 13.2 2.6 17.1 26 – <29 16.7 8.8 22.2 ≥29 16.6 2.9 20.9			were presented for gestational subgroups and SGA/AGA subgroups but number of cases and number of children in each subgroup were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr><td></td><td>Child Gender<table><tr><td>Male</td><td>18.3</td><td>0.334</td><td>5.3</td><td>0.545</td><td>23.5</td><td>0.222</td></tr><tr><td>Female</td><td>13.9</td><td></td><td>3.5</td><td></td><td>17.4</td><td></td></tr></table></td><td></td><td></td><td></td></tr>
<tr><td>Ref Id

347449

Full citation

Anonymous,, Outcome at 2 years of children 23-27 weeks' gestation born in Victoria in 1991-92. The Victorian Infant Collaborative Study Group, Journal of Paediatrics & Child Health, 33, 161-5, 1997

Study type</td><td>Setting

Birth cohort of very preterm infants in the state of Victoria in Australia in 1991-1992.

Inclusion criteria

Liveborn children born at 23-27 completed weeks of gestation in the state of Victoria, Australia in the 2-year period staring from 1 January 1991.

Exclusion criteria

None reported.

Sample size

n=401 liveborn children born at 23-27 weeks
n=225 children survived to 2 years of age (56.1%)
n=219 were assessed at 2 years (97.3% of the survivors)</td><td>Gestational age ascertainment

Gestational age was determined by menstrual history and/or obstetric ultrasound before 20 weeks.

Outcome(s) of interest in this study

Cerebral palsy;
Blindness;
Deaf;
Mental developmental impairment (Bayley MDI)

Outcome(s) ascertainment/measures

A developmental paediatrician and a psychologist assessed</td><td>Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)

At 2 years
<u>CP</u>
23-27 wks GA: 24/219, 11.0% (7.2-15.9%)

<u>Blind</u>
23-27 wks GA: 5/219, 2.3% (0.8-5.3%)

<u>Deaf</u>
23-27 wks GA: 2/219, 0.9% (0.1-3.3%)

<u>MDI <-3 SD</u>
23-27 wks GA: 12/219, 5.5% (2.9-9.4%)

<u>MDI -2 to -3SD</u></td><td>Overall quality

Low

1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No.</td></tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
A geographically determined cohort study (Victoria, Australia) **Aim of the study** To determine the survival and sensorineural disability rates in very preterm infants born in 1991-1992, and to compare the results with contemporaneous normal birthweight controls and with preterm infants born in 1985-87. **Study dates** Children born 1991-1992, follow-up at 2 years of age.	**Characteristics** Characteristics, e.g. sociodemographic characteristics, are not described.	the children at 2 years of age. They were blinded to the knowledge of prematurity. The paediatric assessment included a neurological examination to determine outcomes such as cerebral palsy, and visual acuity. The criteria for cerebral palsy was not reported in this publication but in another publication: "Cerebral palsy was diagnosed in children with increased active tone, increased deep tendon reflexes, and, if affecting both lower limbs, positive Babinski reflexes." (Kitchen et al. 1991 Changing two-year outcome of infants weighin 500 to 999 grams at birth: a hospital study. J Pediatr 118(6):938-43.) Children were considered blind if visual acuity in both eyes was assessed as worse than 6/60. Children were usually screened for major hearing loss earlier at 7-8 months of corrected age by distraction testing with calibrated noise makers. Those who had not been screened, or those with	23-27 wks GA: 28/219, 12.8% (8.7-18.0%) MDI <=-2SD 23-27 wks GA: 40/219, 18.3% (13.4-24.0%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	Low precision (wide confidence intervals) due to relatively low sample size. **4. Were the study subjects and the setting described in detail?** No. No description of background characteristics. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Unclear.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out Australia **Source of funding** NH & MRC, and Victorian Health Promotion Foundation		suspected deafness or delayed language at 2 years of age were referred again for audiological assessment. The psychological assessment included the Mental Developmental Index (MDI) of the Bayley Scales of Infant Development, or alternative psychological tests if the children were assessed by a psychologist where the Bayley Scales were not available. The test scores were expressed as standardised normal developmental quotients using the mean and standard deviation for the MDI obtained from the normal birthweight controls. The children were considered to have severe mental developmental impairment if the score was below <-3 SD and moderate impairment if the score was between -2 and -3 SD. **Age at assessment** At 2 years of age.		Mental developmental assessment was done mainly with the Bayley Scales but also with other psychological tests (not specified which ones or for how many children) when the Bayley Scales was not available. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 409847 **Full citation** Beaino, G., Khoshnood, B., Kaminski, M., Marret, S., Pierrat, V., Vieux, R., Thiriez, G., Matis, J., Picaud, J. C., Roze, J. C., Alberge, C., Larroque, B., Breart, G., Ancel, P. Y., Epipage Study Group, Predictors of the risk of cognitive deficiency in very preterm infants: the EPIPAGE prospective cohort, Acta Paediatrica, 100, 370-8, 2011 **Study type**	**Setting** Population-based prospective cohort of preterm children in nine regions in France (EPIPAGE). **Inclusion criteria** Any infant born between 22 and 32 weeks of gestation in nine regions of France throughout 1997. **Exclusion criteria** Infants who died before five year follow up. Moderate to severe neurosensory disabilities (defined as walking with aid or unable to walk, or having severe hearing or visual deficiency). The protocol included the option of following at random only one of every two infants born at 32 weeks, to reduce the regional workload. Two regions exercised this option. **Sample size** n=1503 **Characteristics**	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Cognitive impairment (MPC <70) **Outcome(s) ascertainment/measures** Children were invited for a check up at 5 years, and assessed by trained psychologists blinded to their perinatal data. The assessment used the Kaufman Assessment Battery for Children (K-ABC) test. Overall cognitive ability was evaluated by the Mental Processing Composite score. Cognitive deficiency was classified as moderate to severe when the MPC score was below 70 (-2SD below the norm).	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years Moderate to severe cognitive impairment (MPC<70) 24-26 wks GA: 16/102, 15.7% (9.2-24.2%) 27-28 wks GA: 50/263, 19.0% (14.5-24.3%) 29-30 wks GA: 36/409, 8.8% (6.2-12.0%) 31-32 wks GA: 65/729, 8.9% (7.0-11.2%) 24-28 wks GA: 66/365, 18.1% (14.3-22.4%) 29-32 wks GA: 101/1138, 8.9% (7.3-10.7%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. Overall the sample was quite large but because the authors decided to stratify the sample according to separate GA weeks rather than examining the overall group, the sample sizes within each GA week group become smaller and

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Population based prospective cohort (EPIPAGE). **Aim of the study** To assess cerebral lesions, medical and social characteristics as predictors of mild and severe cognitive deficiencies in very preterm infants. **Study dates** 1997-2002. Cohort established in 1997. Follow up at 5 years of age. **Country/ies where the study was carried out** France	24-26 weeks: 6.8% 27-28 weeks: 17.5% 29-30 weeks: 27.2% 31-32 weeks: 48.5% Male gender: 51.2% Small for gestational age: 8.8% Multiple pregnancy: 31% Exposure to antenatal steroids: 74.5% Maternal age < 25 years: 19.5% Maternal age 25-29 years: 36.6% Maternal age 30-34 years: 27.8%	**Age at assessment** 5 years.		number of cases are relatively low, decreasing the precision of the prevalence estimate. **4. Were the study subjects and the setting described in detail?** No. Limited information on background characteristics was provided. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. High attrition. 1503 children were followed-up regarding cognitive impairment data out of 2357 children who were eligible and alive for a follow-up (64%). **6. Were objective, standard criteria used for**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Source of funding French National Institute of Health and Medical Research, the Directorate General for Health of the Ministry for Social Affairs, Merck Sharp and Dohme-Chibret, the Medical Research Foundation, the 'Hospital Program for Clinical Research 2001 no. AOM01117' of the French Department of Health, La Fondation Motrice and the Ile-de-France Region.	Maternal age ≥ 35 years: 15.6% High socioeconomic status: 16.1% High intermediate socioeconomic status: 50.7% Low intermediate socioeconomic status: 14.7% Low socioeconomic status: 18.5%			**the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence not provided. Also, number of cases in each subgroup was not reported but rather percentage and the number of participants assessed (denominator). **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				10. Were subpopulations identified using objective criteria? Not applicable.
Ref Id 409915 **Full citation** Bodeau-Livinec, F., Surman, G., Kaminski, M., Wilkinson, A. R., Ancel, P. Y., Kurinczuk, J. J., Recent trends in visual impairment and blindness in the UK, Archives of Disease in Childhood, 92, 1099-1104, 2007 **Study type** Population based register study.	**Setting** Data source was from *4Child*-four counties database of cerebral palsy, vision loss and hearing loss in children, originally established in 1984 as the Oxford Register of Early Childhood Impairments. (from english counties of Berkshire, Buckinghamshire, Oxfordshire, and Northamptonshire). **Inclusion criteria** Children with vision impairment or severe visual impairment/blindness. **Exclusion criteria** Unilateral vision impairment. **Sample size** n=172, 584 live births in 1994-1998.	**Gestational age ascertainment** Ascertainment of gestational age was not reported. **Outcome(s) of interest in this study** Severe visual impairment/blindness **Outcome(s) ascertainment/measures** Rahi and Cable classification: Vision impairment was defined as visual acuity in the better eye of 6/18 or less with glasses or aids if worn (moderate impairment). Severe visual impairment or blindness was defined as	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 12 years age Vision impairment** (including moderate and severe impairment) <28 wks GA: 182.5 (102.5 to 299.1) 29-32 wks GA: 37.1 (14.9 to 76.2) 33-36 wks GA: 27.0 (17.3 to 40.1) **data refers to the number of cases per 10,000 live births	**Overall quality** Very low. **1. Was the sample representative of the target population?** The study reported cumulative trends in visual impairment nationwide, therefore, not specifically at preterm-cohort. **2. Were the study participants recruited in an appropriate way?** Data was obtained from a population-based national register.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Aim of the study

To study recent trends in the cumulative incidence of visual impairment in childhood over a 15-year period and to assess progress against WHO goals for prevention.

Study dates

Children born 1994-1998.

Country/ies where the study was carried out

UK.

Source of funding</td>
<td>Characteristics
<table>
<tr><td></td><td>Vision impairment in 1994-1998 cohort (n=171)</td></tr>
<tr><td>Male (n=103)</td><td>60.2%</td></tr>
<tr><td>Female (n=68)</td><td>39.8%</td></tr>
<tr><td>Singletons (n=156)</td><td>91.2%</td></tr>
<tr><td>Multiples (n=15)</td><td>8.8%</td></tr>
<tr><td></td><td></td></tr>
</table>
</td>
<td>visual acuity in the better eye of <6/60 or no useful vision.

Age at assessment

12 years age (89%).</td>
<td></td>
<td>3. Was the sample size adequate?

Yes.

4. Were the study subjects and the setting described in detail?

How data was obtained was reported, but characteristics of children were not reported.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear. The number of cases with visual impairment in the 1994-1998 cohort was small (n=171), and reasons for exclusions were not reported.

6. Were objective, standard criteria used for</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Department of Health, UK. 4Child, funded by the Department of Health Policy Research Programme.				**the measurement of the condition?** Unclear. Classification of vision impairment was defined according to Rahi and Cable, but the authors acknowledge that capacity to accurately classify children was limited by the extent of the clinical information available for analysis. **7. Was the condition measured reliably?** Unclear. Authors relied on data available from the register, therefore it was not clear how accurate the measurement of visual impairment was. **8. Was there appropriate statistical analysis?** Yes. **9. Are all important confounding**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				factors/subgroups/differences identified and accounted for? N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 321566 **Full citation** Burguet,A., Monnet,E., Pauchard,J.Y., Roth,P., Fromentin,C., Dalphin,M.L., Allemand,H., Maillet,R., Menget,A., Some risk factors for cerebral palsy in very premature infants: importance of	**Setting** All live born, very premature infants born in 20 maternity hospitals of the Franche-Comté region. **Inclusion criteria** All infants born very preterm from 25 to 32 weeks of gestation. **Exclusion criteria** Those infants who did not survive to the evaluation tome of 2 years age. **Sample size**	**Gestational age ascertainment** Gestational age was defined as the obstetrician's best estimation based menstrual data and/or an ultrasonic examination in the first trimester.8.4 **Outcome(s) of interest in this study** CP **Outcome(s) ascertainment/measures**	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 2 years age CP 25-32 wks GA: 22/167, 13.2% (8.4-19.3%) CP severe spastic tetraplegia with mental retardation 25-32 wks GA: 8/167, 4.8% (2.1-9.2%) CP isolated spastic tetraplegia 25-32 wks GA: 2/167, 1.2% (0.2-4.3%) CP spastic diplegia	**Overall quality** Very low. **1. Was the sample representative of the target population?** Yes. **2. Were the study participants recruited in an appropriate way?** The infants were consecutively recruited to the study.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>premature rupture of membranes and monochorionic twin placentation, Biology of the Neonate, 75, 177-186, 1999

Study type

Prospective regional cohort study.

Aim of the study

To delineate the perinatal risk factors of neurodevelopmental disabilities in very preterm birth applying logistic regression analysis.

Study dates

Infants born from 1990 to 1992, assessed at 2 years age.</td>
<td>Total number of live births in region=14,350
N=203 premature neonates were enrolled to the study
n=171 survived to 2 years age.
n=167 surviving infants were evaluated at 2 years age.

Characteristics
<table>
<tr><th></th><th>Very preterms assessed at 2 years age (n=167)</th><th>Children who died (n=32)</th></tr>
<tr><td>GA 25-28 weeks (n)</td><td>32</td><td>15</td></tr>
<tr><td>GA 29-30 weeks (n)</td><td>46</td><td>10</td></tr>
<tr><td>GA 31-32 weeks (n)</td><td>89</td><td>7</td></tr>
<tr><td>Male (n)</td><td>86</td><td>19</td></tr>
<tr><td>Female (n)</td><td>81</td><td>13</td></tr>
<tr><td>Singleton (n)</td><td>119</td><td>24</td></tr>
</table>
</td>
<td>A physician examined the child at 2 years age, completed a questionnaire that was mailed to the inquirers.
Abnormal infants were considered to have CP or sensorineural impairment when one or more of the following signs were observed: hemiplegia, diplegia, tetraplegia, dystonia, athetosis, blindness, or neurosensory deafness.
Evaluation was prospective for 93% (155/167) and retrospective for 7% (12/167) infants.

Age at assessment

2 years age (not reported whether corrected).</td>
<td>25-32 wks GA: 10/167, 6.0% (2.9-10.7%)
CP hemiplegia
25-32 wks GA: 2/167, 1.2% (0.2-4.3%)

Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>3. Was the sample size adequate?

No. The precision was low (confidence intervals were wide), due to small sample size, especially in the CP subgroups.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear. The follow up rate was 84%, and there were 4/171 children who were lost to follow up and were mostly in the 31-32 weeks GA group, mostly female, and had been exposed to maternal corticosteroids.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out France. **Source of funding** Not reported.	Outborn (n): 85 / 17 PROM (n): 39 / 6 Foetus exposed to maternal corticosteroids (n, %): 7 / 1			**6. Were objective, standard criteria used for the measurement of the condition?** Yes. **7. Was the condition measured reliably?** Unclear. The condition was measured prospectively for 93% and retrospectively for 7% of the infants evaluated at 2 years age. **8. Was there appropriate statistical analysis?** No. The confidence intervals for prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				10. Were subpopulations identified using objective criteria? N/A
Ref Id 433082 **Full citation** Burnett, A., Davey, C. G., Wood, S. J., Wilson-Ching, M., Molloy, C., Cheong, J. L., Doyle, L. W., Anderson, P. J., Extremely preterm birth and adolescent mental health in a geographical cohort born in the 1990s, Psychological Medicine, 44, 1533-44, 2014	**Setting** Cohort of preterms in the state of Victoria, Australia recruited at birth. The cohort had been assessed previously at 2, 5 and 8 years age (Victorian Infant Collaborative Study Group) **Inclusion criteria** Participants: infants born extremely preterm (<28 weeks gestation) or extremely low birth weight (<1000 g) in Victoria, Australia during 1991 and 1992 and surviving. **Exclusion criteria** None reported. **Sample size** n=215 early preterm/extremely low birth weight infants n=157 normal birth weight (>2499 g) controls n=372 in total	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** ADHD any type ADHD combined type ADHD inattentive type ADHD hyperactive/impulsive type Any anxiety or mood disorder Any mood disorder Any anxiety disorder co-morbid anxiety and mood disorder **Outcome(s) ascertainment/measures**	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 18 years age Any ADHD diagnosis (n=205) <28 wks GA/<1000g: 30/205, 14.6% (10.0-20.2%) ADHD combined type (n=205) < 28 wks GA/<1000g: 7/205, 3.4% (1.4-7.0%) ADHD inattentive type (n=205) < 28 wks GA/<1000g: 22/205, 10.7% (6.9-16.0%) ADHD hyperactive/impulsive type (n=205) < 28 wks GA/<1000g: 1/205, 0.5% (0.01-2.7%) Any SCID-I/NP diagnosis (n=205)	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes. **2. Were the study participants recruited in an appropriate way?** The participants were derived from consecutive survivors born preterm/ELBW. **3. Was the sample size adequate?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Study type

Prospective regional cohort study.

Aim of the study

To characterise mental health and personality traits in a prospective geographical cohort of adolescents born EP/ELBW in Victoria, Australia in 1991 and 1992.

Study dates

Adolescents born between 1991 and 1992, assessed at 18 years age.

Country/ies where the study was carried out</td>
<td>Characteristics
<table>
<tr><td></td><td>Extremely premature/extremely low birth weight</td><td>Control (normal birth weight)</td><td></td><td></td></tr>
<tr><td></td><td>Followed up (n=215)</td><td>Lost to follow-up (n=83)</td><td>Followed up (n=157)</td><td>Lost to follow-up (n=105</td></tr>
<tr><td>GA in weeks, mean (SD)</td><td>26.6 (2.0)</td><td>26.9 (1.7)</td><td>39.2 (1.5)</td><td>39.2 (1.4)</td></tr>
</table></td>
<td>Standardized face-to-face clinical interview and questionnaires were used to assess the mental health status in late adolescence: ADHD, any type (All ADHD types assessed with the ADHD module of the Children's Interview for Psychiatric Syndromes (ChIPS)) ADHD, combined type ADHD, inattentive type ADHD, hyperactive/impulsive type Any anxiety or mood disorder (All DSM-IV Axis I disorders (mood, anxiety, substance use, psychotic, eating and adjustment disorders) assessed with the Structured Clinical Interview dor DSM-IV Disorders, Axis 1 Non-Patient version (SCIP-I/NP), administered by 5 interviewers blinded to group. Experienced consultant psychiatrists, also blinded by group, were consulted extensively and consensus diagnoses were reached for all participants. These assessments were supplemented by questionnaires examining recent anxiety and depression symptoms: the Beck Anxiety</td>
<td>< 28 wks GA/<1000g: 47/205, 23.0% (17.4-29.3%)
<u>Any anxiety or mood disorder (n=205)</u>
< 28 wks GA/<1000g: 43/205, 21.0% (15.6-27.2%)
<u>Any mood disorder (n=205)</u>
< 28 wks GA/<1000g: 33/205, 16.1% (11.4-22.0%)
<u>Major depressive disorder (n=205)</u>
< 28 wks GA/<1000g: 28/205, 13.7% (9.3-19.1%)
<u>Any anxiety disorder (n=205)</u>
< 28 wks GA/<1000g: 23/205, 11.2% (7.3-16.4%)
<u>Obsessive-compulsive disorder (n=205)</u>
< 28 wks GA/<1000g: 4/205, 2.0% (0.5-5.0%)
<u>Co-morbid anxiety and mood disorder (n=205)</u>
< 28 wks GA/<1000g: 13/205, 6.3% (3.4-10.6%)
<u>Psychotic disorders (n=205)</u>
< 28 wks GA/<1000g: 0/0</td>
<td>No. Low precision (wide confidence intervals) due to low sample size.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear. The follow up rate was 72%, some adolescents were unable to complete the interviews because of difficulties in understanding the questions. Those who did not participate tended to have higher rates of major disability in childhood, younger mothers and poor childhood emotional/behavioural functioning.</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Australia (Victoria).

Source of funding

Victorian Government's Operational Infrastructure Support Programme. Australian National Health and Medical Research Council.</td>
<td>
<table>
<tr><td>Birth weight in grams, mean (SD)</td><td>889 (159)</td><td>885 (166)</td><td>3408 (460)</td><td>3341 (409)</td></tr>
<tr><td>Female, %</td><td>55</td><td>49</td><td>59</td><td>42</td></tr>
<tr><td>Singleton, %</td><td>68</td><td>73</td><td>99</td><td>94</td></tr>
<tr><td>Major neonatal brain injury, %</td><td>10</td><td>12</td><td>0</td><td>0</td></tr>
<tr><td>SGA, %</td><td>16</td><td>14</td><td>0.6</td><td>0</td></tr>
<tr><td>Postnatal steroids, %</td><td>31</td><td>37</td><td>0</td><td>0</td></tr>
</table>
</td>
<td>Inventory (BAI) and the Center for Epidemiologic Studies Depression Scale -Revised (CESD-R).) Any mood disorder Any anxiety disorder Co-morbid anxiety and mood disorder.

Age at assessment

18 years age.</td>
<td></td>
<td>6. Were objective, standard criteria used for the measurement of the condition?

Yes.

7. Was the condition measured reliably?

Unclear. It was not clear how anxiety and mood disorders were measured. SCID-I/NP was used but they also used the Beck Anxiety Inventory (BAI) and the Center for Epidemiologic Studies Depression Scale - Revised (CESD-R), not clear with whom or with all?

8. Was there appropriate statistical analysis?

No. Confidence intervals for prevalence estimates were not provided.

9. Are all important confounding</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr><td></td><td>
<table>
<tr><td>Neonatal surgery, %</td><td>26</td><td>27</td><td>0</td><td>0</td></tr>
<tr><td>Maternal age in years, mean (SD)</td><td>28.9 (6.0)</td><td>27.7 (5.3)</td><td>29.9 (4.9)</td><td>28.0 (5.5)</td></tr>
<tr><td>Mother completed high school, %</td><td>50</td><td>41</td><td>69</td><td>44</td></tr>
<tr><td>Father completed high school, %</td><td>44</td><td>33</td><td>68</td><td>46</td></tr>
<tr><td>Major disability</td><td>13</td><td>32</td><td>2</td><td>8</td></tr>
</table>
</td><td></td><td></td><td>factors/subgroups/differences identified and accounted for?
N/A

10. Were subpopulations identified using objective criteria?
N/A</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr><td></td><td>
<table>
<tr><td>at age 8 years, %</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Higher SES at age 8 years, %</td><td>60</td><td>45</td><td>72</td><td>66</td></tr>
<tr><td>Age at current assessment in years, mean (SD)</td><td>17.9 (0.9)</td><td>NA</td><td>18.1 (0.8)</td><td>NA</td></tr>
<tr><td></td><td></td><td></td><td></td><td></td></tr>
</table>
</td><td></td><td></td><td></td></tr>
<tr><td>Ref Id

410055

Full citation

Charkaluk, M. L., Truffert, P., Fily,</td><td>Setting

Children born in the Nord-Pas de Calais region of France (one of the 9 study areas in the EPIPAGE study).

Inclusion criteria</td><td>Gestational age ascertainment

Gestational age referred to completed weeks of amenorrhea and was the best obstetric estimate based on the date of last menstrual</td><td>Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)

At 2 years corrected age</td><td>Overall quality

Low.</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>A., Ancel, P. Y., Pierrat, V., Neurodevelopment of children born very preterm and free of severe disabilities: The Nord-Pas de Calais Epipage cohort study, Acta Paediatrica, International Journal of Paediatrics, 99, 684-689, 2010

Study type

Population based prospective cohort study (EPIPAGE).

Aim of the study

To describe the development of very preterm children free of cerebral palsy or severe sensory impairment in the domains of gross and fine motor</td>
<td>Children born alive at a gestational age of <33 weeks.

Exclusion criteria

Children with congenital abnormalities interfering with development.

Sample size

N=634 children born alive at GA <33 weeks.
n=546 surviving children included at follow up.

Characteristics

<table>
<tr><td></td><td>Preterm cohort (N=634)</td></tr>
<tr><td><33 weeks GA (n)</td><td>634</td></tr>
<tr><td>Deaths in delivery room (n)</td><td>37</td></tr>
<tr><td>Deaths in NICU (n)</td><td>49</td></tr>
</table>
</td>
<td>period and an early prenatal ultrasound scan, which is routine practice in France.

Outcome(s) of interest in this study

Developmental quotients (DQ).

Outcome(s) ascertainment/measures

Developmental quotients were ascertained by the revised Brunet-Lezine scale, an early childhood psychomotor development scale covering four domains of development: gross motor function, fine motor function, language and sociability.
Four separate DQs could be calculated for children aged 2-30 months, which can be combined to give a global DQ. (Global DQ cut off not reported in paper; DQ ≤70 is defined as moderate developmental delay; DQ <70 is defined as severe developmental delay)
Children were considered to have an achievement</td>
<td><u>Global DQ/developmental delay <70 (severe) (n=347 very preterm group)</u>
<33 wks GA: 8/347, 2.3% (1.0-4.5%)
<u>Global DQ/developmental delay <85 (moderate) (n=347 very preterm group)</u>
<33 wks GA: 62/347, 17.9% (14.0-22.0%)

Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>1. Was the sample representative of the target population?

Yes.

2. Were the study participants recruited in an appropriate way?

Yes.

3. Was the sample size adequate?

Yes.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

The follow up rate was 83%, and differences between</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>functions, language and sociability at a corrected age of 2 years; to identify factors associated with performances in each domain.

Study dates

Children born in 1997, assessed at 2 years corrected age.

Country/ies where the study was carried out

France.

Source of funding

Not reported.</td>
<td>
<table>
<tr><td>Down's syndrome (n)</td><td>1</td></tr>
<tr><td>Agenesis of corpus callosum (n)</td><td>1</td></tr>
<tr><td>Cerebral palsy (n)</td><td>29 (quadriplegia (15), diplegia (20), hemiplegia (4)</td></tr>
<tr><td>Sensory impairment (n)</td><td>9 (hearing aid (7; one associated with CP), blind (2; both associated with CP))</td></tr>
<tr><td>Loss to follow up (n)</td><td>85</td></tr>
<tr><td>Refusal of test (n)</td><td>69</td></tr>
</table>
</td>
<td>discrepancy if the difference between the global DQ and at least one partial DQ was a value obtained by only 5% of the reference sample.

Age at assessment

At 2 years corrected age.</td>
<td></td>
<td>children followed-up and those who were lost to follow up or refused to take the test were more frequently boys and small for gestational age. They had a higher CRIB score and were more often diagnosed as having severe ultrasound abnormality. Their parents had a lower educational and occupational level.

6. Were objective, standard criteria used for the measurement of the condition?

The BLR scale (screening tool) was used to identify moderate or severe developmental delay as DQ.

7. Was the condition measured reliably?

Yes.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				8. Was there appropriate statistical analysis? No. Confidence intervals for percentage estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 336268 **Full citation** De Groote, I., Vanhaesebrouck, P., Bruneel, E., Dom, L., Durein, I.,	**Setting** Population-based cohort of all surviving extremely preterm infants in Flanders, Belgium (the Extremely Preterm Infants in Belgium [EPIBEL] Study). **Inclusion criteria**	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Hearing disability;	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 3 years <u>CP total</u> <27 wks GA: 19/77, 24.7% (15.6-35.8%)*	**Overall quality** Low **1. Was the sample representative of the target population?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Hasaerts, D., Laroche, S., Oostra, A., Ortibus, E., Roeyers, H., Van Mol, C., Outcome at 3 years of age in a population-based cohort of extremely preterm infants, Obstetrics and Gynecology, 110, 855-864, 2007 **Study type** Population-based geographically defined cohort study (EPIBEL) **Aim of the study** To assess health and neurodevelopmental outcome at 3 years of age in neonatal intensive care unit-surviving children who were born at 26 or fewer	All infants who were born at less than 27 weeks of gestation in one of the perinatal centres of Flanders, Belgium from January 1, 1999 to January 1, 2001, who were admitted to a neonatal intensive care unit and who survived to discharge from the neonatal intensive care unit. **Exclusion criteria** None reported. **Sample size** n=95 children that survived to discharge from NICU n=77 children assessed at 3 years (n=3 died before follow-up, n=12 parents did not give consent, n=3 could not be reached), 81% follow-up rate (84% of the ones who were alive at follow-up). **Characteristics** The mean body weight at 36 months of age was 1.25 (+-1.48) standard deviation below the mean of the specific Flemish population norms. Average head circumference was 0.80 (+-1.30) standard deviation lower. Stature -0.76 (+-1.23) standard deviation shorter than the corresponding figures in age-matched controls. 54% had one or more somatic difficulties (data available for 87 of the 92 longterm survivors). Recurrent upper (25%) and/or lower (23%) airway disease were most frequently encountered with chronic aerosol treatment in 18% of the children. Chronic intestinal disorders were present in 10%,	vision disability; cerebral palsy; Mental Developmental Index (MDI) Problems: Psychomotor Developmental Index (PDI) **Outcome(s) ascertainment/measures** The assessement at 3 years comprised of a detailed clinical examination and full developmental evaluation. The clinical evaluation included collecting the recent medical history and a global health and anthropometric assessment as well as standardised neurologic and sensory examination. The Dutch edition of the second version of the Bayley Scales of Infant Development (BSID-II-NL) was used to assess ental and psychomotor development. The BSID-II-NL is standardised on a mean score of 100 and a SD of 15 points. Moderate impairment is defined as a score of 55-69	By type of CP: Spastic CP <27 wks GA: 14/77, 18.2% (10.3-28.6%) Extrapyramidal dystonia CP <27 wks GA: 3/77, 3.9% (0.8-11.0%) Hypotonic CP <27 wks GA: 1/77, 1.3% (0.03-7.0%) Ataxia CP <27 wks GA: 1/77, 1.3% (0.03-7.0%) By location of CP: CP hemiparesis <27 wks GA: 3/77, 3.9% (0.8-11.0%) CP diparesis <27 wks GA: 9/77, 11.7% (5.5-21.0%) CP triparesis <27 wks GA: 2/77, 2.6% (0.3-9.1%) CP quadriparesis <27 wks GA: 4/77, 5.2% (1.4-12.8%)	**2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to low sample size. **4. Were the study subjects and the setting described in detail?** No. Limited description of characteristics provided. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Unclear.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
weeks of gestation in a geographically defined region of Blgium from 1999 through 2000. **Study dates** Children born in 1999-2000, follow-up at 3 years of age. **Country/ies where the study was carried out** Belgium **Source of funding** The Foundation Marguerite Marie Delacroix and the Belgian Ministry of Health	with two toddlers dependent on gastrostomy feeding. Shunt got hydrocephalus was present in five children (6%). Other background characteristics not provided.	and severe impairment as a score of <55. The classification of type and location of cerebral palsy was based on describing function, tone and reflexes in each limb. In addition, it comprised the results of the neurologic examination. Hearing impairment was classified as "no useful hearing", "impairment but useful hearing", and "hearing aids". Vision impairment was classified as "impaired, but some useful vision", "impaired, and little useful vision", and "no useful vision". **Age at assessment** 3 years	By severity of CP: Severe CP (regardless of type or location)* <27 wks GA: 1/77, 1.3% (0.03-7.0%) Moderate CP (regardless of type or location)* <27 wks GA: 10/77, 13.0% (6.4-22.6%) Mild CP (regardless of type or location)* <27 wks GA: 8/77, 10.4% (4.6-19.5%) Hearing impairment but useful hearing <27 wks GA: 3/77, 3.9% (0.8-11.0%) Hearing impairment, no useful hearing <27 wks GA: 0/77, 0% (0-4.7%) Hearing impairment, use of hearing aids <27 wks GA: 4/77, 5.2% (1.4-12.8%) Vision impairment and little useful vision	84% of the children still alive at follow-up were followed-up. **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. For some outcomes, for example, hearing and vision, it is not clear how they were assessed and if "no useful hearing/vision" is an objective and standard criteria. **7. Was the condition measured reliably?** Unclear. Some outcomes yes (e.g. MDI and PDI) but for other outcomes, the methods of assessment are not described in detail. **8. Was there appropriate statistical analysis?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			<27 wks GA: 7/77, 9.1% (3.7-17.8%) <u>Vision impairment, no useful vision</u> <27 wks GA: 2/77, 2.6% (0.3-9.1%) <u>Severe mental developmental delay (MDI <55)</u> <27 wks GA: 14/77, 18.2% (10.3-28.6%) <u>Moderate mental developmental delay (MDI 55-69)</u> <27 wks GA: 8/77, 10.4% (4.6-19.5%) <u>Moderate to severe mental developmental delay (MDI <70)*</u> <27 wks GA: 22/77, 28.6% (18.9-40.0%) Problems: <u>Severe psychomotor developmental delay (PDI <55)</u> <27 wks GA: 21/77, 27.3% (17.7-38.6%)	No. Confidence intervals were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			Moderate psychomotor developmental delay (PDI 55-69) <27 wks GA: 16/77, 20.8% (12.4-31.5%) Moderate to severe psychomotor developmental delay (PDI <70)* <27 wks GA: 37/77, 48.1% (36.5-59.7%) *Calculated by the NGA technical team. Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	
Ref Id 410216 **Full citation** de Kleine, M. J., den Ouden, A. L., Kollee, L. A., Nijhuis-van der Sanden, M. W.,	**Setting** Three Dutch neonatal intensive care units. **Inclusion criteria** 5-year old survivors born before 32 weeks of gestation or weighing <1500 g and treated in one of three Dutch neonatal intensive care units in 1/10/1992-15/6/1994 (NICU at the University Medical Centre Nijmegen); 15/11/1992-1/1/1994	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Disorders:	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years Disorders: Cognitive delay (IQ <-2SD) <32 wks GA/bw <1500 g: 25/402, 6.2% (4.1-9.0%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Sondaar, M., van Kessel-Feddema, B. J., Knuijt, S., van Baar, A. L., Ilsen, A., Breur-Pieterse, R., Briet, J. M., Brand, R., Verloove-Vanhorick, S. P., Development and evaluation of a follow up assessment of preterm infants at 5 years of age, Archives of Disease in Childhood, 88, 870-5, 2003

Study type

A prospective cohort study

Aim of the study

To develop and validate an assessment tool that can help paediatricians to identify before 6</td>
<td>(Academic Medical Centre Amsterdam); and 1/1/1993-1/1/1995 (Maxima Mecical Centre Veldhoven.

Exclusion criteria

Children who participated in another study (n=46).~
Children with known severe cerebral palsy, blindness, severe mental retardation, chromosomal abnormalities, or inborn error of metabolism (n=21) because it was obvious they would not be able to perform the assessment tests.

Sample size

n=566 eligible children
n=431 assessed at 5 years (76%)
n=404 assessed for motor functioning (M-ABC)
n=402 assessed for IQ (IQ test)
n=407 assessed for behavioural problems (CBCL)

Characteristics

<table>
<tr><td></td><td>Eligible children n=431</td></tr>
<tr><td>Male, %</td><td>55</td></tr>
</table>
</td>
<td>Cognitive delay (IQ test, <-2SD)
Motor function delay (M-ABC, 5th centile)
Problems:
Behavioural problems (CBCL, score of >=64);

Outcome(s) ascertainment/measures

Disorders:
At 5 years, cognitive delay was assessed with revised Amsterdam child intelligence test (IQ test) by trained child psychologists. The revised Amsterdal child intelligence test has been nornalised for Dutch children between 4-7 years. Children with a score between -2 and -1 SD were considered at risk and those below -2 SD were abnormal.
At 5 years, motor function delay was assessed with the Movement ABC. Total scores above 17.0 (5th centile) were considered abnormal.
Problems:
At 5 years, behavioural problems were assessed with</td>
<td><u>Motor function delay (M-ABC <5th centile)</u>
<32 wks GA/bw <1500 g: 90/404, 22.3% (18.3-26.7%)

Problems:
<u>Total behavioural problems (CBCL, score >=65)</u>
<32 wks GA/bw <1500 g: 56/407, 56/407, 13.8% (10.6-17.5%)

Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Unclear.
Somewhat low precision (somewhat wide confidence intervals) due to relatively low sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
More than 20% of the eligible children were not</td>
</tr>
</table>

Study details	Participants		Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
years of age which survivors have developmental disturbances that may interfere with normal education and normal life. **Study dates** Children 1992-1995, assessed at 5 years. **Country/ies where the study was carried out** The Netherlands **Source of funding** The Dutch Health Organisations Praeventiefonds and ZorgOnderzoek Nederland (ZON).	Multiple pregnancy, %	36	the full Child Behaviour Checklist (CBCL) by trained child psychologists. Total scores up to and including 59 are considered normal, from 60 up to and including 63 intermediate and from 64 upwards "clinically important" disturbance of behaviour. **Age at assessment** 5 years		followed-up. However, the study compares the characteristics of the ones assessed and the ones not assessed. Statistically, the ones followed-up were more often multiple pregnancies, otherwise no big differences between the groups were observed. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates were not provided.
	GA in weeks, mean? (SD)	30.2 (2.0)			
	Birth weight in grams, mean? (SD)	1276 (332)			
	CS, %	48			
	Apgar score <7 at 5 min, %	17			
	Positive pressure ventilation, %	49			
	Surfactant administration, %	19			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	BPD, % 14 IVH grade I-IV, % 19			**9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 433133 **Full citation** Doyle, L. W., Anderson, P. J., Callanan, C., Carse, E., Charlton, M. P., Davey, M. A., Davis, N., Duff, J., Hunt, R., De Luca, C., Hayes, M., Hutchinson, E.,	**Setting** A regional population-based cohort of extremely low birth weight infants in the state of Victoria, Australia. **Inclusion criteria** All live-births of birthweight 500-999 g born in the state of Victoria (Australia) in 2005. **Exclusion criteria** Live births that were late terminations of pregnancy because of lethal anomalies (n=10).	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Cerebral palsy; blindness; deafness; moderate or severe developmental delay	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 2 years (corrected) CP BW 500-999 g (mean GA 25.7 [SD 2.3]): 12/165, 7.3% (3.8-12.4%) Blindness BW 500-999 g (mean GA 25.7 [SD 2.3]): 0/165, 0% (0-2.2%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Kelly, E., McDonald, M., Opie, G., Roberts, G., Stewart, M., Ung, L., Watkins, A., Williamson, A., Woods, H., Changing long-term outcomes for infants 500-999 g birth weight in Victoria, 1979-2005, Archives of Disease in Childhood: Fetal and Neonatal Edition, 96, F443-F447, 2011

Study type

A population-based cohort study (in the State of Victoria).

Aim of the study

To determine the survival and neurological outcome at 2 years of age of</td>
<td>Sample size

n=257 live births with bw 500-999 g (excl. cases with lethal anomalies)
n=172 survived to 2 years
n=165 assessed at 2 years (96%)

Characteristics

Characteristics of the n=257 live births with bs 500-999 g in 2005
<table><tr><td>Birth weight in grams, mean (SD)</td><td>751 (145)</td></tr><tr><td>GA in weeks, mean (SD)</td><td>25.7 (2.3)</td></tr><tr><td>Female, %</td><td>51.4</td></tr></table></td>
<td>Outcome(s) ascertainment/measures

Survivors were assessed at 2 years by paediatricians and psychologists blinded to perinatal details.
Criteria for diagnosis of CP included abnormal tone and loss of motor function, and its severity was assessed by the Gross Motor Function Classification System (GMFCS)
Blindness was diagnosed by paediatric ophthalmologists during the first 2 years of life.
Deafness was defines as requiring hearing aids or more advanced requirements.
Development delay was assessed with the Bayley Scales of Infants and Toddler Development (Bayley-III) and Cognitive Scale and Language Composite Scale. The scores for ELBW infants were compared with with the term controls rather than the test norms. Moderate developmental delay was defined as a score on either scale from -3SD to -2SD. Severe developmental delay</td>
<td>Deafness
BW 500-999 g (mean GA 25.7 [SD 2.3]): 4/165, 2.4% (0.7-6.1%)

Moderate developmental delay (Bayley-III), -3SD to -2SD
BW 500-999 g (mean GA 25.7 [SD 2.3]): 19/165, 11.5% (7.1-17.4%)

Severe developmental delay (Bayley-III), <-3SD
BW 500-999 g (mean GA 25.7 [SD 2.3]): 6/165, 3.6% (1.4-7.8%)

Moderate to severe developmental delay (<=2SD)
BW 500-999 g (mean GA 25.7 [SD 2.3]): 25/165, 15.2% (10.1-21.6%)

Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>Yes

3. Was the sample size adequate?

No.
Low precision (wide confidence intervals) due to relatively low sample size.

4. Were the study subjects and the setting described in detail?

No.
Limited information on background characteristics provided.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes.
96% of survivors were followed up.

6. Were objective, standard criteria used for</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
extremely low birthweight (ELBW) infants born in the state of Victoria compared with term controls and contrasted with ELBW cohorts from previous eras. **Study dates** Children born 2005, follow-up at 2 years (corrected). **Country/ies where the study was carried out** Australia **Source of funding** National Health and Medical Research Council, Australia.		was defined as a score <-3SD. **Age at assessment** 2 years (corrected)		**the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				Not applicable.
Ref Id 316035 **Full citation** Drummond,P.M., Colver,A.F., Analysis by gestational age of cerebral palsy in singleton births in north-east England 1970-94, Paediatric and Perinatal Epidemiology, 16, 172-180, 2002 **Study type** Epidemiological register data study **Aim of the study** To report an epidemiological study of CP by gestational age in	**Setting** Register data of CP from north-east England, UK. **Inclusion criteria** All infants with CP born to mothers resident in Newcastle, North Tyneside, and Northumberland at birth and all live births in the area (to be used as a denominator). **Exclusion criteria** Multiple births; infants with post-neonatal insult. **Sample size** n=2858 singleton neonatal survivors in 1990-94 with <37 weeks of GA at birth **Characteristics** None reported.	**Gestational age ascertainment** Gestational age data was available from the Regional Standard Maternity Information System. Gestational age was assessed from menstrual history and clinical findings at booking. If the mother was uncertain of her menstrual dates or if these differed from an early ultrasound assessment (<20 weeks) by more than 14 days, the ultrasound estimate was then recorded. **Outcome(s) of interest in this study** Cerebral palsy (CP) **Outcome(s) ascertainment/measures** The North of England Collaborative CP survey records all infants with CP	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** Age at assessment not reported. Time period 1990-94 <u>CP</u> <37 wks: 16.8/1000 neonatal survivors (95% CI 12-22) (number of cases 48, number for neonatal survivors 2858) <36 wks: 24.5/1000 neonatal survivors (95% CI 18-33) (number of cases 42, number for neonatal survivors 1713) <35 wks: 33.9/1000 neonatal survivors (95% CI 24-46) (number of cases 37, number for neonatal survivors 1093) <34 wks: 50.5/1000 neonatal survivors (95% CI 36-69) (number of cases 37, number for neonatal survivors 732) <33 wks: 61.8/1000 neonatal survivors (95% CI	**Overall quality** Low **1. Was the sample representative of the target population?** Unclear. CP register data was used so the participants, it is unclear if this actually includes all children with CP in the target area. The sample was not described either. **2. Were the study participants recruited in an appropriate way?** Unclear. Register data, they were not recruited. **3. Was the sample size adequate?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
a geographically defined population using data from a well-established CP register. **Study dates** 1970-1994 (only time period 1990-94 used for the review). **Country/ies where the study was carried out** UK **Source of funding** SCOPE, and Health Authorities in the Northern and Yorkshire Region funded administrative support for the register.		born to mothers resident in Newcastle, North Tyneside and Northumberland at birth. The Little Club definition of CP is used (Mac Keith RC., MacKenzie ICK., Polani PE. (1959) The Little Club. Memorandum on terminology and classification of 'cerebral palsy'. Cereb Palsy Bull 1: 27–35.), updated by Bax (Bax MC. (1964) Terminology and classification of Cerebral Palsy. Dev Med Child Neurol 6: 295-7.). Spastic CP is classified as unilateral (hemiplegia and monoplegia) or bilateral (diplegia, quadriplegia and any other combination of bilateral spastic involvement) in line with the agreement of the European Collaboration. **Age at assessment** Not reported.	42-87) (number of cases 31, number for neonatal survivors 502) <32 wks: 67/1000 neonatal survivors (95% CI 44-99) (number of cases 24, number for neonatal survivors 355) 32-36 wks: 9.6/1000 neonatal survivors (95% CI 6-14) (number of cases 24, number for neonatal survivors 2503) 28-31 wks: 56.3/1000 neonatal survivors (95% CI 33-90) (number of cases 16, number for neonatal survivors 284) <28 wks: 112.7/1000 neonatal survivors (95% CI 50-210) (number of cases 8, number for neonatal survivors 71) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	Yes **4. Were the study subjects and the setting described in detail?** No. Characteristics of the sample were not provided. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Not applicable. Register data was used. **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Register data of CP so no description how CP was diagnosed/assessed. The definition of CP was standard.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				7. Was the condition measured reliably? Unclear. Register data of CP so no description how CP was diagnosed/assessed. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 410388 **Full citation** Farooqi, A., Hagglof, B., Sedin, G., Serenius, F., Impact at age 11 years of major neonatal morbidities in children born extremely preterm, Pediatrics, 127, e1247-57, 2011 **Study type** Prospective national cohort study **Aim of the study** To determine the impact of bronchopulmonary dysplasia, ultrasonographic signs of brain injury, and severe	**Setting** National cohort of children born at <26 weeks in Sweden in 1990-1992. **Inclusion criteria** All infants born at gestational age <26 weeks in Sweden between March 1990 and April 1992 and survived to 36 weeks post-menstrual age. **Exclusion criteria** Died before 36 months post-menstrual age. **Sample size** n=89 children born at <26 weeks gestation and survived to follow-up (36% of all 247 children born at <26 weeks in Sweden of which the rest died) n=88 children with data (1 child was lost to follow up, was followed-up but did not participate) **Characteristics** Children <26 weeks	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Cerebral palsy (CP); severe visual impairment; hearing loss in both ears resulting in amplification. **Outcome(s) ascertainment/measures** Not reported how the following disorders were diagnosed. Cerebral palsy (CP), classified as hemiplegia, diplegia, or quadriplegia. CP was categorized functionally as as mild (no evidence of clinically important functional difficulty related to gait or use of hands), moderate (independent walking but with an abnormal gait); or disabling (not walking, severe motor diability). Severe visual impairment, including unilateral or bilateral	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 11 years Moderate or disabling CP <26 wks GA: 6/88, 6.8% (2.5-14.3%) Severe visual impairment <26 wks GA: 11/88, 12.5% (6.4-21.3%) Moderate, severe or profound hearing loss in both ears requiring amplification <26 wks GA: 5/88, 5.7% (1.9-12.8%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Relatively small sample size, thus, low precision (wide confidence intervals for prevalence estimates). **4. Were the study subjects and the setting described in detail?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
retinopathy of prematurity on 11-year outcomes in infants born at <26 weeks of gestation. **Study dates** Children born 1990-1992, follow-up at 11 years **Country/ies where the study was carried out** Sweden **Source of funding** The Sven-Jerring Fond Foundation and the Oskarfonden Foundation	GA in weeks, mean (SD): 24.6 (0.7) Birth weight in grams, mean (SD): 765 (111) SGA, %: 9 Multiple birth, %: 18 Female, %: 54 Received antenatal steroids, %: 30 Maternal age in years, mean (SD): 29.8 (4.8) Maternal education 9 y, %: 12	blindness or visual acuity <20/200 without glasses in at least one eye. Moderate, severe or profound hearing loss in both ears resulting in amplification. **Age at assessment** 11 years		**5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Not described what assessments/methods were used to assess outcome. **7. Was the condition measured reliably?** Unclear. Not described what assessments/methods were used to assess outcome. **8. Was there appropriate statistical analysis?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	Maternal education 10-12 y, % 59 Maternal education >12 y, % 29 Low-income, % 28			No. Confidence intervals not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 410443 **Full citation** Foix-L'Helias, L., Marchand, L., Theret, B., Larroque, B., Ancel, P. Y., Blondel, B., Garel, M., Maillard, F.,	**Setting** All maternity units in nine regions of France, EPIPAGE study. **Inclusion criteria** For this analysis, any birth between 24^{+0} and 32^{+6} weeks of gestation in all maternity units of nine French regions in 1997. **Exclusion criteria**	**Gestational age ascertainment** Gestational age was determined from the last menstrual period and findings from early prenatal ultrasound scans and calculated in completed weeks.	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years Disorders: CP 24-32 wks GA: 158/1781, 8.9% (7.6-10.3%) 24-27 wks GA: 39/266, 14.7% (10.6-19.5%)	**Overall quality** Moderate. **1. Was the sample representative of the target population?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Missy, P., Sehili, F., Supernant, K., Durand, M., Matis, J., Messer, J., Treisser, A., Burguet, A., Abraham-Lerat, L., Menget, A., Roth, P., Schaal, J. P., Thiriez, G., Leveque, C., Marret, S., Marpeau, L., Boulot, P., Picaud, J. C., Donadio, A. M., Ledesert, B., Andre, M., Fresson, J., Hascoet, J. M., Arnaud, C., Bourdet-Loubere, S., Grandjean, H., Rolland, M., Leignel, C., Lequien, P., Pierrat, V., Puech, F., Subtil, D., Truffert, P., Boog, G., Rouger-Bureau, V., Roze, J. C., Ancel, P. Y., Breart, G., Kaminski, M., Du Mazaubrun, C.,	Missing data on antenatal steroid use. For the purpose of this analysis children who died before 5 years were excluded. The protocol included the option of not following up one of every two infants born at 32 weeks (to reduce the workload). 2 regions exercised this option leading to the exclusion of 68 infants. **Sample size** Disorders: n=1781 children with data on CP (77% of n=2300 survivors up to follow-up) n=1508 children with data on cognition (66% of the n=2300 survivors up to follow-up) Problems: n=1645 children with data on behavioural difficulties (72% of the n=2300 survivors up to follow-up) **Characteristics** Baseline characteristics not described in this publication.	**Outcome(s) of interest in this study** Disorders: Cerebral palsy (CP); severe CP (unable to walk or walking with aid only); cognitive impairment (MPC 55-69 and MPC <55) Problems: Total behavioural difficulties (SDQ) **Outcome(s) ascertainment/measures** Follow up was at 5 years of age, and involved a medical and neuropsychological assessment. The assessment included a thorough physical examination and neurological assessment (tone, reflexes, posture and movements). Physicians recorded their findings on a standardized form. The definition of cerebral palsy was that established by the European Cerebral Palsy Network, which requires at least 2 of the following: abnormal posture or	28-32 wks GA: 119/1515, 7.9% (6.6-9.3%) <u>Severe CP</u> 24-32 wks GA: 50/1781, 2.8% (2.1-3.7%) 24-27 wks GA: 13/266, 4.9% (2.6-8.2%) 28-32 wks GA: 37/1515, 2.4% (1.7-3.4%) <u>Moderate cognitive impairment (MPC 55-69)</u> 24-32 wks GA: 145/1508, 9.6% (8.2-11.2%) 24-27 wks GA: 33/222, 14.9% (10.5-20.2%) 28-32 wks GA: 112/1286, 8.7% (7.2-10.4%) <u>Severe cognitive impairment (MPC <55)</u> 24-32 wks GA: 35/1508, 2.3% (1.6-3.2%) 24-27 wks GA: 6/222, 2.7% (1.0-5.8%) 28-32 wks GA: 29/1286, 2.3% (1.5-3.2%) <u>Cognitive impairment (MPC <70)</u> 24-32 wks GA: 180/1508, 11.9% (10.3-13.7%)	**2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. Around 30% lost to follow-up. **6. Were objective, standard criteria used for**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Dehan, M., Zupan-Simunek, V., Vodovar, M., Voyer, M., Impact of the use of antenatal corticosteroids on mortality, cerebral lesions and 5-year neurodevelopmental outcomes of very preterm infants: The EPIPAGE cohort study, BJOG: An International Journal of Obstetrics and Gynaecology, 115, 275-282, 2008 **Study type** Prospective population based cohort study (EPIPAGE). **Aim of the study** To assess the impact of antenatal steroids		movement, increased tone and hyperreflexia. Cerebral palsy was considered to be severe if infants were unable to walk, or only able to walk with assistance. Cognitive ability was assessed using the mental processing composite (MPC) of the Kaufman Assessment Battery for Children (K-ABC). This score is standardised to a mean (±SD) of 100 (±15) based on a reference population of French children born in the late 1990s. MPC scores of less than 70 indicate cognitive impairment. Total behavioural difficulties were assessed using the French version of the Strengths and Difficulties Questionnaire (SDQ) completed by parents. This questionnaire includes 25 items structured into five scales which assess hyperactivity-inattention, conduct problems, emotional symptoms, peer problems and prosocial behaviour. Scores for the first four symptom scales are summed to provide an overall difficulties score	24-27 wks GA: 39/222, 17.6% (12.8-23.2%) 28-32 wks GA: 141/1286, 11.0% (9.3-12.8%) Problems: Total behavioural difficulties (SDQ, 10th percentile) 24-32 wks GA: 348/1645, 21.2% (19.2-23.2%) 24-27 wks GA: 52/234, 22.2% (17.1-28.1%) 28-32 wks GA: 296/1411, 21.0% (18.9-23.2%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
on neurodevelopmental outcome of infants born at 24-27 weeks and 28-32 weeks gestation. **Study dates** Recruitment took place in 1997. Follow up was at 5 years. **Country/ies where the study was carried out** France **Source of funding** INSERM (National Institute of Health and Medical Research), Directorate General for Health of the Ministry for		with a range of 0-40. The cut-offs were defined such that about 10% of the children in contemporaneous reference group of children born at term (born between 39 and 40 weeks of GA) were considered at high risk of having a behavioural problem. **Age at assessment** 5 years.		

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Social Affairs, Merck-Sharp and Dohme-Chibret, Medical Research Foundation, HAS (French National Authority for Health) and "Hospital Program for Clinical Research 2001 n° AOMO1117" of the French Department of Health.				
Ref Id 397225 **Full citation** Foulder-Hughes, L. A., Cooke, R. W., Motor, cognitive, and behavioural disorders in children born very preterm, Developmental Medicine & Child	**Setting** All preterm infants born before 32 completed weeks of gestation from 1991 to 1992 in eight hospitals within the Liverpool, UK postal districts. **Inclusion criteria** All preterm infants born before 32 completed weeks of gestation from 1991 to 1992 in eight hospitals within the Liverpool, UK postal districts. Children who attended mainstream school at the time of the follow-up. **Exclusion criteria**	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Developmental coordination disorder (DCD) **Outcome(s) ascertainment/measures**	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 7-8 years DCD <32 weeks GA: 86/280, 30.7% (25.4-36.5%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Neurology, 45, 97-103, 2003 **Study type** Geographically determined cohort study **Aim of the study** To examine the rate or motor impairment and associated behavioural and cognitive disabilities in a geographically determined cohort of 7- to 8-year-old children born before 32 weeks of gestation from 1991 to 1992. **Study dates** Children born 1991-1992, follow-up at 7-8 years.	Those who died before discharge or whose mothers were not resident within a Liverpool postal district at the time of the birth. **Sample size** n=280 children born at <32 weeks **Characteristics** Mean gestational age was 29.8 weeks (23-32 range) and mean birth weight was 1467 g (SD 424, range 512-2860). There were 215 singleton births, 56 twins and 9 triplets.	DCD: Fine and motor gorss skills were assessed using age band 2 of the Movement Assessment Battery for Children (MABC). The test comprises eight items, two in each of four subsections: manual dexterity, ball skills, static balance, and dynamic balance. The scoring system for each item ranges from 0 (no impairment) to 5 (severe impairment). The scores for each item are added and converted to centiles. A score <=5th centile was taken to indicate motor difficulties consistent with DCD. **Age at assessment** 7-8 years		**3. Was the sample size adequate?** No. Low precision, wide confidence interval due to relatively small sample. **4. Were the study subjects and the setting described in detail?** No. Limited description of the characteristics of the sample given. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Unclear. Not reported how many eligible individuals were not included in the final sample. **6. Were objective, standard criteria used for**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out UK **Source of funding** None reported.				**the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence interval for the prevalence estimate not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				Not applicable.
Ref Id 347851 **Full citation** Glinianaia, S. V., Rankin, J., Colver, A., Cerebral palsy rates by birth weight, gestation and severity in North of England, 1991-2000 singleton births, Archives of Disease in Childhood, 96, 180-185, 2011 **Study type** Prospective population-based survey (NECCPS) **Aim of the study** To investigate changes in rates	**Setting** Population-based study in the North of England. **Inclusion criteria** All singleton children born in the geographically defined area in the north of England (North Cumbria, Northumberland, Tyne and Wear, Durham and Darkington and Teesside) and who survived the neonatal period. **Exclusion criteria** Multiple births; children who did not survive past the neonatal period. **Sample size** n=331154 total study population (all liveborn neonatal survivors) n=18797 liveborn neonatal survivors born at <37 weeks of gestation (n=846 liveborn neonatal survivors born at <28 weeks of gestation n=2070 liveborn neonatal survivors born at 28-31 weeks of gestation n=15881 liveborn neonatal survivors born at 32-36 weeks of gestation)	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Cerebral palsy (CP) **Outcome(s) ascertainment/measures** CP is classified according to the agreement of the Surveillance of Cerebral Palsy in Europe: spastic CP (unilateral or bilateral), dyskinetic and ataxic. Data on CP was obtained from the North of England Collaborative Cerebral Palsy Survey (NECCPS) that prospectively records all infants with CP born to mothers resident in the region from 1991. Cases are notified to the survey by the District Convenors who are consultant community	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At age up to 8 years <u>CP</u> 1991-1995 <28 wks GA: 28/463, 6.1% (4.1-8.6%) 28-31 wks GA: 58/1111, 5.2% (4.0-6.7%) 32-36 wks GS: 81/8276, 1.0% (0.8-1.2%) 1996-2000 <28 wks GA: 29/383, 7.6% (5.1-10.7%) 28-31 wks GA: 64/959, 6.7% (5.2-8.4%) 32-36 wks GS: 70/7605, 0.9% (0.7-1.2%) 1991-2000 <28 wks GA: 57/846, 6.7% (5.1-8.6%) 28-31 wks GA: 122/2070, 5.9% (4.9-7.0%) 32-36 wks GS: 151/15881, 1.0% (0.8-1.1%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
of cerebral palsy (CP) by birth weight, gestational age, severity of disability, clinical subtype and maternal age in the |North of England, 1991-2000. **Study dates** Children born 1991-2000, follow-up up to 8 years of age. **Country/ies where the study was carried out** UK **Source of funding** Personal Award Scheme Career Scientist Award from the National	**Characteristics** Not reported.	paediatricians. They coordinate services for such children and receive information about children needing services from other paediatricians, paediatric neurologists, physiotherapists, speech therapists, and the regional child development centre. The convenor completes the notification form. Further details are forwarded to the survey when the child reached 5 years of age to confirm the diagnosis and provide details of associated impairments. it is very unusual to for a case of CP to be diagnosed after age 6 years, however, the process of ascertainment by the convenor and the requirement to obtain parent consent means that sometimes children are added to the register up to age 8 years even though diagnosed a year or two earlier. Cases are notified from multiple sources, there is a regional network of interested clinicians and close links with the long standing prospective Perinatal Mortality Survey and	CP non-spastic 1991-2000 <37 wks GA: 13/18797, 0.07% (0.04-0.12%) CP spastic bilateral <37 wks GA: 240/18797, 1.3% (1.1-1.5%) CP spastic unilateral <37 wks GA: 77/18797, 0.4% (0.3-0.5%) Confidence intervals were calculated by the NGA staff team using http://statpages.info/confint.html	No. No description of characteristics provided. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Data on the diagnosis of CP was obtained from various sources and the methods of assessment/diagnosis is not described and might not be similar to all participants. **7. Was the condition measured reliably?** Unclear. Data on the diagnosis of CP was obtained from various sources and the methods of

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Institute of Health Research (UK Department of Health), the Regional Health Authority, District Health Authorities and Primary Care Trusts (administrative support).		Northern Congenital Abnormality Survey housed on the same premises. Every case of CP mentioned on a child death certificate and every case mentioned as a co-morbidity on a late notification of a congenital abnormality is ascertained by the survey. **Age at assessment** Up to 8 years		assessment/diagnosis is not described and might not be similar to all participants. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 357437	**Setting** Cohort of preterm children in 9 regions in France (EPIPGAGE).	**Gestational age ascertainment**	**Prevalence n/N and % (with 95% CI) (incl. GA at**	**Overall quality** Low.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Full citation

Guellec, I., Lapillonne, A., Renolleau, S., Charlaluk, M. L., Roze, J. C., Marret, S., Vieux, R., Monique, K., Ancel, P. Y., Neurologic outcomes at school age in very preterm infants born with severe or mild growth restriction, Pediatrics, 127, e883-e891, 2011

Study type

Population based prospective cohort study (EPIPGAGE study)

Aim of the study

To determine whether mild and severe growth restriction at birth</td>
<td>Inclusion criteria

All children born at <33 completed weeks of gestation in all maternity units of 9 regions of France in 1997 who survived to discharge. In addition, all children born at 32 weeks of gestation were included in 7 of the regions and in 2 regions, every other child born at 32 weeks were included.

Exclusion criteria

Children who died before discharge from the hospital. Children whose neurologic status was unknown at follow-up due to artificial respiration (n=4).

Sample size

N=2855 live births at 24-32 weeks GA.
n=2357 infants eligible for follow-up.

Characteristics

<table>
<tr><td>Live births 24-32 weeks GA =2864)</td><td></td></tr>
<tr><td>24-28 wks GA (SGA)</td><td>8.6%</td></tr>
</table>
</td>
<td>Gestational age referred to completed weeks of amenorrhoea, which was the best obstetric estimate and combined last menstrual period and early prenatal ultrasound and clinical assessments, which is routine practice in France.

Outcome(s) of interest in this study

CP
Inattention-hyperactivity symptoms
Total behavioural difficulties

Outcome(s) ascertainment/measures

Cerebral palsy (CP), defined according to the European CP Network definition, children were classified as having CP if they had abnormal posture or movement, increased tone or hyperreflexia (spastic CP), involuntary movements (dyskinetic CP), or loss of coordination (ataxic CP).</td>
<td>birth and age at assessment)

At 5 years age
<u>CP</u>
24-28 wks GA: CP: 22/542, 4.1% (2.6-6.1%)
24-28 wks GA: CP+SGA: 4/22, 18.1% (5.2-40.3%)
29-32 wks GA: CP: 125/1815, 6.9% (5.8-8.2%)
29-32 wks GA: CP+SGA: 4/125, 3.2% (0.9-8.0%)
Problems:
<u>Inattention-hyperactivity symptoms</u>
24-28 wks GA: CP+SGA: 4/21, 19% (5.5-42.0%)
29-32 wks GA: CP+SGA: 27/115, 23.5% (16.0-32.3%)
<u>Total behavioural difficulties</u>
24-28 wks GA: SGA: 7/21, 33.3% (14.6-57%)
29-32 wks GA: SGA: 22/115, 19.1% (12.4-27.5%)</td>
<td>1. Was the sample representative of the target population?

Yes.

2. Were the study participants recruited in an appropriate way?

Yes.

3. Was the sample size adequate?

No. Low precision (wide confidence intervals) due to low sample size in GA subgroups.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>among preterm infants is associated with neonatal mortality and cerebral palsy and cognitive performance at 5 years of age and school performance at 8 years age.

Study dates

Children born 1997, assessed at 5 years.

Country/ies where the study was carried out

France.

Source of funding

Not reported.</td>
<td>
<table>
<tr><td>29-32 wks GA (SGA)</td><td>9.5%</td></tr>
<tr><td>Singleton (SGA) at 24-28 wks GA</td><td>9.5%</td></tr>
<tr><td>Singleton (SGA) at 29-32 wks GA</td><td>10.2%</td></tr>
<tr><td>Maternal age <25 yrs (24-28 wks GA, SGA)</td><td>7.9%</td></tr>
<tr><td>Maternal age <25 yrs (29-32 wks GA, SGA)</td><td>10.7%</td></tr>
</table>
</td>
<td>Detaimedical and neurologic examintion in which tone, reflexes, postures and movements were assessed. Trained paediatricians reviewed data for children with abnormal results on neurologic examination to validate the diagnosis of CP and assess the severity.
Cognitive deficiency, defined by an Mental processing Composite (MPC) <85 (-1SD) assessed by the French version of the Kaufman Assessment Battery for Children, administered by trained psychologist.

Developmental problems: Inattention-hyperactivity symptoms, assessed with the French version of the Strength and Difficulties Questionnaire completed by the parents.Total behavioural difficulties, including a sum score of scales on hyperactivity-inattention, conduct, emotional and peer problems, assessed with the French version of the Strength and Difficulties Questionnaire completed by the parents.</td>
<td></td>
<td>coverage of the identified sample?

Follow up rate was 83%. Differences between children followed up and lost to follow up were not reported.

6. Were objective, standard criteria used for the measurement of the condition?

It was not clear how the medical or neurologic examination was carried out, although a definition of CP was reported.

7. Was the condition measured reliably?

The method of assessment of CP was not described.

8. Was there appropriate statistical analysis?</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
		Age at assessment Age 5 years		Confidence intervals for proportion estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 347181 **Full citation** Himmelmann, K., Uvebrant, P., The panorama of cerebral palsy in Sweden. XI. Changing patterns in the birth-year	**Setting** A birth cohort of all live-births in Vastra Gotaland, Jonkoping and Halland in 2003-2006. **Inclusion criteria** Children with CP were included if they were born in Sweden and lived in the study area on December 31 2010. Children diagnosed with CP who had died after 2 years of age were also included. All live-births in the region between 2003-2006 were included as the denominator.	**Gestational age ascertainment** Gestational age was based primarily on early ultrasound. If this information was not available, menstrual data was used. **Outcome(s) of interest in this study**	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** CP verified at 4 to 8 years of age <u>CP</u> <28 wks GA: 71.4/1000 live births (95% CI 42-112/1000 live births) (number of cases 17, number of live births 238)	**Overall quality** Moderate. **1. Was the sample representative of the target population?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
period 2003-2006, Acta Paediatrica, 103, 618-24, 2014 **Study type** A population-based epidemiological study (using register data). **Aim of the study** To describe the epidemiology of cerebral palsy (CP) in western Sweden. **Study dates** Children born 2003-2006. **Country/ies where the study was carried out** Sweden	**Exclusion criteria** Children with obvious postneonatal cause for CP (n=11, due to central nervous system infection; prolonged febrile status epilecticus; cerebral infarction; diabetic hyperosmolar coma complicated by a sinus thrombosis; circulatory collapse in a child with cardiomyopathy; trauma). **Sample size** n=94466 live births in the region in 2003-2006, of which n=238 children born at <28 weeks of gestation, n=581 children born at 28-31 weeks of gestation, n=4544 children born at 32-26 weeks of gestation **Characteristics** Not reported for the whole birth cohort. Among the ones with CP, 60% were boys, 9% had a birth weight of <1000 g, 9% of the children with CP were from multiple pregnancies, 3.6% were small for gestational age, 4.1% were large for gestational age. The mean maternal age was 31 years (compared with 30 years in the general population). In 54% of the cases, this was the first child, the second child in 29% and the third child in 17%. Care in neonatal unit was given to 71% of the children with CP, as compared with around 10% in the general population.	Cerebral palsy (CP) **Outcome(s) ascertainment/measures** CP was verified at 4 to 8 years of age by the local neuropaediatrician. In doubtful cases, a second diagnostic assessment was performed by the first author of the publication. The definition of CP was agreed at an international consensus meeting in Bethesda. The Swedish and internationally accepted classification of CP syndromes was applied, in parallel with the classification suggested by the Surveillance of Cerebral Palsy in Europe (SCPE) where hemiplegia corresponds to unilateral spastic CP and diplegia and tetraplegia are combined to create bilateral spastic CP. **Age at assessment** CP was verified at 4 to 8 years of age.	28-31 wks GA: 39.6/1000 live births (95% CI 25-59/1000 live births) (number of cases 23, number of live births 581) 32-36 wks GA: 6.4/1000 live births (95% CI 4-9/1000 live births) (number of cases 29, number of live births 4544) <37 wks GA: 13/1000 live births (95% CI 10-16/1000 live births) (number of cases 69, number of live births 5363) Bilateral spastic CP (diplegia and tetraplegia) <37 wks GA: 7.5/1000 live births (95% CI 5-10/1000 live births) (number of cases 40, number of live births 5363) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Unclear. The birth cohort is large but since preterm birth is relatively rare, the sample sizes of these subgroups are relatively small and confidence intervals within preterm subgroups are somewhat wide. **4. Were the study subjects and the setting described in detail?** No. The whole birth cohort (general population) was not but the children with CP were described to an extent. Sociodemographic characteristics were not described.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Source of funding Supported by grants from the Norrbacka-Eugenia Foundation, the AnnMari and Per Ahlqvist Foundation, the Linnes and Josef Carlsson Foundation, the Torbjorn Jebner Memorial Foundation, the Vastra Gotaland Region and the Folke Bernadotte Foundation.				**5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Unclear. Method of diagnosing CP was not described in detail. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates were not provided.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				9. Are all important confounding factors/subgroups/differences identified and accounted for? Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 347185 **Full citation** Hirvonen, M., Ojala, R., Korhonen, P., Haataja, P., Eriksson, K., Gissler, M., Luukkaala, T., Tammela, O., Cerebral palsy among children	**Setting** National register data from Finland. **Inclusion criteria** All infants born in Finland from 1991 to 2008. **Exclusion criteria** Infants who died before the age of 1 year and children with at least 1 major congenital anomaly, and cases lacking data on gestational age were excluded.	**Gestational age ascertainment** Based on early pregnancy ultrasound and correction of GA was made if the ultrasound-based estimation had a discrepancy of 5 to 7 days or more compared with menstrual anamnesis. **Outcome(s) of interest in this study** Cerebral palsy	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** Up to 7 years of age (Study period 1991-2008) <u>CP (total)</u> <32 wks GA: 550/6347, 8.7% (8.0-9.4%) 32-33 wks GA: 160/6799, 2.4% (2.0-2.7%) 34-36 wks GA: 225/39932, 0.56% (0.49-0.64%) 32-36 wks GA: 385/46731, 0.8% (0.7-0.9%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>born moderately and late preterm, Pediatrics, 134, e1584-93, 2014

Study type

National register study

Aim of the study

To compare the incidence of and risk factors for cerebral palsy in moderately preterm (32-33 weeks) and late preterm (34-36 weeks) infants with those in very preterm (<32 weeks) and term (>=37 weeks) infants.

Study dates

Children born 1991-2008, followed up to 7</td>
<td>Sample size

n=6347 children born at <32 weeks
n=6799 children born at 32-33 weeks
n=39932 children born at 34-36 weeks

Characteristics
<table>
<tr><th></th><th><32 wks</th><th>32-33 wks</th><th>34-36 wks</th><th>>=37 wks (term)</th></tr>
<tr><td>Mother's age, mean (SD)</td><td>30.2 (5.8)</td><td>29.8 (5.7)</td><td>29.7 (5.5)</td><td>29.2 (5.3)</td></tr>
<tr><td>Singleton, %</td><td>71.3</td><td>67.6</td><td>77.8</td><td>98.3</td></tr>
<tr><td>CS, %</td><td>59.8</td><td>52.7</td><td>33.1</td><td>14.9</td></tr>
<tr><td>Birth weight in grams, median (IQR)</td><td>1290 (995-1570)</td><td>1970 (1730-2200)</td><td>2670 (2360-2985)</td><td>3590 (3276-3910)</td></tr>
</table>
</td>
<td>Outcome(s) ascertainment/measures

A case with CP was recorded if the individual was detected in the Hospital Discharge Register (HDR) and/or in the Reimbursement Register of the Social Insurance Institution with ICD-10 cides G80 to G83 in 1996 to 2008 and ICD-9 codes 342 to 344 in 1991 to 1995. Subtypes of CP were defined by topographic involvement (hemiplegia, diplegia, guadriplegia and other types) and sought from registers with corresponding ICD codes. All inpatient or outpatient visits due to a CP diagnosis in public hospitals were registered to the HDR. The diagnosis of CP in Finland is based on medical history, ultrasound and MRI data, and multidisciplinary evaluations in the pediatric neurology units of 20 secondary-level central hospitals and 5 tertiary-level university hospitals.</td>
<td><u>CP hemiplegia</u>
<32 wks GA: 80/6347, 1.3% (1.0-1.6%)
32-33 wks GA: 37/6799, 0.5% (0.4-0.8%)
34-36 wks GA: 57/39932, 0.14% (0.11-0.19%)
32-36 wks GA: 94/46731, 0.2% (0.16-0.25%))
<u>CP diplegia</u>
<32 wks GA: 213/6347, 3.4% (2.9-3.8%)
32-33 wks GA: 48/6799, 0.7% (0.5-0.9%)
34-36 wks GA: 52/39932, 0.13% (0.10-0.17%)
32-36 wks GA: 100/46731, 0.2% (0.17-0.26%)
<u>CP quadriplegia</u>
<32 wks GA: 37/6347, 0.6% (0.4-0.8%)
32-33 wks GA: 11/6799, 0.2% (0.1-0.3%)
34-36 wks GA: 16/39932, 0.04% (0.02-0.06%)
32-36 wks GA: 27/46731, 0.06% (0.04-0.08%)
<u>CP other types</u>
<32 wks GA: 220/6347, 3.5% (3.0-4.0%)
32-33 wks GA: 64/6799, 0.9% (0.7-1.2%)
34-36 wks GA: 100/39932, 0.25% (0.20-0.30%)</td>
<td>Yes

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes.
Register data was used.

6. Were objective, standard criteria used for the measurement of the condition?

Yes</td>
</tr>
</table>

Study details	Participants					Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
years or up to year 2009. **Country/ies where the study was carried out** Finland **Source of funding** Pirkanmaa Hospital District and Central Finland Health Care District.	SGA, %	16.1	13.0	8.1	1.7	**Age at assessment** Up to 7 years of age. The authors write that "CP is usually evident within first 2 years of life and almost alwatys by the age of 3 to 4 years and the diagnosis is included in the HDR as soon as it has been established".	32-36 wks GA: 164/46731, 0.35% (0.3-0.4%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**7. Was the condition measured reliably?** Unclear. Register data was used so it is not clear if conditions were assessed in similar ways although authors do write that "The diagnosis of CP in Finland is based on medical history, ultrasound and MRI data, and multidisciplinary evaluations in the pediatric neurology units of 20 secondary-level central hospitals and 5 tertiary-level university hospitals." **8. Was there appropriate statistical analysis?** No. Number of case not provided, only percentages and total number of participants assessed. Confidence intervals of prevalence estimates not provided.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				9. Are all important confounding factors/subgroups/differences identified and accounted for? Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 357465 **Full citation** Holmstrom, G. E., Kallen, K., Hellstrom, A., Jakobsson, P. G., Serenius, F., Stjernqvist, K., Tornqvist, K., Ophthalmologic outcome at 30 months' corrected age of a prospective	**Setting** National cohort of extremely preterm children (<27 weeks) born April 2004-2007 in Sweden. **Inclusion criteria** All children born at <27 weeks of gestation in Sweden between April 1, 2004 and March 31, 2007 who survived until follow-up at 30 months corrected age. **Exclusion criteria** None reported.	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Visual impaiment **Outcome(s) ascertainment/measures** Ophthalmologic examintiona was scheduled at 30 months (+-3 months) corrected age.	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 30 months' corrected age Visual impairment (blind or able to only fixate and follow a light binocularly) <27 wks GA: 12/390, 3.1% (1.6-5.3%) 22-23 wks GA: 2/42, 4.8% (0.6-16.2%) 24 wks GA: 4/70, 5.7% (1.6-14.0%) 25 wks GA: 4/131, 3.1% (0.8-7.6%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Swedish cohort of children born before 27 weeks of gestation: the extremely preterm infants in sweden study, JAMA Ophthalmology, 132, 182-9, 2014 **Study type** Prospective national cohort study (the Extremely Preterm Infants in Sweden Study EXPRESS) **Aim of the study** To investigate the ophthalmologic outcome of extremely preterm children at 30 months' corrected age. **Study dates**	**Sample size** n=491 eligible children (<27 wks GA) n=411 (83.7% of the eligible sample) were assessed at 30 months' corrected age **Characteristics** 55.7% were boys. Mean gestational age was 25.4 weeks (range 22.1-26.9 weeks) and mean birth weight was 783 g (range 348-1315 g). Retinopathy of prematurity (ROP) was found in the neonatal period in 73.7% of the infants: 38.5% had mild ROP (stages 1 and 2), 35.2% had severe ROP (stages 3-5) and 20.4% had been treated for ROP.	Visual impaiment: defined as blind or able to only fixate and follow a light binocularly. Three different test with gradually decreasing difficulty were used: 1) ability to identidy single optotypes 0.4 Lea Hyvarinen test at 3 m distance, 2) ability to fixate and follow a toy of 5 cm at 30 cm, and 3) ability to fixate and follow a light/torch at 30 cm. Children or eyes that were not able to identify an optotype at 3 m or a toy at 30 cm were considered to have impaired vision. Children or eyes that were not able to fixate and follow a light were considered to be blind. **Age at assessment** 30 months of corrected age (2.5 years)	26 wks GA: 2/147, 1.4% (0.2-4.8%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to small sample size, especially in the gestational age subgroups. **4. Were the study subjects and the setting described in detail?** No. Limited description of the background characteristics provided. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Unclear. 83.7% of the eligible children were followed-up. No description of the potential differences between the ones lost to

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Children born between April 1, 2004 and March 31, 2007, follow-up at 30 months' corrected age. **Country/ies where the study was carried out** Sweden **Source of funding** The Birgit and Sven Hakan Olsoon Foundation; the Evy and Gunnar Sandberg Foundation; the "Lilla Barnets Fond" Children's Fund; the Nordstromer Foundation; a research grant from Region Skane; Stiftelsen for synskadade i fd				follow-up and the ones assessed. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
M-lan; the Swedish Association of the Visually Impaired; and grants 2006 to 3855 from the Swedish Research Council.				**10. Were subpopulations identified using objective criteria?** N/A
Ref Id 410692 **Full citation** Hreinsdottir, J., Ewald, U., Strand Brodd, K., Ornkloo, H., von Hofsten, C., Holmstrom, G., Ophthalmological outcome and visuospatial ability in very preterm children measured at 2.5 years corrected age, Acta Paediatrica, 102, 1144-9, 2013 **Study type**	**Setting** Cohort of children in Uppsala County, Sweden, run by the Departments of Women's and Children's Health, Psychology and the Department of Neuroscience/Opthalmology of Uppsala University. **Inclusion criteria** Children born at <32 weeks gestational age were enrolled in the LOVIS study and those who survived were scheduled for follow-up at 2.5 years CA. **Exclusion criteria** Not reported. **Sample size** n=98 (90% eligible for follow-up)	**Gestational age ascertainment** Definition of gestational age ascertainment not reported. **Outcome(s) of interest in this study** Binocular or monocular vision **Outcome(s) ascertainment/measures** At 2.5 years CA, children were examined by paediatric opthalmologists and orthoptists and testing of spatial function was carried out by the same orthoptist.	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 2.5 years (corrected age) Impaired vision (blind or only able to fixate a torch) *Best eye* <32 wks GA: 1/93, 1.1% (0.03-5.9%) *Worst eye* <32 wks GA: 2/93, 2.2% (0.3-7.6%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low **1. Was the sample representative of the target population?** Yes. **2. Were the study participants recruited in an appropriate way?** Unclear, it is not reported how participants were recruited. **3. Was the sample size adequate?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Population based prospective study (Longitudinal Multidisciplinary Study of Visuomotor Capacity in Very Preterm Infants (LOVIS study))

Aim of the study

To investigate the opthalmological outcome of very preterm children at 2.5 years corrected age (CA) and perform a test of visuospatial and cognitive abilities.

Study dates

Children born from 1 January 2005 to 31 December 2007, assessed at 2.5 years CA.</td>
<td>(eleven children were lost to follow-up as n=6 refused to take part in the study, and n=5 had moved from the area)
n=25 control group (recruited from the department of psychology and consisted of healthy normally developed term-born children (GA 38-42) in Uppsala county).

Characteristics
<table>
<tr><td></td><td>Preterm cohort (n=98)</td></tr>
<tr><td>Males (%)</td><td>56</td></tr>
<tr><td>Females (%)</td><td>44</td></tr>
<tr><td>GA (mean wks, range)</td><td>28.8 (22.3-31.9)</td></tr>
<tr><td>Birthweight (mean g, range)</td><td>1235 (520-2030)</td></tr>
</table>
</td>
<td>Best corrected visual acuity was assessed using the Lea single optotypes test at 3 metre distance. Ability to fixate and follow a small toy at 30 cm was investivated, as well as ability to fixate and follow a torch at 30 cm. Impaired vision was defined as blind or only able to fixate a torch.

Age at assessment

2.5 years corrected age.</td>
<td></td>
<td>Yes.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes.

6. Were objective, standard criteria used for the measurement of the condition?

Yes.

7. Was the condition measured reliably?

Yes.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out Sweden. **Source of funding** Not reported.	History of ROP in neonatal period (%): 25 Mild ROP (stage I-II) (%): 16.3 Severe ROP (stage III or more) (%): 8.2 Laser treatment received (%): 6.12			**8. Was there appropriate statistical analysis?** No. Confidence intervals for proportions were not reported. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 433220	**Setting** Cohort of preterm children born in the state of Victoria, Australia (at four neonatal intensive care units in the state).	**Gestational age ascertainment**	**Prevalence n/N and % (with 95% CI) (incl. GA at**	**Overall quality** Very low.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Full citation

Hutchinson, E. A., De Luca, C. R., Doyle, L. W., Roberts, G., Anderson, P. J., Victorian Infant Collaborative Study, Group, School-age outcomes of extremely preterm or extremely low birth weight children.[Erratum appears in Pediatrics. 2013 Oct;132(4):780], Pediatrics, 131, e1053-61, 2013

Study type

Prospective cohort study (Victorian Infant Collaborative Study Group)

Aim of the study</td>
<td>Inclusion criteria

All children with a gestational age <28 weeks or birth weight <1000g born in the state of Victoria, Australia in 1997 (63,4% survived to 2 years age).

Exclusion criteria

Not reported.

Sample size

n=189 preterm/low birth weight cohort (94% eligible for follow-up; 12 children were not seen, but 10/12 were assessed at 2 years corrected age).

Characteristics

<table>
<tr><td></td><td>EP/ELBW (n=189)</td><td>T/NBW (n=173)</td></tr>
<tr><td>Male (n)</td><td>100</td><td>92</td></tr>
</table>
</td>
<td>Ascertainment of gestational age not reported.

Outcome(s) of interest in this study

CP
Blindness
Hearing impairment

Outcome(s) ascertainment/measures

Definitions of measurement of CP, blindness or deafness were not reported in the study.

Age at assessment

At 8 years age.</td>
<td>birth and age at assessment)

At 8 years age
<u>CP (n=189)</u>
EP/ELBW: 24/189, 12.7% (8.3-18.3%)
<u>Blindness (n=189)</u>
EP/ELBW: 3/189, 1.6% (0.3-5.0%)
<u>Hearing impairment (requiring hearing aids, n=189)</u>
EP/ELBW: 4/189, 2.1% (0.6-5.3%)</td>
<td>1. Was the sample representative of the target population?

Yes.

2. Were the study participants recruited in an appropriate way?

Yes.

3. Was the sample size adequate?

No. Low precision (confidence intervals were wide) due to low sample size.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>To examine cognitive, academic and behavioural outcomes at age 8 years in a regional cohort of extremely preterm (EP) or birth weight <1000g (ELBW)

Study dates

Children born in 1997, assessed at 8 years age.

Country/ies where the study was carried out

Australia.

Source of funding

National Medical Research Council Senior Research Fellowship (part</td>
<td>
<table>
<tr><td>Female (n)</td><td>89</td><td>81</td></tr>
<tr><td>GA, mean±SD, completed wk</td><td>26.5±2.0</td><td>39.9±1.1</td></tr>
<tr><td>Birth weight, mean±SD, g</td><td>833±164</td><td>3506±1455</td></tr>
<tr><td>Birth weight <-2SDs (n)</td><td>34</td><td>0</td></tr>
<tr><td>Age at evaluation, mean±SD, y</td><td>8.45±0.41</td><td>8.50±0.39</td></tr>
<tr><td>Antenatal corticosteroids (n)</td><td>166</td><td>2</td></tr>
<tr><td>Surfactant (n)</td><td>154</td><td>1</td></tr>
<tr><td>Postnatal corticosteroids (n)</td><td>70</td><td>0</td></tr>
<tr><td>O2 dependency at 36 wks (n)</td><td>72</td><td>0</td></tr>
</table>
</td>
<td></td>
<td></td>
<td>coverage of the identified sample?

Yes. the follow up rate was 94%.

6. Were objective, standard criteria used for the measurement of the condition?

No. Criteria for measurement of outcome was not reported.

7. Was the condition measured reliably?

No. Measurement of outcome was not reported.

8. Was there appropriate statistical analysis?

No. Confidence intervals for percentage estimates were not provided.

9. Are all important confounding</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr><td>funding) and Victorian Government's Operational Infrastructure Support Programme.</td><td><table><tr><td>Grade 3/4 intraventricular haemorrhage (n)</td><td>7</td><td>0</td></tr><tr><td>Cystic periventricular leukomalacia (n)</td><td>6</td><td>0</td></tr><tr><td></td><td></td><td></td></tr></table></td><td></td><td></td><td>factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td></tr>
<tr><td>Ref Id

410768

Full citation

Johnson, S., Hollis, C., Kochhar, P., Hennessy, E., Wolke, D., Marlow, N., Psychiatric Disorders in Extremely Preterm Children: Longitudinal Finding at Age 11 Years in the EPICure Study, Journal of the</td><td>Setting

National cohort of all children born <26 weeks of gestation in the UK and Ireland from March to December 1995.

Inclusion criteria

All babies born at <26 weeks of gestation and admitted for neonatal intensive care in the UK and Ireland from March through December 1995 and who survived.

Exclusion criteria

No parental consent, died before follow-up.

Sample size</td><td>Gestational age ascertainment

Not reported.

Outcome(s) of interest in this study

Any ADHD;
ADHD inattentive subtype;
ADHD combined type;
any emotional disorder;
separation anxiety;
specific phobia;
social phobia;
posttraumatic stress disorder;
generalized anxiety disorder;
childhood emotional disorder NOS;</td><td>Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)

At 11 years
<u>Any DSM-IV clinical diagnosis</u>
<26 wks GA: 51/219, 23.3% (17.9-29.5%)

<u>Any ADHD</u>
<26 wks GA: 21/183, 11.5% (7.3-17.0%)

<u>ADHD inattentive subtype</u>
<26 wks GA: 13/183, 7.1% (3.8-11.8%)

<u>ADHD combined type</u></td><td>Overall quality

Low

1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes</td></tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
American Academy of Child and Adolescent Psychiatry, 49, 453-463.e1, 2010 **Study type** Population-based cohort study **Aim of the study** To investigate the prevalence and risk factors for psychiatric disorders in extremely preterm children. **Study dates** Children born 1995, follow-up at 11 years of age. **Country/ies where the study was carried out**	n=219 children born at <26 weeks of GA were followed up at 11 years **Characteristics** Not described for the included sample but for the ones lost to follow-up this was reported: "Extremely preterm survivors not assessed at 11 years (n=88) were more likely to be born at 25 weeks, to unemployed parents of nonwhite ethnic origin or to have more frequent cognitive impairment at 2.5 and 6 years of age than those assessed (n=219) There were no significant differences in parent-rated behavior problem scores at 2.5 years between children assessed and not assessed at 11 years."	major depression any ASD; autistic disorder; atypical autism; any conduct disorder; oppositional defiant disorder; conduct disorder; tic disorder **Outcome(s) ascertainment/measures** The Development And Well Being Assessment (DAWBA), a structured psychiatric evaluation regarding children's development and behaviour was administered to parents via telephone interview (92%) or online (8%) from which information required for assigning ICD-10 and DSM-IV-TR diagnoses of childhood psychiatric disorders was obtained. Supplemental information was provided by teachers who completed a corresponding questionnaire-based version of the DAWBA. Multi-informant data were collated by study assessors (pediatricians and psychologist), and potential	<26 wks GA: 8/183, 4.4% (1.9-8.4%) <u>Any emotional disorder</u> <26 wks GA: 18/201, 9.0% (5.4-13.8%) <u>Separation anxiety</u> <26 wks GA: 5/201, 2.5% (0.8-5.7%) <u>Specific phobia</u> <26 wks GA: 3/200, 1.5% (0.3-4.3%) <u>Social phobia</u> <26 wks GA: 1/200, 0.5% (0.01-2.8%) <u>Posttraumatic stress disorder</u> <26 wks GA: 1/200, 0.5% (0.01-2.8%) <u>Generalized anxiety disorder</u> <26 wks GA: 4/201, 2.0% (0.5-5.0%) <u>Childhood emotional disorder NOS</u> <26 wks GA: 1/200, 0.5% (0.01-2.8%)	**3. Was the sample size adequate?** No. Low precision (wide confidence intervals for prevalence estimates) due to relatively small sample. **4. Were the study subjects and the setting described in detail?** No. Background characteristics were not provided. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. 88/307 (29%) children eligible for follow-up were lost to followed-up, however, the potential differences between the ones followed-up and the ones lost to follow-up were described.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
UK and Ireland **Source of funding** The Medical Research Council, UK.		cases were identified using computer-generated scoring algorithms (www.dawba.com). Summary sheets and clinical transcripts (with any reference to birth status removed) were then reviewed by two child and adolescent psychiatrists who had no prior knowledge of the children or their birth status and were therefore blind to group allocation, and who assigned DSM-IV and ICD-10 consensus diagnoses. **Age at assessment** 11 years	Major depression <26 wks GA: 3/200, 1.5% (0.3-4.3%) Any ASD <26 wks GA: 16/201, 8.0% (4.6-12.6%) Autistic disorder <26 wks GA: 13/201, 6.5% (3.5-10.8%) Atypical autism <26 wks GA: 3/201, 1.5% (0.3-4.3%) Any conduct disorder <26 wks GA: 12/219, 5.5% (2.9-9.4%) Oppositional defiant disorder <26 wks GA: 11/219, 5.0% (2.5-8.8%) Conduct disorder <26 wks GA: 1/219, 0.5% (0.01-2.5%) Confidence intervals were calculated by the NGA technical team using	**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. No confidence intervals for prevalence estimates given. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			http://statpages.info/confint.html	**10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 397352 **Full citation** Johnson, S., Wolke, D., Hennessy, E., Marlow, N., Educational outcomes in extremely preterm children: neuropsychological correlates and predictors of attainment, Developmental Neuropsychology, 36, 74-95, 2011 **Study type** National population-based	**Setting** Population-based national cohort of all children born extremely preterm (<26 weeks) in the UK and Ireland between March and December 1995. **Inclusion criteria** All children born at <26 weeks of gestation and admitted for neonatal intensive care in the UK and Ireland between March and December 1995 and who survived to discharge. **Exclusion criteria** None reported. **Sample size** n=219 children assessed at 11 years (data missing for some individuals in the outcomes of interest) (of n=307 survivors at 11 years, 71%)	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Disorders: Learning impairment - Reading composite Learning impairment - Mathematics composite Problems: Special educational needs (SEN) **Outcome(s) ascertainment/measures** At 11 years, children were assessed at school by a paediatrician and psychologist blind to group allocation.	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 11 years Learning impairment in reading (WIAT-II reading composite score <-2SD) <26 wks GA: 64/212, 30.2% (24.1-36.9%) Learning impairment in mathematics (WIAT-II mathematics composite score <-2SD) <26 wks GA: 94/215, 43.7% (37.0-50.6%) Problems: Identified SEN <26 wks GA: 134/215, 62.3% (55.5-68.8%) SEN provision <26 wks GA: 132/215, 61.4% (54.5-67.9%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to relatively small sample.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>cohort study (EPICure)

Aim of the study

First, to investigate educational outcomes at 11 years of age in children born extremely preterm compared with term-born classmates in order to quantify the effect of extremely preterm birth on school performance in middle school. Second, using outcome data obtained at 6 years, investigate social and neuropsychological antecedents of attainment in reading and mathematics at 11 years and examine the relative impact of</td>
<td>Characteristics
<table>
<tr><td></td><td>n=219</td></tr>
<tr><td>GA <=23 wks, n (%)</td><td>23 (10.5)</td></tr>
<tr><td>GA 24 wks, (%)</td><td>70 (32.0)</td></tr>
<tr><td>GA 25 wks, (%)</td><td>126 (57.5)</td></tr>
<tr><td>Birthweight in grams, median (IQR)</td><td>740 (660-840)</td></tr>
<tr><td>Male, %</td><td>46.1</td></tr>
<tr><td>White maternal ethnicity, %</td><td>82.1</td></tr>
<tr><td>Mother's education:</td><td></td></tr>
<tr><td>Up to 16 years of age, %</td><td>76.0</td></tr>
<tr><td>Post-16 years of age, %</td><td>24.0</td></tr>
</table>
</td>
<td>Examiners received training in administration of standardised tests and achieved a high criterion for inter-rater reliability (>95% agreement across test items) prior to commencing study assessments.
Academic attainment was assessed using the Wechsler Individual Achievement Test-II (WIAT-II) from which standardised scores (mean=100, SD=15) were obtained for Word Reading, Reading Comprehension, Pseudo-word Decoding, Numerical Operations, Mathematical Reasoning, and the composite scales of Reading and Mathematics. For children in whom severe cognitive deficit precluded testing (n=18), a score 1-point below the basal score for the Reading and Mathematics composite scales was substituted. Learning impairment was classified as score <2SD below the mean of the comparison group of term-born classmates on each scale.</td>
<td>Children in mainsteam schools only:
<u>Identified SEN</u>
<26 wks GA: 105/186, 56.5% (49.0-63.7%)
<u>SEN provision</u>
<26 wks GA: 103/186, 55.4% (47.9-62.7%)*
*In the paper, the number of cases is reported as 105 but the percentage is reported as 55.4% (out of 186), therefore, presumably, there is a mistake in the number of cases and it should say 103 instead.

Confidence intervals for the prevalence estimates were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
71% of the children alive at 11 years were assessed.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
these antecedents between children born extremely preterm and at term. Finally, to examine neonatal variables and early neurodevelopmental outcomes at 30 months of age as predictors of attainment in reading and mathematics and the need for SEN provision in children born extremely preterm at 11 years of age. **Study dates** Children born between March and December 1995, follow-up at 11 years of age. **Country/ies where the study was carried out**	SES at 11 years: | High, % | 43.9 Medium, % | 24.4 Low, % | 31.7 Age at assessment, mean (SD) | 10.9y (0.38y))	Teachers completed a questionnaire to elicit information detailing whether SEN provison was utilised by the child. **Age at assessment** 11 years		**8. Was there appropriate statistical analysis?** No. Confidence intervals for the prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
UK and Ireland **Source of funding** None reported.				
Ref Id 397372 **Full citation** Kiechl-Kohlendorfer, U., Ralser, E., Pupp Peglow, U., Pehboeck-Walser, N., Fussenegger, B., Early risk predictors for impaired numerical skills in 5-year-old children born before 32 weeks of gestation, Acta Paediatrica, 102, 66-71, 2013 **Study type**	**Setting** Cohort of preterm children in the western Austrian region of Tyrol. **Inclusion criteria** Children born before 32 completed weeks of pregnancy at Innsbruck Medical University in the neonatal intensive care unit **Exclusion criteria** Children who did not survive to 5 year follow up assessment. Children with severe disabilities who were not able to perform tests as the authors were interested in variables that contributed to numerical skills in those children for whom arithmetic problems could not be attributed to sensory or neurological handicap. Non-resident or moved from region.	**Gestational age ascertainment** Gestational age was calculated from the first day of the last menstrual period, and was compared to assessment by ultrasound scans performed before 24 weeks. If there was a difference of more than 1 week between menstrual and ultrasound assessment, the scan assessment was preferred. **Outcome(s) of interest in this study** Specific learning difficulty (delayed numerical skills)	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years age Specific learning difficulty (delayed numerical skills) (n=135) <32 wks GA: 27/135, 20% (13.6-27.8%)	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes. **2. Were the study participants recruited in an appropriate way?** Yes. **3. Was the sample size adequate?** Yes.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Prospective population-based cohort study.

Aim of the study

To identify risk predictors for impaired numerical skills at 5 years of age in a population-based cohort of very preterm infants.

Study dates

Children born between 2003 and 2006, assessed at 5 years age.

Country/ies where the study was carried out

Austria.</td>
<td>Sample size

N=303 (children live birth with gestational age <32 weeks)
n=223
n=161 (children whose parents consented to take part in the study).
n=153 assessed at 5 years age.
n=135 assessed for numerical skills.

Characteristics

<table>
<tr><td></td><td>Preterms (n=135)</td></tr>
<tr><td>GA (weeks)</td><td><32</td></tr>
<tr><td>Multiple birth (n)</td><td>51</td></tr>
<tr><td>Antenatal steroids (n)</td><td>115</td></tr>
<tr><td>SGA (n)</td><td>11</td></tr>
<tr><td>Male (n)</td><td>77</td></tr>
<tr><td>Female (n)</td><td>58</td></tr>
</table>
</td>
<td>Outcome(s) ascertainment/measures

Delay in numerical skills was assessed individually with the TEDI-MATH which is a multi-componential dyscalculia test based on cognitive neuropsychological models of number processing and calculation [11]. The TEDI-MATH consists of several subtests designed for the assessment of preschoolers: In the counting principles subtest, children's mastery of the verbal counting sequence and its flexibility is tested (e.g. counting in steps of two, and counting backwards). Delay in numerical skills was defined as a Sum T-score <40.

Age at assessment

5 years age.</td>
<td></td>
<td>4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

The follow up rate was 72.2%, with 27.8% not willing to participate.

6. Were objective, standard criteria used for the measurement of the condition?

Yes.

7. Was the condition measured reliably?

Yes.

8. Was there appropriate statistical analysis?</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Source of funding Not reported.				No. Confidence intervals for prevalence estimates were not reported. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 410915 **Full citation** Larroque, B., Ancel, P. Y., Marret, S., Marchand, L., Andre, M., Arnaud, C., Pierrat, V., Roze, J. C.,	**Setting** All live-births between 22-32 weeks in 9 regions in France in 1997 (EPIPAGE). **Inclusion criteria** All births between 22 and 32 completed weeks of gestation in all maternity units in nine French regions (more than a third of the country) from Jan 1, 1997, to Dec 31, 1997. In two regions, every second child was included.	**Gestational age ascertainment** The best obstetric estimate on the basis of the date of the last menstrual period and an early prenatal ultrasound. **Outcome(s) of interest in this study**	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years <u>CP</u> <33 weeks GA: 159/1812, 8.8% (7.5-10.2%) 24-25 weeks GA: 11/60, 18.3% (9.5-30.4%) 26 weeks GA: 13/72, 18.1% (10.0-28.9%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Messer, J., Thiriez, G., Burguet, A., Picaud, J. C., Breart, G., Kaminski, M., Epipage Study group, Neurodevelopmental disabilities and special care of 5-year-old children born before 33 weeks of gestation (the EPIPAGE study): a longitudinal cohort study, Lancet, 371, 813-20, 2008

Study type

A longitudinal cohort study (EPIPAGE).

Aim of the study

To investigate neurodevelopmental outcome and use of special health care at 5</td>
<td>Exclusion criteria

None reported.

Sample size

n=1817 children born at 22-32 weeks were followed at 5 years of age (77% of the population that survived)
n=1812 children born at 22-32 weeks with data on CP outcome
n=1534 children born at 22-32 weeks with data on MPC score outcome

Characteristics

<table>
<tr><td></td><td>%</td></tr>
<tr><td>SES of family</td><td></td></tr>
<tr><td>Professional</td><td>16</td></tr>
<tr><td>Interediate</td><td>25</td></tr>
</table>
</td>
<td>Cerebral palsy (CP)
Cognitive function
Moderate and severe visual definciency
Severe auditory deficiency

Outcome(s) ascertainment/measures

Cerebral palsy (CP): The European Cerebral Palsy Network definition of cerebral palsy was used. At 5 years of age, children were invited for a check-up with a physician. A medical questionnaire was completed by the physician after the clinical assessment, which included a standardised neurological examination, and a questionnaire (regarding child's health, family situation) was completed by the parents. Questionnaires for children with abnormal findings from neurological examination were checked by a group of paediatricians to validate the diagnosis.

Cognitive function: At 5 years of age, children were invited for a check-up with a</td>
<td>27 weeks GA: 16/136, 11.8% (6.9-18.4%)
28 weeks GA: 24/178, 13.5% (8.8-19.4%)
29 weeks GA: 23/189, 12.2% (7.9-17.7%)
30 weeks GA: 18/288, 6.3% (3.8-9.7%)
31 weeks GA: 33/379, 8.7% (6.1-12.0%)
32 weeks GA: 21/510, 4.1% (2.6-6.2%)

<28 wks GA: 40/268, 14.9% (10.9-19.8%)
28-31 wk GA: 98/1034, 9.5% (7.8-11.4%)

<u>Cognitive impairment (MPC <70)</u>
<33 weeks GA: 182/1534, 11.9% (10.3-13.6%)
24-25 weeks GA: 6/48, 12.5% (4.7-25.3%)
26 weeks GA: 12/57, 21.1% (11.4-33.9%)
27 weeks GA: 22/118, 18.6% (12.1-26.9%)
28 weeks GA: 31/150, 20.7% (14.5-28.0%)
29 weeks GA: 17/167, 10.2% (6.0-15.8%)
30 weeks GA: 25/252, 9.9% (6.5-14.3%)</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No.
Low precision (wide confidence intervala) due to relatively low sample size, also the study stratified the sample into different GA groups.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
77% of the survivors were followed up at 5 years.</td>
</tr>
</table>

Study details	Participants		Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
years of age in a population-based cohort of very preterm children. **Study dates** 1997, follow-up at 5 years of age **Country/ies where the study was carried out** France **Source of funding** INSERM (National Institute of Health and Medical Research), the Directorate General for Health of the Ministry for Social Aff airs, Merck-Sharp and Dohme-Chibret, Medical Research Foundation, and	Administrative/public service, self/employed, student	23	psychologist especially trained in use of the Kaufman assessment battery for children (K-ABC). The K-ABC13 was used to assess cognitive function. The mental processing composite (MPC) scale,13 which is considered to be equivalent to intelligence quotient (IQ), is a global measure of cognitive ability in two dimensions: a sequential processing scale and a simultaneous processing scale. The achievement scale assesses knowledge of facts, language ideas, and skills related to school. Each scale is standardised to a mean of 100 (SD 15). MPC score <70 considered a cognitive impairment. Moderate and severe visual deficiency: Vision was assessed, without correction, with the Rossano test12 and visual deficiency classified as severe (<3/10 for both eyes), abd moderate (<3/10 for one eye). Children born very preterm who did not take the Rossano test were classifi ed according to information	31 weeks GA: 34/319, 10.7% (7.5-14.6%) 32 weeks GA: 35/423, 8.3% (5.8-11.3%) <28 wks GA: 40/223, 17.9% (13.1-23.6%) 28-31 wk GA: 107/888, 12.1% (10.0-14.4%) <u>Moderate to severe visual deficiency</u> <33 weeks GA: 34/1697, 2.0% (1.4-2.8%) 24-25 weeks GA: 5/54, 9.3% (3.1-20.3%) 26 weeks GA: 6/60, 10.0% (3.8-20.5%) 27 weeks GA: 6/128, 4.7% (1.7-9.9%) 28 weeks GA: 4/165, 2.4% (0.7-6.1%) 29 weeks GA: 6/178, 3.4% (1.3-7.2%) 30 weeks GA: 2/280, 0.7% (0.09-2.6%) 31 weeks GA: 8/348, 2.3% (1.0-4.5%) 32 weeks GA: 9/484, 1.9% (0.9-3.5%) <28 wks GA: 17/242, 7.0% (4.1-11.0%)	**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals of prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable.
	Shop assistant, service worker	15			
	Manual worker or unemployed	21			
	Maternal level of education				
	University	32			
	Secondary school 2nd part	21			
	Secondary school 1st part	41			
	Primary school or no school	6			
	Mother born in another country than France	10			
	Maternal age <25 y at birth	21			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
"Hospital Program for Clinical Research 2001 n°AOM01117" of the French Department of Health.	Maternal age 25-34 y at birth: 63 Maternal age >=35 y at birth: 16 Parity 0: 55 Parity 1-2: 36 Parity >=3: 9 Multiple pregnancy: 32 Male: 52	obtained from the medical questionnaire, interviews with parents, and medical sources. Severe auditory deficiency: Severe auditory defi cit was defi ned as a hearing loss of more than 70 decibel (dB) for one or both ears, or the use of a hearing aid (reported in the medical questionnaire). **Age at assessment** 5 years	28-31 wk GA: 20/971, 2.1% (1.3-3.2%) <u>Severe hearing deficiency</u> <33 weeks GA: 8/1784, 0.45% (0.2-0.9%) 24-25 weeks GA: 1/58, 1.7% (0.04-9.2%) 26 weeks GA: 1/71, 1.4% (0.04-7.6%) 27 weeks GA: 0/132, 0% (0-2.8%) 28 weeks GA: 2/174, 1.2% (0.1-4.1%) 29 weeks GA: 1/185, 0.5% (0.01-3.0%) 30 weeks GA: 1/285, 0.4% (0.01-1.9%) 31 weeks GA: 1/376, 0.3% (0.01-1.5%) 32 weeks GA: 1/503, 0.2% (0.01-1.1%) <28 wks GA: 2/261, 0.8% (0.1-2.7%%) 28-31 wk GA: 5/1020, 0.5% (0.2-1.1%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**10. Were subpopulations identified using objective criteria?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 316512 **Full citation** Leversen,K.T., Sommerfelt,K., Elgen,I.B., Eide,G.E., Irgens,L.M., Juliusson,P.B., Markestad,T., Prediction of outcome at 5 years from assessments at 2 years among extremely preterm children: a Norwegian national cohort study, Acta Paediatrica, 101, 264-270, 2012 **Study type** Prospective observational national cohort study	**Setting** National cohort of all children born extremely preterm in Norway in 1999-2000 (same cohort as in other Leversen publications). **Inclusion criteria** All children born at 22-27 weeks of gestation or with birth weight between 500 and 999 g born in Norway in 1999 and 2000. **Exclusion criteria** None reported. **Sample size** n=232 assessed for mental delay at both 2 and 5 years n=260 assessed for motor delay at both 2 and 5 years (n=373 children survived to follow-up at 2 years; after which n=1 died, n=1 was excluded due to Down's syndrome, n=65 were lost to follow-up, thus, n=306 were assessed at 5 years but for the outcomes of interest, the sample sizes are lower) **Characteristics**	**Gestational age ascertainment** Gestational age was based on ultrasound at 17-18 weeks' gestation, except for a few patients (5%) for whom gestational ages were based on the last menstrual period because an ultrasound was not performed. **Outcome(s) of interest in this study** Disorders: Mental delay Problems: Motor delay **Outcome(s) ascertainment/measures** Disorders: Mental delay: At 2 years of corrected age, a qualified paediatrician assessed the child's mental function by addressing four specific issues	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 2 years of age (corrected) Disorders <u>Mental delay (paediatrician's assessment on 4 specific issues)</u> <28 wks GA/bw <1000 g: 41/232, 17.7% (13.0-23.2%) Problems <u>Motor delay (paediatrician's assessment on 8 milestone abilities)</u> <28 wks GA/bw <1000 g: 36/260, 13.9% (9.9-18.7%) At 5 years of age (chronological) Disorders <u>Mental delay (WPPSI-R, IQ <85)</u> <28 wks GA/bw <1000 g: 63/232, 27.2% (21.5-33.4%) Problems <u>Motor delay (M-ABC, >95th percentile)</u> <28 wks GA/bw <1000 g: 49/260, 18.9% (14.3-24.1%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No Low precision, confidence intervals are wide due to relatively small sample. **4. Were the study subjects and the setting described in detail?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Aim of the study To examine the predictive value of early assessments on developmental outcome at 5 years in children born extremely preterm. **Study dates** Children born 1999-2000, follow-up at 2 and 5 years. **Country/ies where the study was carried out** Norway **Source of funding** The Norwegian Foundation for	Not reported in this publication, see other Leversen publications included in this review.	and was classified as delayed if they did not respond appropriately when asked to perform tasks such as fetching objects, did not understand and speak words, co-operate and concentrate and generally respond as expected for age. At 5 years of age (chronological), a psychologist assessed cognitive abilities with the Welchsler Preschool and Primary Scale of Intelligence -Revised (WPPSI-R). On the WPPSI-R, verbal IQ, performance IQ and full-scale IQ were calculated from the subscales. Reference means (SD) for the IQ scores are 100. IQ <85 was considered a delay. Problems: Motor delay: At 2 years of corrected age, a paediatrician assessed motor function by addressing eight milestone abilities and was classified as delayed if the children without major neurosecnsory disability were unable to walk and run unattended, grasp independently with both hands and pick small objects with a normal pincer grasp. At 5	The publication also reports that compared n=42 children's mental function was classified as delayed at 5 years even though it was classified as normal at 2 years; and n=20 children's mental function was classified as delayed at 2 years but as normal at 5 years. For motor function, n=36 children was classified as having motor delay at 5 years but not at 2 years and n=13 had a motor delay at 2 years but no delay at 5 years. Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	Unclear. Not described in detail in this publication but are described in detail in other publications of the same cohort. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** No. Of the n=373 children who survived and were followed-up at 2 years, only n=232 and n=260 were assessed for mental motor delay at both 2 and 5 years. **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. At 5 years yes but at 2 years, it is not clear if the assessment was a standardized method of assessing mental and motor delay.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Health and Rehabilitation through the Unexpected Child Death Society of Norway, the Research Council of Norway and Helse Vest Hospital Trust.		years of age (chronological), a phyciotherapist assessed motor function with the Movement Assessment Battery for children (M-ABC). The ABC test consists of eight tasks in three major fields: manual dexterity, ball skills and balance (static and dynamic). Total age-specific scores range from 0 to 40, and increasing score means poorer function. According to the ABC manual, a score >13.0 for 6-year-old children and >16.5 for 5-year-old children indicates a motor problems and presented as a total score > the 95th percentile in the present paper. **Age at assessment** 2 years corrected and 5 years chronological age.		**7. Was the condition measured reliably?** Unclear. At 5 years yes but at 2 years, it is not clear if the assessment was done similarly to all children. The issues addressed when assessing mental and motor function at 2 years were the same for all children but because it seems a standardized tool was not used, it is not clear if the assessment was done similarly to all children. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differe**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				nces identified and accounted for? Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 357521 **Full citation** Leversen, K. T., Sommerfelt, K., Ronnestad, A., Kaaresen, P. I., Farstad, T., Skranes, J., Stoen, R., Bircow Elgen, I., Rettedal, S., Egil Eide, G., Irgens, L. M., Markestad, T., Prediction of neurodevelopmental and sensory outcome at 5	**Setting** National cohort of all children born extremely preterm in Norway in 1999-2000 (same cohort as in other Leversen publications). **Inclusion criteria** All infants born at 22-27 weeks of gestation or with birth weight between 500 and 999 g born in Norway in 1999 and 2000. **Exclusion criteria** Children with Down's syndrome **Sample size**	**Gestational age ascertainment** Gestational age was based on ultrasound at 17-18 weeks' gestation, except for a few patients (5%) for whom gestational ages were based on the last menstrual period because an ultrasound was not performed. **Outcome(s) of interest in this study** Full-scale IQ; CP class 2-3; CP class 4-5; hearing impairment; vision impairment	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years <u>CP any class</u> 22-27 wks GA or bw 500-999 g: 29/306, 9.5% (6.4-13.3%) <u>CP class 4-5</u> 22-27 wks GA or bw 500-999 g: 10/306, 3.3% (1.6-5.9%) 23-25 wks GA: 8/87, 9.2% (4.1-17.3%) 26-27 wks GA: 2/152, 1.3% (0.2-4.7%) >27 wks GA (bw <1000 g): 0/67, 0% (0-5.4%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>years in Norwegian children born extremely preterm, Pediatrics, 127, e630-8, 2011

Study type

Prospective observational national cohort study

Aim of the study

To examine the prevalence of neurodevelopmental disability and the predictive value of pre- peri-, and postnatal data on neurologic, sensory, cognitive and motor function in children born extremely preterm.

Study dates</td>
<td>n=306 children assessed at 5 years
(n=638 children born, of which n=376 survived to discharge, of which 3 died and n=373 were followed-up at 2 years, of which 1 died and 1 child with Down's syndrome were excluded and 65 were lost to follow-up)

Characteristics
<table>
<tr><td></td><td>n=306</td></tr>
<tr><td>GA in wks, median (IQR)</td><td>26 (25-27)</td></tr>
<tr><td>SGA (<5th percentile), %</td><td>19</td></tr>
<tr><td>Male, %</td><td>55</td></tr>
<tr><td>Multiple birth, %</td><td>22</td></tr>
<tr><td>Prenatal steroids, %</td><td>71</td></tr>
<tr><td>CS, %</td><td>66</td></tr>
</table>
</td>
<td>Outcome(s) ascertainment/measures

Cognitive abilities (verbal IQ, performance IQ, and full-scale IQ) were assessed with the Wechsler Preschool and Primary Scale of Intelligence - Revised (WPPSI-R). Reference means for the IQ scores are 100.

CP (total, and classes 1-5) was assessed with the Gross Motor Function Classification System for Cerebral Palsy, which is a 5-level classification. Class 1 means that the child is freely ambulatory; class 2 means that the child is unable to run or jump; class 3 means that the child depends on deviced for walking; and classes 4 and 5 means that the child has nonambulatory CP.

Hearing impairment was registered from from the clinical examination or previous examinations. All</td>
<td><u>CP class 2-3</u>
22-27 wks GA or bw 500-999 g: 9/306, 2.9% (1.4-5.5%)
23-25 wks GA: 4/87, 4.6% (1.3-11.4%)
26-27 wks GA: 3/152, 2.0% (0.4-5.7%)
>27 wks GA (bw <1000 g): 1/67, 1.5% (0.04-8.0%)

<u>Blindness</u>
22-27 wks GA or bw 500-999 g: 5/306, 1.6% (0.5-3.8%)
23-25 wks GA: 5/87, 5.8% (1.9-12.9%)
26-27 wks GA: 0/152, 0% (0-2.4%)
>27 wks GA (bw <1000 g): 0/67, 0% (0-5.4%)

<u>Severe visual impairment</u>
22-27 wks GA or bw 500-999 g: 1/306, 0.3% (0.01-1.8%)
23-25 wks GA: 1/87, 1.2% (0.03-6.2%)
26-27 wks GA: 0/152, 0% (0-2.4%)
>27 wks GA (bw <1000 g): 0/67, 0% (0-5.4%)</td>
<td>3. Was the sample size adequate?

No
Low precision, confidence intervals are wide due to relatively small sample.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear.
82% were followed-up, the study provides information about the characteristics of the ones lost to follow-up vs the ones followed-up and there were some differences, e.g. the ones followed-up were more often children with CP, blindness or deafness at 2 years of age; and the ones followed-up had had</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Children born 1999 and 2000, follow-up at 5 years. **Country/ies where the study was carried out** Norway **Source of funding** The Norwegian Foundation for Health and Rehabilitation through the Unexpected Child Death Society of Norway, the Research Council of Norway and Helse Vest Hospital Trust.	Mother higher education, % 43	children in Norway have a pure-tone audiometry at the age of 5 years at the public health care clinics, using methods and standards according to national guidelines. Any significant deviation results in a referral to an auditory clinic with ear-nose-throat specialists. Hearing was classified as normal; mild hearing loss (ie no audiological intervention needed); in a need of hearing aid; or complete deafness. Vision impairment: registered from from the clinical examination or previous examinations. All children in Norway have a vision screen at the age of 4 years at the public health care clinics, using methods and standards according to national guidelines. Any significant deviation results in a referral to an ophthalmologist. Minor visual deficits were squints, myopia, hypermetropia, astigmatism, or other visual deficits requiring glasses. Severe visual impairment was not defined but the most	<u>Deafness</u> 22-27 wks GA or bw 500-999 g: 3/306, 1.0% (0.2-2.8%) 23-25 wks GA: 3/87, 3.5% (0.7-9.8%) 26-27 wks GA: 0/152, 0% (0-2.4%) >27 wks GA (bw <1000 g): 0/67, 0% (0-5.4%) <u>Hearing aid in both ears</u> 22-27 wks GA or bw 500-999 g: 4/306, 1.3% (0.04-3.3%) 23-25 wks GA: 2/87, 2.3% (0.3-8.1%) 26-27 wks GA: 2/152, 1.3% (0.2-4.7%) >27 wks GA (bw <1000 g): 0/67, 0% (0-5.4%) <u>Full-scale IQ <55</u> 22-27 wks GA or bw 500-999 g: 2/306, 0.7% (0.08-2.3%) 23-25 wks GA: 2/87, 2.3% (0.3-8.1%) 26-27 wks GA: 0/152, 0% (0-2.4%) >27 wks GA (bw <1000 g): 0/67, 0% (0-5.4%)	chorioamnionitis more often than the ones lost to follow-up. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
		severe visual impairment was classified as legal blindness. **Age at assessment** 5 years	Full-scale IQ 55-70 22-27 wks GA or bw 500-999 g: 15/306, 4.9% (2.8-8.0%) 23-25 wks GA: 6/87, 6.9% (2.6-14.4%) 26-27 wks GA: 4/152, 2.6% (0.7-6.6%) >27 wks GA (bw <1000 g): 5/67, 7.5% (2.5-16.6%) Full-scale IQ <70 22-27 wks GA or bw 500-999 g: 17/306, 5.6% (3.3-8.8%) 23-25 wks GA: 8/87, 9.2% (4.1-17.3%) 26-27 wks GA: 4/152, 2.6% (0.7-6.6%) >27 wks GA (bw <1000 g): 5/67, 7.5% (2.5-16.6%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id	**Setting**	**Gestational age ascertainment**	**Prevalence n/N and % (with 95% CI) (incl. GA at**	**Overall quality** Low

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
321718 **Full citation** Leversen,K.T., Sommerfelt,K., Ronnestad,A., Kaaresen,P.I., Farstad,T., Skranes,J., Stoen,R., Elgen,I.B., Rettedal,S., Eide,G.E., Irgens,L.M., Markestad,T., Predicting neurosensory disabilities at two years of age in a national cohort of extremely premature infants, Early Human Development, 86, 581-586, 2010 **Study type** Prospective observational nationally representative cohort study	National cohort of children born at 22-27 weeks of gestation or with birthweight 500-999 g in Norway during 1999 and 2000 (same cohort as in other Leversen publications). **Inclusion criteria** All children born at 22-27 weeks of GA or with birth weight 500-999 g in Norway in 1999-2000. **Exclusion criteria** None reported. **Sample size** n=373 children born 22-27 wks GA or with birthweight 500-999 g who survived **Characteristics** | | n=373 | | Birthweight in grams, median (IQR) | 861 (740-975) |	Gestational age was determined by ultrasound at 17-18 postmenstrual weeks, except for 20 (5%) based on the last menstrual period. **Outcome(s) of interest in this study** Cerebral palsy (CP); blindness; complete deafness **Outcome(s) ascertainment/measures** Limited information provided. At 2 years a paediatrician completed forms developed for the study on somatic health and neurological status. They were not blinded. Children who missed the planned follow-up, data were collected in retrospect from the medical records if a routine follow-up had been performed within 1 year of planned evluation, and from an additional structures telephone interview.	**birth and age at assessment)** At 2 years corrected age CP 22-27 wks GA or bw 500-999 g: 26/373, 7.0% (4.6-10.1%) Blindness 22-27 wks GA or bw 500-999 g: 6/373, 1.6% (0.6-3.5%) Deafness 22-27 wks GA or bw 500-999 g: 3/373, 0.8% (0.2-2.3%)	**1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to relatively small sample. **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Aim of the study To examine which information obtained pre-, peri- and postnatally may be predictive of neurosensory disabilities at 2 years of age. **Study dates** Children born in 1999-2000, follow-up at 2 years' corrected age. **Country/ies where the study was carried out** Norway **Source of funding**	Male, % 54 Single birth, % 78 SGA, % 19 CS, % 65 Higher education of mother, % 43 Surfactant, % 80 prenatal steroids, % 69	No definition or classification of CP provided. Blindness meaning that the child was classified as legally blind. Complete deafness, not further defined. **Age at assessment** 2 years (not reported if corrected or not)		**coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Details on assessments or definition of outcomes are not provided. **7. Was the condition measured reliably?** Unclear. Details on assessments or definition of outcomes are not provided. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence were not provided.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
The Norwegian Foundation for Health and Rehabilitation through the Unexpected Child Death Society of Norway, the Research Council of Norway and Helse Vest Hospital Trust.				**9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 347258 **Full citation** Marlow, N., Wolke, D., Bracewell, M. A., Samara, M., E. PICure Study Group, Neurologic and developmental disability at six years of age after extremely preterm	**Setting** National cohort of all children born extremely premature (<26 weeks) in the UK and Ireland from March to December 1995. **Inclusion criteria** All extremely preterm (gestation at birth no more than 25 weeks and 6 days) who were born in the UK and Ireland between March and December 1995 and who survived to 30 months and who lived in the UK or Ireland at 6 years of age. **Exclusion criteria**	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Cognitive impairment; cerebral palsy (CP); hearing impairment; vision impairment	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 6 years CP, nonambulatory <26 wks GA: 15/241, 6.2% (3.5-10.1%) <=23 wks GA: 1/24, 4.2% (0.1-21.1%) 24 wks GA: 8/73, 11.0% (4.9-20.5%) 25 wks GA: 6/144, 4.2% (1.5-8.9%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
birth, New England Journal of Medicine, 352, 9-19, 2005 **Study type** Population-based national cohort study (EPICure) **Aim of the study** To describe the outcomes (neurologic and developmental disability) among this cohort at six years of age, when the children were involved in full-time education. **Study dates** Children born 1995, follow-up at 6 years of age.	None reported. **Sample size** n=241 (82% of the eligible ones, n=293) (also n=160 term controls) **Characteristics** The 241 children assessed for this report were representative of the whole population of survivors with regard to birth weight, GA, and several perinatal variables. The children who were assessed at 30 months but not at 6 years (n=47) were more likely to have young mothers compared to the ones assessed at 6 years as well. The distribution of neonatal complications, other socioeconomic factors and outcomes at 30 months of age (corrected) was similar in the two groups.	**Outcome(s) ascertainment/measures** The children in mainstream schools (n=207) were evaluated by means of a clinical examination including neuropsychological assessment. Children with disabilities in special-needs schools were evaluated without the use od a comparison child by means of an appropriate assessment. The developmental panel included seven experienced developmental paediatricians and eight psychologists who received formal training in performing assessments. The assessors were unaware of the neonatal courses of the children they evaluated and were not informed as to which children were preterm and which were controls. Cognitive impairment: when cognitive assessment was appropriate, it was made with the use of the Kaufman Assessment Battery for Children (K-ABC). If the child's disability precluded the use of the K-ABC, either the Griffiths	<u>CP with disability, ambulatory</u> <26 wks GA: 17/241, 7.1% (4.2-11.1%) <=23 wks GA: 3/24, 12.5% (2.7-32.4%) 24 wks GA: 6/73, 8.2% (3.1-17.0%) 25 wks GA: 8/144, 5.6% (2.4-10.7%) <u>CP, nonambulatory or ambulatory</u> (calculated by the NGA technical team) <26 wks GA: 32/241, 13.3% (9.3-18.2%) <=23 wks GA: 4/24, 16.7% (4.7-37.4%) 24 wks GA: 14/73, 19.2% (10.9-30.1%) 25 wks GA: 14/144, 9.7% (5.4-15.8%) <u>Severe cognitive impairment (IQ <-3SD)</u> <26 wks GA: 50/241, 20.8% (15.8-26.4%) <=23 wks GA: 6/24, 25.0% (9.8-46.7%) 24 wks GA: 20/73, 27.4% (17.6-39.1%) 25 wks GA: 24/144, 16.7% (11.0-23.8%)	Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to relatively small sample size. **4. Were the study subjects and the setting described in detail?** No. Description of background characteristics was limited. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Unclear. 82% of the eligible ones were assessed at 6 years. The study reports the differences between the ones lost to follow-up and the ones assessed, including that the ones lost

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out UK and Ireland **Source of funding** BLISS, the premature baby charity; the Health Foundation; and WellBeing of Women		Scales of Mental Development (n=35) or the neuropsychological instrument knows as NEPSY (n=6) were used. The results for these children were substituted for the missing values in the Mental Processing Composite of K-ABC to produce an overall cognitive score. The cognitive performance (IQ) was classified as severely impaired if the score was <-3 SD of the mean and moderate if the score of -2 to -3 SD. The contemporary classmates were the reference group. Cerebral palsy (CP): The classification of CP was made retrospectively, at the completion of the study, according to the description of function for each limb, by two assessors. Severe CP was defined as nonambulant CP; moderate CP was defined as ambulant CP. Hearing impairment: Severe hearing impairment was defined as profound sensorineural hearing loss, moderate hearing loss was defined as sensorineural	<u>Moderate cognitive impairment (IQ -2 to -3SD)</u> <26 wks GA: 48/241, 19.9% (15.1-25.5%) <=23 wks GA: 8/24, 33.3% (15.6-55.3%) 24 wks GA: 13/73, 17.8% (9.8-28.5%) 25 wks GA: 27/144, 18.8% (12.7-26.1%) <u>Moderate to severe cognitive impairment (IQ <=-2SD)</u> <26 wks GA: 98/241, 40.7% (34.4-47.2%) <=23 wks GA: 14/24, 58.3% (36.6-77.9%) 24 wks GA: 33/73, 45.2% (33.5-57.3%) 25 wks GA: 51/144, 35.4% (27.6-43.8%) <u>Severe hearing impairment</u> <26 wks GA: 7/241, 2.9% (1.2-5.9%) <=23 wks GA: 1/24, 4.2% (0.1-21.1%) 24 wks GA: 4/73, 5.5% (1.5-13.4%) 25 wks GA: 2/144, 1.4% (0.1-4.9%)	to follow-up were more likely to have young mothers. Other characteristics (neonatal complications, socioeconomic factors and outcomes at 30 months of age) were similar in both groups. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Unclear. Cognitive impairment was assessed differently for some children due to their disability. There was limited description of the assessment of CP, hearing and vision.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
		hearing loss corrected with hearing aids. Vision impairment: Severe vision impairment was defined as blindness, moderate vision impairment was defined as impaired vision but ability to see. **Age at assessment** 6 years	<u>Moderate hearing impairment (use of hearing aids)</u> <26 wks GA: 7/241, 2.9% (1.2-5.9%) <=23 wks GA: 0/24, 0% (0-14.3%) 24 wks GA: 2/73, 2.7% (0.3-9.6%) 25 wks GA: 5/144, 3.5% (1.1-7.9%) <u>Moderate to severe hearing impairment</u> <26 wks GA: 14/241, 5.8% (3.2-9.6%) <=23 wks GA: 1/24, 4.2% (0.1-21.1%) 24 wks GA: 6/73, 8.2% (3.1-17.0%) 25 wks GA: 7/144, 4.9% (2.0-9.8%) <u>Blind</u> <26 wks GA: 6/241, 2.5% (0.9-5.3%) <=23 wks GA: 2/24, 8.3% (1.0-27.0%) 24 wks GA: 3/73, 4.1% (0.9-11.5%) 25 wks GA: 1/144, 0.7% (0.02-3.8%)	**8. Was there appropriate statistical analysis?** Yes. Confidence intervals for the prevalence estimates for the whole preterm group were provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			Moderate vision impairment (not blind) <26 wks GA: 11/241, 4.6% (2.3-8.0%) <=23 wks GA: 2/24, 8.3% (1.0-27.0%) 24 wks GA: 5/73, 6.9% (2.3-15.3%) 25 wks GA: 4/144, 2.8% (0.8-7.0%) Visually impaired or blind <26 wks GA: 17/241, 7.1 (4.2-11.1%) <=23 wks GA: 4/24, 16.7% (4.7-37.4%) 24 wks GA: 8/73, 11.0% (4.9-20.5%) 25 wks GA: 5/144, 3.5% (1.1-7.9%)	
Ref Id 339498 **Full citation** Marret, S., Ancel, P. Y., Marpeau, L., Marchand, L., Pierrat, V., Larroque, B., Foix-	**Setting** Population-based cohort of preterm infants in nine regions in France (EPIPAGE). **Inclusion criteria** Any infant born between 30-34 weeks of gestation in nine regions of France throughout 1997.	**Gestational age ascertainment** Gestational age was determined based on last menstrual period and findings from the early prenatal ultrasonogram.	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years of age CP (any type) 30 wks GA: 18/288, 6.3% (3.8-9.7%) 31 wks GA: 33/379, 8.7% (6.1-12.0%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>L'Helias, L., Thiriez, G., Fresson, J., Alberge, C., Roze, J. C., Matis, J., Breart, G., Kaminski, M., Epipage Study, Group, Neonatal and 5-year outcomes after birth at 30-34 weeks of gestation, Obstetrics & Gynecology, 110, 72-80, 2007

Study type

Population based prospective cohort (EPIPAGE).

Aim of the study

To assess cerebral lesions, medical and social characteristics as predictors of mild and severe cognitive</td>
<td>Exclusion criteria

Infants who died before five year follow up. Moderate to severe neurosensory disabilities (defined as walking with aid or unable to walk, or having severe hearing or visual deficiency).
The protocol included the option of following at random only one of every two infants born at 32 weeks, to reduce the regional workload. Two regions exercised this option.

Sample size

n=1455

Characteristics
<table>
<tr><th></th><th>30 wk</th><th>31 wk</th><th>32 wk</th><th>33 wk</th><th>34 wk</th></tr>
<tr><td>Multiple pregnancy, %</td><td>29.5</td><td>34.5</td><td>31.5</td><td>35.0</td><td>30.3</td></tr>
<tr><td>ANS, %</td><td>78.1</td><td>72.7</td><td>72.9</td><td>71.9</td><td>63.4</td></tr>
<tr><td>CS, %</td><td>59.7</td><td>61.2</td><td>63.7</td><td>55.4</td><td>47.0</td></tr>
</table>
</td>
<td>Outcome(s) of interest in this study

CP;
visual deficiency;
hearing deficiency;
cognitive impairment (MPC <70)

Outcome(s) ascertainment/measures

Children were invited for a check up at 5 years, and assessed by trained psychologists blinded to their perinatal data. The assessment used the Kaufman Assessment Battery for Children (K-ABC) test. Overall cognitive ability was evaluated by the Mental Processing Composite (MPC) score. Cognitive deficiency was classified as moderate to severe when the MPC score was below 70 (-2SD below the norm).
The 5-year assessment also included a thorough physical examination and neurological assessment (tone, reflexes, posture, and movements)</td>
<td>32 wks GA: 21/509, 4.1% (2.6-6.2%)
33 wks GA: 5/135, 3.7% (1.2-8.4%)
34 wks GA: 1/140, 0.7% (0.2-3.9%)

30-31 wks GA: 51/667, 7.7% (5.8-9.9%)
32-34 wks GA: 27/784, 3.4% (2.3-4-5.0%)

<u>Bilateral spastic CP</u>
30 wks GA: 12/288, 4.2% (2.2-7.2%)
31 wks GA: 26/379, 6.9% (4.5-9.9%)
32 wks GA: 14/509, 2.8% (1.5-4.6%)
33 wks GA: 2/135, 1.5% (0.2-5.3%)
34 wks GA: 1/140, 0.7% (0.2-3.9%)

30-31 wks GA: 38/667, 5.7% (4.1-7.7%)
32-34 wks GA: 17/784, 2.2% (1.3-3.5%)

<u>CP hemiplegia</u>
30 wks GA: 1/288, 0.4% (0.01-1.9%)</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Unclear.
Some of the outcomes are rare, therefore, the precision of the results is low.

4. Were the study subjects and the setting described in detail?

No.
Limited information about the background characteristics of the sample.

5. Was the data analysis conducted with sufficient coverage of the identified sample?</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
deficiencies in very preterm infants. **Study dates** 1997-2002. Cohort established in 1997. Follow up at 5 years of age. **Country/ies where the study was carried out** France **Source of funding** French National Institute of Health and Medical Research, the Directorate General for Health of the Ministry for Social Affairs, Merck Sharp and Dohme-Chibret, the Medical	<table><tr><td>Birth weight in grams, mean (SD)</td><td>1344 (283)</td><td>1525 (295)</td><td>1660 (345)</td><td>1883 (399)</td><td>2120 (381)</td></tr><tr><td>Male, %</td><td>51.7</td><td>53.9</td><td>54.5</td><td>54.5</td><td>57.4</td></tr></table>	carried out by experienced physicians and neuropsychologists. Physicians recorded their findings on a standardized questionnaire. The definition used for CP was developed by the European Cerebral Palsy Network, which requires at least two of the following: abnormal posture or movement, increased tone, and hyperreflexia. Three categories of CP were distinguished: bilateral spastic CP, hemiplegia, and other. When the diagnosis of CP was in doubt, a panel of trained pediatrcians met to discuss the case. Visual impairment was defined as visual acuity less than 3/10 in one or both eyes. Hearing impairment was defined as loss of more than 70 decibels or use of hearing aid in one or both ears. **Age at assessment** 5 years.	31 wks GA: 3/379, 0.8% (0.2-2.3%) 32 wks GA: 4/509, 0.8% (0.2-2.0%) 33 wks GA: 1/135, 0.7% (0.02-4.1%) 34 wks GA: 0/140, 0% 30-31 wks GA: 4/667, 0.6% (0.2-1.5%) 32-34 wks GA: 5/784, 0.6% (0.2-1.5%) <u>Visual deficiency</u> 30 wks GA: 2/280, 0.7% (0.1-2.6%) 31 wks GA: 7/335, 2.2% (0.8-4.3%) 32 wks GA: 9/484, 1.9% (0.9-3.5%) 33 wks GA: 3/132, 2.3% (0.5-6.5%) 34 wks GA: 1/134, 0.8% (0.02-4.1%) 30-31 wks GA: 9/615, 1.5% (0.7-2.8%) 32-34 wks GA: 13/750, 1.7% (0.9-3.0%) <u>Hearing deficiency</u> 30 wks GA: 1/285, 0.3% (0.01-1.9%)	No. Of the ones eligible for a follow-up at 5 years, 24-39% (depending on the gestational age) were lost to follow-up, therefore, the sample might not be representative of the original sample/population. Reasons for losses to follow-up were not described or the characteristics of the ones lost to follow-up were not compared with the ones included in the follow-up analysis. **6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Research Foundation, the 'Hospital Program for Clinical Research 2001 no. AOM01117' of the French Department of Health, La Fondation Motrice and the Ile-de-France Region.			31 wks GA: 1/376, 0.3% (0.01-1.5%) 32 wks GA: 1/503, 0.2% (0.01-1.1%)10.3 33 wks GA: 0/130, 0% 34 wks GA: 2/135, 1.5% (0.2-5.3%) 30-31 wks GA: 2/661, 0.3% (0.04-1.1%) 32-34 wks GA: 3/768, 0.4% (0.1-1.1%) <u>Cognitive impairment (MPC <70)</u> 30 wks GA: 25/252, 9.9% (6.5-14.3%) 31 wks GA: 34/319, 10.7% (7.5-14.6%) 32 wks GA: 34/423, 8.0% (5.6-11.1%) 33 wks GA: 9/110, 8.2% (3.8-15.0%) 34 wks GA: 6/113, 5.3% (2.0-11.2%) 30-31 wks GA: 59/571, 10.3% (8.0-13.1%) 32-34 wks GA: 49/646, 7.6% (5.7-9.9%) Percentages or numerators calculated by the NGA technical team from	**8. Was there appropriate statistical analysis?** No. Confidence intervals of prevalence were not reported (they were calculated by the NGA technical team) and reporting of prevalence was at times unclear. Number of participants observed was reported (denominator) but the number of cases was not always reported, only percentage of the denominator that were cases. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			information provided by the study publication (either percentage or number of cases [numerator] was given, denominator was always given). Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	
Ref Id 111065 **Full citation** Mikkola,K., Ritari,N., Tommiska,V., Salokorpi,T., Lehtonen,L., Tammela,O., Paakkonen,L., Olsen,P., Korkman,M., Fellman,V., Neurodevelopmental outcome at 5 years of age of a	**Setting** National cohort of extremely low birth weight infant survivors in Finland, data collected prospectively into the Finnish National Research and Development Center for Welfare and Health register. **Inclusion criteria** Children with a birth weight of <1000 g born in Finland between 1 Jan 1996 and 31 Dec 1997 who survived until 5 years of age. **Exclusion criteria** None reported.	**Gestational age ascertainment** Not described. The population was children born with birth weight <1000 g so gestational age was not the primary inclusion criteria. The mean GA in the sample population was 27.3 (SD 2.1). **Outcome(s) of interest in this study** Cerebral palsy (CP); cognitive impairment (IQ <70)	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years CP Children born with birth weight <1000 g (mean GA 27.3 (SD 2.1): 28/203, 13.8% (9.4-19.3%) <27 wks GA: 19/102, 18.6% (11.6-27.6%) Cognitive impairment (IQ <70) Children born with birth weight <1000 g (mean GA	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>national cohort of extremely low birth weight infants who were born in 1996-1997, Pediatrics, 116, 1391-1400, 2005

Study type

National population-based prospective cohort study

Aim of the study

To assess the 5-year outcome, especially neurodevelopmental and cognitive outcome, in 3 groups: in all extremely low birth weight infants who were born during the 2-year period of 1996-1997, in a subcohort born at <27 gestational weeks, and in</td>
<td>Sample size

n=203 children with birth weight <1000 g (of n=206 children who survived up to follow-up)
n=102 children with <27 weeks GA

Characteristics

<table>
<tr><td></td><td>All ELBW infants included in study n=206</td></tr>
<tr><td>Maternal age, y</td><td>31.6 +-5.8</td></tr>
<tr><td>Multiparity, %</td><td>45</td></tr>
<tr><td>Multiple pregnancy, %</td><td>26</td></tr>
<tr><td>Antenatal steroids, %</td><td>79</td></tr>
</table>
</td>
<td>Outcome(s) ascertainment/measures

Cerebral palsy (CP), defined as a nonprogressive motor disorder with abnormal muscle tone, persistent or exaggerated primitive reflexes, or a positive Babinski sign associated with delayed motor development. Data on CP was collected from hospital records and child welfare clinics.
Cognitive impairment, defined as IQ score <70, assessed by the Wechsler Preschool and Primary Scale of Intelligence-revised (WPPSI-R).

Age at assessment

5 years.</td>
<td>27.3 (SD 2.1): 19/203, 9.4% (5.7-14.2%)
<27 wks GA: 12/102, 11.8% (6.2-19.7%)</td>
<td>3. Was the sample size adequate?

No.
Low precision (confidence intervals are wide) because of relatively low sample size and relatively rare outcomes.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
those who were small for gestational age versus appropriate gestational age. **Study dates** 1996-1997, follow-up at 5 years of age. **Country/ies where the study was carried out** Finland **Source of funding** The Finnish Pediatric Research Foundation, the Medical Society of Finland, and the Signe and Ane Gyllenberg Foundation.	Premature rupture of membranes >24h, % — 23 vaginal delivery, % — 32 Gestational age, weeks — 27.3 +-2.1 Birth weight, g — 806 +-136 Birth weight SD score — -2.1 +-1.4 SGA <-2SD, % — 51 Male, % — 46 Surfactant treatment, % — 61			**7. Was the condition measured reliably?** Unclear. Not described clearly how CP was diagnosed, just that the data on CP diagnosis was obtained from health care records. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	Respirator treatment, % 92 Respirator treatment in days 19 +-18 IVH grade 3-4, % 11 Perforated NEC, % 6 O2 dependence at 36 weeks, % 39			Not applicable.
Ref Id 316656 **Full citation** Moore,T., Hennessy,E.M., Myles,J., Johnson,S.J., Draper,E.S., Costeloe,K.L.,	**Setting** National cohort of all children born between 22-26 weeks GA in England in 2006, evaluated in hospital and home settings (EPICure 2). **Inclusion criteria** All children born between 22 and 26 completed weeks of gestation during 2006 to mothers resident in England survived until follow-up.	**Gestational age ascertainment** The earliest ultrasound dating scan was used and, in the absence of any scan, the date of the last menstrual period if it was certain.15 In the absence of either scan or certain dates, we based gestation on clinical estimation (reported in an earlier publication).	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 3 years (generally, some assessments delayed) Severe motor disability (CP level 3-5 in GMFCS) 22-26 wks GA: 30/576, 5.2% (3.5-7.4%)	**Overall quality** (Low **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Marlow,N., Neurological and developmental outcome in extremely preterm children born in England in 1995 and 2006: the EPICure studies, BMJ, 345, e7961-, 2012

Study type

Prospective national cohort study (EPICure 2, this publication also used data from the original EPICure when comparing children born in 2006 to children born in 1995).

Aim of the study

To determine outcomes at age 3 years in babies born before 27 completed weeks'</td>
<td>Exclusion criteria

None reported.

Sample size

n=576 children born 22-26 weeks' gestation, assessed at follow-up
(n=38 born at 22-23 weeks; n=98 born at 24 weeks; n=189 born at 25 weeks; n=251 born at 26 weeks)

Characteristics

<table>
<tr><th></th><th>Formal study evaluation (n=576)</th><th>Non-respondents (n=455)</th></tr>
<tr><td>Maternal age in years, mean (SD)</td><td>30.2 (6.3)</td><td>27.7 (6.5)</td></tr>
<tr><td>Maternal ethnicity: white, %</td><td>73.7</td><td>53.2</td></tr>
</table>
</td>
<td>Outcome(s) of interest in this study

Motor disability (cerebral palsy);
hearing disability;
vision disability;
cognitive disability;
communication disability

Outcome(s) ascertainment/measures

Motor disability: Cerebral palsy was identified by neurological examination using the Palisano method (a standardized methods of identifying CP). The functional motor outcomes for children with CP using the 5 levels defined in the Gross Motor Function Classification System (GMFCS) from 1 for minimal impairment to 5 for severe impairment with dependence on carers for most daily activities. Severe motor disability comprises of any non-ambulant CP (GMFCS levels 3-5). Moderate motor</td>
<td>22-23 wks GA: 4/38, 10.5% (2.9-24.8%)
24 wks GA: 5/98, 5.1% (1.7-11.5%)
25 wks GA: 10/189, 5.3% (2.6-9.5%)
26 wks GA: 11/251, 4.4% (2.2-7.7%)

<u>Moderate motor disability (CP level 2 in GMFCS)</u>
22-26 wks GA: 15/576, 2.6% (1.5-4.3%)
22-23 wks GA: 0/38, 0% (0-9.3%)
24 wks GA: 4/98, 4.1% (1.1-10.1%)
25 wks GA: 6/189, 3.2% (1.2-6.8%)
26 wks GA: 5/251, 2.0% (0.7-4.6%)

<u>Moderate to severe motor disability (CP level 2-5 in GMFCS)</u>
22-26 wks GA: 45/576, 7.8% (5.8-10.3%)
22-23 wks GA: 4/38, 10.5% (2.9-24.8%)
24 wks GA: 9/98, 9.2% (4.3-16.7%)
25 wks GA: 16/189, 8.5% (4.9-13.4%)</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Unclear.
In the gestational subgroups, the precision was low (wide confidence intervals) but the overall group of extremely preterm children, the precision was better.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
Of the ones who survived to</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>gestation in 2006, and to evaluate changes in outcome since 1995 for babies between 22 and 25 weeks' gestation.

Study dates

Children born in 2006 (this publication also compared the children born in 2006 to children born in 1995).

Country/ies where the study was carried out

UK

Source of funding

The Medical Research Council</td>
<td>
<table>
<tr><td>Maternal ethnicity: black, %</td><td>14.1</td><td>27.3</td></tr>
<tr><td>Maternal ethnicity: Indian subcontinent, %</td><td>7.3</td><td>12.5</td></tr>
<tr><td>Primigravida, %</td><td>41</td><td>29.8</td></tr>
<tr><td>ANS, %</td><td>88.3</td><td>86.2</td></tr>
<tr><td>PROM (<24h), %</td><td>28.5</td><td>25.8</td></tr>
<tr><td>Chorioamnionitis, %</td><td>21.5</td><td>23.4</td></tr>
<tr><td>Male, %</td><td>50.2</td><td>46.1</td></tr>
<tr><td>Singleton, %</td><td>71.4</td><td>81.8</td></tr>
<tr><td>Gestional age in weeks, mean (SD)</td><td>25.6 (0.97)</td><td>25.6 (0.92)</td></tr>
</table>
</td>
<td>disability comprises of ambulant CP (GMFCS level 2).
Hearing disability: Severe hearing disability defined as profound sensorineural hearing loss not improved by aids. Moderate hearing disability defined as hearing loss improved by aids. The publication reports that a standard set of definitions was used to record auditoory functions.
Vision disability: Severe vision disability defined as blindness. Moderate vision disability defined as functionally impaired vision. The publication reports that a standard set of definitions was used to record visual functions.
Cognitive disability and communication disability: Cognitive and communication disability were assessed with the third edition of the Bayley Scales of Infant Development (BSID-III) cognitive and language scales by trained assessors. A subgroup of the cohort (=208) was evaluated using a combination of the</td>
<td>26 wks GA: 16/251, 6.4% (3.7-10.2%)

<u>Severe hearing disability (profound hearing loss not improved with aids)</u>
22-26 wks GA: 1/576, 0.2% (0-1.0%)
22-23 wks GA: 1/38, 2.6% (0.1-13.8%)
24 wks GA: 0/98, 0% (0-3.7%)
25 wks GA: 0/189, 0% (0-1.9%)
26 wks GA: 0/251, 0% (0-1.5%)

<u>Moderate hearing disability (hearing loss improved with aids)</u>
22-26 wks GA: 30/576, 5.2% (3.5-7.4%)
22-23 wks GA: 2/38, 5.3% (0.6-17.8%)
24 wks GA: 5/98, 5.1% (1.7-11.5%)
25 wks GA: 10/189, 5.3% (2.6-9.5%)
26 wks GA: 13/251, 5.2% (2.8-8.7%)

<u>Moderate to severe hearing disability</u></td>
<td>follow-up, only 60% were assessed. The study did report on the differences in characteristics between then ones lost to follow-up and the ones included. Especially socioeconomic factors differed between the groups (please see the table on 'Characteristics' section).

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Unclear.
For other outcomes yes but for hearing and vision, the methods of assessment are not described.</td>
</tr>
</table>

Study details	Participants			Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	Received surfactant, %	99.3	98.5	cognitive and language scales of the BSID-III and the mental developmental index (MDI) from the second edition (BSID-II). As assessments were sometimes delayed, children older than 42 months were evaluated using the Wechsler preschool and primary scales of intelligence (WPPSI), the assessors were trained and validated to administer the scales. Severe cognitive disability was defined as developmental score of <-3SD of the mean. Moderate cognitive disability was defined as developmental score of -2 to -3 SD of the mean. **Age at assessment** At 3 years (for some individuals assessments were delayed)	22-26 wks GA: 31/576, 5.4% (3.7-7.6%) 22-23 wks GA: 3/38, 7.9% (1.7-21.4%) 24 wks GA: 5/98, 5.1% (1.7-11.5%) 25 wks GA: 10/189, 5.3% (2.6-9.5%) 26 wks GA: 13/251, 5.2% (2.8-8.7%) <u>Severe vision disability (blind)</u> 22-26 wks GA: 6/576, 1.0% (0.4-2.3%) 22-23 wks GA: 1/38, 2.6% (0.1-13.8%) 24 wks GA: 1/98, 1% (0.03-5.6%) 25 wks GA: 1/189, 0.5% (0.01-2.9%) 26 wks GA: 3/251, 1.2% (0.3-3.5%) <u>Moderate vision disability (functionally impaired vision)</u> 22-26 wks GA: 34/576, 5.9% (4.1-8.2%) 22-23 wks GA: 6/38, 15.8% (6.0-31.3%) 24 wks GA: 8/98, 8.2% (3.6-15.5%)	**8. Was there appropriate statistical analysis?** Yes. Confidence intervals for the prevalence estimates were provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
	Postnatal steroids for bronchopulmonary dysplasia, %	16.9	13.4			
	Severe abnormality in cranial ultrasound, %	19.2	23.5			
	NEC, %	6.6	8.8			
	Treatment for ROP, %	14.8	16.7			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			25 wks GA: 12/189, 6.4% (3.3-10.8%) 26 wks GA: 8/251, 3.2% (1.4-6.2%) <u>Moderate to severe vision disability</u> 22-26 wks GA: 40/576, 6.9% (5.0-9.3%) 22-23 wks GA: 7/38, 18.4% (7.7-34.3%) 24 wks GA: 9/98, 9.2% (4.3-16.7%) 25 wks GA: 13/189, 6.9% (3.7-11.5%) 26 wks GA: 11/251, 4.4% (2.2-7.7%) <u>Severe cognitive disability (Bayley or WPPSI, <-3SD)</u> 22-26 wks GA: 57/576, 9.9% (7.6-12.6%) 22-23 wks GA: 7/38, 18.4% (7.7-34.3%) 24 wks GA: 11/98, 11.2% (5.7-19.2%) 25 wks GA: 20/189, 10.6% (6.6-15.9%) 26 wks GA: 19/251, 7.6% (4.6-11.6%) <u>Moderate cognitive disability (Bayley or WPPSI, -2 to -3SD)</u>	

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			22-26 wks GA: 37/576, 6.4% (4.6-8.8%) 22-23 wks GA: 5/38, 13.2% (4.4-28.1%) 24 wks GA: 6/98, 6.1% (2.3-12.9%) 25 wks GA: 15/189, 7.9% (4.5-12.8%) 26 wks GA: 11/251, 4.4% (2.2-7.7%) <u>Moderate to severe cognitive disability (Bayley or WPPSI, <=-2SD)</u> 22-26 wks GA: 94/576, 16.3% (13.4-19.6%) 22-23 wks GA: 12/38, 31.6% (17.5-48.7%) 24 wks GA: 17/98, 17.4% (10.4-26.3%) 25 wks GA: 35/189, 18.5% (13.3-24.8%) 26 wks GA: 30/251, 12.0% (8.2-16.6%) <u>Severe communication disability (Bayley or WPPSI, <-3SD)</u> 22-26 wks GA: 36/576, 6.3% (4.4-8.6%) 22-23 wks GA: 6/38, 15.8% (6.0-31.3%) 24 wks GA: 7/98, 7.1% (2.9-14.2%)	

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			25 wks GA: 13/189, 6.9% (3.7-11.5%) 26 wks GA: 10/251, 4.0% (1.9-7.2%) <u>Moderate communication disability (Bayley or WPPSI, -2 to -3SD)</u> 22-26 wks GA: 31/576, 5.4% (3.7-7.6%) 22-23 wks GA: 4/38, 10.5% (2.9-24.8%) 24 wks GA: 5/98, 5.1% (1.7-11.5%) 25 wks GA: 11/189, 5.8% (2.9-10.2%) 26 wks GA: 11/251, 4.4% (2.2-7.7%) <u>Moderate to severe communication disability (Bayley or WPPSI, <=-2SD)</u> 22-26 wks GA: 67/576, 11.6% (9.1-14.5%) 22-23 wks GA: 10/38, 26.3% (13.4-43.1%) 24 wks GA: 12/98, 12.2% (6.5-20.4%) 25 wks GA: 24/189, 12.7% (8.3-18.3%) 26 wks GA: 21/251, 8.4% (5.3-12.5%)	

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 321764 **Full citation** Nordmark,E., Hagglund,G., Lagergren,J., Cerebral palsy in southern Sweden I. Prevalence and clinical features, Acta Paediatrica, 90, 1271-1276, 2001 **Study type** Population-based study **Aim of the study** To analyse the prevalence and clinical features of the different types of CP in southern Sweden.	**Setting** Population-based study from southern Sweden (population of 1.27 million people) where children with CP were identified through medical files and diagnostic records. The total live births in the same region, retrieved from the census were used as the denominator. **Inclusion criteria** All children with CP (based on medical files and diagnostic records) born in 1990-1993 and lived in southern Sweden (counties of Skane and Blekinge) at a time of the 1998 census. Total live births in the same area as the denominator (based on census data). **Exclusion criteria** Children born abroad. **Sample size** n=145 children with CP (born in Sweden, all gestational ages) n=46 preterm children with CP (<37 weeks of gestation) **Characteristics**	**Gestational age ascertainment** Gestational age based on the medical records, method of estimation not described. **Outcome(s) of interest in this study** Cerebral palsy (CP) **Outcome(s) ascertainment/measures** Children with CP were identified through medical files and diagnostic records from all paediatric departments and habilitation centres in the area. The CP status of children were classified according to the internationally widely accepted Swedish classification system and definitions. The classification was done by an experienced neuropaediatrician in	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 4-7 years old <u>CP</u> <28 wks GA: 72.3/1000 live births (95% CI 39.0-120.3/1000 live births) (13 children with CP, the number of GA-specific total live births 180) 28-31 wks GA: 32.2/1000 live births (95% CI 18.1-52.5/1000 live births) (15 children with CP, the number of GA-specific total live births 466) 32-36 wks GA: 4.6/1000 live births (95% CI 2.7-7.3/1000 live births) (18 children with CP, the number of GA-specific total live births 3913) The number of GA-specific total live births not reported by the study but calculated by the NGA technical team.	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) especally among the extremely preterm children.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Study dates Children born 1990-1993. **Country/ies where the study was carried out** Sweden **Source of funding** The Swedish National Health Board, the Josef and Linnea Carlsson Foundation and the Folke Bernadotte Foundation.	Not reported for the preterms separately. Of all the 145 children with CP, 15 were twins.	agreement with the child's local doctor. **Age at assessment** By the time when the medical records were assessed, the children were 4-7 years old.	Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**4. Were the study subjects and the setting described in detail?** No. No description given of the characteristics. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. CP diagnosis data retrieved from medical records, therefore, unclear what criteria was used for each children. **7. Was the condition measured reliably?** Unclear.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				CP diagnosis data retrieved from medical records, therefore, unclear how the condition was assessed and diagnosed. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates not provided. Also, the number of GA-specific total live births not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 316738 **Full citation** Odd,D.E., Lingam,R., Emond,A., Whitelaw,A., Movement outcomes of infants born moderate and late preterm, Acta Paediatrica, 102, 876-882, 2013 **Study type** Regional prospective cohort. **Aim of the study** To investigate whether children born between 32 and 36 weeks of gestation have an increased risk of motor co-	**Setting** The ALSPAC study is an on-going longitudinal study in Bristol in which data on cohort members and their families have been collected from half-day research clinics or retrieved from routine medical or educational records. **Inclusion criteria** Children born in the Bristol area, UK in 1991-1992. Gestational age: 32-36 weeks (preterm) or 37-42 weeks (term) **Exclusion criteria** None reported. **Sample size** n=741 moderate to late preterm children **Characteristics** 32-36 wks	**Gestational age ascertainment** Data on gestational age were extracted from clinical notes (based on the last menstrual period), ultrasound or paediatric assessment. If gestational age was <37 weeks, then this was confirmed by a single paediatrician after reviewing the clinical records. If the last menstrual period was considered unreliable, then the earliest ultrasound measurement was used. **Outcome(s) of interest in this study** Cerebral palsy (CP) **Outcome(s) ascertainment/measures** CP was identified from hospital and community health service records and the diagnosis confirmed at age 4 years using the Standard Recording of	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 7 years CP 32-36 wks GA: 7/741, 0.9% (0.4-1.9%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Unclear. Not described. **3. Was the sample size adequate?** Yes. **4. Were the study subjects and the setting described in detail?** Yes.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
ordination difficulties or cerebral palsy at age 7 years. **Study dates** April 1991 to December 1992 **Country/ies where the study was carried out** UK **Source of funding** None.	Maternal age, mean? 27y 8 mo Non-white ethnicity, % 8.9 Multiple birth, % 18.5 Male, % 57.0 Birth weight in grams, mean (SD) 2495 (489)	Central Motor Deficit. Not other details given. **Age at assessment** 7 years		**5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes. **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Assessment of CP not described. **7. Was the condition measured reliably?** Unclear. Assessment of CP not described. **8. Was there appropriate statistical analysis?** No. Confidence interval for prevalence not provided.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				9. Are all important confounding factors/subgroups/differences identified and accounted for? Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 433396 **Full citation** Rieger-Fackeldey, E., Blank, C., Dinger, J., Steinmacher, J., Bode, H., Schulze, A., Growth, neurological and cognitive development in infants with a birthweight <501 g at age 5 years,	**Setting** Cohort of preterm children born in three tertiary perinatal centres in Germany. **Inclusion criteria** All inborn infants with a birth weight of <501g and a gestational age of ≥22 weeks in three tertiary perinatal centres formed the initial cohort. One infant born at 21 weeks GA was included because parents insisted on life support being provided. **Exclusion criteria** No infants were excluded.	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** CP (GMFCS levels) Cognitive development Visual impairment Hearing impairment	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years age <u>CP</u> ≥22 wks GA/BW <501g; GMFCS level >1 (abnormal): 7/19, 37% (16-62%) ≥22 wks GA/BW <501g; GMFCS level 2: 5/19, 26% (9-52%) ≥22 wks GA/BW <501g; GMFCS level 3: 2/19, 11% (1.3-33%)	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes. **2. Were the study participants recruited in an appropriate way?** Yes.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Acta Paediatrica, 99, 1350-5, 2010

Study type

Prospective cohort study.

Aim of the study

To determine growth, neurological and cognitive development at 5 years of preterm infants with birth weights <501g born in three German tertiary perinatal centres between 1998 and 2001.

Study dates

Children born between 1998 and 2001, assessed at 5 years age.</td>
<td>Sample size

n=107 initial cohort
n=27 survived at 5 years follow up
n=19 eligible for follow up (8/27 were not able to be evaluated due to refusal of consent by parents (n=3), or family had moved away, failed appointment, or moved to another follow-up care (n=5))

Characteristics
<table><tr><th></th><th>Preterm group (n=19)</th></tr><tr><td>GA (median, range)</td><td>25.1 (22.4-27.9)</td></tr><tr><td>GA (mean, SD)</td><td>25.4 (1)</td></tr><tr><td>Birth weight (median, range)</td><td>430 (320-490)</td></tr><tr><td>Birth weight (mean, SD)</td><td>424 (58)</td></tr><tr><td>Female (%)</td><td>63</td></tr></table></td>
<td>Outcome(s) ascertainment/measures

All parents completed a questionnaire requesting their child's history including general health, learning development, family and social life, and cultural aspects.
A standardised neurological examination was conducted by a consultant neurologist (unblended to child's history in each centre).
The Gross Motor Function Classification System (GMFCS) was used to assess mobility for CP, level 1 (normal) to level 5 (Lack of mobility).
Visual perception and hearing ability was based on records of ophthalmologists and pedaudiologists. Severe visual impairment was defined as refractory error of >±diptre. Visual acuity after best possible correction for ametropia by refractive lenses of <20/200 was defined as blindness.
Severe hearing disability was defined when a hearing aid for</td>
<td><u>Cognitive development (Mental Processing Composite, IQ</u>
≥22 wks GA/BW <501g; IQ<85: 10/17, 59% (33-82%)
≥22 wks GA/BW <501g; IQ<70: 7/17, 41% (18-67%)

<u>Visual impairment (blindness)</u>
≥22 wks GA/BW <501g: 2/19, 11% (1.3-33%)
<u>Hearing impairment (requiring hearing aid)</u>
≥22 wks GA/BW <501g: 2/19, 11% (1.3-33%)</td>
<td>3. Was the sample size adequate?

No. Low precision (wide confidence intervals) due to low sample size, especially in the final group assessed at 5 years age.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No. The follow up rate was 18% and the differences between the ones followed up and lost to follow up were reported. The ones lost to follow up were majority singletons, with the higher birth weight, and slightly high mean GA. Majority of the group</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out Germany **Source of funding** Not reported.	Male (%) 37	one or both ears was necessary. Cognitive function was assessed by a child psychologist with the Kaufmann Assessment Battery for Children (K-ABC), which comprises the mental processing composite (global measure of cognitive ability/IQ). IQ <85 (mild impairment); IQ <70 (severe impairment). **Age at assessment** 5 years age		had complete antenatal steroids course, and all had stayed in hospital for >100 days. **6. Were objective, standard criteria used for the measurement of the condition?** Yes. **7. Was the condition measured reliably?** Yes. **8. Was there appropriate statistical analysis?** No. Confidence intervals for percentage proportion estimates were not provided for all outcomes. **9. Are all important confounding factors/subgroups/differe**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				nces identified and accounted for? N/A **10. Were subpopulations identified using objective criteria?** No.
Ref Id 422793 **Full citation** Roberts, G., Anderson, P. J., Davis, N., De Luca, C., Cheong, J., Doyle, L. W., Developmental coordination disorder in geographic cohorts of 8-year-old children born extremely preterm or extremely low birthweight in the 1990s,	**Setting** EP/ELBW 1997 cohort were born in the state of Victoria, with term born children selected from three tertiary perinatal centres in Victoria. EP/ELBW 1991-1992 cohort were born in the state of Victoria, with term born children selected from three tertiary perinatal centres in Victoria. **Inclusion criteria** All children born EP/ELBW with a completed gestational age range of 22 to 27 weeks or a birth weight of 500g to 999g. Term born children had a gestational age of >36 weeks or a birth weight >2499g. All children surviving to 8 years age. **Exclusion criteria**	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** DCD **Outcome(s) ascertainment/measures** DCD was defined as motor impairment in the absence of CP or an intellectual impairment. Motor impairment was determined by using the	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 8 years age Moderate DCD (1997 cohort) 22-27 wks GA: 21/132, 16% (10.1-23.3%) Moderate DCD (1991-1992 cohort) 22-27 wks GA: 30/298, 10% (6.9% to 14.1%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes. **2. Were the study participants recruited in an appropriate way?** Population was recruited consecutively.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Developmental medicine and child neurology, 53, 55-60, 2011

Study type

Prospective cohort study (The Victorian Infant Collaborative Study Group)

Aim of the study

(1) To examine the prevalence of DCD in a geographical cohort of extremely preterm (EP) or extremely low birth weight (ELBW) children compared to term-born children born in 1997.
(2) To compare academic outcomes in EP/ELBW children</td>
<td>Children who did not survive to 8 years assessment.
To measure DCD, children who had cerebral palsy or intellectual impairment (children with an IQ > 2SD below the mean).

Sample size

EP/ELBW (1997 cohort) n=201 survivors to 8 years age out of 283 consecutive live births.
EP/ELBW (1991-1992) cohort n=298 survivors to 8 years age out of 533 consecutive live births.

Characteristics
<table>
<tr><th></th><th>Preterm group 1991-1992</th><th>Preterm group 1997</th></tr>
<tr><td>22-27 wks GA (n)</td><td>298 survivors/533 consecutive live births</td><td>201 survivors/283 consecutive live births</td></tr>
<tr><td>Birth weight (g)</td><td>500-999</td><td>500-999</td></tr>
</table>
</td>
<td>Movement Aassessment Battery for Children carried out by a paediatrician.
Moderate motor impairment was defined as a total score that was less than the 5th centile.

Age at assessment

8 years age.</td>
<td></td>
<td>3. Was the sample size adequate?

Yes.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

The follow up rate was 94%; children who had CP related motor impairment (lack of data) were excluded from the analysis.

6. Were objective, standard criteria used for the measurement of the condition?

Unclear. Information on assessment of outcome in the 1997 cohort was not clearly reported in</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
with or without DCD. (3) To assess parents' perceptions of motor performance relative to clinical diagnosis of DCD. (4) To compare the prevalence of DCD at school age among those born in the early 1990s and those born in the late 1990s in the same geographical region (Davis 2007?). **Study dates** Children born 1997 assessed at 8 years age. Children born 1991-1992 assessed at 8 years age.	<table><tr><td></td><td></td><td></td></tr><tr><td></td><td></td><td></td></tr></table>			comparison to assessment made in the 1991-1992 cohort. **7. Was the condition measured reliably?** Unclear how condition was measured in the 1997 cohort. **8. Was there appropriate statistical analysis?** No. Confidence intervals were not reported for prevalence estimates. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out Australia **Source of funding** Victorian government (part funding) National Health and Medical Research Council Centre for Clinical Research Excellence in Newborn Medicine				N/A
Ref Id 347329 **Full citation** Roberts, G., Anderson, P. J., De Luca, C., Doyle, L. W., Changes in neurodevelopment	**Setting** Regional cohort of preterm children in the state of Victoria Australia. **Inclusion criteria** Children born at 22-27 weeks of gestation in the state of Victoria, Australia between 1/1-31/12/1997 and survived to follow-up at age 8 years (corrected).	**Gestational age ascertainment** **Outcome(s) of interest in this study** Cerebral palsy (CP); intellectual impairment (severe and moderate);	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 8 years (corrected) <u>CP</u> 22-27 wks GA: 16/141, 11.3% (6.6-17.8%) <u>Blindness</u>	**Overall quality** Low **1. Was the sample representative of the target population?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>al outcome at age eight in geographic cohorts of children born at 22-27 weeks' gestational age during the 1990s, Archives of Disease in Childhood: Fetal and Neonatal Edition, 95, F90-F94, 2010

Study type

A regional cohort study

Aim of the study

To determine the outcomes at age eight for a regional cohort of children born at 22-27 weeks during 1997 and to compare their rates of disability with a cohort of the same gestational age born in 1991-1992.</td>
<td>Exclusion criteria

None reported.

Sample size

n=223 total live births
n=151 consecutive live births at 22-27 weeks completed gestation
n=144 survived to age 8 years

Characteristics
<table><tr><td></td><td>n=144</td></tr><tr><td>GA, completed weeks (mean, SD gestation)</td><td>25.6 (1.2)</td></tr><tr><td>Male gender seen at age 8 years (n, %)</td><td>80 (55.6)</td></tr><tr><td>Mean birth weight (mean g, SD)</td><td>821 (175)</td></tr></table></td>
<td>blindness;
severe hearing impairment

Outcome(s) ascertainment/measures

The participants were assessed at 8 years of age (corrected) by paediatricians and psychologists blinded to perinatal details, predominantly in specialised follow-up clinics, although a few were tested at school or home if they could not attend the clinics.
No information was provided how CP was diagnosed/assessed or how CP was defined but includes at least the following aspects: the child not walking, the child walking with considerable difficulty, with or without appliances, walking with minimal limitation.
Intelligence was assessed using the Welchsler Intelligence Scale for Children, 4th edition (WISC-IV). The preterm children were compared with the term controls of the study rather</td>
<td>22-27 wks GA: 3/144, 2.1% (0.4-6.0%)

<u>Hearing impairment</u>
22-27 wks GA: 3/144, 2.1% (0.4-6.0%)

<u>Severe intellectual impairment (IQ <-3SD)</u>
22-27 wks GA: 9/144, 6.3% (2.9-11.5%)

<u>Moderate intellectual impairment (IQ-3SD to <-2SD)</u>
22-27 wks GA: 12/144, 8.5% (4.4-14.1%)

<u>Intellectual impairment (IQ <-2SD)</u>
22-27 wks GA: 21/144, 14.6% (9.3-21.4%)

Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

No.
Low precision (wide confidence intervals) due to relatively low sample size. Precision was especially low in the gestational age subgroups (the study reported prevalence of each outcome by GA week) because of very low samples (e.g. 22 GA weeks group has 1 individual), thus, not presented in this review.

4. Were the study subjects and the setting described in detail?

No.
Limited information given on the background</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Study dates Children born in 1997, follow-up at 8 years of age (corrected). **Country/ies where the study was carried out** Australia **Source of funding** The Victorian Government.		than the test norms when assigning disability criteria in order to study the preterm children in the context of their typically developing peers from the same geographical area. A small number of children were not able to complete all the subtests of of the WISC-IV, primarily due to CP-related motor impairment or visual impairment (n=4), their verbal comprehension index was used as an estimate for IQ. For the child who was unable to complete language-based subscales of the WISC-IV due to significant hearing impairment (n=1), the perceptual reasoning index score was used as an estimate of IQ. Two children were unable to complete any of the WISC-IV subtests due to a severe disability, these children were assigned an IQ standard score of -4SD. Two children did not complete all subscales of the WISC-IV due to lack of compliance and their IQ score was calculated based on the completed subscales. Severe intellectual disability was defined as IQ <-3SD;		characteristics of the sample. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes (95% follow-up rate). **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Assessment of intelligence used a well-known validated tool and standard cut-offs but for other outcomes, limited information was given about the assessment/methods/definition. **7. Was the condition measured reliably?** Unclear. Assessment of intelligence used a well-known validated

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
		moderate intellectual disability was defined as IQ -3SD to <-2SD. Blindness was defined as visual acuity <6/60 in the better eye). No details about how it was assessed. Severe hearing impairment was defined as requiring hearing aids or worse). No details about how it was assessed. **Age at assessment** 8 years corrected age		tool but for other outcomes, limited information was given about the assessment/methods/definition. **8. Was there appropriate statistical analysis?** No. Number of cases were not provided. Confidence intervals of prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 339592 **Full citation** Robertson, C. M., Watt, M. J., Yasui, Y., Changes in the prevalence of cerebral palsy for children born very prematurely within a population-based program over 30 years, JAMA, 297, 2733-40, 2007 **Study type** A prospective population-based longitudinal outcome study. **Aim of the study** To assess the changes in population-based, gestational age-specific	**Setting** All infants weighing <1250 g at birth who were born in Northern Alberta from August 1, 1974 until 31 December, 2003 and admitted to neonatal intensive care were prospectively enrolled in the follow-up cohort. **Inclusion criteria** All infants born at 20-27 weeks of gestation with birth weight of 500-1249 g who were born in Northern Alberta of Albertan parents from August 1, 1974 until 31 December, 2003 and admitted to neonatal intensive care and who survived to 2 years of age. **Exclusion criteria** None reported. **Sample size** n=975 number of children who were live born between 1992-2003 n=506 number of children who survived to 2 years between 1992-2003 n=??? number of children who were followed up at 2 years between 1992-2003 (Not reported for these years. Over the whole study period 1974-2003, out of 881 survivors at 2 years, 23 were lost to follow-up.)	**Gestational age ascertainment** From the mid 1980s, early second trimester fetal ultrasound guided gestational age determination. **Outcome(s) of interest in this study** Cerebral palsy (CP) **Outcome(s) ascertainment/measures** For the entire study period, the follow-up was under the direction of the same neurodevelopmental paediatrician (the first author). The multidisciplinary format of repeated assessments were done every 6 months with additional visits if required. At the first follow-up visit, each child was seen by the physician, nurse, physical therapist and audiologist and if delay or feeding difficulties were suspected, the child was also seen by an occupational	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 2 years of age (confirmed at 3 years of age) <u>CP</u> 1992-1994 22-27 wks GA: 131/1000 live births (95% CI 90-183/1000 live births) (cases of CP 29, number of live births 221, number of survivors at 2 years who were assessed is not reported) 1995-1997 22-27 wks GA: 69/1000 live births (95% CI 41-108/1000 live births) (cases of CP 17, number of live births 246, number of survivors at 2 years who were assessed is not reported) 1998-2000 22-27 wks GA: 69/1000 live births (95% CI 41-108/1000 live births) (cases of CP 17, number of live births 246, number of survivors at 2 years who were assessed is not reported) 2001-2003	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to relatively small sample size. **4. Were the study subjects and the setting described in detail?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>prevalence rates of CP among extremely premature infants over 30 years.

Study dates

Children born 1974-2003 (only years 1992-2003 considered for the review), assessment of CP at 18-24 months corrected age (confirmation of diagnosis at 3 years or older).

Country/ies where the study was carried out

Canada

Source of funding

One of the the authors is</td>
<td>Characteristics

Characteristics for the survivors at 2 years of the whole study period (1974-2003) (n=858)
<table>
<tr><td></td><td>CP (n=122)</td><td>No CP (n=736)</td></tr>
<tr><td>Male, %</td><td>54</td><td>50</td></tr>
<tr><td>Inborn (at a tertiary-care hospital), %</td><td>84</td><td>87</td></tr>
<tr><td>Multiple birth, %</td><td>14</td><td>16</td></tr>
<tr><td>CS, %</td><td>28</td><td>37</td></tr>
<tr><td>Birth weight <10% for GA, %</td><td>2.5</td><td>4.3</td></tr>
<tr><td>Gestational age in weeks, mean (SD)</td><td>25.6 (1.3)</td><td>26.0 (1.1)</td></tr>
</table>
</td>
<td>therapist and/or dietitian. If motor delay was present, these physical and occupational therapists became the treating therapists for the child. All children were seen at 18 to 24 month adjusted age by the physician, nurse, psychologist and speech language pathologist, and if needed, the physiotherapist, occupational therapist or audiologist.
Throughout the 30 years of the whole study period, the diagnoses of CP was done by only 6 physicians in total, all which were reviewed by a single physician and all children with the diagnosis of CP have been seen by the same paediatric physiatrist (second author) and a consensus diagnosis of CP (spastic, dyskinetic, ataxic) and subtype (hemiplegic, diplegic, quadriplegic) made. Outcome of all children diagnosed with CP were confirmed after 3 years of age.
The definition of CP was a disorder of movement and posture due to a defect or</td>
<td>22-27 wks GA: 19/1000 live births (95% CI 6-44/1000 live births) (cases of CP 5, number of live births 262, number of survivors at 2 years who were assessed is not reported)
1992-2003
22-27 wks GA: 70/1000 live births (95% CI 55-88/1000 live births) (cases 68, number of live births 975, number of survivors ar 2 years who were assessed is not reported)

<u>Nonambulatory CP</u>
1992-1994
22-27 wks GA: 59/1000 live births (95% CI 32-99/1000 live births) (cases of CP 13, number of live births 221, number of survivors at 2 years who were assessed is not reported)
1995-1997
22-27 wks GA: 16/1000 live births (95% CI 5-41/1000 live births) (cases of CP 4, number of live births 246, number of survivors at 2 years who were assessed is not reported)
1998-2000</td>
<td>5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.
Confidence intervals for the prevalence estimates were not provided.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
supported by the Canada Research Chair Program, the Alberta Heritage Foundation for Medical Research.	Birth weight in grams, mean (SD) 864 (169) 883 (168)	lesion of the immature brain. Children were grouped, using outcomes collected from those older than 3 years, as 1) ambulatory, i.e. capable of walking independently with or without ankle-foot orthoses, assistive mobility devices or both, or 2) nonambulatory, i.e. requiring transportation or power mobility devices. The latter group might include some children with less spasticity but associated severe mental delay or blindness leading to failure of ambulation. **Age at assessment** Assessment/diagnosis at 18-24 months corrected age and confirmed at 3 years of age or later.	22-27 wks GA: 8/1000 live births (95% CI 1-29/1000 live births) (cases of CP 2, number of live births 246, number of survivors at 2 years who were assessed is not reported) 2001-2003 22-27 wks GA: 8/1000 live births (95% CI 1-27/1000 live births) (cases of CP 2, number of live births 262, number of survivors at 2 years who were assessed is not reported) 1992-2003 22-27 wks GA: 22/1000 live births (95% CI 13-33/1000 live births) (cases 21, number of live births 975, number of survivors ar 2 years who were assessed is not reported) Confidence intervals for the prevalence estimates calculated by the NGA technical team using http://statpages.info/confint.html	**9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 336849 **Full citation** Salokorpi, T., Rautio, T., Sajaniemi, N., Serenius-Sirve, S., Tuomi, H., von Wendt, L., Neurological development up to the age of four years of extremely low birthweight infants born in Southern Finland in 1991-94, Acta Paediatrica, 90, 218-21, 2001 **Study type** A population-based cohort study. **Aim of the study** To find the rate of neurological	**Setting** All extremely low birth weight (<1000 g) infants born in Southern Finland admitted to NICU, followed-up at 4 y. The catchment area covers approximately 1.2 million people, all extremely low birth weight infants born in this area are taken care of at the Hospital for Children and Adolescents, University Central Hospital of Helsinki. **Inclusion criteria** All extremely low birth weight (<1000 g) infants born between 1 January 1991 and 31 December 1994 and admitted to the neonatal intensive care unit at the Hospital for Children and Adolescents, University Central Hospital of Helsinki and survived over the corrected age of 12 months. **Exclusion criteria** None reported. **Sample size** n=228 extremely low birth weight infants born n=156 survived over the age of 12 months (corrected) (69%) n=142 were followed up at 4 years (91% of the ones who survived) **Characteristics**	**Gestational age ascertainment** Not reported. Inclusion according to birth weight but mean GA reported, however, not reported how estimated. **Outcome(s) of interest in this study** Cerebral palsy (CP) and cognitive impairment (IQ<71). **Outcome(s) ascertainment/measures** At 4 years chronological age (+-4 weeks), the children were examined by the neurologist (first author) with an assessment of motor skills, fine motor skills and drawing (handedness), eye movements, muscle tone, tendon reflexes, speech and attention during the examination. A diagnosis of CP was confirmed when abnormal muscle tone, exaggerated tendon reflexes and a positive Babinsky sign,	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 4 years of age (chronological) <u>CP</u> Birth weight <1000g (mean GA 27 wks): 27/142, 19.0% (12.9-26.5%) <u>CP bilateral spastic (diplegia or tetraplegia)</u> Birth weight <1000g (mean GA 27 wks): 15/142, 10.6% (6.0-16.8%) <u>CP hemiplegia</u> Birth weight <1000g (mean GA 27 wks): 8/142, 5.6% (2.5-10.8%) <u>CP dystonic or athetoid type</u> Birth weight <1000g (mean GA 27 wks): 4/142, 2.8% (0.8-7.1%) <u>IQ <71 (WPPSI)</u> Birth weight <1000g (mean GA 27 wks): 6/142, 4.2% (1.6-9.0%) Confidence intervals calculated by the NGA technical team using	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision, wide confidence intervals due to relatively small sample size. **4. Were the study subjects and the setting described in detail?** Unclear.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>disorders at age 4 years in the premature infants at highest risk, and to compare the rates with international figures.

Study dates

Children born 1/1/1991-31/12/1994, follow-up at 4 years of age.

Country/ies where the study was carried out

Finland

Source of funding

The Arvo and Lea Ylppo Foundation.</td>
<td>
<table>
<tr><td></td><td>Children with normal outcome</td><td>Children with CP</td><td>Children with cognitive impairment</td></tr>
<tr><td>Mean birth weight in grams</td><td>822</td><td>833</td><td>872</td></tr>
<tr><td>Mean GA in weeks</td><td>27</td><td>27</td><td>27</td></tr>
<tr><td>SGA, %</td><td>32</td><td>37</td><td>33</td></tr>
<tr><td>Multiple births, %</td><td>28</td><td>15</td><td>50</td></tr>
<tr><td>Boys, %</td><td>30</td><td>33</td><td>67</td></tr>
<tr><td>Intraventricular haemorrhage grade III-IV or periventricular</td><td>5</td><td>37</td><td>16</td></tr>
</table>
</td>
<td>persistent or exaggerated primitive reflexes, dyskinesia or ataxia were found. Cognitive impairment (mental retardation in the study) was assessed (by two of the authors) with the revised Finnish form of the Wechsler Preschoool and Primary Scale of Intelligence (WPPSI). IQ value of <71 was considered as "mental retardation". Theexaminations took place at the Department of Pediatric Neurology at the Hospital for Children and Adolescents, Univeristy Central Hospital of Helsinki.

Age at assessment

4 years (chronological).</td>
<td>http://statpages.info/confint.html</td>
<td>Limited description of the background characteristics, e.g. no description of socioeconomic characteristics.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes.
Only 9% of the survivors lost to follow-up.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	leukomalacia, % >=28 days in ventilator, % 21 37 67			No. Confidence intervals of the prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 336876 **Full citation** Serenius, F., Kallen, K., Blennow, M., Ewald, U., Fellman, V., Holmstrom, G.,	**Setting** National study conducted throughout Sweden. **Inclusion criteria** Preterm infants: all infants born at < 27 weeks within the study time period throughout Sweden. Controls: Singleton, term infants with a five minute Apgar score greater than 3, with matching of control participants for place of living, sex, day of birth and maternal country of birth.	**Gestational age ascertainment** Gestational age was based on ultrasound dating in 95% of the pregnancies. **Outcome(s) of interest in this study** CP	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 2.5 years corrected age CP (n=456, formally assessed or assessed by chart review) <27 wks GA: mild CP: 13/456, 2.9% (1.5-4.8%)	**Overall quality** Moderate. **1. Was the sample representative of the target population?** Yes.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Lindberg, E., Lundqvist, P., Marsal, K., Norman, M., Olhager, E., Stigson, L., Stjernqvist, K., Vollmer, B., Stromberg, B., Neurodevelopmental outcome in extremely preterm infants at 2.5 years after active perinatal care in Sweden, JAMA - Journal of the American Medical Association, 309, 1810-1820, 2013

Study type

Population-based prospective cohort study (EXPRESS group).

Aim of the study

To determine neurodevelopmental outcome in</td>
<td>Exclusion criteria

Death before follow up period. Declined follow up. Mother had protected identity, family moved abroad or error on identification number at birth.

Sample size

Sample recruited:
n = 707 liveborn preterm infants
n = 701 term controls
Sample analysed after exclusions:
n = 456 preterm infants
n = 701 full term controls

Characteristics
<table><tr><td></td><td>Preterm <27 wks GA (n=456)</td></tr><tr><td>GA at birth (mean, SD, wk)</td><td>25.4 (1.1)</td></tr><tr><td>Birth weight (mean, SD, g)</td><td>783 (172.3)</td></tr></table></td>
<td>Cognitive impairment
Language impairment
Vision impairment
Hearing impairment

Outcome(s) ascertainment/measures

At 2.5 years of corrected age, certified psychologists assessed cognitive, language and motor development with the Bayley Scales of Infant and Toddler Development. 41 preterm infants were assessed through chart review, with information from local paediatricians, low-vision centres and rehabilitation centres that provided information which the authors regarded as sufficient to allow assessment of developmental and neurosensory outcome. Cognitive, language and motor development was considered normal if the composite score on the respective Bayley-III scale was within 1 SD of the norm, mildly impaired if the score was between 1 and 2SD below the</td>
<td><27 wks GA: moderate CP: 13/456, 2.9% (1.5-4.8%)
<27 wks GA: severe CP: 6/456, 1.3% (0.48-2.8%)
<27 wks GA: moderate/severe CP: 19/456, 4.2% (2.5-6.4%)*
<27 wks GA: any CP: 32/456, 7% (4.9-9.8%)
*calculated by NGA team
<u>Vision impairment (n=456, formally assessed or assessed by chart review)</u>
<27 wks GA: moderate: 13/456, 2.9% (1.5-4.8%)
<27 wks GA: blindness: 4/456, 0.9% (0.24-2.3%)
<27 wks GA: any vision impairment: 17/456, 3.7% (2.2-5.9%)
<u>Hearing impairment (n=456, formally assessed or assessed by chart review)</u>
<27 wks GA: impaired hearing, corrected with hearing aid: 3/456, 0.7% (0.14-2.0%)
<27 wks GA: deaf: 1/456, 0.2% (0.01-1.2%)
<27 wks GA: any hearing impairment: 4/456, 0.9% (0.24-2.2%)</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes.

3. Was the sample size adequate?

Yes.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes.

6. Were objective, standard criteria used for the measurement of the condition?

Yes.</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>extremely preterm children at 2.5 years corrected age.

Study dates

Children born between 2004 and 2007, assessed at 2.5 years corrected age.

Country/ies where the study was carried out

Sweden

Source of funding

Swedish Research Council
Uppsala-Orebro Regional Research Council grant
Research Council South East Region of Sweden</td>
<td>
<table>
<tr><td>SGA infant (<-2SD of Swedish standard population)</td><td>73 (16.0)</td></tr>
<tr><td>Male (%)</td><td>54.4</td></tr>
<tr><td>Female (%)</td><td>45.6</td></tr>
</table>
</td>
<td>norm, moderately impaired if the score was between 2 and 3 SD below the norm, and severely impaired if the score was < 3SD below the norm. Mental developmental delay was also included as an outcome and classified as follows: Mild: a score of between 1 and 2 SD below the norm on either the cognitive or the language composite score. Moderate: a score of between 2 and 3 SD below the norm on either the cognitive or language composite score. Severe: a score of less than 3 SD below the norm on either the cognitive of language composite score.

Age at assessment

2.5 years corrected age.</td>
<td><u>Cognitive impairment (n=399, assessed by Bayley III)</u>
<27 wks GA: mild (scores 83-94): 258/399, 64.7% (60.0-70.0%)
<27 wks GA: moderate (scores 72-82): 96/399, 24% (20.0-29.0%)
<27 wks GA: severe (scores <72): 25/399, 6.3% (4.1-9.1%)
<u>Language impairment (n=393, assessed by Bayley III)</u>
<27 wks GA: mild (scores 85-96): 241/393, 61.3% (56.0-66.0%)
<27 wks GA: moderate (scores 72-84): 37/393, 9.4% (6.7-12.7%)
<27 wks GA: severe (score <72): 26/393, 6.6% (4.4-9.5%)</td>
<td>7. Was the condition measured reliably?

Yes.

8. Was there appropriate statistical analysis?

No. Confidence intervals were not provided for percentages of estimates for proportions, some percentages were incorrect.

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
University of Umea and Vasterbotten County Council Stockholm County Council and Karolinska Institute Lilla Barnets Fond Children's fund Evy and Gunnar Sandberg Marie Curie individual intra-European Fellowship				
Ref Id 322168 **Full citation** Stahlmann,N., Rapp,M., Herting,E., Thyen,U., Outcome of extremely premature infants at early school age: health-related quality of life and	**Setting** Geographically defined cohort of extremely preterm (<27 weeks) children born in one of 8 perinatal centres in Northern Germany between 1997-1999. **Inclusion criteria** All preterm infants with gestational age <27 weeks born between January 1997 and December 1999 in one of eight perinatal centres in Schleswig-Holstein, Northern Germany. **Exclusion criteria**	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Disorders: cerebral palsy (CP); cognitive impairment (K-ABC) Problems: behavioural problems (SDQ total difficulties; emotional	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 7-9 years **Disorders:** <u>CP</u> <27 wks GA: 11/75, 14.7% (7.6-24.7%) <u>Non-ambulatory CP (GMFCS 3-5)</u> <27 wks GA: 8/75, 10.7% (4.7-19.9%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>neurosensory, cognitive, and behavioral outcomes in a population-based sample in northern Germany, Neuropediatrics, 40, 112-119, 2009

Study type

A geographically defined cohort study.

Aim of the study

To collect regional data to support and establish evidence-based decision-making. The report focuses on morbidity at early school age regarding neurosensory status, cognitive status, disability status as well as behavioural problems and</td>
<td>None reported.

Sample size

n=154 infants identified
n=95 survived until discharge to home
n=92 survived until follow-up at 7-9 years
n=75 children were assessed at 7-9 years (81.5% of the surviving children)

Characteristics

<table>
<tr><td></td><td>Study group (n=75)</td><td>Drop-outs (n=17)</td></tr>
<tr><td>Maternal age at birth in years, median (range)</td><td>30 (17-40)</td><td>32.5 (18-45)</td></tr>
<tr><td>Maternal ethnicity non-German, %</td><td>23</td><td>11</td></tr>
<tr><td>Singleton, %</td><td>75</td><td>71</td></tr>
<tr><td>CS, %</td><td>85</td><td>85</td></tr>
</table>
</td>
<td>symptoms; hyperactivity-inattention; conduct problems; peer-relationship problems; prosocial behaviour)

Outcome(s) ascertainment/measures

Assessment at 7-9 years of age took place in the outpatient clinic of the Department of Child Health and Adolescent Medicine, University of Luebeck. In exceptional cases home visits (n=16) or appointments in one of the participating hospitals (n=1) were arranged. The assessment consisted of a standardised interview about sociodemographic characteristics, a clinical neurosensory examintion, and several standardised questionnaires.
Disorders:
All neurosensory examinations were conducted by the first author who was unaware of the neonatal course of the child and the outcome of the follow-up at 3-5 years. CP was</td>
<td><u>Severe cognitive impairment (IQ <55)</u>
<27 wks GA: 11/75, 14.7% (7.6-24.7%)

<u>Moderate cognitive impairment (IQ 55-69)</u>
<27 wks GA: 8/75, 10.7% (4.7-19.9%)

<u>Moderate to severe cognitive impairment (IQ <70)</u>
<27 wks GA: 19/75, 25.3% (16.0-36.7%)

Problems:
<u>Abnormal SDQ total difficulties (score 17-40)</u>
<27 wks GA: 21/75, 28.0% (18.2-39.6%)

<u>Abnormal emotional symptoms (SDQ subscale score 7-10)</u>
<27 wks GA: 20/75, 26.7% (17.1-38.1%)

<u>Abnormal hyperactivity-inattention score (SDQ subscale score 9-10)</u>
<27 wks GA: 28/75, 37.3% (26.4-49.3%)</td>
<td>Yes

3. Was the sample size adequate?

No.
Low precision (wide confidence intervals) due to relatively low sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear.
81.5% of the children who survived up to follow-up were included.

6. Were objective, standard criteria used for</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>health-related quality of life among very immature preterm infants.

Study dates

Children born 1997-1999, follow-up at 7-9 years of age.

Country/ies where the study was carried out

Germany

Source of funding

Stiftung fuer das behinderte Kind</td>
<td>
<table>
<tr><td>Male, %</td><td>44</td><td>41</td></tr>
<tr><td>Gestational age in days, median (range)</td><td>182 (164-188)</td><td>181 (167-188)</td></tr>
<tr><td>Birth weight in grams, median (range)</td><td>790 (430-1165)</td><td>905 (620-1290)</td></tr>
<tr><td>IVH grade III-IV/PVL, %</td><td>19</td><td>29</td></tr>
<tr><td>BPD, %</td><td>38</td><td>33</td></tr>
<tr><td>NEC, %</td><td>12</td><td>12</td></tr>
<tr><td>ROP >II or lasertherapy, %</td><td>33</td><td>24</td></tr>
</table>
</td>
<td>assessed through Gross Motor Function Classification System (GMFCS). Non-ambulant CP was considered severe dysfunction (GMFCS III-V) and CP with low functional impairment (GMFCS I-II). Cognitive status was assessed with the Kaufman Assessment Battery for Children (K-ABC) German version. The Scale Mental Processing provides information about fundamental mental processes and represents the cognitive abilities, reported as intelligent quotient (IQ). Using the original test standardsation norms standard deviation (SD) was 15. We classified an IQ <55 severely impaired and IQ 55-69 as moderately impaired. In cases where the child had been recently tested (within the last year) with the K-ABC or another equivalent instrument (n=7), e.g. the Hamburg Wechsler Intelligence Test for Children (HAWIK), the Snijders-Oomen Nonverbal Intelligence Test (SON-R) or the Culture Fair Intelligence Tests (CFT) we used the reported results.</td>
<td><u>Abnormal conduct problems score (SDQ subscale score 6-10)</u>
<27 wks GA: 15/75, 20.0% (11.7-30.8%)

<u>Abnormal peer relationship score (SDQ subscale 5-10)</u>
<27 wks GA: 15/75, 20.0% (11.7-30.8%)

<u>Abnormal prosocial behaviour score (SDQ subscale 0-5)</u>
<27 wks GA: 7/75, 9.3% (3.8-18.3%)

Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html</td>
<td>the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No.
Confidence intervals for the prevalence estimates were not provided.

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
		Problems: Behavioural problems was assessed the Strengths and Difficulties Questionnaire (SDQ-Deu). Twenty-five items on five scales measure emotional symptoms, hyperactivity-inattention, conduct problems, peer relationship problems, and prosocial behaviour. Added scales scores (excluding prosocial behaviour) generates the total difficulties score. The scoring was classified into normal, borderline and abnormal. Abnormal scores were based on the SDQ website's scoring instructions (according to the SDQinfo.com, in the total difficulties score, a score of 17-40 points is abnormal; for emotional symptoms, a score of 7-10 is abnormal; for hyperactivity-inattention, a score of 9-10 is abnormal; for conduct problems, a score of 6-10 is abnormal; for peer relationship problems, a score of 5-10 is abnormal; and for prosocial behaviour, a score of 0-5 is abnormal. These are		N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
		based on a population-based survey.) **Age at assessment** 7-9 years of age		
Ref Id 357511 **Full citation** Sutton, L., Bajuk, B., Population-based study of infants born at less than 28 weeks' gestation in New South Wales, Australia, in 1992-3, Paediatric and Perinatal Epidemiology, 13, 288-301, 1999 **Study type**	**Setting** State-wide audit of infants admitted to tertiary neonatal intensive care units in New South Wales. There were 8 tertiary NICUs in NSW, two located in free-standing children's hospitals, one in an obstetric hospital and 5 in multidisciplinary hospitals. Seven of the hospitals were within the Sydney Metroplitan area, and the eighth was 150km north of Sydney. **Inclusion criteria** All infants born <29 weeks gestational age with birthweight <1000g, major surgery, mechanical ventilation or continuous positive airway pressure (CPAP) for ≥4 hours that commenced during the neonatal period. **Exclusion criteria** Not reported.	**Gestational age ascertainment** Gestational age was determined by the best obstetric estimate, ideally from the last normal menstrual period, supplemented if necessary by early ultrasound examination or neonatal examination. **Outcome(s) of interest in this study** CP Major developmental delay Bilateral hearing impairment Blindness	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 12 months corrected age CP (surviving children who had a neurological examination) All <27 wks GA: 22/139, 15.8% (10.2-23.0) 23 wks GA: 1/1, 100% (25-100%) 24 wks GA: 4/25, 16% (4.5-36.0%) 25 wks GA: 7/36, 19,4% (8.2-36.0%) 26 wks GA: 10/77, 13.0% (6.4-22.6%) 27 wks GA: 20/105, 19.1% (12.0-27.9%) Major developmental delay (surviving children who had	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes. **2. Were the study participants recruited in an appropriate way?** The study was a population based statewide audit of infants admitted to tertiary NICUs.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Prospective population- based cohort study.

Aim of the study

To study all births from 20 to 27 weeks gestation in a population base in New South Wales in 1992-1993 and compare neonatal mortality data and also major morbidity of survivors at 12 months corrected age.

Study dates

Infants born between 1992-1993, assessed at 12 months corrected age.</td>
<td>Sample size

N=1170 (including live and still births in 1992-1993).
n=614 live births.
n=434 admitted to tertiary NICU (180 died in the labour ward).
n=244 children who had a neurological examination.

Characteristics
<table>
<tr><td></td><td>Preterm group (n=434)</td></tr>
<tr><td>Gestational age 27 weeks (%)</td><td>35.7</td></tr>
<tr><td>Gestational age 26 weeks (%)</td><td>26</td></tr>
<tr><td>Gestational age 25 weeks (%)</td><td>20</td></tr>
</table>
</td>
<td>Outcome(s) ascertainment/measures

Babies were assessed by a developmental paediatrician with or without a clinical psychologist, and in some cases a developmentally trained physiotherapist, with a full physical examination and Griffiths developmental assessment.
Major developmental disability was defined as a general quotient of ≥ 2 SD below the mean on the Griffiths scale.
The follow-up consisted of a neurological checklist. The neurological outcome at 12 months was expressed as normal, provisional diagnosis of cerebral palsy, or motor delay greater than expected with or without equivocal neurological signs.
Blindness was defined as bilateral vision loss with visual acuity < 6/60.
Hearing impairment was defined as bilateral hearing loss corrected with hearing aids.</td>
<td>a formal Griffiths assessment)
All <27 wks GA: 14/135, 10.4% (5.8-16.8%)
23 wks GA: 1/1, 100% (25-100%)
24 wks GA: 4/23, 17.4% (5.0-39%)
25 wks GA: 6/34, 17.7% (6.8-34.5%)
26 wks GA: 3/77, 3.9% (0.81-11%)
27 wks GA: 12/104, 11.5% (6.1-19.3%)
Major sensory deficits (bilateral hearing aids or blind)
All <27 wks GA: 8/148, 5.4% (2.4-10.4%)
23 wks GA: 1/1, 100% (25-100%)
24 wks GA: 1/25, 4% (0.1-20.4%)
25 wks GA: 1/40, 2.5% (0.06-13.2%)
26 wks GA: 5/82, 6.1% (2.0-13.7%)
27 wks GA: 4/107, 3.7% (1.0-9.3%)

Infants born at 20-27 wks GA in 1992-1993 =6.6 per 1000 total births (n=1170)</td>
<td>3. Was the sample size adequate?

No. Low precision (confidence intervals) due to low sample size especially in GA subgroups.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes.

6. Were objective, standard criteria used for the measurement of the condition?

No. The criteria for measurement of CP was not clearly reported.</td>
</tr>
</table>

Study details	Participants		Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out Australia. **Source of funding** Not reported.	Gestational age 24 weeks (%)	11	**Age at assessment** 12 months corrected age.	556/1170= still births (475.2 per 1000 births) 614/1170= live births (524.8 per 1000 births)	**7. Was the condition measured reliably?** No. For CP, it is not clear how the measurement was assessed. **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/a
	Gestational age 23 weeks (%)	3			
	Babies born to mothers resident in Sydney and major centres within 50-150km of Sydney (%)	76			
	Babies born in tertiary obstetric hospital (%)	85			

Study details	Participants		Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	Infants exposed to maternal corticosteroids in last week of pregnancy at 23 weeks gestation (%, n)	14.5 (2/14)			
	Infants exposed to maternal corticosteroids in last week of pregnancy at 24 weeks gestation (%, n)	63 (29/46)			
	Infants exposed to maternal	67 (58/86)			

Study details	Participants		Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	corticosteroids in last week of pregnancy at 25 weeks gestation (%, n)				
	Infants exposed to maternal corticosteroids in last week of pregnancy at 26 weeks gestation (%, n)	70 (93/133)			
	Infants exposed to maternal corticosteroids in last week of pregnancy at	77 (120/155)			

Study details	Participants		Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	27 weeks gestation (%, n)				
	Birth weight (whole group, median, range, g)	867.5 (744-990)			
	Birth weight (23 weeks GA group, median, range, g)	595 (500-625)			
	Birth weight (27 weeks GA group, median, range, g)	1005 (902-1120)			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 317149 **Full citation** Tommiska,V., Heinonen,K., Kero,P., Pokela,M.L., Tammela,O., Jarvenpaa,A.L., Salokorpi,T., Virtanen,M., Fellman,V., A national two year follow up study of extremely low birthweight infants born in 1996-1997, Archives of Disease in Childhood Fetal and Neonatal Edition, 88, F29-F35, 2003 **Study type** Prospective cohort study	**Setting** National cohort of all infants born with birth weight <1000 g and gestational age at least 22 full weeks born in Finland 1996-1997. **Inclusion criteria** All infants born with birth weight <1000 g and gestational age at least 22 full weeks born in Finland 1996-1997. **Exclusion criteria** None reported. **Sample size** n=208 extremely low birth weight infants (born with bw <1000 g) of which n=104 children were born at 22-26 wks GA **Characteristics** Characteristic	**Gestational age ascertainment** The estimation of gestation age was based on ultrasound examination before the end of 20 weeks (82%) or the last menstrual period (18%). **Outcome(s) of interest in this study** Cerebral palsy (CP); CP diplegia; CP tetraplegia; CP hemiplegia; CP ataxia/athetosis; hearing impairment; bilateral and unilateral blindness **Outcome(s) ascertainment/measures** A national neurological follow up program included an opthalmologic assessment at 12-18 months (corrected), and	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 18 months corrected age <u>CP</u> 22-23 wks GA: 1/5, 20.0% (0.5-71.6%) 24 wks GA: 2/18, 11.1% (1.4-34.7%) 25 wks GA: 4/34, 11.8% (3.3-27.5%) 26 wks GA: 5/47, 10.6% (3.6-23.1%) 22-26 wks GA: 12/104, 11.5% (6.1-19.3%) The whole cohort of children born <1000 g (mean GA 27.3 with range 22.3-34.9): 23/208, 11.1% (7.1-16.1%) <u>CP diplegia</u> The whole cohort of children born <1000 g (mean GA 27.3 with range 22.3-34.9): 15/208, 7.2% (4.1-11.6%) <u>CP tetraplegia</u> The whole cohort of children born <1000 g (mean GA	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Very low precision (wide confidence intervals) due to low sample size, especially can be seen in GA subgroups.

Study details	Participants		Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Aim of the study To study neurodevelopmental outcome in extremely low birthweight infants at 18 months of age, including comparisons to term born children, and assessment of risk factors for unfavourable outcome. **Study dates** Recruitment from 1st January 1996 to 31st December 1997, follow-up at 18 months of corrected age. **Country/ies where the study was carried out** Finland	Gestational age, mean (range), weeks	27.3 (22.3-34.9)	examinations by a neurologist, physiotherapist and speech therapist at the corrected age of 18 months. CP was defined as a non-progressive motor impairment with spastic or dystonic muscle tone, brisk tendon reflexes, positive Babinski's sign, and persistent primitive reflexes. Four categories were used: diplegia, hemiplegia, tetraplegia, ataxia or athetosis syndrome. Hearing impairment defined as necessitating hearing rehabilitation or the use of a hearing aid. Bilaterla blindess ("legally blind") and unilateral blindness (has lost vision in one eye). **Age at assessment** 12-18 and 18 months corrected age.	27.3 with range 22.3-34.9): 4/208, 1.9% (0.5-4.9%) <u>CP hemiplegia</u> The whole cohort of children born <1000 g (mean GA 27.3 with range 22.3-34.9): 2/208, 1.0% (0.1-3.4%) <u>CP ataxia/athetosis</u> The whole cohort of children born <1000 g (mean GA 27.3 with range 22.3-34.9): 2/208, 1.0% (0.1-3.4%) <u>Hearing impairment*</u> The whole cohort of children born <1000 g (mean GA 27.3 with range 22.3-34.9): 6/195, 3.1% (1.1-6.6%) *Data available for 195 children. At 12-18 months corrected age <u>Bilateral blindness**</u> The whole cohort of children born <1000 g (mean GA 27.3 with range 22.3-34.9): 1/197, 0.5% (0.01-2.8%) <u>Unilateral blindness**</u>	**4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes **6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Not clearly described how the outcomes were assessed and measured. **7. Was the condition measured reliably?** Unclear. Not clearly described how the outcomes were assessed and measured.
	Birthweight, mean (range), grams	807 (447-995)			
	Male gender, n (%)	97 (47)			
	Multiple pregnancy, n (%)	55 (26)			
	Antenatal steroid treatment, n (%)	164 (79)			
	Vaginal delivery, n (%)	68 (33)			
	Lower social classes 3-4, n (%)	120 (65)			
	Maternal smoking, n (%)	37 (19)			
	Small for gestational age, n (%)	84 (40)			
	IVH grades 2-4, n (%)	24 (12)			
	RDS, n (%)	144 (69)			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Source of funding The Finnish Paediatric Foundation and Signe and Ane Gyllenberg Foundation.	Septicaemia, n (%) 53 (26) ROP stages 3-5, n (%) 19 (9) Oxygen dependency at the age equivalent to 36 weeks, n (%) 81 (39)		The whole cohort of children born <1000 g (mean GA 27.3 with range 22.3-34.9): 2/197, 1.0% (0.1-3.6%) **Data available for 197 children.	**8. Was there appropriate statistical analysis?** No. Confidence intervals of the prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 322175 **Full citation**	**Setting** Population based cohort. **Inclusion criteria**	**Gestational age ascertainment** Gestational age ascertainment not reported.	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 2 years corrected age CP	**Overall quality** Low.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Toome,L., Varendi,H., Mannamaa,M., Vals,M.A., Tanavsuu,T., Kolk,A., Follow-up study of 2-year-olds born at very low gestational age in Estonia, Acta Paediatrica, 102, 300-307, 2013

Study type

Population based national cohort study (follow up study)

Aim of the study

To assess the growth, neurosensory and developmental impairment of very low gestational age (VLGA) infants at the age of two years, and to identify risk</td>
<td>Preterm infants: all infants born at a gestational age of 22+0 to 31+6 in Estonia, during the study dates.
Full term controls: born at term with a gestational age of ≥37 weeks, no requirement for medical care during the first week of life, born in the same area of the country, and the same gender and nationality as the preterm infant, born shortly after the expected date of the preterm infant.

Exclusion criteria

Death before the follow up examination.

Sample size

n = 187 very low gestational age infants (83% eligible for follow up 155/187)
n = 153 full term controls

Characteristics

<table>
<tr><th></th><th>VLGA infants</th><th>Full term infants</th></tr>
<tr><td>Gestational age, mean (95% CI), weeks</td><td>28.8 (28.4-29.1)</td><td>39.6 (39.4-39.7)</td></tr>
</table>
</td>
<td>Outcome(s) of interest in this study

CP
Cognitive delay
Language delay
Vision impairment
Hearing impairment

Outcome(s) ascertainment/measures

Families were invited for a physical assessment by a paediatrician, neurological examination by a child neurologist and an assessment of development by a child psychologist. Cerebral palsy was defined according to the guidelines of the Surveillance of Cerebral Palsy in Europe collaborative group, and the Gross Motor Function Classification System (GMFCS) was used to quantify motor function in infants with CP. The Bayley Scales of Infant and Toddler Development were used to</td>
<td><32 wks GA: 17/155, 11.0% (6.5-17.0%)
GMFCS level 2-5
<32 wks GA: 13/155, 8.4% (4.5-13.9%)
Spastic displegia
<32 wks GA: 7/155, 4.5% (1.8-9.1%)
<u>Cognitive delay</u>
<32 wks GA: 26/155, 17% (11-24%)
<u>Language delay</u>
<32 wks GA: 51/155, 33%(26-41%)
<u>Vision impairment</u>
<32 wks GA: 1/155, 0.64% (0.02-3.5%)
<u>Hearing impairment</u>
<32 wks GA:2/155, 1% (0.16-4.6%)</td>
<td>1. Was the sample representative of the target population?

Yes.

2. Were the study participants recruited in an appropriate way?

Yes.

3. Was the sample size adequate?

No. There was some imprecision (wide confidence intervals) due to the low sample size.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>factors associated with unfavourable outcomes in VLGA infants

Study dates

Children born 2007, assessed at 2 years corrected age.

Country/ies where the study was carried out

Estonia.

Source of funding

Tallinn Children's Hospital Foundation and by the grant GARLA 7094 from the Estonian Science Foundation.</td>
<td>
<table>
<tr><td>Birthweight, mean (95% CI), grams</td><td>1314 (1252-1377)</td><td>3611 (3536-3685)</td></tr>
<tr><td>Male, %</td><td>57</td><td>57</td></tr>
<tr><td>Multiple birth, %</td><td>25</td><td>1</td></tr>
<tr><td>Small for gestational age, %</td><td>10</td><td>7</td></tr>
<tr><td>Maternal age, mean (95% CI), years</td><td>31.4 (30.3-32.5)</td><td>30.5 (29.7-31.3)</td></tr>
<tr><td>Maternal higher education, %</td><td>27</td><td>50</td></tr>
</table>
</td>
<td>generate composite scores for cognitive, language and motor skills, with a mean (SD) score of 100 (±15). Results are presented according to the number of participants with scores <2SD below the mean for cognitive and language composite scores. A composite outcome measure of neurodevelopmental impairment was also used. This includes any one (or more) of the following criteria: CP with GMFCS level 2,3,4 or 5; cognitive and/or language composite scores of ≤-2SD below the norm; hearing loss corrected with hearing aids or deafness; vision moderately reduced or blindness.

Age at assessment

At 2 years corrected age</td>
<td></td>
<td>coverage of the identified sample?

The overall 2 year survival rate was 83%, with 47% in 22-25wk GA group and 92% in infants born 26-31 wks GA.

6. Were objective, standard criteria used for the measurement of the condition?

Yes.

7. Was the condition measured reliably?

Yes.

8. Was there appropriate statistical analysis?

N/A

9. Are all important confounding factors/subgroups/differe</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				nces identified and accounted for? N/A **10. Were subpopulations identified using objective criteria?** Yes.
Ref Id 323928 **Full citation** Vincer,M.J., Allen,A.C., Allen,V.M., Baskett,T.F., O'Connell,C.M., Trends in the prevalence of cerebral palsy among very preterm infants (<31 weeks' gestational age), Paediatrics and	**Setting** Three tertiary hospitals in Nova Scotia, Canada. Nova Scotia Atlee Perinatal Database and the Perinatal Follow-up Program Database were used. **Inclusion criteria** All very preterm liveborn infants (<31 weeks GA) born to mothers who resided in Nova Scotia. **Exclusion criteria** None reported. **Sample size**	**Gestational age ascertainment** GA was determined shortly after birth in the following hierarchical order: -contraception dating if mother was receiving fertility treatments -last menstrual period if it correspond to ultrasound dating within 10 days -ultrasound if it was >10 days difference from the last menstrual period or no dates were known -physical examination of the infant at birth if none of the three preceding estimates were available.	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 12 to 42 months' corrected age <u>CP</u> Children born 1993-1997 <31 wks GA: 23/288, 8.0% (5.1-11.7%) Children born 1998-2002 <31 wks GA: 42/251, 16.7% (12.3-21.9%) Children born 2003-2007 <31 wks GA: 16/262, 6.1% (3.5-9.7%) Children born 1993-2007	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Child Health, 19, 185-189, 2014

Study type

Population-based cohort study

Aim of the study

To describe the variation in the prevalence of cerebral palsy among very preterm infants over time and to relate these differences to other maternal and neonatal factors.

Study dates

1988-2007 (data from 1993 onwards used for this review)</td>
<td>n=1014 the whole cohort born in 1988-2007
n=801 cohort born in 1993-2007

Characteristics
<table>
<tr><th></th><th>1993-1997</th><th>1998-2002</th><th>2003-2007</th></tr>
<tr><td>Maternal age in years, mean (SD)</td><td>28.1 (5.9)</td><td>28.6 (6.2)</td><td>28.8 (5.6)</td></tr>
<tr><td>Single-parents family, %</td><td>15.8</td><td>23.3</td><td>18.3</td></tr>
<tr><td>Birth weight in grams, m (SD)</td><td>994 (346)</td><td>1048 (399)</td><td>1062 (379)</td></tr>
<tr><td>GA in weeks, mean (SD)</td><td>27.2 (2.6)</td><td>27.0 (2.7)</td><td>27.1 (2.6)</td></tr>
</table>
</td>
<td>Outcome(s) of interest in this study

Cerebral palsy (CP)

Outcome(s) ascertainment/measures

A neurological examination between 12 and 42 months' corrected age was used to presence or absence of CP and to define the gross motor functional classification. CP was defined as a disorder of control of movement or posture secondary to a nonproggressive brain lesion.

Age at assessment

12 to 42 months' corrected age</td>
<td><31 wks GA: 81/801, 10.1% (8.1-12.4%)

<u>Level 1 CP (mild)</u>
Children born between 1993-1997
<31 wks GA: 12/288, 4.2% (2.2-7.2%)
Children born between 1998-2002
<31 wks GA: 31/251, 12.4% (8.6-17.1%)
Children born between 2003-2007
<31 wks GA: 11/262, 4.2% (2.1-7.4%)

Children born between 1993-2007
<31 wks GA: 54/801, 6.7% (5.1-8.7%)

<u>Level 2-5 CP (moderate to severe)</u>
Children born between 1993-1997
<31 wks GA: 11/288, 3.8% (1.9-6.7%)
Children born between 1998-2002
<31 wks GA: 11/251, 4.4% (2.2-7.7%)
Children born between 2003-2007</td>
<td>3. Was the sample size adequate?

No.
Overall, the sample size was relatively large but because the study subgrouped according to epoch, the sample becomes smaller. Therefore, overall prevalence estimate for the time of interest was also calculated by the NGA technical team.

4. Were the study subjects and the setting described in detail?

Unclear.
To an extent yes but information on the background characteristics of the sample is rather limited.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out Canada **Source of funding** None reported.			<31 wks GA: 5/262, 1.9% (0.6-4.4%) Children born between 1993-2007 <31 wks GA: 27/801, 3.4% (2.2-4.9%) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**6. Were objective, standard criteria used for the measurement of the condition?** Unclear. Limited information provided about the assessments. **7. Was the condition measured reliably?** Unclear. Limited information provided about the assessments. **8. Was there appropriate statistical analysis?** No. Confidence intervals of prevalence not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
Ref Id 317215 **Full citation** Vohr,B.R., Wright,L.L., Poole,W.K., McDonald,S.A., Neurodevelopmental outcomes of extremely low birth weight infants <32 weeks' gestation between 1993 and 1998, Pediatrics, 116, 635-643, 2005 **Study type** A multicentre cohort study	**Setting** Using data collected from 12 different centers of the National Institute of Child Health and Human Development Neonatal Research Network in the US. **Inclusion criteria** Infants born prematurely at 22-32 weeks of gestation with an extremely low birth weight (401-1000 g) who were being cared for in 1 of the 12 centres of the National Institute of Child Health and Human Development Neonatal Research Network during 1993-1998. Deaths in the delivery room were included. **Exclusion criteria** None reported. **Sample size**	**Gestational age ascertainment** Not reported. The study included children born with extremely low birth weight, not gestational as such. **Outcome(s) of interest in this study** Disorders: Cerebral palsy (CP); moderate to severe CP; Bayley MDI <70; unilateral blindness; bilateral blindness; permanent hearing loss Problems: Bayley PDI <70	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 18-22 months corrected age Disorders: <u>CP</u> Years 1993-94 22-26 wks GA: 134/665, 20.1% (17.2-23.4%) 27-32 wks GA: 55/444, 12.4%, (9.5-15.8%) Years 1995-96 22-26 wks GA: 134/716, 18.7% (15.9-21.8%) 27-32 wks GA: 60/538, 11.2% (8.6-14.1%) Years 1997-98 22-26 wks GA: 165/910, 18.1% (15.7-20.8%) 27-32 wks GA: 58/512, 11.3% (8.7-14.4%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Aim of the study

This study evaluated the impact of changes in perinatal management of neurodevelopmental impairment at 18 to 22 months' corrected age of low gestation (22-26 weeks) and higher gestation (27-32 weeks) extremely low birth weight infants (401-1000 g birth weight) who were cared for in the National Institute of Child Health and Human Development Neonatal Research Network during 3 epochs (1993-1994, 1995-1996, and 1997-1998). It was hypothesized that outcomes would</td>
<td>n=3785 infants included in analysis (51% of the original sample, 79.5% of the ones who survived up to discharge or 120 days)

Characteristics
<table>
<tr><td></td><td colspan="2">1993-94</td><td colspan="2">1995-96</td><td colspan="2">1997-98</td></tr>
<tr><td></td><td>22-26 weeks</td><td>27-32 weeks</td><td>22-26 weeks</td><td>27-32 weeks</td><td>22-26 weeks</td><td>27-32 weeks</td></tr>
<tr><td>Evaluated at 18 mo, n</td><td>665</td><td>444</td><td>716</td><td>538</td><td>910</td><td>512</td></tr>
<tr><td>White, %</td><td>33.8</td><td>35.6</td><td>32.4</td><td>38.3</td><td>37.1</td><td>46.2</td></tr>
<tr><td>Maternal age <19 y, %</td><td>14.6</td><td>10.4</td><td>11.6</td><td>11.7</td><td>11.5</td><td>11.1</td></tr>
</table>
</td>
<td>Outcome(s) ascertainment/measures

At 18-22 months corrected age, families were invited to participate in a comprehensive assessment that consisted of a battery of developmental, neurologic, and behavioural assessment, a medical and social history and parent interviews. Bayley Scales of Infant Development II (BSID-II) was administered by a certified examiner who was trained to reliability and previous formal training in test administration. The Mental Developmental Index (MDI) was derived, a score of <70 was considered abnormal.
The neurologic examinations were based on the Amiel Tison neurologic assessment, performed by experienced, certified examiners who had been trained to reliability in a 2-day workshop. CP was defined as nonprogressive central nervous system disorder characterised by abnormal muscle tone in at least 1 extremity and abnormal control of movement or</td>
<td>All epochs, 1993-98
22-26 wks GA: 433/2291, 18.9% (17.3-20.6%)
27-32 wks GA: 173/1494, 11.6% (10.0-13.3%)
22-32 wks GA: 606/3785, 16.0% (14.9-17.2%)

Moderate to severe CP
Years 1993-94
22-26 wks GA: 80/665, 12.1% (10.0-14.8%)
27-32 wks GA: 35/444, 7.8% (5.6-10.8%)
Years 1995-96
22-26 wks GA: 77/716, 10.8% (8.6-13.3%)
27-32 wks GA: 38/538, 7.1% (5.1-9.6%)
Years 1997-98
22-26 wks GA: 95/910, 10.4% (8.5-12.6%)
27-32 wks GA: 32/512, 6.3% (4.3-8.7%)

All epochs, 1993-1998
22-26 wks GA: 252/2291, 11.0% (9.8-12.4%)
27-32 wks GA: 105/1494, 7.0% (5.8-8.4%)
22-32 wks GA: 357/3785, 9.4% (8.5-10.4%)</td>
<td>4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No
Around 20% were lost to follow-up of the survivors.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes</td>
</tr>
</table>

Study details	Participants							Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
improve over the 3 epochs. **Study dates** 1993-1998, follow-up at 18 to 22 months of corrected age. **Country/ies where the study was carried out** USA **Source of funding** National Institute of Child Health and Human Development through Cooprative Agreements, Brown University; , Indiana University; Cincinnati University; , Emory	Maternal education <12 y, %	34.4	26.6	27.2	23.3	28.7	24.0	posture. Moderate to severe CP included children who were nonambulatory or required an assistive device for ambulation. Detailed interim medical history was obtained including data on hearing status and vision status. Blindness is defined as blind with no functional vision. Permanent hearing loss is defined as a hearing loss requiring amplification in both ears. Problems: Bayley Scales of Infant Development II (BSID-II) was administered by a certified examiner who was trained to reliability and previous formal training in test administration. The Psychomotor Developmental Index (PDI) was derived, a score of <70 was considered abnormal. **Age at assessment** 18-22 months' corrected age	<u>Bayley MDI <70</u> Years 1993-94 22-26 wks GA: 278/665, 41.8% (38.0-45.7%) 27-32 wks GA: 133/444, 29.9% (25.7-34.5%) Years 1995-96 22-26 wks GA: 276/716, 38.5% (35.0-42.2%) 27-32 wks GA: 137/538, 25.5% (21.8-29.4%) Years 1997-98 22-26 wks GA: 339/910, 37.2% (34.1-40.5%) 27-32 wks GA: 117/512, 22.8% (19.3-26.7%) All epochs, 1993-1998 22-26 wks GA: 893/2291, 39.0% (37.0-41.0%) 27-32 wks GA: 387/1494, 25.9% (23.7-28.2%) 22-32 wks GA: 1280/3785, 33.8% (32.3-35.4%) <u>Unilateral blindness</u> Years 1993-94 22-26 wks GA: 28/665, 4.2% (2.8-6.0%) 27-32 wks GA: 9/444, 2.1% (0.9-3.8%) Years 1995-96 22-26 wks GA: 18/716, 2.5% (1.5-3.9%)	**8. Was there appropriate statistical analysis?** No Confidence intervals were not provided. Number of cases were not provided either, only percentage and denominator (number of children evaluated). **9. Are all important confounding factors/subgroups/differences identified and accounted for?** Not applicable. **10. Were subpopulations identified using objective criteria?** Not applicable.
	Medicaid, %	63.8	63.7	65.3	55.5	58.8	51.6			
	Outborn, %	13.1	11.7	11.6	7.6	9.1	8.6			
	Ceasarean section, %	41.6	68.8	46.0	73.9	50.7	73.0			
	Birth weight, mean g	752.6	858.4	750.4	857.7	744.9	860.2			
	SGA, %	4.1	38.1	3.3	37.2	4.7	35.3			
	Surfactant, %	75.8	62.6	79.9	68.2	84.9	67.8			

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>University; Case Western University; University of Texas-Houston; Miami University; Wayne State University; University of Tennessee; Stanford University; University of New Mexico; U10 HD27871, Yale University, and RTI International.</td>
<td>
<table>
<tr><td>IVH grades 3-4, %</td><td>28.0</td><td>14.0</td><td>28.4</td><td>12.9</td><td>17.2</td><td>9.5</td></tr>
<tr><td>PVL, %</td><td>7.3</td><td>5.2</td><td>8.8</td><td>7.0</td><td>6.2</td><td>4.7</td></tr>
<tr><td>O2 at 36 weeks, %</td><td>47.7</td><td>30.2</td><td>51.9</td><td>33.8</td><td>54.3</td><td>34.5</td></tr>
<tr><td>Days on ventilator, mean</td><td>36.6</td><td>16.5</td><td>34.7</td><td>15.7</td><td>35.2</td><td>14.5</td></tr>
<tr><td>Sepsis, %</td><td>48.0</td><td>31.1</td><td>45.1</td><td>29.4</td><td>43.4</td><td>28.1</td></tr>
<tr><td>Multiple births, %</td><td>18.3</td><td>20.9</td><td>17.2</td><td>19.1</td><td>24.0</td><td>25.6</td></tr>
<tr><td>Days in hospital, mean</td><td>114.4</td><td>86.0</td><td>109.8</td><td>83.30</td><td>108.7</td><td>77.7</td></tr>
</table>
</td>
<td></td>
<td>27-32 wks GA: 6/538, 1.1% (0.4-2.4%)
Years 1997-98
22-26 wks GA: 15/910, 1.6% (0.9-2.7%)
27-32 wks GA: 4/512, 0.8% (0.2-2.0%)

All epochs, 1993-1998
22-26 wks GA: 61/2291, 2.7% (2.0-3.4%)
27-32 wks GA: 19/1494, 1.3% (0.8-2.0%)
22-32 wks GA: 80/3785, 2.1% (1.7-2.6%)

<u>Bilateral blindness</u>
Years 1993-94
22-26 wks GA: 15/665, 2.3% (1.3-3.7%)
27-32 wks GA: 6/444, 1.4% (0.5-2.9%)
Years 1995-96
22-26 wks GA: 11/716, 1.5% (0.8-2.7%)
27-32 wks GA: 2/538, 0.4% (0.05-1.3%)
Years 1997-98
22-26 wks GA: 9/910, 1.0% (0.5-1.9%)
27-32 wks GA: 2/512, 0.4% (0.05-1.4%)

All epochs, 1993-1998</td>
<td></td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	<table><tr><td>Coorected age, months</td><td>19.4</td><td>19.6</td><td>19.3</td><td>19.4</td><td>19.6</td><td>19.9</td></tr></table>		22-26 wks GA: 35/2291, 1.5% (1.1-2.1%) 27-32 wks GA: 10/1494, 0.7% (0.3-1.2%) 22-32 wks GA: 45/3785, 1.2% (0.9-1.6%) <u>Permanent hearing loss</u> Years 1993-94 22-26 wks GA: 23/665, 3.4% (2.2-5.1%) 27-32 wks GA: 8/444, 1.7% (0.8-3.5%) Years 1995-96 22-26 wks GA: 16/716, 2.3% (1.3-3.6%) 27-32 wks GA: 4/538, 0.8% (0.2-1.9%) Years 1997-98 22-26 wks GA: 16/910, 1.8% (1.0-2.8%) 27-32 wks GA: 9/512, 1.8% (0.8-3.3%) All epochs, 1993-1998 22-26 wks GA: 55/2291, 2.4% (1.8-3.1%) 27-32 wks GA: 21/1494, 1.4% (0.9-2.1%) 22-32 wks GA: 76/3785, 2.0% (1.6-2.5%) Problems: <u>PDI <70</u>	

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			Years 1993-94 22-26 wks GA: 210/665, 31.6% (28.1-35.3%) 27-32 wks GA: 104/444, 23.4% (19.6-27.7%) Years 1995-96 22-26 wks GA: 228/716, 31.8% (28.4-35.4%) 27-32 wks GA: 98/538, 18.3% (15.0-21.7%) Years 1997-98 22-26 wks GA: 237/910, 26.0% (23.2-29.0%) 27-32 wks GA: 87/512, 16.9% (13.8-20.5%) All epochs, 1993-1998 22-26 wks GA: 675/2291, 29.5% (27.6-31.4%) 27-32 wks GA: 289/1494, 19.3% (17.4-21.4%) 22-32 wks GA: 964/3785, 25.5% (24.1-26.9%) Number of cases were not provided, therefore, they were calculated by the NGA technical team using the prevalence percentage and the denominator given. Confidence intervals were calculated by the NGA technical team using	

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			http://statpages.info/confint.html	
Ref Id 433505 **Full citation** Wolke, D., Samara, M., Bracewell, M., Marlow, N., Specific Language Difficulties and School Achievement in Children Born at 25 Weeks of Gestation or Less, Journal of Pediatrics, 152, 256-262.e1, 2008 **Study type** Prospective national cohort study (EPICURE study group).	**Setting** Population based study, EPICURE. **Inclusion criteria** All surviving children born at 25 weeks, 6 days gestational age or less. Children alive at age 30 months. Children in mainstream education. **Exclusion criteria** Children who did not survive age 30 months. **Sample size** n=241 children for whom parents consented to the study. **Characteristics**	**Gestational age ascertainment** Definition of gestational age ascertainment not reported. **Outcome(s) of interest in this study** Language ability **Outcome(s) ascertainment/measures** Repetitive and expressive language was assessed using the PreSchool Language Scale-3 (PLS-3). **Age at assessment** Median 6 years and 4 months.	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At median age 6 years and 4 months Language abilities (PLS-3 score), serious impairment (<2SD) ≤25 wks and 6 days GA: total PLS-3: 31/199, 15.6% (10.8-21.4%) ≤25 wks and 6 days GA: PLS-3 boys: 20/94, 21.3% (13.5-31%) ≤25 wks and 6 days GA: PLS-3 girls: 11/105, 10.5% (5.3-18.0%) Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes. **2. Were the study participants recruited in an appropriate way?** Yes. **3. Was the sample size adequate?** No. Low precision (wide confidence intervals) due to low sample size, especially in gender subgroups.

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Aim of the study To determine whether language and educational problems are specific or due to general cognitive deficits in children born at 25 weeks' gestation or less. **Study dates** Children born 1995, assessed at median age 6 years and 4 months. **Country/ies where the study was carried out** UK. **Source of funding** Not reported.				**4. Were the study subjects and the setting described in detail?** Yes. **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes. **6. Were objective, standard criteria used for the measurement of the condition?** Yes. **7. Was the condition measured reliably?** Yes. **8. Was there appropriate statistical analysis?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				No. Confidence intervals for proportions were not reported. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 433508 **Full citation** Wood, N. S., Marlow, N., Costeloe, K., Gibson, A. T., Wilkinson, A. R., Neurologic and developmental	**Setting** Infants born in all 276 maternity units in the UK and Ireland from March through to December 1995. **Inclusion criteria** All infants born at 20-25 weeks of gestation. **Exclusion criteria**	**Gestational age ascertainment** Gestational age was determined by the date of the mother's last menstrual period and by early ultrasonography. For infants who were admitted to NICU, gestation was calculated using the date of the last menstrual period, by review of ultrasound studies done before 20 weeks, or on	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At median age 30 months CP (children with neuromotor disability) 22-25 wks GA: 50/283, 17.7% (13.4-22.6%) Diplegia CP 22-25 wks GA: 27/283, 9.5% (6.4-13.6%)	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>disability after extremely preterm birth. EPICure Study Group, New England Journal of Medicine, 343, 378-84, 2000

Study type

Population based prospective cohort study.

Aim of the study

To assess the neurologic and developmental disabilities among extremely premature infants who survived to a median age of 30 months.

Study dates

Infants born 1995, assessed at median age 30 months.</td>
<td>Infants who were considered to be born ≥26 weeks.
Infants who did not survive to assessment time of study.

Sample size

N=4004 infants identified
n=1185 survived at birth (843/1185 were admitted to NICU; 342/1185 died in the delivery room)
n=283 assessed at follow-up

Characteristics
<table>
<tr><td></td><td>preterm cohort 20*-25 wks GA (N=1185)</td></tr>
<tr><td>GA 22 wks (n)</td><td>138 (116 died in delivery room)</td></tr>
<tr><td>GA 23 wks (n)</td><td>241 (110 died in delivery room)</td></tr>
<tr><td>GA 24 wks (n)</td><td>382 (84 died in delivery room)</td></tr>
</table>
</td>
<td>the basis of clinical examination by a paediatrician.

Outcome(s) of interest in this study

Neuromotor (Gait, sitting, hand use, head control)
Sensory and communication (vision, hearing, communication)
Recurrent non-febrile seizures

Outcome(s) ascertainment/measures

All children had clinical examination including detailed medical history obtained from semi-structured interview with family, and a neurologic assessment, classification of degree and type of disability, and functional classification of hearing and visual ability. Development was assessed using the Bayley Scales of Infant Development II (BSID II) for mental and psychomotor development (MDI or PDI; score <55 considered as</td>
<td><u>Severe diplegia CP</u>
22-25 wks GA: 12/283, 4.2 (2.2-7.3%)
<u>Hemiplegia CP</u>
22-25 wks GA: 5/283, 1.8% (0.6-4.1%)
<u>Severe hemiplegia CP</u>
22-25 wks GA: 1/283, 0.4% (0.01-2.0%)
<u>Quadriplegia CP</u>
22-25 wks GA: 12/283, 4.2 (2.2-7.3%)
<u>Severe quadriplegia CP</u>
22-25 wks GA: 11/283, 3.9% (2.0-6.9%)

<u>Vision impairment (severe disability, n=283)</u>
22-25 wks GA: blind or perceives light: 7/283, 2.5% (1-5%)
<u>Hearing impairment (severe disability, n=283)</u>
22-25 wks GA: impaired, corrected with hearing aid:3/283, 1.1% (0.2-3.1%)
22-25 wks GA: impaired, uncorrected even with hearing aid: 5/283, 1.8% (0.58-4.1%)
<u>Speech/communication (severe disability, n=283)</u>
22-25 wks GA: communicating by</td>
<td>2. Were the study participants recruited in an appropriate way?

Yes.

3. Was the sample size adequate?

No. For assessment of CP, the precision was low (wide confidence intervals) due to low sample size.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes.
302 of the survivors were eligible for follow up, but 16 children were not assessed because parents declined invitation for assessment, or</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Country/ies where the study was carried out UK and Ireland. **Source of funding** Serono Laboratories UK Baby Life Support Systems	<table><tr><td>GA 25 wks (n)</td><td>424 (67 died in delivery room)</td></tr><tr><td></td><td></td></tr><tr><td></td><td></td></tr></table>*Three infants, all of whom died, were admitted at <22 wks GA.	severe impairment, 55-69 considered as moderate impairment, 70-84 considered as mild impairment). If the child was unable to complete the BSID II assessment, the paediatrician estimated the child's development level as severely or moderately impaired (equivalent to Bayley score <55 or 55-69) or as not impaired. Assessments were carried out by 10 experienced developmental paediatricians who were trained in administering the Bayley assessment. Severe disability was defined as a child needing physical assistance to perform daily activities. Disabilities that did not fall under this category were classed as 'other disabilities'. Cerebral palsy was classified retrospectively according to the description of function for each limb in children with abnormal results or neurological examination (diplegia, hemiplegia,	systemised method only: 3/283, 1.1% (0.2-3.1%) 22-25 wks GA: not communicating by speech or other method: 15/283, 5.3% (3.0-8.6%) Neuromotor domain, severe disability (n=283) (problems?) 22-25 wks GA: unable to walk without assistance: 27/283, 9.5% (6.4-13.6%) 22-25 wks GA: unable to sit: 8/283, 2.8% (1.2-5.5%) 22-25 wks GA: unable to use hands to feed self: 12/283, 4.2% (2.2-7.3%) 22-25 wks GA: unable to control head movement without support: 3/283, 1.1% (0.2-3.7%) Problems (n=283): Neuromotor (mild/moderate): 22-25 wks GA: non-fluent gait: 33/283, 11.7% (8.2-16%) 22-25 wks GA: abnormal gait, reduced mobility: 6/283, 2.1% (0.8-4.6%)	failed to bring the children for evaluation 283/302 (94%) were assessed for follow up. **6. Were objective, standard criteria used for the measurement of the condition?** Yes. **7. Was the condition measured reliably?** Yes. **8. Was there appropriate statistical analysis?** No. For CP outcome, confidence intervals were not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?**

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
		quadriplegia, other non-spastic types (hypotonia, dyskinesia)). **Age at assessment** Median 30 months.	22-25 wks GA: sitting unsupported but unstable: 7/283, 2.5% (1.0-5.0%) 22-25 wks GA: sitting supported: 6/283, 2.1% (0.8-4.6%) 22-25 wks GA: some difficulty feeding with both hands: 26/283, 9.2% (6.1-13.2%) 22-25 wks GA: unstable head control, but no support required: 6/283, 2.1% (0.8-4.6%)	N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 451621 **Full citation** Anderson, P., Doyle, L. W., Victorian Infant Collaborative	**Setting** Cohort of very preterm children in the region of Victoria, Australia (Victorian Infant Collaborative Study Group). **Inclusion criteria**	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study**	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 8 years age Major intellectual impairment (WISC-III IQ<70, n=275)	**Overall quality** Low. **1. Was the sample representative of the target population?** Yes.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Study, Group, Neurobehavioral outcomes of school-age children born extremely low birth weight or very preterm in the 1990s, JAMA, 289, 3264-72, 2003

Study type

Prospective regional cohort study (Victorian Infant Collaborative Study Group)

Aim of the study

To determine the cognitive, educational, and behavioural outcome of ELBW or very preterm infants born in the 1990s compared with normal birth weight controls.</td>
<td>All surviving children with birth weights <1000g or with gestational ages younger than 28 completed weeks in Victoria, Australia between 1991-1992.

Exclusion criteria

Children who were not able to complete the psychological assessment due to significant neurosensory impairments.

Sample size

N=568 consecutive live births of neonates with BW <1000g or <28 weeks GA.
n=298 infants survived to 2, and 5 years assessment.
n=275 children assessed at 8 years age.

Characteristics

<table>
<tr><td></td><td>ELBW/very preterm group (n=275)</td></tr>
<tr><td>Small for gestational age (<-2SD)(n,%)</td><td>38 (13.8)</td></tr>
<tr><td>Male (n, %)</td><td>128 (46.5)</td></tr>
</table>
</td>
<td>Intellectual impairment (Cognitive ability)
Specific learning difficulty (Educational progress)
(also reports behavioural problems)

Outcome(s) ascertainment/measures

Cognitive ability was assessed using the Wechsler Intelligence Scale for Children (WISC-III). Full scale IQ was a measure of general intellectual ability. Major intellectual impairment was classified as an IQ below 70 (<-2SDs). Educational progress was assessed using the Wide Range Achievement Test (WRAT3: reading, spelling, arithmetic) and the Comprehensive Scales of Student Abilities (CSSA, teacher assessed for verbal thinking, speech, reading, writing, handwriting, maths, general facts, basic motor generalisations, social behaviour). For WRAT3 major impairment represented a score <70. The CSSA scale</td>
<td><28 wks GA or ELBW: Full scale IQ: 14/275, 5.1% (2.8-8.4%)
<u>Educational progress (WRAT3 score <70, n=275)</u>
<28 wks GA or ELBW: major reading impairment: 16/275, 5.8% (3.4-9.3%)
<28 wks GA or ELBW: major spelling impairment: 7/275, 2.54% (1.0-5.2%)
<28 wks GA or ELBW: major arithmetic impairment: 18/275, 6.6% (4.0-10.2%)

the study also reported the following, but no outcome measurements were reported:
<u>CP</u>
29/275, 10.5% (7.2-14.8%)
<u>Blindness</u>
3/275, 1.1% (0.2-3.2%)
<u>Hearing impairment (requiring hearing aids)</u>
4/275, 1.5% (0.4-3.7%)</td>
<td>2. Were the study participants recruited in an appropriate way?

The participants were recruited consecutively.

3. Was the sample size adequate?

Yes.

4. Were the study subjects and the setting described in detail?

Yes.

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear. The follow up rate was 92.3%, of which some of the group were lost to follow up or refused to participate, or were living in another country. The</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Study dates

Infants born 1991-1992, assessed at 8 years age.

Country/ies where the study was carried out

Australia.

Source of funding

Health and Community Services, Australia. National Health and Medical Research Council, Australia.</td>
<td>
<table>
<tr><td>Married mother (n, %)</td><td>180/271 (66.4)</td></tr>
<tr><td>Low SES (n, %)</td><td>132 (48.0)</td></tr>
<tr><td>Maternal education (≥12 years schooling)</td><td>129/269 (48.0)</td></tr>
<tr><td>Maternal ethnicity (born in English-speaking country)</td><td>220/274 (80.3)</td></tr>
<tr><td>Maternal ethnicity (black)</td><td>3/274 (1.1)</td></tr>
</table>
</td>
<td>was age standardised with a mean of 100 (SD 15).

Age at assessment

8 years age.</td>
<td></td>
<td>children who were not assessed at 8 years age, tended to be from lower social class.

6. Were objective, standard criteria used for the measurement of the condition?

Unclear. For CP, blindness and hearing impairment, criteria for measurement of the outcomes were not reported.

7. Was the condition measured reliably?

Unclear. For CP, blindness and hearing impairment, criteria for measurement of the outcomes were not reported.

8. Was there appropriate statistical analysis?

No. Confidence intervals for prevalence estimates were not provided.</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				9. Are all important confounding factors/subgroups/differences identified and accounted for? N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 321687 **Full citation** Johnson,S., Fawke,J., Hennessy,E., Rowell,V., Thomas,S., Wolke,D., Marlow,N., Neurodevelopmental disability through 11 years	**Setting** National cohort of all children born at <26 weeks of gestation in UK and Ireland. **Inclusion criteria** All children born at <26 weeks of gestation in UK and Ireland. **Exclusion criteria** None reported.	**Gestational age ascertainment** Not reported. **Outcome(s) of interest in this study** Cerebral palsy, cognitive ability (intellectual disability), vision, hearing	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 11 years <u>CP any</u> <26 wks GA: 38/219, 17.4% (12.6-23.0%) 25 wks GA: 18/126, 14.3% (8.7-21.6%) 24 wks GA: 15/70, 21.4% (12.5-32.9%) <=23 wks GA: 5/23, 21.7% (7.5-43.7%)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?**

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>of age in children born before 26 weeks of gestation, Pediatrics, 124, e249-e257, 2009

Study type

National population-based prospective cohort study

Aim of the study

To assess functional disability in children born before 26 weeks of gestation at 11 years of age and the stability of findings in individuals between 6 and 11 years of age.

Study dates</td>
<td>Sample size

N=219 followed up at 11 years of age

Characteristics

<table>
<tr><th></th><th>Assessed at 11 y</th><th>Not assessed at 11y</th></tr>
<tr><td>Male, %</td><td>46</td><td>55</td></tr>
<tr><td>White ethnicity, %</td><td>82</td><td>65</td></tr>
<tr><td>GA <25wks, %</td><td>42</td><td>37</td></tr>
<tr><td>Singleton, %</td><td>72</td><td>80</td></tr>
<tr><td>Primigravid, %</td><td>30</td><td>33</td></tr>
<tr><td>O2 at 36 wks, %</td><td>73</td><td>74</td></tr>
</table>
</td>
<td>Outcome(s) ascertainment/measures

Cognitive ability was assessed by using the Kaufman-Assessment Battery for Children (K-ABC). This yields a mental processing score (MPC) for global cognitive ability (mean 100 [SD 15]). Cogtivie impairment was categorised by using conventional SD-banded cutoffs. The scores of the comparison group was used as reference data (mild 82-92; moderate 71-81; severe <=70).
Nueormotor function was assessed by using a standard paediatric evaluation and presence and type of CP, independent of degree of disability and was classified retrospectively by using clinical information obtained at the study assessment. Objective ratings of neuromotor function were made using the Gross Motor Function Classification System (GMFCS) and the Manual Abilities Classification System (MACS).</td>
<td><u>Severe CP (Class 4 or 5)</u>
<26 wks GA: 14/219, 6.4% (3.5-10.5%)
25 wks GA: 6/126, 4.8% (1.8-10.1%)
24 wks GA: 6/70, 8.6% (3.2-17.7%)
<=23 wks GA: 2/23, 8.7% (1.1-28.0%)

<u>Moderate CP</u>
<26 wks GA: 7/219, 3.2% (1.3-6.5%)
25 wks GA: 3/126, 2.4% (0.5-6.8%)
24 wks GA: 3/70, 4.3% (0.9-12.0%)
<=23 wks GA: 1/23, 4.4% (0.1-22.0%)

Severe cognitive impairment (MPC <=70)
<26 wks GA: 32/219, 14.6% (10.2-20.0%)
25 wks GA: 13/126, 10.3% (5.6-17.0%)
24 wks GA: 15/70, 21.4% (12.5-32.9%)
<=23 wks GA: 4/23, 17.4% (5.0-38.8%)

Moderate cognitive impairment (MPC 71-81)</td>
<td>Yes

3. Was the sample size adequate?

No.
Low precision (wide confidene intervals) due to relatively small sample size.

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

No.
71% of the eligible ones were assessed at 11 years of age.

6. Were objective, standard criteria used for</td>
</tr>
</table>

Study details	Participants			Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Children born in 1995, assessed at 11 years of age. **Country/ies where the study was carried out** UK and Ireland **Source of funding** The Medical Research Council.	Chorioamnionitis, %	22	33	Sensory impairment (hearing, vision) were assessed by clinical examination. Severe vision impairment defined as blind or can only see light. Moderate vision impairment defined as visually impaired but not blind. Severe hearing impairment defined as profound hearing impairment and moderate hearing impairment defined as hearing loss with aids. **Age at assessment** 11 years	<26 wks GA: 55/219, 25.1% (19.5-31.4%) 25 wks GA: 32/126, 25.4% (18.1-33.9%) 24 wks GA: 18/70, 25.7% (16.0-37.6%) <=23 wks GA: 5/23, 17.4% (5.0-38.8%) Moderate to severe cognitive impairment (MPC <82) <26 wks GA: 87/219, 39.7% (33.2-46.5%) 25 wks GA: 45/126, 35.7% (27.4-44.7%) 24 wks GA: 33/70, 47.1% (35.1-59.5%) <=23 wks GA: 9/23, 39.1% (19.7-61.5%) Severe vision impairment (blind or sees light only) <26 wks GA: 3/219, 1.4% (0.3-4.0%) 25 wks GA: 3/126, 2.4% (0.5-6.8%) 24 wks GA: 1/70, 1.4% (0.04-7.7%) <=23 wks GA: 2/23, 8.7% (1.1-28.0%) Moderate vision impairment (visually impaired, not blind)	**the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals for prevalence estimates not provided (apart from overall CP). **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A
	Abnormal cerebal ultrasound, %	17	18			
	Operation for NEC, %	3	7			

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
			<26 wks GA: 16/219, 7.3% (4.2-11.6%) 25 wks GA: 6/126, 4.8% (1.8-10.1%) 24 wks GA: 7/70, 10.0% (4.1-19.5%) <=23 wks GA: 3/23, 13.0% (2.8-33.6%) Severe hearing impairment (profound hearing loss) <26 wks GA: 1/219, 0.5% (0.01-2.5%) 25 wks GA: 0/126, 0% 24 wks GA: 1/70, 1.4% (0.04-7.7%) <=23 wks GA: 0/23, 0% Moderate hearing impairment (hearing loss with aids) <26 wks GA: 3/219, 1.4% (0.3-4.0%) 25 wks GA: 1/126, 0.8% (0.02-4.3%) 24 wks GA: 2/70, 2.9% (0.4-9.9%) <=23 wks GA: 0/23, 0% Confidence intervals calculated by the NGA technical team using http://statpages.info/confint.html	**10. Were subpopulations identified using objective criteria?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Ref Id 409707 **Full citation** Agerholm, H., Rosthoj, S., Ebbesen, F., Developmental problems in very prematurely born children, Danish Medical Bulletin, 58, A4283, 2011 **Study type** Regional birth cohort study **Aim of the study** To describe the developmental outcome of routine follow-up assessments at the age of five years in a regional	**Setting** A regional cohort of all live births in the catchment area of Aalborg hospital in the County of North Jutland in Denmark. **Inclusion criteria** All livebirths with gestational age >=24 and <32 weeks in the County of North Jutland, Denmark within the catchment area of Aalborg hospital during the period from 1 January 1996 t0 31 December 2000. **Exclusion criteria** None reported. **Sample size** N=237 live born children with 24-31 weeks GA in the geographical area N=204 children survived N=175 children followed-up at 5 years of age (86% of the ones who survived) N=168 children included in analysis (7 children with CP could not be assessed)	**Gestational age ascertainment** Not reported **Outcome(s) of interest in this study** Motor delay (MABC <5th percentile) **Outcome(s) ascertainment/measures** At 5 years of age, the children were assessed at the outpatient clinic of Aalborg hospital; according to the routine follow-up assessment program for very premature born children. Assessment was carried out by experiences physiotherapists and occupational therapists who are trained in the use of test manuals available for even and precise assessment. After all the children in the birth cohort for a given year	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 5 years age Motor deficit (M-ABC <5th percentile total score) (disorder) 24-31 wks GA: 30/168, 17.9% (12.4-24.5%)	**Overall quality** Moderate **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** No. Low precision, wide confidence intervals, due to relatively small sample size.

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>cohort of children born at a gestational age <32 weeks and to investigate neonatal risk factors associated with developmental problems.

Study dates

Children born 1996-2000, follow-up at 5 years of age.

Country/ies where the study was carried out

Denmark

Source of funding

None reported</td>
<td>Characteristics
<table>
<tr><th></th><th>Normal development n=70</th><th>Developmental problems n=105</th></tr>
<tr><td>GA <28 wks, %</td><td>13</td><td>27</td></tr>
<tr><td>Singleton, %</td><td>64</td><td>74</td></tr>
<tr><td>SGA, %</td><td>21</td><td>22</td></tr>
<tr><td>Male, %</td><td>40</td><td>68</td></tr>
<tr><td>Asphyxia (Apgar score <=7 at 5 min), %</td><td>7</td><td>11</td></tr>
<tr><td>Septicaemia, %</td><td>9</td><td>24</td></tr>
</table>
</td>
<td>had been assessed at five years of age, they were categorised by the same physiotherapist or occupational therapist according to their developmental outcome within the following areas: gross motor function, fine motor function, perception, cognition and behaviour. They were divided into three categories: category 1 contained children with a normal developmental outcome corresponding to their age; category 2 contained children under observational for developmental deficiencies i.e. children with slight deficiencies in 1-3 areas compared with a normal developmental outcome and who needed suggestions for stimulation, but otherwise had no further need for supportive measures; category 3 contained children with developmental deficiencies i.e. moderate to severe developmental deficiencies in more than two areas compared with a normal developmental outcome and in</td>
<td></td>
<td>4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Unclear. 86% of the survived children were followed up.

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?</td>
</tr>
</table>

Study details	Participants			Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
	Respiratory distress syndrome, %	37	39	need of extra or extensive supportive measures. Motor function was examined using the Movement Assessment Battery for Children (M-ABC), it measures three items in the area of manual dexterity, two items in the area of ball skills and three items in the area of balance. The items were scored from 0 to 5, where 0 was the optimum score. The test is standardised and the scores are presented in relation to the 5th and the 15th percentile in the reference group. A score above the 15th percentile show normal motor skills. A score between the 5th and 15th percentile indicates need for observation for motor function deficit, and a score under 5th percentile indicates motor function deficit. **Age at assessment** 5 years		No. Confidence intervals of prevalence estimates not provided. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A **10. Were subpopulations identified using objective criteria?** N/A
	BPD, %	3	16			
	Abnormal cerebral ultrasound, %	3	12			
	Persistent ductus arteriosus, %	1	16			
	Social class group 1 (lowest), %	6	24			

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Ref Id

473260

Full citation

Hellgren, K. M., Tornqvist, K., Jakobsson, P. G., Lundgren, P., Carlsson, B., Kallen, K., Serenius, F., Hellstrom, A., Holmstrom, G., Ophthalmologic outcome of extremely preterm infants at 6.5 years of age: Extremely preterm infants in Sweden study (EXPRESS), JAMA Ophthalmology, 134, 555-562, 2016

Study type

National cohort study (EXPRESS study)</td>
<td>Setting

National cohort study (EXPRESS cohort), at 7 university hospitals in Sweden at 6.5 years (+/- 3 years)

Inclusion criteria

Infants with a GA at birth of <27 weeks who were alive at 6.5 years age

Exclusion criteria

Not reported

Sample size

N=494 EPT infants alive at 1 year
n=486 EPT infants surviving at 6.5 years age
n=434 EPT infants included in the study

Characteristics

<table>
<tr><td>Visual impairment follow up data for children at 6.5 years age</td><td>n=406</td></tr>
<tr><td>Gestational age (median, range, week)</td><td>25 (22-26)</td></tr>
</table>
</td>
<td>Gestational age ascertainment

Not reported

Outcome(s) of interest in this study

Any visual impairment
Visual impairment according to WHO criteria

Outcome(s) ascertainment/measures

Monocular and binocular distance linear visual acuity with habitual correction was assessed at 3 m. The best measurable VA was 20/10. For VA, at least 4 of 5 optotypes had to be correctly identified. Based on results of monocular VA, a better eye an a worse eye were identified in children with unequal VA, and the right eye was chosen as the better eye in the remaining children.
Visual impairment was defined according to the WHO criteria:</td>
<td>Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)

At 6.5 years age
Any visual impairment (best estimated visual acuity <20/40 at age 6 years and up in younger ages, adjusted for age)
22-23 wks GA: 10/42, 23.8% (95%CI 12-40)
24 wks GA: 11/82, 13.4% (95%CI 6.9-22.7)
25 wks GA: 10/142, 7% (95%CI 3.4-12.6)
26 wks GA: 7/138, 5.1% (95%CI 2.1-10.2)
Visual impairment according to WHO criteria (Best-estimated visual acuity below 20/60 at age 6 years and up in younger ages adjusted for age)
22-23 wks GA: 7/42, 16.7% (95%CI 7.0-31.4)
24 wks GA: 6/82, 7.3% (95%CI 2.7-15.3)
25 wks GA:5/142, 3.5% (95%CI 1.2-8.0)
26 wks GA: 3/138, 2.2% (95%CI 0.4-6.2)</td>
<td>Overall quality

Moderate

1. Was the sample representative of the target population?

Yes

2. Were the study participants recruited in an appropriate way?

Yes

3. Was the sample size adequate?

Yes

4. Were the study subjects and the setting described in detail?

Yes

5. Was the data analysis conducted with sufficient</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Aim of the study

To investigate the ophthalmologic outcome of a national cohort of extremely preterm children at 6.5 years age and to evaluate the impact of prematurity and ROP

Study dates

2004-2007

Country/ies where the study was carried out

Sweden

Source of funding

Swedish Research Council</td>
<td>
<table>
<tr><td>Birth weight (median, range, g)</td><td>770 (348-1315)</td></tr>
<tr><td>Sex (male:female)</td><td>221:185</td></tr>
<tr><td>ROP in either eye (no./total) (%) stage 1-2</td><td>148/404 (36.6%)</td></tr>
<tr><td>ROP in either eye (no./total) (%) stage 3-5</td><td>143/404 (35.4%)</td></tr>
<tr><td>Age at examination, (median, range, y)</td><td>6.6 (6.5-6.7)</td></tr>
</table>
</td>
<td>blindness was best VA <20/400, severe visual impairment was <20/60, moderate visual impairment was defined as <20/40 VA.

Age at assessment

6.5 years age</td>
<td>Confidence intervals calculated by NGA using: http://statpages.info/confint.html</td>
<td>coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?

No. Confidence intervals were not provided in the study

9. Are all important confounding factors/subgroups/differences identified and accounted for?</td>
</tr>
</table>

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Jerring Foundation Stockholm City Council Karolinska Institutet The Sivgard and Marianne Bernadotte Research Foundation for Children Eye care Kronprinsessan Mararetas Arbetsnamnd for Synskadade, Ogonfonden Swedish Society of Medicine Nordstromer Foundation Foundation for Visually Impaired in Former Malmohus Ian, and Stig Ragna Gorthon Foundation				N/A **10. Were subpopulations identified using objective criteria?** N/A
Ref Id 512287	**Setting** Women were enrolled in the ELGAN study at 14 sites in 11 cities in 5 states (Connecticut, Illinois, Massachusetts, Michigan, North Carolina)	**Gestational age ascertainment** Not reported (reference to O'Shea study 2009)	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)**	**Overall quality** Moderate

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
Full citation Joseph, R. M., O'Shea, T. M., Allred, E. N., Heeren, T., Hirtz, D., Paneth, N., Leviton, A., Kuban, K. C. K., Prevalence and associated features of autism spectrum disorder in extremely low gestational age newborns at age 10 years, Autism Research., 2016 **Study type** Prospective cohort study (ELGAN study) **Aim of the study** To estimate the prevalence of autism spectrum disorder (ASD) in children born extremely preterm	**Inclusion criteria** Women delivering before 28 weeks gestation **Exclusion criteria** Not reported **Sample size** N=1198 preterm infants surviving to 10 years n=966 children recruited for follow-up n=889 mothers of infants who agreed to participate **Characteristics** Maternal characteristics at birth (n=1198) Age (years, n): <21: 170 21-35: 802 >35: 226 Education (years, n): <=12 years: 506 >12 and <16 years: 270 >=16 years: 376 Single marital status (n): 513 Ethnicity (n):	**Outcome(s) of interest in this study** ASD **Outcome(s) ascertainment/measures** Participants were screened for ASD symptoms with the Social Communication Questionnaire (SCQ), the SCQ includes 39 ratings for children with simple sentence speech, and 33 ratings for those without simple sentence speech. To increase screener sensitivity, a score 11, recommended by the authors for individuals at higher-than-normal risk for ASD was used instead of the standard criterion of 15. Children who met SCQ screening criteria were evaluated with the Autism Diagnostic Interview–Revised (ADI-R), an in-depth parent interview that assesses symptoms in the core domains of communication, social, and repetitive behavior, and	**At 10 years** ASD (assessed by ADI-R): <28 wks GA: 79/857, 9.2% (95% CI 7.4-11.4%) ASD (assessed by ADOS-2 criteria): 23-24 wks GA: 26/173, 15% (95%CI 10-21.2) 25-26 wks GA: 25/386, 6.5% (95%CI 4.2-9.4) 27 wks GA: 10/298, 3.4% (95%CI 1.6-6.1) <28 wks GA: 61/857, 7.1% (95%CI 5.5-9.0) Confidence intervals were calculated by the NGA technical team using http://statpages.info/confint.html	**1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes **4. Were the study subjects and the setting described in detail?** Yes **5. Was the data analysis conducted with sufficient coverage of the identified sample?** Yes

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
at the age of 10 years **Study dates** 2002–2004 **Country/ies where the study was carried out** USA **Source of funding** National Institute of Neurological Disorders and Stroke National Institute of Child Health and Human Development	White: 706 Black: 322 Other: 151 <u>Newborn characteristics (n=1198)</u> <u>Male sex (n):</u> 621 <u>Gestational age, weeks (n):</u> 23-24 wks: 245 25-26 wks: 553 27 wks: 400 <u>Birth weight (g, n):</u> <=750:436 751-1000: 520 >1000: 242	classifies autism based on 30–36 ratings, depending on the child's language level. Children who met criteria for autism or ASD on the ADI-R were assessed with the Autism Diagnostic Observation Schedule, a semistructured, observation protocol in which the examiner interacts with the child to assess social-communicative and repetitive behavior symptoms. **Age at assessment** 10 years		**6. Were objective, standard criteria used for the measurement of the condition?** Yes **7. Was the condition measured reliably?** Yes **8. Was there appropriate statistical analysis?** No. Confidence intervals were not reported in the study. **9. Are all important confounding factors/subgroups/differences identified and accounted for?** N/A

Study details	Participants	Definitions and measurement	Results	Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool
				10. Were subpopulations identified using objective criteria? N/A
Ref Id 539165 **Full citation** Joseph, R. M., O'Shea, T. M., Allred, E. N., Heeren, T., Hirtz, D., Jara, H., Leviton, A., Kuban, K. C., Elgan Study Investigators, Neurocognitive and Academic Outcomes at Age 10 Years of Extremely Preterm Newborns, Pediatrics, 137, 2016 **Study type**	**Setting** 11 cities in 5 states in the USA **Inclusion criteria** Women delivering before 28 weeks' gestation **Exclusion criteria** Not reported **Sample size** N=1506 infants n=1198 survived to age 10 years **Characteristics**	**Gestational age ascertainment** Not reported **Outcome(s) of interest in this study** Severe gross motor function Visual impairment Cognitive ability Academic achievement **Outcome(s) ascertainment/measures** Severe gross motor function was defined as level 5 (GMFCS, no self-mobility) Severe visual impairment was defined as uncorrected functional blindness in both eyes Cognitive ability (IQ): School-Age Differential Ability Scales–	**Prevalence n/N and % (with 95% CI) (incl. GA at birth and age at assessment)** At 10 years age <u>Severe motor impairment</u> 22-27 wks GA: 17/873, 1.9% (95%CI 1.1-3.1) <u>Functional blindness:</u> 22-27 wks GA: 7/873, 0.8% (95%CI 0.3-1.7) <u>General cognitive ability (22-27 weeks GA; <=-2SD)</u> DAS-II Verbal: 148/873, 17.0% (95%CI 14.5-19.6) DAS-II Nonverbal Reasoning: 131/873, 15% (95%CI 12.7-17.6) <u>Achievement (<28 weeks GA; <=-2SD)</u> WIAT-III Word Reading: 122/873, 14% (95%CI 11.7-16.5) WIAT-III Pseudoword Decoding: 140/873, 16% (95%CI 13.7-18.6)	**Overall quality** Low **1. Was the sample representative of the target population?** Yes **2. Were the study participants recruited in an appropriate way?** Yes **3. Was the sample size adequate?** Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Prospective cohort study (ELGAN)

Aim of the study

To assess the rate of neurocognitive impairment in a contemporary US cohort of 873 children aged 10 years who were born <28 Weeks' gestation

Study dates

2002-2004

Country/ies where the study was carried out

USA

Source of funding

National Institute of Neurologic</td>
<td>
<table>
<tr><td>Maternal characteristics</td><td>23-24 wks GA (n)</td><td>25-26 wks GA (n)</td><td>27 wks GA (n)</td></tr>
<tr><td>Age (y)
<21 25
21-35
>35</td><td>
25
21
18</td><td>
47
46
43</td><td>
28
34
38</td></tr>
<tr><td>Education (y)
≤12 years (high school)
>12 and <16 years
≥16 years (college or higher)</td><td>
22
36
16</td><td>
48
37
46</td><td>
30
198
38</td></tr>
<tr><td>Racial identity
White
Black
Other</td><td>
21
22
17</td><td>
43
51
44</td><td>
37
27
39</td></tr>
<tr><td>Single marital status
Yes
No</td><td>21
20</td><td>45
45</td><td>34
34</td></tr>
<tr><td>Newborn characteristics</td><td></td><td></td><td></td></tr>
</table>
</td>
<td>II (DAS-II) 28 Verbal and Nonverbal Reasoning scales. Academic achievement: The Wechsler Individual Achievement Test–III (WIATIII) 32 Word Reading, Pseudoword Decoding, and Spelling subtests were used to assess proficiency in word recognition, decoding, and spelling, respectively. WIAT-III Numeric Operations was used to assess math related computational skills.

Distribution of neurocognitive test scores were compared to expected normal distribution:

2.3% of ELGAN children would be expected to have z scores ≤ -2,

13.7% to have z scores >-2 and ≤ -1,

68.2% to have z scores > -1 and ≤ 1, and 15.8% to have z scores >1</td>
<td>WIAT-III Spelling: 122/873, 14% (95%CI 11.7-16.5)
WIAT-III Numeric Operations 148/873, 17.0% (95%CI 14.5-19.6)

Confidence intervals calculated by NGA using: http://statpages.info/confint.html</td>
<td>4. Were the study subjects and the setting described in detail?

No. The measurement of gestational age was not reported

5. Was the data analysis conducted with sufficient coverage of the identified sample?

Yes

6. Were objective, standard criteria used for the measurement of the condition?

Yes

7. Was the condition measured reliably?

Yes

8. Was there appropriate statistical analysis?</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Definitions and measurement</th><th>Results</th><th>Quality assessment (based on NICE guideline manual 2014 and the Joanna Briggs Institute Prevalence Critical Appraisal Tool</th></tr>
<tr>
<td>Disorders and Stroke
National Institute of Child Health and Human Development
National Institutes of Health</td>
<td>
<table>
<tr><td>Gender
Male
Female</td><td>
23
18</td><td>
45
46</td><td>
32
36</td></tr>
<tr><td>Birth weight (g)
≤750
751–1000
>1000</td><td>
50
5
0</td><td>
37
61
24</td><td>
13
33
76</td></tr>
<tr><td>Necrotising enterocolitis (Bell stage 3b)
Yes
No</td><td>
33
20</td><td>
57
45</td><td>
10
35</td></tr>
<tr><td>Bronchopulmonary dysplasia (oxygen at 36 weeks)
Yes
No</td><td>
32
9</td><td>
46
44</td><td>
22
47</td></tr>
</table>
</td>
<td>Age at assessment

10 years age</td>
<td></td>
<td>No. Confidence intervals were not reported in the study

9. Are all important confounding factors/subgroups/differences identified and accounted for?

N/A

10. Were subpopulations identified using objective criteria?

N/A</td>
</tr>
</table>

Developmental follow up of pre-term babies

1 Information provision

Study details	Participants	Methods	Findings	Comments
Full citation Ardal,F., Sulman,J., Fuller-Thomson,E., Support like a walking stick: parent-buddy matching for language and culture in the NICU, Neonatal network : NN, 30, 89-98, 2011 **Ref Id** 307661 **Country/ies where the study was carried out** Canada. **Study type** Qualitative study using semi-structured interviews. **Aim of the study** To explore the experience of non-English speaking mothers with preterm, very low birth weight infants, and to examine mothers' assessment of a peer support program matching them with	**Sample size** N = 8 **Characteristics** All participants were mothers of very low birth weight or very preterm infants, who spoke no English or limited English. The mothers' first languages were: • Spanish (n = 4) • Portuguese (n = 1) • Mandarin (n = 2) • Tamil (n = 1) Maternal age ranged from 27 to 39 years. Five women had other children. There were nine infants in the study - seven singletons and one set of twin boys. Gestation periods ranged from 24 to 29 weeks, with a mean of 26.8 weeks. Length of stay in NICU ranged from 36 to 140 days. **Inclusion criteria** Mothers of infants who weighed <1500g at birth, and who were born at <30 weeks gestation.	**Setting** Participating mothers were identified from a single university teaching hospital. All mothers had been assigned a parent-buddy who spoke the same language as them, and had previously had a preterm baby admitted to the same NICU. Bilingual research assistants interviewed the mothers by telephone, using a tape recorder, between 4 and 12 weeks after the infant was discharged home. **Data collection** In depth interviews were conducted, transcribed and translated by trained bilingual research assistants who were linguistically matched with the mothers. Open-ended questions were developed that used themes and data that emerged from previous research. All mothers were asked about their experience of preterm birth, their experience in the NICU, and their relationship with the parent-buddy. They were asked specific questions about difficulties related to language and culture, and their perception of whether they were treated differently from	**Themes/categories** **Need to provide information which is understandable to the parents** <u>Use of interpreters where needed</u> Mothers stated that staff who spoke their language, or interpreters, facilitated their understanding of the situation. *"She [the doctor] used medical terminology. I personally don't understand medical terminology . . . I went outside the unit and called my husband to tell him that Michael was dying. Only after a nurse who speaks [my language] arrived, she helped me . . . As a result, I knew that Michael only had a minor infection."* It was also highlighted that written information may not be readily available to parents who speak little/no English, and that this may impede their understanding of the NICU, prematurity and their own role as a parent. <u>Not using medical terminology</u> Mothers emphasised that medical terminology was difficult for them to understand, and that it could lead to serious misunderstanding. *"But for me, no, the doctor never explained it in terms that I could understand. She used a lot of medical terminology, and for me, that was the end of the world."*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Relationship between the researcher and sample is not clearly described. Unclear whether the researcher has managed his/her own pre-understanding in relation to the analysis. There is no description of the relationship between the researchers and the study participants - it is not clear whether the researchers work on the NICU involved in the study, and whether they were involved in the care of the study participants. Paid bilingual research assistants collected the data, and it is assumed that these individuals were not known to the mothers', although this is also not reported. The role of the researchers is not clearly defined, and consequently there is no discussion of their pre-understanding of the area of interest. **Overall quality** Moderate.

Study details	Participants	Methods	Findings	Comments
linguistically and culturally similar parent-buddies. **Source of funding** Not reported.	Non-English speaking or very limited English. **Exclusion criteria** None reported.	other families on the NICU. The role of the parent buddy was explored in depth. Transcripts were translated by the interviewers. **Data analysis** The first author reviewed the transcripts as they were completed to ensure that the mothers' narratives reflected the broad topics included in the interview guide. Data processing was iterative in terms of thematic analysis. As each interview was transcribed it was read by the first author to gain insight into the content and to identify common themes and cultural distinctions arising from the data. Thematic saturation was assessed through repetition in the current sample and by comparison with themes from previous qualitative research in this setting. After all interviews were completed one member of the research team and a research assistant (who was not involved in data collection) reviewed all transcripts. Computerised qualitative analysis software was used to code the responses into themes. For reliability, another member of the research team independently coded the transcripts. Over several meeting	**Need for practical information about the NICU** Mothers highlighted that the same-language buddy system meant they were able to find out practical information about the NICU, for example facilities in the family room, where they could eat, where they could express milk. **Need for information about roles and responsibilities** The mothers highlighted that they were able to access information about the way the NICU was run, or things they could expect during their stay. *"[The parent-buddy] gave us a lot of information: how to touch your baby, or things you could request, such as kangaroo care . . . She explained to me what a primary nurse was, how the neonatologists work . . ."* *"She told me that transferring to Level II means that the baby is improving. This is useful."*	

Study details	Participants	Methods	Findings	Comments
		a consensus coding system was determined.		
Full citation Arockiasamy,V., Holsti,L., Albersheim,S., Fathers' experiences in the neonatal intensive care unit: a search for control, Pediatrics, 121, e215-e222, 2008 **Ref Id** 307059 **Country/ies where the study was carried out** Canada. **Study type** Qualitative study - semi-structured interview. **Aim of the study** To understand the experiences of fathers of very ill neonates in the NICU. **Source of funding**	**Sample size** N = 16 **Characteristics** Age range 21 to 48 years Gestational age of infant at birth: • ≤25 weeks: n = 8 • 26-32 weeks: n = 4 • 32-36 weeks: n = 1 • ≥37 weeks: n = 3 Surviving infants at the time of the interview: n = 13 3 of the infants were still admitted at the time of the interview. **Inclusion criteria** English speaking fathers of infants who had been admitted to a single level III NICU for >30 days. **Exclusion criteria** Not reported.	**Setting** All infants had been admitted to a single, level III NICU. Fathers were interviewed individually about their experiences by a single male physician. The location of the interview is not reported. At the time of the interview 3 of the infants were still admitted, 10 had been discharged home, and 3 had died. **Data collection** Each father was interviewed using a semi-structured interview format, with open-ended questions. Interviews were audiotaped. The interview began with questions about the infants current condition, and the fathers social and demographic information. Fathers were then asked to describe their experience in the NICU and were encouraged to speak freely in a narrative form. At the end of the interview specific questions on a variety of topics were asked, to ensure that relevant areas had been covered. These included fathers' expectations of their experiences in the NICU,	**Themes/categories** **Information** Most fathers perceived that obtaining information helped in their decision making, and feeling in control whilst in the NICU. However, some fathers wanted only limited information. *"There were times when it was too much information"* **Consistency of information** All the fathers expressed a desire for consistency in information provision, and having a particular physician identified as their primary contact, as well as a nurse or group of nurses with whom they could talk. **Framing of information** When asked about how information should be provided, several fathers suggested receiving short written materials about the more common medical conditions, and one father suggested having on-line access to information that they could discuss with the doctor. **Including both partners in discussions about available support** One father also suggested that when helping services (such as social services) are offered, fathers	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Insufficient data are presented to support the findings. Unclear whether the researcher has managed his own pre-understanding in relation to the analysis. Unclear whether a theory/hypothesis/model is generated. There are sparse quotations to support the findings of the study, especially with regard to information provision. When quotations are used, only small fragments are reported, therefore the data are not presented as richly as they could be. The first author (who interviewed the participants) had been involved in caring for many of the infants in this study. This may have affected how the participants responded to questions. This is discussed in the conclusions to the paper, but it is unclear whether the affect on the study conclusions has been appropriately interpreted.

Study details	Participants	Methods	Findings	Comments
Canadian Child Health Clinician Scientist Development Award. Child and Family Research Institute Establishment Funding.		their level of understanding of their infants illness, views on the timing, amount and way in which information had been provided, expectations and experiences of decision making with regard to their infant - both for day-to-day care and life and death decisions, the way in which fathers' thought support systems may be improved in future, feelings regarding the interview itself, particularly regarding the benefits or difficulties in speaking with a male physician. **Data analysis** Interviews were transcribed by an independent transcriptionist. Data was coded by hand using the constant comparative method of content analysis. Transcripts were coded line by line by a research assistant, and themes were then constructed from the codes. Interviews were also reviewed by the three researchers to code themes. Codes were analysed and discussed between the three investigators and the research assistant until consensus was reached. A documented audit trail was kept, including memos of decisions made.	should be included equally in these discussions.	It is unclear whether the authors generate a hypothesis from the results about the fathers' experiences, rather than simply present the summarised data. **Overall quality** Moderate.

Study details	Participants	Methods	Findings	Comments
Full citation Brazy,J.E., Anderson,B.M., Becker,P.T., Becker,M., How parents of premature infants gather information and obtain support, Neonatal Network - Journal of Neonatal Nursing, 20, 41-48, 2001 **Ref Id** 307117 **Country/ies where the study was carried out** USA **Study type** Qualitative study - semi-structured interviews. **Aim of the study** To discover how parents of premature babies obtain information and support. To identify the parents' process of seeking information, the kind of information they sought and the resources they used to meet these needs.	**Sample size** **Interview data** N = 19 (15 mothers and 4 of their spouses, identified from three different NICUs) (Additional participants were recruited for the questionnaire part of the study, but these are reported as quantitative data only therefore have not been included in the review). **Characteristics** Maternal age: range 19 to 39 years (median 30 years) Gestational age of infants at birth: range 24-33 weeks (median 27 weeks) 12 singleton birth and three sets of twins. Age range of children at the time of interview: 3 months to 2.5 years. **Inclusion criteria** A non-random, convenience sample of parents was chosen to represent a range of ages, race, socioeconomic status, marital status, maternal and neonatal illness severity. All parents had infants weighing <1500g at birth. **Exclusion criteria**	**Setting** Participants had all had preterm infants who were cared for in the NICU of one of the three participating hospitals. The location for conducting the interviews is not stated, but was presumably away from the family home, as the article reports covering travel expenses for participants. **Data collection** The authors developed the interview structure after conducting in-depth interviews with NICU nurses and social workers. A volunteer parent also reviewed the interview for content and clarity. The questions covered four time periods: • the prenatal phase - from first indication of a possible preterm birth to the time of delivery • acute phase - whilst the mother was hospitalised, and any additional time when the baby was acutely unwell • convalescent phase - the time between the baby's transfer to the intermediate care nursery and discharge	**Themes/categories** Information needs were summarised according to the different stages of having a premature baby. **Antenatal** The information topics covered at this stage were maintaining the pregnancy, the possible outcomes of the pregnancy, and the mother's condition. Topics that parents wanted more information on at this stage were infant health, "typical" premature labour and delivery, and how to get more information. **Acute** Topics covered at this stage were infant health, infant care and maternal recovery. Topics that parents wanted more information on were infant health, technical information and coping. **Convalescent** Topics covered at this stage were infant health, infant care and coping. These three topics were also identified by parents as things that they needed more information about. **Discharge** At this stage the only topic covered for parental information was infant care. Parents felt they would have liked more information on infant health, infant care and coping.	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear whether data saturation was achieved in terms of collection and analysis. Data analysis was not clearly described. It is not clear how themes were derived during analysis. Sufficient data are not presented to support the findings. Unclear whether the researcher managed their own pre-understanding in relation to the analysis. The analysis was not independently validated. The authors do not report assessing whether data saturation had been reached, or continuing collection until saturation. A single researcher analysed the transcripts and grouped them into categories. The process used for this is not reported, and there is no report of validation of the themes generated by a second researcher. Overall themes are presented, but there is no report of direct quotations to support these themes. The researchers describe interviewing neonatal nurses and social workers to identify what subjects should form the content of

Study details	Participants	Methods	Findings	Comments
A secondary aim of this study was to ask parents about the potential usefulness of a computer-based information program. **Source of funding** The Perinatal Foundation of Wisconsin.	None reported.	• post-discharge phase - after the baby came home Questions were similar for each time period. They focused on the information parents received and sought, resources for information, the process by which parents acquired information, barriers to getting information, who initiated the learning, and the impact the resources had on parents' learning. Parents were asked to identify the most helpful resources, fears and frustrations, things that helped them, and sources of support. Parents were asked to suggest ways that health care professionals could improve parental understanding and better meet parents' needs. Finally, parents were asked to comment on any aspects of their experience not included in the questions. The initial intention was to interview parents in small groups of 4-6, to facilitate recall and allow interaction. However, it became apparent that the more vocal parents inhibited the less vocal ones. Therefore subsequent interviews were conducted individually, or with couples if both parents agreed to participate. Three couples participated by phone.		the questionnaire used. Therefore it is possible that their pre-understanding of the topic has influenced the analysis (as parents may have identified different areas of importance to be discussed). This is not described in the conclusions. **Overall quality** Low quality.

Study details	Participants	Methods	Findings	Comments
		A single educator conducted all interviews and taped them for later review. **Data analysis** After all the interviews were completed, one health educator reviewed the tapes, recorded and summarised the responses and grouped them into categories.		
Full citation Brinchmann, B. S., Forde, R., Nortvedt, P., What matters to the parents? A qualitative study of parents' experiences with life-and-death decisions concerning their premature infants, Nursing Ethics, 9, 388-404, 2002 **Ref Id** 470227 **Country/ies where the study was carried out** Norway **Study type**	**Sample size** N = 20 interviews with a total of 35 parents **Characteristics** 15 of the interviews were carried out with both parents together, 4 with just the mother and one with just the father. The majority of the 26 infants were very premature (born at 24 to 29 weeks). Three were full term. At the time of interview 10 infants had died and 16 were still alive. The life-and-death decisions made concerned terminating active medical treatment - usually turning off a respirator. The period of time between the decision and the interview varied between one year and 8 years.	**Setting** Participants were contacted through the Parents Association for Premature and Prematurely Dead Children, the Cerebral Paresis Association, health visotirs, paediatricians and other health service professionals. Potential participants were given written information about the study and those who wished to participate contacted the first author. The parents came from different locations in Norway. The location of the interview is not described. **Data collection** Face-to-face, unstructured, in depth interviews were conducted with the parents. Interviews were tape recorded and transcribed.	**Themes/categories** **Timing of information provision** Parents emphasised the need to take adequate time to discuss such decisions. They also made it clear that they should be told at the right time, when they are ready to receive such serious information *"It was very important for us to get some time with these very busy doctors."* *"He just stood there and asked us whether we had thought about whether, should she get worse, she should be put on a respirator. He showed humility and asked in a pleasant manner, but I still felt that it was an awful imposition. I mean, if they are going to ask you whether to let your baby die, I think that they should have asked us to discuss it with them, asked if we wanted to talk about it."* **Appropriate amount of information**	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear whether saturation in terms of data collection has been achieved. Unclear whether analysis has been independently verified. Unclear whether a hypothesis/theory/model is generated. The authors highlight the ethical challenges inherent in studying this topic. In particular they highlight that all parents who volunteered to participate were included in the study, as they felt it was unethical to exclude parents who had volunteered to discuss such a traumatic time. Therefore there is no discussion of whether data saturation occurred.

Study details	Participants	Methods	Findings	Comments
Qualitative study using unstructured interviews. **Aim of the study** To generate knowledge about parents' participation in life-and-death decisions concerning seriously ill infants on the neonatal unit. **Source of funding** None reported.	**Inclusion criteria** Not reported **Exclusion criteria** Not reported.	**Data analysis** Data were analysed using the comparative method, in parallel with data collection. Computer software for text analysis was used in the data analysis. The process involved open and selective coding (identifying preliminary codes, then relating codes to a core category), writing memos, theoretical sorting and coding and theoretical writing.	*"I think that on certain occasions the doctors should perhaps take the initiative to work out an agreement with parents such as: 'Shall I bother you with all the details that worry me, or shall I not say anything, or shall we try to find a good middle ground about what I tell you?' I had more than enough problems without having to worry about all the things that could go wrong."*	The authors state that findings were independently verified through discussion with neonatal nurses and one neonatal doctor, but it is unclear whether the analysis of the data was conducted by more than one person, and whether verification of emerging themes took place. **Overall quality** Moderate.
Full citation Doyle, L. W., Anderson, P. J., Battin, M., Bowen, J. R., Brown, N., Callanan, C., Campbell, C., Chandler, S., Cheong, J., Darlow, B., Davis, P. G., DePaoli, T., French, N., McPhee, A., Morris, S., O'Callaghan, M., Rieger, I., Roberts, G., Spittle, A. J., Wolke, D., Woodward, L. J., Long term follow up of high risk children: who, why and how?, BMC Pediatrics, 14, 279, 2014	**Sample size** Not described. **Characteristics** Participants in the workshop included health care professionals from paediatrics, psychology, nursing, occupational therapy and physiotherapy. Parents of high-risk children also attended. **Inclusion criteria** Not reported.	**Setting** Discussion group/workshop. **Data collection** The themes highlighted in the workshop were documented and summarised in the article, which was approved by attendees. **Data analysis** Not reported.	**Themes/categories** **Lack of information** Parents perceived a lack of long-term outcome information for their high risk children. It was noted that this information was also needed for other health care professionals (including family or allied health practitioners) and the education system. Accurate information regarding long term outcome was highlighted as being important to inform decisions regarding the initiation of intensive care, or redirection to palliative care. It was noted that information needs to be provided at the appropriate time to facilitate decision making for	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Method of participant selection (and the exact composition of the group) is not clearly described. The nature of the article is such that it does not report the full discussions from the workshop, but a summary of salient points. This reduces the richness of the data with regard to this review. **Overall quality** Low.

Study details	Participants	Methods	Findings	Comments
Ref Id 412542 **Country/ies where the study was carried out** Australia. **Study type** Workshop discussion group of healthcare professionals and parents of high-risk children. **Aim of the study** To provide a framework for identifying which children need specialised follow-up, what outcomes should or could be of interest, and how, where and when follow-up should be commenced. **Source of funding** Funding to support the workshop came from a Centre of Clinical Research Excellence Grant from the National Health and Medical Research Council of Australia.	**Exclusion criteria** Not reported.		life events (for example school choices, deferred or delayed school entry), screening and assessment for developmental disorders (for example Autism Spectrum disorder) and monitoring for less visible medical conditions (for example hypertension). **Information about support** The authors conclude that parents should be given information about support available for their preterm infant after discharge. **Information about prognosis** The authors conclude that parents should be given information about the likely prognosis for their child, along with written information to reinforce the messages. **Where to find further information** Parents should be given information on appropriate websites, so that they do not have to search the internet for information which may not be relevant to their needs.	

Study details	Participants	Methods	Findings	Comments
Full citation Gaucher,N., Payot,A., From powerlessness to empowerment: Mothers expect more than information from the prenatal consultation for preterm labour, Paediatrics and Child Health, 16, 638-642, 2011 **Ref Id** 307076 **Country/ies where the study was carried out** Canada. **Study type** Qualitative study - semi-structured interviews. **Aim of the study** To explore mothers concerns regarding premature labour and their expectations of the consultation with the neonatologist.	**Sample size** N = 5 **Characteristics** The participants ranged in age from 24-36 years. The gestation at the time of interview ranged from 26 to 30+2 weeks. 2 of the women proceeded to deliver their babies prematurely (within days of the interview) and three continued to a full-term pregnancy. Maximum variation purposeful sampling was used to try and identify themes common to a diverse group of women. **Inclusion criteria** Adult women, hospitalised due to threatened preterm labour, with a gestation of 26 to 32 weeks who had not yet had contact with the neonatal team for counselling about preterm labour. **Exclusion criteria** Unable to read/write basic English or French, psychiatric disorder, known fetal malformation.	**Setting** Women were interviewed during their admission to a tertiary care high risk obstetric unit. **Data collection** In depth interviews, using a semi-directive approach, were conducted and audiotaped. Each lasted 30 to 60 minutes. Women were encouraged to speak freely, and to elaborate in particular about their main current concerns and stressors, topics they thought the neonatologist should discuss and explain, expectations from the consultation process and roles they believed the neonatologist should play for them. **Data analysis** The constant comparative method of content analysis was used. Transcripts were coded line by line by the primary researcher to construct themes. A second researcher also reviewed the interviews. Codes and themes were discussed to confirm uniformity in approach and, where necessary, consensus was reached.	**Themes/categories** **Information about the infant** <u>Information about the health of the infant</u> Mothers wanted clear, precise and detailed information and statistics about the short and long-term complications of prematurity, relevant to their gestational age. In particular, subjects they anticipated receiving information on were respiratory distress, neurological complications, sepsis, feeding difficulties and the anticipated duration of hospitalisation. <u>Information about care of the infant and interaction</u> Mothers also wanted information on how they would be able to care for their baby - whether they could touch or hold the baby, and information on breast feeding and feeding strategies. **Information about the NICU** <u>Information about technology</u> Mothers wanted information about the sort of technology that they would expect to see in the NICU. <u>Information about roles and responsibilities</u> Mothers wanted information on what their role and responsibilities were, and what would be expected of them. **Nature of the information**	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Relationship between the researcher and participants is not clearly described. Insufficient data are presented to support the findings. Unclear whether the researcher has managed his/her own pre-understanding in relation to the analysis. It is not clear who conducted the interviews and whether they were involved in the care of the women and their infants. Therefore it is not clear whether the researchers pre-understanding has been managed appropriately. Although the data are rich and well reported for many aspects of the study, the data regarding information provision are sparse and insufficiently supported by direct quotation. **Overall quality** Moderate.

Study details	Participants	Methods	Findings	Comments
Source of funding None reported.		Interviews were analysed before each new participant was recruited, until data saturation was reached.	Mothers expected consistent information from health care providers, and an opportunity to ask questions and clarify details. *"Sometimes I find it goes fast, that we don't have time to ask our questions.(...) It would only take the doctor an extra minute or two, but it would save us from being anxious and having unanswered questions"*	
Full citation Guillen,U., Suh,S., Munson,D., Posencheg,M., Truitt,E., Zupancic,J.A., Gafni,A., Kirpalani,H., Development and pretesting of a decision-aid to use when counseling parents facing imminent extreme premature delivery, Journal of Pediatrics, 160, 382-387, 2012 **Ref Id** 175282 **Country/ies where the study was carried out** USA. **Study type**	**Sample size** N = 31 clinicians N = 30 parents of preterm infants. **Characteristics** **Clinicians characteristics** 11 neonatologists, 8 neonatal fellows, 10 neonatal nurses and 2 materno-fetal medicine specialists. 25.8% were male. 22.6% were single. 51.6% were aged over 35 years. Years of experience: • <5 years: 48.4% • 5-10 years: 25.8% • >10 years: 22.6% 12.9% of them (n = 4) had experienced a previous preterm birth themselves. **Parents characteristics**	**Setting** Clinicians were interviewed at one of three urban tertiary care hospitals. Parents were approached to participate during attendance at high-risk follow up clinics in Philadelphia. **Data collection** A semi-structured interview guide was designed after a review of the literature. Clinicians were asked to attend either a one-to-one interview, or a focus group of 3-5 participants to discuss how and what should be covered during antenatal counselling at the limits of viability, and the detail that should be provided. Parents were asked to recall details of their own experience with counselling prior to delivery, including how information was	**Themes/categories** **Communication of information** How the information is provided Many clinicians felt that written information, in the form of a pamphlet, picture or film would help to inform and prepare parents. The majority of parents also wanted to receive information in a visual format, although there was some concern that visual images could cause increased stress. **Framing of the information** Detail of the information Many physicians felt that exact statistics should not be used during antenatal counselling, but they often used terms such as "about a half" or "many" to quantify risk. However, the majority of nurses felt that parents should, and want to, hear exact statistics. The majority of parents discussed a preference for receiving exact	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Method of sample selection is not clearly defined. Relationship between the researcher and the study sample is not clearly described. Role of the researcher is not clearly defined. Insufficient data are presented to support the findings. Unclear whether the researcher has managed his own pre-understanding in relation to the analysis. No hypothesis/theory or model is generated. Parents were recruited during attendance at high-risk follow-up clinics. It is unclear how clinicians were recruited.

Study details	Participants	Methods	Findings	Comments
Qualitative study - semi-structured interviews. **Aim of the study** To develop and pre-test a decision aid regarding delivery-room resuscitation of preterm infants, to be used when counselling parents at imminent risk of a preterm delivery. **Source of funding** None reported.	27.6% were single Age • <25 years: 10% • 25-35 years: 73.3% • >35 years: 16.7% Gestational age of child at delivery 24.7 ± 0.7 weeks Birth weight at delivery 682g ± 100 Age of child at time of interview 18 ± 9 months **Inclusion criteria** Parents: infants born before 26 weeks attending high risk follow up clinics. Not otherwise reported. **Exclusion criteria** Not reported.	presented, and how it could be done better. Interviews were face-to-face and were audiotaped and transcribed for analysis. **Data analysis** Data collection was continued until saturation was reached. Transcribed interviews were first described as statements, which were then converted into more abstract 'items' on the basis of content. Similar items were organised into themes. Two independent reviewers agreed each step with an iterative process.	statistics, rather than generalities about outcomes. **Information about the infant** Most clinicians felt that parents needed information on survival, short-term morbidities, and how these short-term morbidities relate to long-term outcomes. Parents wanted information about survival and long-term outcomes for their baby. They would have liked specific information about intraventricular haemorrhage, lung disease and bronchopulmonary dysplasia, retinopathy of prematurity and the need for surgery for a patent ductus arteriosus. Parents and clinicians felt that information about the likely size and appearance of a preterm infant would be useful.	The role of the researcher and their relationship to participants (parents and clinicians) is not clearly described. It is consequently unclear whether the researcher has managed their own pre-understanding in relation to the analysis. As the aim of the study was to highlight important topics (rather than explore experiences), only summary themes are reported, without direct quotations. Therefore inadequate data are presented to support the findings. The purpose of the study was to generate a decision-aid for counselling, therefore no hypothesis/theory/model was generated from the results. Parents were interviewed many months after the birth of their preterm infant, and their perception of what information would have been useful during antenatal counselling is likely to have been affected by the experiences of their own child during their stay in NICU. **Overall quality** Low.
Full citation Harvey, M. E., Nongena, P., Gonzalez-Cinca, N.,	**Sample size** N = 18 (n = 13 mothers; n=5 fathers)	**Setting** Participants were recruited at a single tertiary neonatal unit.	**Themes/categories** **The right amount of information should be provided**	**Adapted from the CASP and the Swedish council on Health Technology Assessment.**

Study details	Participants	Methods	Findings	Comments
Edwards, A. D., Redshaw, M. E., Parents' experiences of information and communication in the neonatal unit about brain imaging and neurological prognosis: A qualitative study, Acta Paediatrica, International Journal of Paediatrics, 102, 360-365, 2013 **Ref Id** 470390 **Country/ies where the study was carried out** UK. **Study type** Qualitative study - semi-structured interviews. **Aim of the study** To explore parental information needs during their baby's care in the neonatal unit, with a particular focus on brain imaging and neurological prognosis.	**Characteristics** Aged 21-49 years (median 34.5 years). Parents of a total of 15 babies (eight boys and seven girls), including 2 sets of twins. Infant gestation range 23+3 to 32+3 Birthweight range 650g to 1720g (median 1230g) Age of infant at the time of interview ranged from 4 to 53 days (median 15 days) **Inclusion criteria** Parents aged 16 years or more, able to give informed consent and participate in interviews in English. Have an infant born before 33 weeks gestation and approaching discharge or transfer at the time of the interview. **Exclusion criteria** Not reported.	Interviews were conducted in a private room in the neonatal unit, whilst the infant was still admitted. **Data collection** A topic guide was used with key questions and possible follow-up question or "probes", focusing on information and communication, brain imaging, ultrasound and MRI, diagnosis and prognosis, emotional impact and support. Audio recordings were made with parental consent to allow transcription and analysis. **Data analysis** Data collection, transcription and analysis were carried out concurrently. Computerised software was used to assist in data analysis. Text was coded into themes, each of which included a number of subthemes. Participant recruitment stopped when data saturation was reached. The coding framework was reviewed, amended and then finalised. One member of the team led the analysis to ensure internal consistency, but the final coding framework and themes were agreed by two other team members for validity.	Parents varied in how much information they wanted to be provided with. Some parents highlighted that they tried to avoid information. *"Too much knowledge can give you too many sleepless nights. She's in the right place, with the right care. I don't need to know anything else."* **Parents wanted information about the routine of the NICU** Parents described wanting to know about when routine investigations (such as cranial ultrasound scans) were conducted. They felt that this would have enabled them to be more proactive about accessing results. *"I found a blob of ultrasound jelly on her head on Saturday, I said what's this? Ah Saturday, we do the routine scans"* **Information about long term prognosis** Parents wanted to know results of investigations, and, when their condition had stabilised, information about their infants prognosis. Parents highlighted that medical staff had a less frequent presence in the special care nursery, and that, as a consequence, they had difficulty obtaining updated information about their baby's developmental prognosis. Parents wanted detailed, specific and individualised information about how their baby was progressing, and the longer term prognosis.	**Limitations** Unclear relationship between the researcher and the sample participants. Unclear whether a hypothesis/theory/model was generated. **Overall quality** Moderate.

Study details	Participants	Methods	Findings	Comments
Source of funding National Institute of Health and Research (NIHR).			*"To say she's fine doesn't really tell me anything at all"* **Information about day-to-day issues with their infant** Parents also valued information about less "medical" issues regarding their infant. *"...the information you want as a Mum, did he go through the night? Did he have all his feed? Was he whinging? The little things, which the staff don't think is important".*	
Full citation Ignell Mode, R., Mard, E., Nyqvist, K. H., Blomqvist, Y. T., Fathers' perception of information received during their infants' stay at a neonatal intensive care unit, Sexual & reproductive healthcare : official journal of the Swedish Association of Midwives, 5, 131-6, 2014 **Ref Id** 470422 **Country/ies where the study was carried out** Sweden. **Study type**	**Sample size** N = 8 **Characteristics** Gestational age of infants at birth ranged form 23 to 36 weeks. Paternal age ranged form 20 to 40 years. **Inclusion criteria** Father of an infant treated at one of two Swedish NICUs. Ability to speak and understand Swedish. Infants were to have been admitted to the NICU for at least 1 week. Purposeful sampling was employed to obtain a sample of father-infant pairs that varied in characteristics.	**Setting** Fathers were interviewed by one of two nurses (who were working on the NICU at the time of the study) in a separate room on the unit. Interviews occurred whilst the infant was still admitted to the hospital. **Data collection** Semi structured interviews were conducted by one of two nurses, and recorded. Interviews were based on relevant literature and the authors experiences as NICU nurses. Recordings were transcribed verbatim. Interviews lasted between 15 and 40 minutes. **Data analysis**	**Themes/categories** **Consistency of information** Fathers perceived a lack of agreement between different staff members as upsetting and confusing. Conflicting information or opinions about, for example, limits for alarms on medical equipment, were perceived as very negative. Conflicting information from different physicians was also seen as confusing. **Quantity of information** A large flow of information was also seen as confusing, as fathers were unable to identify which information was relevant for them. **Prognosis** Fathers wanted early information about the care of their infant, and the possible course of events, to help them view the situation in the long term and bond with the baby.	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear whether data saturation has been achieved in terms of collection and analysis. Insufficient data are presented to support the findings. Unclear whether the researcher has managed his/her own pre-understanding in relation to analysis Unclear whether a hypothesis/theory/model has been generated. The authors do not discuss whether saturation was achieved in terms of data collection. Although the quantity of data presented in the paper is adequate overall, there are limited data

Study details	Participants	Methods	Findings	Comments
Qualitative study - semi-structured interviews. **Aim of the study** To explore fathers' perception of information received whilst their infant was admitted in the NICU. **Source of funding** Not reported.	**Exclusion criteria** Acute life-threatening condition in the infant.	The interviews were analysed with content analysis. Two authors listened to the whole interview and then read the transcribed text to gain an understanding of the full meaning. 'Meaning units' were identified - the parts of the text that contained a meaningful statement for further analysis. The meaning units were then condensed to abbreviate the text. Codes were then created for separate meaning units. Subcategories and categories were then formed with the aim of creating mutually exclusive categories, as far as possible. The two authors discussed and reflected on the analysis.	*"I mean, the kind of information you want, will they survive or will they die, and that is probably difficult to answer...."* **Terminology** The use of medical terminology was seen as impeding the flow of information to parents. **Technical aspects of the NICU** Several fathers wanted a complete introduction to the infants care space, as it was the natural location for discussions to occur, and could be perceived as frightening. They suggested a demonstration of some of the technical equipment and information about acceptable values on the monitoring equipment would make them feel less anxious. **Emergencies** Some fathers wanted information about guidelines for emergencies to help reduce the anxiety they felt about not knowing what could be done. **Practical information about the NICU** Some fathers wanted written information about the NICU and neonatal intensive care, so that they would have an idea about what would happen during the rest of their infants stay. **Roles and responsibilities** One father wanted information about what the staff would expect from him whilst he was at the unit	reported for the specific areas relevant to this review. The authors were both working as nurses on the neonatal unit at the time of the interview, and there is not a full analysis of how this may have impacted on the views expressed by the fathers. It is not clear whether a hypothesis is generated from the study findings. **Overall quality** Moderate.

Study details	Participants	Methods	Findings	Comments
			"If possible, more spontaneous information about what is expected from parents when they are here" **Sources of information** Several fathers found the daily medical round a good source of information. One father thought the whole care team should be present so that they could all be updated about the infants condition. *"I think that information is the best, when the round is there....then everyone in the room knows what the physician said and the plan for the care...."* **Format of information** Several fathers agreed that they valued both oral and written information. The NICU parent information folder was also seen as a good source of information. **Prenatal information about the unit** Most fathers valued the information that they received before the baby was born, and the chance to visit the NICU before delivery. *"What was fantastic was that we could meet a physician and a nurse from here already at the delivery unit, before the infant was born. That information was nearly the most valuable of it all"*	
Full citation Keenan,H.T., Doron,M.W., Seyda,B.A.,	**Sample size** N = 15 mothers	**Setting** All women were treated at a public teaching hospital with a	**Themes/categories** **The need to understand what will happen**	**Adapted from the CASP and the Swedish council on Health Technology Assessment.**

Study details	Participants	Methods	Findings	Comments
Comparison of mothers' and counselors' perceptions of predelivery counseling for extremely premature infants, Pediatrics, 116, 104-111, 2005 **Ref Id** 117175 **Country/ies where the study was carried out** USA. **Study type** Qualitative study - standardised interview form including multiple choice questions and open-ended questions. **Aim of the study** To understand the perceived roles of mothers of preterm babies and their counsellors with regard to discussions about delivery room resuscitation. **Source of funding**	(N = 33 antenatal counsellors were also included, but the data provided was predominantly for the quantitative part of the study and does not have relevance for this review) **Characteristics** **Mothers characteristics** Age, years, median (IQR): 27 (23-29) Education, years, median (IQR): 12 (10 to 15.3) 53.3% married Gestational age of infant, weeks, median (range): 26.0 (23.6 to 27.5) Infant survival at time of interview (6 weeks of age): 73.3% **Inclusion criteria** Mothers of preterm infants born at 22 to 27 weeks, who received at least one session of antenatal counselling. **Exclusion criteria** Termination of pregnancy, known lethal abnormalities, non-English speaking, <18 years old, multiple gestations.	level III NICU. The hospital acts as a regional referral centre for perinatal and neonatal care, as well as treating women from the surrounding area. Before discharge from hospital, all eligible mothers (n=33) were asked to identify the person who provided them with antenatal counselling. These individuals were then contacted by the study team and were interviewed separately. **Data collection** Mothers of preterm infants were contacted 6 weeks after delivery and asked if they were willing to participate. Mothers who gave consent to participate (n = 15) were interviewed by telephone **Data analysis** Interviews were reviewed qualitatively to delineate the main themes of the mothers' responses to open ended questions. Answers to open ended questions were recorded on the questionnaire.	Mothers expressed a desire for information about what would happen in the delivery room when the baby was born. *"Explained step-by-step what they would do"* **The need to make information understandable** Mothers explained that they wanted information with less medical jargon. *"When doctors would explain the words kept getting bigger and bigger; it would be helpful to have someone to break it down into more simple explanations"* Some mothers expressed a wish for written information or leaflets.	**Limitations** Relationship between the researcher and participants is not clearly described. Unclear whether data collection procedure was according to a specific theoretical framework. Role of the researcher is not clearly described. Unclear whether data saturation has been achieved in terms of collection and analysis. Analysis not clearly described. Unclear how themes were generated during analysis. Insufficient data are reported to support the analysis. Unclear whether researcher has managed their own pre-understanding in relation to the analysis Unclear whether analysis has been independently verified. Unclear whether a hypothesis/theory/model is generated. There is no description of the relationship between the researcher and the participants, therefor it is unclear whether their pre-understanding has been managed appropriately. Data collection was using a questionnaire, and responses to open ended questions were noted, rather than recorded and transcribed. There is no mention of whether data collection continued

Study details	Participants	Methods	Findings	Comments
University Research Council Grant from the University of North Carolina.				until saturation. The analysis of the open ended responses is not clearly described. **Overall quality** Low.
Full citation Nicolaou,M., Rosewell,R., Marlow,N., Glazebrook,C., Mothers' experiences of interacting with their premature infants, Journal of Reproductive and Infant Psychology, 27, 182-194, 2009 **Ref Id** 307296 **Country/ies where the study was carried out** UK. **Study type** Qualitative study -semi-structured interviews.	**Sample size** N = 20 **Characteristics** Maternal age range 24-40 years (median = 31 years) 90% married/co-habiting. 85% primiparous. 95% White European. 60% educated to degree level or above. Infant gestation, weeks: median 27 (range 23-34) Median days in hospital: 78 (range 18-165) Median infant age at interview: 9.5 months (4-24) Singleton birth: n = 19 (95%) **Inclusion criteria** Mothers of premature infants.	**Setting** Recruitment was conducted through the website of BLISS, a charity for premature infants. Interviews were conducted over the telephone. **Data collection** A research announcement was posted on the parent message board of the BLISS website. Women who contacted the research team were sent an information sheet, a consent form and a freepost envelope. The researcher then contacted the individuals one week later to give them the opportunity to ask questions and discuss the study further. If they wished to participate then a day and time for the interview were set. Interviews (lasting 25-30 minutes on average) were conducted via telephone, recorded and transcribed verbatim.	**Themes/categories** **Transition preparation emphasised information not interaction** 14 of the 20 mothers identified issues relating to lack of information relating to interacting with their premature infant when they took him/her home. *"We were given information but it was all very medical. We had booklets and discussions about RSV, meningitis, all the things he could pick up, but in terms of actually how to care for him and what to do when we got home there wasn't really anything."* *"We had, we did have a resuscitation course. But that was pretty well it....I think that's probably one of the things I found the hardest, the limited amount of information that is available regarding dealing with preterm babies".* **Information on interaction after discharge**	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear if a hypothesis/model/theory is generated. Majority of participants were educated to degree level or above, and may not be representative of the general population. **Overall quality** Moderate.

Study details	Participants	Methods	Findings	Comments
Aim of the study To explore the thoughts and experiences of mothers concerning their early interactions with their preterm infants. To explore the support and information needs of mothers of preterm infants. **Source of funding** None reported.	**Exclusion criteria** None reported.	A semi-structured interview technique was used. Questions centred on the early interactions between a mother and her preterm infant - both in hospital and at home. Participants were also asked about the amount of information they were given regarding interaction with their infant. Towards the end of the interview participants were asked more direct questions, including "Do you feel you were adequately prepared for taking your infant home?", "Do you think more information on interacting with your baby would have been useful?" and "What information do you think would have been useful?". The sample size was set at 20, and recruitment continued until the sample size was reached. However, before completing recruitment the sample size was reviewed to determine if saturation had been achieved. **Data analysis** Thematic analysis was used to analyse the interviews. Transcripts were repeatedly read by the researcher and initial ideas were noted down. Following this, initial codes were produced for the data to help organise it into meaningful groups. These codes were later reviewed, combined or	With directive questioning, 19 out of 20 mothers stated that they did not feel completely prepared to take their infants home from hospital. They agreed that they would have found more information on interaction useful when they were taking their babies home. Ares they highlighted as needing more information on were: • developmental play • information on how to play with preterm infants • information on interaction with preterm infants • information about toys • information about developmental milestones and how they differ for premature infants.	

Study details	Participants	Methods	Findings	Comments
		discarded to identify possible themes. Inter-rater reliability for the themes was conducted by an experienced qualitative reviewer who was not involved with the study and was presented with a code book including detailed descriptions of the themes and matching sections of the interviews. Inter-rater agreement was 95%.		
Full citation Niela-Vilen, H., Axelin, A., Melender, H. L., Salantera, S., Aiming to be a breastfeeding mother in a neonatal intensive care unit and at home: A thematic analysis of peer-support group discussion in social media, Maternal and Child Nutrition, 11, 712-726, 2015 **Ref Id** 413084 **Country/ies where the study was carried out** Finland. **Study type**	**Sample size** N = 30 **Characteristics** Age 20 to 46 years (median 29 years) Number of previous children ranged from 0 to 4, but the majority of women (n = 21) were primiparous. **Inclusion criteria** Premature infant born at <35 weeks and admitted to a NICU. All women were participating in a randomised controlled trial where they were given (or not given) access to a breast feeding peer support group via Facebook. 3 voluntary mothers (who had previously had their own preterm infant) provided peer support to the group. This study	**Setting** The infants had all been cared for in a single tertiary care NICU. The study involved an analysis of Facebook posts from the participating mothers and their 3 peer supporters and 1 midwife participant. **Data collection** Data were collected between June 2011 and February 2013. All postings from the peer-support group were downloaded and all of the mothers agreed to have their postings analysed. **Data analysis** Inductive thematic analysis was used. In the first phase, the data were inductively coded by the	**Themes/categories** **Information about breast feeding** The mothers wanted individual guidance and support from the neonatal nurses about breast feeding. This was felt to be crucial for them to be able to manage breast feeding at home. *"...I was hoping for more information especially about how to manage at home, when the baby is used to the bottle, and what kind of problems may exist and how to manage them."* *"They didn't provide much support or instructions for home. 'You can breastfeed once a day for a start'. That was the only advice I got."* Mothers also wanted to know if there were guidelines regarding the optimal age or weight of the infant when switching from bottle to breast feeding. They asked questions about whether the infants	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear whether research design was appropriate to address the objective. Unclear whether saturation was achieved for data collection or analysis. Unclear whether the researcher has managed her own pre-understanding in relation to the analysis. Unclear whether a hypothesis/theory/model was generated. Study used posts from a Facebook peer support group. It is unclear whether women would have posted comments about all issues that were of importance to them on

Study details	Participants	Methods	Findings	Comments
Qualitative study - analysis of social media postings. **Aim of the study** To describe the perceptions, issues and problems relevant to mothers when they were breastfeeding their preterm infants. **Source of funding** Finnish Doctoral Network in Nursing Science.	utilised data from the mothers who were able to access the group. **Exclusion criteria** Not reported.	first author and the initial themes were identified. The second author also familiarised herself with the raw data and formed the initial codes. Based on discussions between the two authors the codes were collated under subthemes. These were then collated under major themes. Two other authors familiarised themselves with the raw data and were involved in all phases of analysis.	were getting enough milk, and how to improve the latch. They also felt that they did not have enough information about maintaining or increasing their milk supply. *"In what phase have you transferred from bottle to breast? Is there any age/weight-based guideline when you can try breastfeeding only? It is so much easier with a bottle, when you know for sure how much the baby is eating. Nevertheless, you can't perform test weighing at home, so how can I manage?"*	this site, and relevant themes may have been missed. 8 participants did not post any comments on the site. Due to the nature of the study it is difficult to determine whether data saturation has been achieved. The authors state that they realised data saturation was reached by the occurrence of repetitive discussion topics, however, this would be promoted by the nature of a social media discussion group. The first author was also a midwife participating in the support group. It is unclear whether her pre-understanding has been managed appropriately when analysing the data. **Overall quality** Low.
Full citation Padden, T., Glenn, S., Maternal experiences of preterm birth and neonatal intensive care, Journal of Reproductive and Infant Psychology, 15, 121-139, 1997 **Ref Id**	**Sample size** N = 36 **Characteristics** Maternal age, years: mean 26.77 (SD 5.32, range 20-39) Gestation age of infant at birth, weeks: mean 31 (SD 1.7, range 27-34)	**Setting** Infants were admitted to one of three NICUs in the North West of England. Interviews were timed to take place at or around the time when the mother decided to go home, leaving her baby in the NICU (4-9 days after the birth).Interviews were conducted in a private room adjacent to the NICU.	**Themes/categories** **Who should provide information** Many mothers indicated that they received sufficient and good information from the nurses on the unit. *"The nurses explain so you can understand"* *"They manage to put some time aside for small talk, they give us lots of information often even before we ask"*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear whether saturation in terms of data collection or analysis was achieved The authors do not report whether any attempt was made to ensure data saturation.

Study details	Participants	Methods	Findings	Comments
461035 **Country/ies where the study was carried out** UK. **Study type** Qualitative - semi-structured interviews. **Aim of the study** To explore the subjective experiences of mothers of preterm infants in the early post-partum period. **Source of funding** None reported.	Birth weight of infant, grams: mean 1694 (SD 324, range 920-2210) **Inclusion criteria** Singleton birth, APGAR score of 7 of more at 5 minutes, appropriately grown for gestational age, less than 34 weeks gestation, not ventilated at 48 hours of age, in less than 51% oxygen at 48 hours of age. Mothers who spoke fluent English. **Exclusion criteria** Congenital anomaly, obvious drug exposure.	**Data collection** Semi-structured interviews were conducted. The interview was developed based on factors highlighted as important in previous research, and partly on a pilot study involving an open-ended interview with 10 mothers. Questions were asked in relation to Feelings, Communication with the NICU staff, Sensitivity to the infant and Perceived meaning of the experience. Interviews were audiotaped. The interviewer was an experienced NICU nurse. It was stressed that the researcher was not a member of staff and individual responses would not be disclosed to the staff of the unit. The duration of the interview ranged from 20 to 45 minutes. **Data analysis** Tape recordings and transcripts were analysed for emerging themes. Content analysis was based on the cognitive adaptation framework, which identified sense of meaning, sense of mastery and self-esteem as key issues in coping. Social comparisons were explored and analysed.	Therefore the majority of women did not express a need to talk to the doctors. However, if the infant was still requiring medical assistance or there were other concerns the doctor's input was seen as more vital. Some mothers suggested that a time should be set for both parents to meet the doctor together, and others wanted more communication with the doctors even though they acknowledged their infant was healthy. *"I know there's nothing to worry about, but it would be nice occasionally, even once, to sit down and discuss things with his doctor"* **The need for repetition of information** Many mothers described having to ask questions repeatedly before feeling certain of what had been said. *"We must have asked a hundred times what each machine does, and they always tell us again and again"*	**Overall quality** Moderate.

Study details	Participants	Methods	Findings	Comments
		25% of the recordings were selected at random and analysed independently for emerging themes. Almost complete congruence (>95%) was achieved in categorising responses. Any differences were resolved by listening to the tapes again and reaching consensus.		
Full citation Reyna, B. A., Pickler, R. H., Thompson, A., A descriptive study of mothers' experiences feeding their preterm infants after discharge, Advances in Neonatal Care, 6, 333-40, 2006 **Ref Id** 445827 **Country/ies where the study was carried out** USA. **Study type** Qualitative study - semi-structured interviews. **Aim of the study**	**Sample size** N = 27 **Characteristics** Most women were <24 years old, first time mothers, black, unmarried and unemployed. 24 singletons and three sets of twins were included. **Inclusion criteria** All women in this study were also participants in a larger study of feeding readiness in preterm infants. Inclusion criteria for the larger study were: infants born at <32 weeks gestational age, and medically stable by 32 weeks post-menstrual age to allow oral feedings. **Exclusion criteria** None reported.	**Setting** The study took place in a 40 bed Level III NICU in a tertiary care, urban university medical centre. Mothers were interviewed 2-3 weeks after the infants discharge. Interviews took place in the school of nursing and were conducted by one of the three authors. **Data collection** The interviews consisted of 6 open-ended questions focusing on the mothers' feeding experiences since discharge, and reflecting on the feeding experiences before discharge. Interviews were audiotaped and transcribed verbatim. **Data analysis** Data were examined using a phenomenologic approach.	**Themes/categories** **Information about feeding schedules** Prior to discharge, all infants were on scheduled feeding with a prescribed feed volume. Routine discharge instructions included advancing the feeds as tolerated to an "ad libitum" schedule. Mothers had difficulty understanding this and wanted more information. *"...basically how much to give him. When I should give it to him and if I feed him and he's still hungry should I give him more? How* much *more should I give him? How do I know when he's not hungry anymore, or if he's not hungry did he get enough milk in his feeding?" "They gave me instruction as every 3 to 4 hours ad lib. I didn't ask that right now she's on 2 ounces, when do I take her to 3 or 2.5 ounces?"*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** The relationship between the researcher and the study participants is unclear. Unclear whether data saturation has been achieved for collection and analysis. Unclear whether the researcher has managed their own pre-understanding in relation to the analysis. Unclear whether a hypothesis/theory/model is generated. There is no description of the relationship between the researcher and the study participants, therefore it is unclear whether the pre-understanding of the researcher has been managed appropriately. The authors state that no attempt was made to

Study details	Participants	Methods	Findings	Comments
To explore mothers' perceptions of their experiences in feeding their preterm infants in the early weeks after hospital discharge. **Source of funding** National Institute of Nursing Research, National Institutes of Health.		Transcripts were read and analysed inductively by 2 authors to obtain an overall sense of the data. Transcripts were then re-read several times to extract themes. Comparison of themes across interviews was made and similar themes were grouped. Field notes taken during the interviews were used to verify themes and clarify portions of the transcripts. The authors compared their analyses and discussed findings on multiple occasions. Themes were refined by reviewing the transcripts and forming consensus about the results.		saturate themes as this was an exploratory study. **Overall quality** Moderate.
Full citation Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., Ayers, S., Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study, BMC Pediatrics, 14, 230, 2014 **Ref Id** 445838 **Country/ies where the study was carried out** UK.	**Sample size** N = 39 **Characteristics** Age range 25 to 44 years Ethnicity • 74% White European • 8% Indian • 5% Pakistani • 5% Filipino • 8% Other 94% married or living with partner Education	**Setting** Parents were recruited at one of three tertiary care centres by posters in the neonatal units or via letter of invitation. The interviews took place in a quiet room in the parent's home (n = 34) or on the neonatal unit (n = 5). **Data collection** Interviews were conducted individually with one of the researchers. Where both parents agreed to participate, they were also interviewed separately. Interviews lasted for	**Themes/categories** **Information about feeding** Parents reported a lack of information about facilities available for breast feeding and expressing milk. *"I kept asking, when do I start expressing.... and it was about day 4, I think before they said to me, oh yea, here's a kit, go and express".* **Conflicting information** Just under a quarter of parents said that being given conflicting information from staff members was confusing and stressful. *"Because you come in one day, say the day before, especially there was a guy there that, he promoted*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear whether saturation in data collection was achieved Unclear whether the analysis was independently verified Unclear whether a hypothesis/theory/model was generated The primary aim of this study was to explore parents feelings about the birth and immediate care of their preterm infant. However, many parents volunteered further

Study details	Participants	Methods	Findings	Comments
Study type Qualitative study - semi-structured interview. **Aim of the study** To explore parents views and experiences of the care for their very premature baby on NICU. **Source of funding** National Institute for Health Research (NIHR).	• 5% None • 23% GCSEs/'O' Levels • 31% 'A' Levels/Diploma/City and Guilds • 15% Undergraduate • 5% Postgraduate • 21% Professional 85% employed Gestation at birth • 24-25 weeks: 9% • 25-26 weeks: 3% • 26-27 weeks: 13% • 27-28 weeks: 13% • 28-29 weeks: 9% • 29-30 weeks: 9% • 30-31 weeks: 9% • 31-32 weeks: 35% Multiple birth: 34% Mean days on neonatal unit (SD and range): 49.6 (25.1, 25 to 115) Baby on neonatal unit at time of interview, n = 6 (19%) Mean time since birth (SD and range): 154 days (57, 44 to 344) **Inclusion criteria** Parent of an infant who was born before 32 weeks gestation in one of	approximately 45 minutes, and were recorded and transcribed. An interview schedule was developed comprising 12 open-ended questions. These questions focused on parents' experiences of preterm birth and the immediate post partum period, and have been reported elsewhere. However, all parents spoke freely and at length about their experiences on the NICU, and it is these data which form the focus of this article. **Data analysis** Inductive thematic analysis was used. Interview transcripts were read and re-read to become familiar with the data. Initial codes were generated and organised into potential themes. Codes were collated under these themes, then the themes were reviewed before being finalised. Computerised software was used to assist in the coding of data.	*to hold her, literally whenever we was in, either of us, he would say, 'Hold her, it's the best thing you could do'. And then you'd come in the next day thinking 'oh yes, I get to hold her'. And you have a different nurse that says, 'no, no you've held her this week, you don't need to hold her for the rest of the week'… and then you'd almost feel devastated that you couldn't do that."* **Information about the babies health and care** Parents valued frequent updates on their baby's health, and also information about their baby's daily routine. *"And I think they were really, you know, explained everything. Every time we went to the incubator, whoever the nurse was on looking after her, you know, always explained how she'd been doing, how she'd been…they talked…it was really lovely".* **Quantity of information** Some parents mentioned that they had difficulty taking in all the information that they were being given *I guess they do explain it to you when you first come in but they don't... you can't remember, you can't take stuff in. I think that follow up explanation of everything… cos it took me ages to ask…"*	information about their experiences of neonatal care, which are summarised in this article. Therefore, although the authors report that interviews were continued until data saturation occurred, it is unclear whether this is also true for these secondary objectives of the study. The description of the analysis does not report how many of the authors were involved in this step, and whether codes and themes were discussed to ensure consensus and validity. **Overall quality** Moderate.

Study details	Participants	Methods	Findings	Comments
	three tertiary care NICUs, and spoke English well. **Exclusion criteria** Not reported.			

Developmental follow up of pre-term babies

Support of children who are born preterm

Study details	Participants	Methods	Findings	Comments
Full citation Benzies, K. M., Magill-Evans, J., Through the eyes of a new dad: experiences of first-time fathers of late-preterm infants, Infant Mental Health Journal, 36, 78-87, 2015 **Ref Id** 460747 **Country/ies where the study was carried out**	**Sample size** N=85 (fathers from one centre) **Characteristics** Age of fathers (range, years): 19-41 Age of infants (gestational age): born at 35 weeks **Inclusion criteria** Fathers were included in the study if they:	**Setting** • At home • Fathers were recruited at time of infant's birth and screened for eligibility when the infant was 2.5 years corrected age • At 4 months (age of infant), families were allocated to groups and were mailed the questionnaires and followed up at either 2 visits (4, 6 and 8 months) or 4 visits (4, 5, 6, 7, and 8 months). At 4 months fathers were given infomraiton about age-appropriate play, and at 8 months, the home	**Themes/categories** **<u>Infant development/interaction with father (facilitators)</u>** Qualitative data from fathers experiences revealed that spending time with the baby, watching the baby grow and learn, and being recognised by the baby were positive aspects of their experiences. **Spending time with infant** *"I love when I can spend the whole day day with the baby" or "getting on the floor and watching them play" or "taking the baby for walks in the park"* Many fathers liked *"playing in the bathtub"* or *"putting him to bed"* **Watching the infant grow and learn** One father stated that he *"looked forward to each new step and each new development"*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Relationship between the researcher and the selected sample was not clearly described Unclear achievement of data saturation Unclear how categories/themes derived for thematic analysis Unclear saturation in terms of analysis Unclear validation of independent validation

Study details	Participants	Methods	Findings	Comments
USA **Study type** Qualitative study (part of the RCT to evaluate efectivements of FIIIP) **Aim of the study** To explore the father's perceptions of the positive and negative aspects of his experiences that influence interactions with his infant and his perceived needs for support in his role **Source of funding** Alberta Centre for Child, Family and Community Research Alberta Innovates Health Solutions Preterm Birth and Healthy Outcomes Team	• Were first time, biological father of a healthy, singleton, late-preterm infant • Were age 18 years or over • Spoke English to their infant at least 50% of the time • Cohabited with the infant's mother **Exclusion criteria** • Fathers who dropped out of the study	visitor captured the fathers' experiences **Data collection** • Multiple interviewers collected the data as one home visitor was assigned to one study group • The home visitors recorded fathers' responses on an interview sheet **Data analysis** • Responses were transcribed verbatim and analysed using a thematic approach	**Being recognised by the infant** Some fathers stated that their child's recognition and excitement contributed to joys of fatherhood: *"I enjoy that he smiles at me, that I make him happy, and that he knows who I am"* **Guidance on interaction between father and infant and provision of informatoin regarding play with infant-facilitator** Fathers stated that visits from the home visitor were positive as they provided *"the guidance for interactions between dad and baby"* One father stated that *"the first visit was my first time alone with her, and that visit made me more comfortable being alone with her"* **Affirmation of parenting skills** Fathers stated that affirmation of their parenting skills was positive as *"it was good to have outside confirmation that I am a good dad"* **Home visits** Fathers in the study found that the home visits were helpful, and they wanted frequent visits to continue: *"A full year of visits would be great..like having a teacher come once a month to help guide"* **Health care professional** Fathers liked having a health care professional as the home visitor. One father stated that he *"found comfort in knowing he could ask questions regarding the baby"* **Concerns regarding development of their baby**	Unclear hypothesis/theory/model generated **Overall quality** Low **Other information**

Study details	Participants	Methods	Findings	Comments
			Fathers were aware of their infant's development regarding developmental milestones. One parent sought information from the home visitor with concerns: *"some of his cousins are the same age and walking-should he be walking?"* **Continued information support** Fathers stated that it would be helpful if they received a programme of ongoing access to information on *" suggestions or links to resources for further learning"*	
Full citation Chiu, T. M. L., Wehrmann, S., Reid, D., Sinclair, G., Transforming mother-infant interaction within cultural and caregiving contexts: Home-based occupational therapy for preterm infants, Hong Kong Journal of Occupational Therapy, 22, 17-24, 2012 **Ref Id** 460796 **Country/ies where the study was carried out** Canada **Study type**	**Sample size** N=12 mother-infant dyads **Characteristics** Infants were born at <37 weeks of gestation at birth (mean 29 weeks (range 24-36)) Male:female ratio of infants: 6:6 Mean age of infants at time of study: 6 months corrected age (range 2-9 months) Mean birth weight of infants: 1294g (range 500-2980g) Mean age of mothers (n=10): 33 years Education of mothers: post secondary school education, not working	**Setting** Each mother-infant dyad was visited in their home **Data collection** By videotape (of mother and infant interaction during free play, feeding, and mother positioning the infant for different movements) in the first visit, and then subsequently shown to mothers after 3 weeks Interviews of mothers (audiotaped) to capture their thoughts and feelings about the interactions, discussion about cultural values, caregiving beliefs, and experience of OT and other services, repeated again after 6 months Written memos following each visit to record contextual base of interviews	**Themes/categories** **Mothers' beliefs (facilitator)** All mothers had spiritual/religious beliefs that were longstanding and rooted in their ethnic culture: Naming of a baby illustrated the influence of the mother's religious beliefs *"[The name is] from one of those that leads you to the Promised Land..because he was premature..birth was so risky and when he came out and I heard him cry. It's like, he made it!..So I gave him the name"* Mothers of Canadian caucasian background told how naming their infant after an ancestors gave the baby the strength to survive *"That was our first kind of leap of faith after she was born because the chances of her making it, weren't 100%...when she was born..we always wanted to name our baby after our mothers..she's going*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear relationship between the researcher and the selected sample Unclear role of researcher Unclear achievement of saturation (data collection or analysis) Unclear independent validation of the analysis **Overall quality** Low quality

Study details	Participants	Methods	Findings	Comments
Qualitative study **Aim of the study** To explore the changes in mother-infant interaction of preterm infants and their mothers who received home care occupational therapy **Source of funding** Hospital for Sick Children Foundation	Cultural background of mothers: n=6 Canadian-born mothers had German, Chinese, Scottish, Jewish or African background; n=3 mothers were born in South America, mainland China or Caribbean **Inclusion criteria** Preterm infants (<37 weeks GA) and their mothers were selected from Toronto, Canada **Exclusion criteria** None reported	(physical surrounding, interaction between mother and infant) Focus groups **Data analysis** Audio-recordings of interviews were transcribed verbatim and translated if necessary Thematic codes were generated iteratively, the categories developed and the findings interpreted substantively	*to make it and we gave her the real name"* **Mother and infant interaction (facilitator)** Focus group: Mothers of Tamil origin talked about massaging (as this is a long tradition), as well as singing and talking to their infants while massaging *"I put some cream and massage him becasue it helps with development. It is alos very important for the baby"* (one mother) Focus group: Chinese mothers considiered playing with the child without toys compared to Canadian mothers" We just play iwth the child without toys. So that's good for the relationship. ...you always hold her, and give her some exercise. So you put your 100% attention on the chid. That is the Chinese mom" (one mother) **Family and infant interaction (facilitator)** Focus group: mothers of Tamil of origin expressed that their extended family being involved was supportive "I know he is very happy because all of them are nearby. He's got so many people around him. So it's good..More people are better. He likes to interact with others" (one mother) Focus group: Chinese mothers stated that "because only allow to have one child...so everyone takes care of the child. They are afraid to hurt them. But here they may have lots of children, so they may have experiences that it's ok for them. But we don't have the experience, so we are very careful" (one mother)	**Other information**

Study details	Participants	Methods	Findings	Comments
			Mothers' emotional adjustment (barrier and facilitator) All mothers interviewed shared the overwhelming feelings of caring for their infant *"You've got to look forward to the next day pretty much and stop thinking about what's going on today. But I never knew it would be that difficult"* A pattern of adjustment was observed during the 6 month assessment, with one mother stated *" I was afraid that she might develop slowly intellectually, I don't have much worries now" (facilitator)* **Perception of care (barrier)** Mothers expressed that they were overwhelmed with caring for their infant during the first few months at home "they were on oxygen for so long...that was difficult.. you have to go to doctors and the appointments...that was difficult" (one mother) Mothers perceptions of care changed with time "I always think he's amazing based on what prognosis we were given at the very beginning for him, so, I'm just proud!" (one mother, facilitator) **Feeding (barrier)** Feeding was indicated as a chore by mothers and required time and patience *" I think I was becoming quite frustrated with her-I don't know what to say-inability. It could have been her inability to feed properly but also her not wanting to, and my frustration at wanting to get her to eat... I am responsible to make sure that what she's getting what she needs to grow*	

Study details	Participants	Methods	Findings	Comments
			as opposed to being the same weight" (one mother) Mothers also felt gratification when their infants fed well *"Whenever he finishes one bottle, I feel so pleased"* Perception of feeding changed over time as they enjoyed feeding time more *"It used to take about a half an hour to feed her..now and it takes her 10 minutes..So that's very encouraging..it also leaves you more time to ..play with her..eating solids is still an issue with her, she doesn't like them, but, that will come"* **Infants responsiveness** The more responsive the infant became, the more the emotional reaction of the mother changed in a positive manner *" I always feel when she responds like that, much better than..when she doesn't"* (one mother) or *"I felt happy... At least he is responsive to something"* (one mother) **Occupational therapist support to mothers at home (facilitator)-general** MOthers learned to modify the physical surrounding to meet the needs of their preterm infant *"We keep the TV on because he comes from a very noisy background (NICU)..but when it is too quiet..he's not used to that"* Focus group: mothers showed appreciation for the OT as a mento and trusted expert "They know what they (the babies) should be doing, and showing me what to do with her..it's amazing. If I didn't have that, I really wouldn't know..'what would she be doing?' Probably wouldn't even get her attention for 5 minutes..because I've	

Study details	Participants	Methods	Findings	Comments
			worked with her every week and it gives us something different to do besides sitting there and playing with toys all day. The exercises are something we can do for an hour.." (one mother) Focus group: Another mother also expressed that the OT helped with learning to play with their infant and facilitated positive interaction and development of the infant"..we don't feel anxiety about the baby because we've had that (OT in the home)...it's been huge, and she's made great progress...the OT has taught us a lot..we know how to play with her in ways that are more therapeutic" (one mother) **Occupational therapist support to mothers at home- Motor develepment (facilitator)** Focus group: Mothers were positive about their infant's progress in motor development" Since the OT has been coming, my child's been developing and changing so quickly. And I think the OT has a lot to do with it..teaching my child the movements" "the OT also gave me extra help with how I can massage him as he grows..and also taught me how to use the beach ball...since I did all that, I saw a very big improvement in my	

Study details	Participants	Methods	Findings	Comments
			child...he is two times more active than before" (tamil mother) **Occupational therapist support to mothers at home-number of visits, emotional support (facilitator)** Focus group: mothers stated that support from the OT once a week was helpful "..having the OT come in every week, was helpful, not only for exercises, she helps me, just by talking to me and telling me that my child is progressing, and that's positive, because the OT is quick to compliment and quick to let you know that you're doing a good job"	
Full citation Frisman,G.H., Eriksson,C., Pernehed,S., Morelius,E., The experience of becoming a grandmother to a premature infant - a balancing act, influenced by ambivalent feelings, Journal of Clinical Nursing, 21, 3297-3305, 2012 **Ref Id** 307741	**Sample size** N=11 women who were grandmothers to premature infants **Characteristics** Infants born at 25-34 weeks of gestation at birth, <3 years corrected age at time of interview Grandmothers age ranged from 52-66 years	**Setting** Interviews were conducted in the grandmothers home or at the hospital in a calm and comfortable room **Data collection** Grandmothers were interviewd to the authors who were conducting the interview Descriptive data were collected including grandmothers age, employment, relation to mother or	**Themes/categories** **Supportive role of the grandmother after the infant is discharged from NICU (facilitator)** Grandmothers support after discharge was helpful with regard to housework and shopping *"Having an infant in the neonatal ward made them isolated from the world. So in that way they needed more practical help than otherwise"* **Balance of involvement (barrier)** Grandmothers felt that they wanted to be involved without being intrusive *"I*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear saturation in data collection Unclear if a theory or model was generated

Study details	Participants	Methods	Findings	Comments
Country/ies where the study was carried out Sweden **Study type** Qualitative study **Aim of the study** To explore and describe the experience of becoming a grandmother to a premature infant **Source of funding** None reported	9 grandmothers were employed 8 grandmothers were mothers of mothers 3 grandmothers were mothers of fathers 6 grandmothers had other grandchildren **Inclusion criteria** The infant should have been a patient in a neonatal ward at one of the hospitals; the infant should have been born before a gestational age of 36 weeks; the infant and the grandmother should live in the same county; and the grandmothers should speak Swedish **Exclusion criteria** None reported	father of the infant, or if she had any other grandchildren All interviews were tape-recorded and transcribed verbatim, and performed by two of the authors who were not involved in the care of the infants **Data analysis** The analysis was conduced by content analysis including four steps: authors reading the transcripts several times individually to reach an agreement with content of transcripts; meaning units with relevance to aim and interview guide were identified; condensation of the meaning units; coding of meaning units and categorisation in agreement with all authors. An overall theme was identified during this process	*recognise that I am very close, although it is not my child. I want so much but without being intrusive"*	**Overall quality** Moderate **Other information** Authors used content analysis not thematic analysis
Full citation Garel, M., Dardennes, M., Blondel, B., Mothers' psychological distress 1 year after very preterm childbirth. Results of the EPIPAGE qualitative study, Child: Care,	**Sample size** N=20 mothers of children born preterm **Characteristics**	**Setting** At home, 2 months post discharge and 1 year after delivery **Data collection**	**Themes/categories** **Concern of infants development (anxiety) (barrier)** Mothers expressed anxiety, which was related to the child's health and development *"Because she was preterm, I am afraid that something might happen to her*" or *" I worry*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear saturation during data collection or analysis

Study details	Participants	Methods	Findings	Comments
Health & Development, 33, 137-43, 2007 **Ref Id** 445602 **Country/ies where the study was carried out** France **Study type** Qualitative study **Aim of the study** To assess qualitatively mothers' physical and psychological health, their perception of their child's health and development, and their difficulties with childcare from 2 months post discharge to 1 year after a very preterm delivery **Source of funding** Not reported	Male:female ratio of children: 15 boys:6 girls Children were born between 26 to 32 weeks of gestation Birthweight of children ranged from 630g to 2100g Children delivered by Caesarean-section (n): 11 Mothers delivered preterm due to premature rupture of membranes (n): 4 Mothers with interuterine growth retardation (n): 6 Mothers history of miscarriage (n): 4 Mothers who already had children (n):5 Mothers interviewed 1 year after delivery (n): 20 **Inclusion criteria** French speaking mothers, living with the child's father, either in Paris or in its close suburb or within 50km of Rouen None of the participants had been included in the EPIPGAGE study **Exclusion criteria** Multiple births	Mothers were initially contacted in the maternal unit by a psychologist Semi-structured interviews were conducted by the same psychologist at home 2 months post discharge and 1 year after delivery Interviews were taped and fully transcribed **Data analysis** Content analysis method was used to identify recurrent themes by listening to raw data Main themes were identified according to their contextual relevance and regardless of frequency Conceptual categories and a thematic framework was developed	*because he should be starting to speak*" Mothers were also anxious about their child's dullness *"I am scared because he is passive. He is lazy. He has to be stimulated to do things, whe have to show him how to do things"* **Coming to terms with preterm child (barrier)** Mothers found it difficult to cope with their child's behaviour *" because she was preterm, I wonder if we were not too lenient with her. This might explain why she is so irritable. We do not know how to cope when she has a tantrum"* **Parent to parent support and written information (barrier)** Mothers felt that their emotions regarding their child's birth did not fade and expressed *"the need for contacts and meetings with other parents of very preterm babies and written information"* **Parent/infant interaction (barrier) at 1 year after discharge** Mothers reported distress associated with rehospitalisation and attachment with their child *"since attachment develops with time, for me this readmission was more distressing than the first hospitalisation just after delivery"* **Family support (barrier) at 1 year after discharge** Mothers of preterm children expressed that they felt isolated and lonely as they were far from their relatives *"I think about my mother in Senegal a lot, I cry when the baby cries"* (one mother) **Partner support (barrier) at 1 year after discharge**	**Overall quality** Moderate quality **Other information** The authors used content analysis for qualitative assessment

Study details	Participants	Methods	Findings	Comments
			Mothers expressed a lack of support and help from the husband *"This year there has been a lot of tension between us. He did not pay attention to me, he did not support me. It's getting better now"* (one mother)	
Full citation Harrison, M. J., Neufeld, A., Women's experiences of barriers to support while caregiving, Health Care for Women International, 18, 591-602, 1997 **Ref Id** 413876 **Country/ies where the study was carried out** Canada **Study type** Qualitative longitudinal study **Aim of the study** To explore women's perceptions of barriers to support during family caregiving in a Canadian setting	**Sample size** N=20 women who were mothers of a premature infant **Characteristics** Infant was 35 or fewer weeks gestational age at birth (n=9/20 <33 weeks GA) Infant weight was <1500g at birth Infants who had necortosing enterocolitis or prolonged hospitalisation (n): 12/20 Age of mothers ranged from 25 to 40 years Mothers were English speaking and came from middle income and working class families Mothers who had post secondary education (n): 15/20 Mothers working full or part time (n): 16/20 Mothers were all living with the father of the infant at the start of the study; one mother	**Setting** Mothers were interviewed in their home shortly after discharge from hospital **Data collection** Interviews were carried out 4 to 5 times over an 18 month period for each mother Interviews lasted 1 to 2 hours and were audiotaped and transcribed **Data analysis** Constant comparative analysis and analytical techniques were used to identify categories and relationships among categories. Specifications for each category were developed and refined Interviews were analysed and the authors met regularly to discuss data analysis and to reach a consensus on the process of analysis and findings	**Themes/categories** **Requesting support (barrier)-general** Mothers who were offered support before they had to request it, they felt a fear of refusal, diminished self-esteem, and concerns for burden on the supporter were reduced *"I don't like to ask other people to do things for me. I will do them on my own if it kills me. So that leads to all kinds of problems"* Mothers were also reluctant to ask for support as fear of exposure *"When you're asking for support, a lot of times you've got to tell them the reason why and go into great depth about it. You can't just say, would you do this for me"* **Acknowledging that support is required (barrier)** Mothers viewed themselves as responsible for the care of their child and were unwilling to share this responsibility with others "I'm the one that had the children, so I should be the one that takes care of them" Mothers were also reluctant to admit that they needed help "when you can't manage on your own, you feel like somehow you've failed, and so if you	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** The study compared two groups, women caring for adults with cognitive impairment compared with women who were caring for infants born preterm Saturation of data was not clearly described, as well as saturation of analysis The analysis was not clearly described Unclear if the process of analysis was thematic Unclear if data sufficient to support findings Unclear if the analysis was validated independently Unclear hypothesis or theory or model generated **Overall quality** Low quality

Study details	Participants	Methods	Findings	Comments
Source of funding Not reported	was separated from her husband by the end of interviews **Inclusion criteria** Not reported **Exclusion criteria** Not reported		're a failure, you hate to point this out to someone else and ask for help" **Partner support (barrier)** Mothers frequently excused their husband from providing help with household duties *"If he's lying on the couch with a very sleepy look on his face and says 'don't worry dear, I'll clean it up', I'll say 'don't worry about it', because I know his heart is not in it"* **Coping with preterm and requesting support (barrier)** Mothers expressed that they used non-verbal signals to communicate need for support, which avoided asking for help verbally. After discharge from hospital, mothers belief was that signs of distress were now inappropriate *"Now Amy is 6 months old and I don't let it show...because I don't want to get hurt"*	**Other information**
Full citation Lasby, K., Newton, S., von Platen, A., Neonatal transitional care, Canadian Nurse, 100, 18-23, 2004 **Ref Id** 427965 **Country/ies where the study was carried out** Canada	**Sample size** N=14 mothers **Characteristics** Infant Weighed <1250g **Inclusion criteria** Mothers whose infants received support from the neonatal transition care	**Setting** At discharge from hospital At home after discharge **Data collection** Focus group interviews of a convenience sample of mothers from the trial **Data analysis** Not reported	**Themes/categories** <u>At discharge from hospital</u> **NTCP support-for mothers who were taking their infant home (facilitator)** Mothers expressed that they were anxious about taking their infants home but nurse visits reduced the levels of anxiety *"The first week I was nervous, but once I had [the nurse] coming and I knew to expect her...it made it so much easier for me to just tend to [my baby] and to get over any apprehensions I had of having him home and not having a full staff of*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** The study was a qualitative component of a randomised trial for NTCP compared with PHN support Method of selection was not clearly described The relationship between the researcher and the selected

Study details	Participants	Methods	Findings	Comments
Study type Qualitative component of a randomised controlled trial **Aim of the study** To explore the experiences of mothers who received support from the neonatal transition care programme, after discharge of their infants from hospital **Source of funding** Not reported	programme (intervention) or from community PHNs (control group) **Exclusion criteria** Not reported		*nurses there and learn that I was his full caregiver and whatever we did was ok" (mother)* **PHN support- for mothers who were taking their infant home (barrier)** Mothers expressed that they were anxious about taking their infant home as they did not know how to care for them *"I found it overwhelming-just the whole thing-new mother stress on top of a baby with an oxygen tank and tubing in my house. You leave [the hospital] with this whole list that says if this happens, call this person, do this...and it was overwhelming. I found myself taking his temperature for no apparent reason" (mother)* Mothers also found it difficult to access services and get information "*It would have been nice not to have to do so much legwork myself-you have enough to do instead of trying to find all the resources" (mother)* <u>After discharge, at home</u> **NTCP support (facilitator)** Mothers found that regular in-home contact and prompt pager support from the NTCP nurses, and telephone contact with the dietician enhanced their maternal confidence and decreased the need to take their infant outside of the home for weight checks, routine assessments, and vaccinations *"It helps you gain confidence [The NTCP] are there for you at every intense time"* or *"I can't imagine what it would be like without them [NTCP]" (mother)*	sample was not clearly described Data collection procedure was not described Roles of the researchers are not clearly described Unclear if saturation had been achieved Analysis method not clearly described Unclear how categories/themes derived Unclear if sufficient data was presented to support findings Unclear if saturation in terms of analysis was achieved Unclear if researcher managed own pre-understanding in relation to analysis Unclear if analysis was independently validated **Overall quality** Very low **Other information**

Study details	Participants	Methods	Findings	Comments
			NTCP support impacted positively on mothers at home with their infants *"they [NTCP] are the hope because they've seen babies like ours-very small and they've grown up to be well-and it's the stories they [NTCP] tell. I can now give that future hope.whereas before I didn't look past this day, this week, or this month*"	
Full citation Lee, T. Y., Lee, T. T., Kuo, S. C., The experiences of mothers in breastfeeding their very low birth weight infants, Journal of Advanced Nursing, 65, 2523-2531, 2009 **Ref Id** 445720 **Country/ies where the study was carried out** Taiwan **Study type** Qualitative study **Aim of the study** To report the breastfeeding experience of mothers with very low birth weight babies	**Sample size** N=31 mothers of very low birth weight infants **Characteristics** Maternal: Age of mother ranged from 25 to 40 years 52% were first time mothers Mothers education ranged from middle school degree to masters degree 71% of mothers had a junior college degree or above 21% had Caesarean section Infant: Gestational age of infant ranged from 23 to 33 weeks 16 boys:22 girls 7 sets of twins Birth weight of infants ranged from 522 to 1480g 32% were < 1000g Length of neonatal hospitalisation ranged from 4 to 19 days	**Setting** After discharge, at parents' home **Data collection** In depth interviews conducted 2 months after discharge from NICU (first interview) Unstructured interview at 6 months after discharge from NICU (second interview) Interviews were audiotaped and transcribed verbatim after the home visit **Data analysis** Content analysis (describing and qualifying phenomena) An open coding process allowed grouping of similar meanings to develop themes of mothers breastfeeding experiences The investigator followed three major phases: preparation, organisation and reporting	**Themes/categories** Meeting the infants' needs **Coping/adjusting with infants' feeding needs after discharge (at home) (facilitator):** Upon discharge from NICU, mothers became familiar with the infants feeding needs in a positive manner *"when my baby came home, I made a time schedule listing what I should do, and recorded what I did and how much I fed her. It took me one month to get familiar with her and learn way to take care of her"* **Coping/adjusting with infants' feeding needs after discharge (at home) (barrier):** Some mothers (who chose to bottle-feed their breast milk) tended to complain of exhaustion *"Everyday feeding occupied the majority of my time. I fed her every 3 hours. The nurse told me to express even at night to supply efficiently. I felt my sleep was dissected into several segments"*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** The data collection procedure was described, but not according to a theoretical framework Unclear if data saturation was achieved in the analysis Unclear hypothesis, theory or model generated from the results **Overall quality** Moderate **Other information**

Study details	Participants	Methods	Findings	Comments
Source of funding National Science Council in Taiwan	**Inclusion criteria** Mothers with an infant whose birth weight was <1500g Infant hospitalised in NICU Mothers could speak Mandarin Mother directly or indirectly breastfed her baby during hospitalisation of the infant **Exclusion criteria** Not reported			
Full citation Lee, T. Y., Lin, F. Y., Taiwanese parents' perceptions of their very low-birth-weight infant with developmental disabilities, Journal of Perinatal & Neonatal Nursing, 27, 345-52, 2013 **Ref Id** 445721 **Country/ies where the study was carried out** Taiwan	**Sample size** N=19 parents (11 mothers , 8 fathers) **Characteristics** Maternal Age ranged from 28 to 40 years Education ranged from a high school degree to a bachelor's degree Paternal Age ranged from 29 to 45 years	**Setting** At discharge At home **Data collection** Data was collected through interviews (in-depth, open-ended) by one researcher Interviews lasted 60 to 90 minutes Interviews were audio taped and later transcribed verbatim **Data analysis**	**Themes/categories** <u>After discharge from NICU (at 6 to 12 months follow-up)</u> **Developmental evaluation-confusion about developmental evaluation (barrier)** Mothers expressed that developmental implications and findings were often not made clear at follow-up by physicians regarding BSID II *"the hardest part was you did not know if the result was good or bad" or "I didn't know whether her failure to reach milestone behaviours was because of immaturity or because of having impairment.."* (mother) **Personal belief (facilitator)** Mothers' personal belief (spiritual) helped them to cope with the	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear saturation during data collection Unclear if analysis was independently validated **Overall quality** Moderate

Study details	Participants	Methods	Findings	Comments
Study type Qualitative study **Aim of the study** To explore the perceptions and experiences of Taiwanese parents in coping with the unfolding evidence of a disability, their response to the official diagnosis, and their views about their child's developmental disability **Source of funding** Not reported	Education ranged from a high school degree to a master's degree Infant Birth weight ranged from 620 to 1470g At time of second interview, every infant required at least one early intervention service **Inclusion criteria** Parents with very low birth weight infants **Exclusion criteria** Not reported	Content analysis was used by reading transcripts several times by two authors, followed by open coding of transcripts Consensus was reached through discussions, and codes with similar meanings were organised and grouped to elucidate themes New data was added to fit into data, until the 19th parent's interview	developmental disability of their preterm infant "..I was very disappointed at first because I planned to teach him to play tennis when he was older...Now I consider my son's condition [possible permanent disability] as a tough trial God gave me...Ever since I knew the possible prognosis related to his physical functioning, I have more empathy when seeing other handicapped children. I think God is fair. I appreciate that my son's current condition is not as severe as the one shown on TV" (Christian father) **Attitudes to follow up services (barrier)** Mothers initially feared that their infants would be permanently labelled as handicapped or disabled, and hesitated to apply for social welfare programmes, which affected follow-up care *"I could not accept he was 'severely handicapped' at first, especially when I saw the doctor write down the term on his report...he needs to be evaluated after three years. So I told myself if we worked harder [at rehabilitation], maybe he would be normal or become mildly disabled"* **Expectations from early intervention services-desire for child to be 'normal'** Parents who accepted early intervention expected that the programme would stop functional deterioration of their infant and also the impairment would disappear or become less obvious *"..I believed if she continued her physical therapy, then*	**Other information**

Study details	Participants	Methods	Findings	Comments
			one day she would walk like a normal child. No one would know she had been a premature baby with impairment" (mother) **Fathers support to rehabilitation programmes (facilitator)** Fathers adopted a flexible attitude toward the care of their infant *"I think her motor function will improve in three years, but we will prepare the rehabilitation device or corrective shoes for her if necessary and accompany her to the rehabilitation centre"* **Family and relationship balance (barrier)** Parents described that there could be disagreement between couples regarding the infant's care and of other siblings *"I knew everyone in the family cared about the baby. You should not take things personal, but you felt hurt. We needed to find a balance point when dealing with the kids' issues"* (mother) Parents found that due to numerous follow-up appointments and special attention at home, they were constantly trying to find a balance point with other healthy siblings in the family *"we try to find ways to distribute time to both of them. We feel sorry for the big [healthy] sister because we are no longer able to read bedside stories or take her out"*	

Study details	Participants	Methods	Findings	Comments
Full citation Little, A. A., Kamholz, K., Corwin, B. K., Barrero-Castillero, A., Wang, C. J., Understanding Barriers to Early Intervention Services for Preterm Infants: Lessons From Two States, Academic Pediatrics, 15, 430-438, 2015 **Ref Id** 413985 **Country/ies where the study was carried out** USA **Study type** Qualitative study **Aim of the study** To explore existing barriers and challenges to early intervention referral, enrolment, and service provision for very low birth weight (<1500g) infants **Source of funding**	**Sample size** N=44 parents (10 focus groups at 5 sites (each group with 3 to 7 participants)) **Characteristics** Parents of VLBW infants: 96% were women 45% women were black/African American 40% women were white 7% were <25 years age 23% were 25-34 years age 11% had high school graduation/GED or less 16% had some college graduation or more 17% had 4 years college graduation or more 69% parents reported that their children were currently enrolled in early intervention **Inclusion criteria** Parents of infants who were born with very low birth weight Parents who could speak English and Spanish **Exclusion criteria** Parents who declined to participate or could not be	**Setting** Three sites were selected in Massachusetts and three sites in South Carolina from hospitals as well as state and local early intervention programmes **Data collection** Discussion guides for focus groups and interviews were developed from staff in NICU, NICU follow-up clinic and local EI programmes An introductory letter was sent out to families of VLBW infants who had been discharged from NICU during the previous year Study staff provided contact information, and parents were interviewed for 30 minutes by trained staff, either in person, via telephone, using a semi-structured interviewer guide Saturation was **Data analysis** Grounded theory (without an a priori hypothesis; based on identification of themes as data are collected) New data was then classified under existing themes or new themes created as necessary Themes were then used to build an explanatory model	**Themes/categories** **EI provider support (facilitator)** Parents described that the EI provider helped them to understand their infant's medical and developmental needs when they could not understand the doctor *" sometimes we don't really understand the doctor, and then the EI provider comes and explains it"* **EI provider/staff support for parents in doctor visits (facilitator)** The EI staff explained their supportive role during doctors visits to facilitate parents in receiving correct information *"we go as support systems, and..to make sure we have information correct. A lot of our families' educational levels make it hard for them to...talk about what their doctor explained"* (local EI coordinator) **EI support for parents/families (facilitator)** Parents explained how EI staff provided support to parents regarding their infant "*My wife says how...she didn't notice...my daughter's problem, her neck. Early intervention did. And then I started to notice it too. So she had 2 therapists, one for the neck and one to help her play"* (parent) **EI support for encouraging parents to attend follow-up clinics (facilitator)** Parents stated that the EI were supportive in prompting them to come back to NICU for follow-up after discharge *"EI has helped us out a lot..in terms of prompting parents to come back to the NICU follow-up clinic"*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** **Overall quality** Moderate Unclear if data collection saturation was achieved Insufficient data presented to support findings **Other information**

Study details	Participants	Methods	Findings	Comments
Robert Wood Johnson Foundation Physician Faculty Scholars Programme National Eye Institute K23 Career Development Award	contacted after three attempts	Codes were generated for themes, and compared by 2 research staff independently to refine the list of codes Theme saturation was achieved when quotations from each new transcript could be classified using the existing set of themes	**EI support for infant development (facilitator)** EI staff explained further their supportive role in making observations about the infant's development and family's social situation *"EI is the eyes and ears for paediatricians and school systems and everybody"* (EI local coordinator) **EI support for parents caring for their infant (facilitator)** Parents explained how EI providers were helpful in keeping them engaged in the their infant's care *"The EI therapist writes what we did and what needs to be worked on and what was the improvement. And I get a copy of that at every visit"* (one parent) **Parent receptiveness to EI services (barrier)** Some parents were unwilling to acknowledge their infants developmental delays *" I don't want to hear my son is backwards...he was 2.5 months early. To the EI he's like seven months, to me he's nine months plus"* (parent) **Lack of support for parents about EI (barrier)** Some parents perceived that EI services were not helpful *"I still was grappling with what EI was doing for my child.. The EI provider played with the baby and that was basically it"* (parent) **EI concerns (barrier)** EI providers stated that some parents do not recognise their infants needs *"families are more concerned about getting food on the table than the fact*	

Study details	Participants	Methods	Findings	Comments
			that their child can ask for milk" (EI coordinator) **Delay in EI services (lack of staff, access to services) (barrier)** Parents stated that there was a delay in the start of EI services *"EI came right out probably within the next week to check him out... then they were waiting for his sister to come home to start services..and they kind of stalled"* (parent of twins) EI coordinators stated that there was a shortage of staff *"I have never been fully staffed in eight years due to shortages in speech therapy and motor therapy. which I understand is really nationwide"* (EI coordinator) Parents stated that home based EI providers were unavailable "*we needed physical therapy, but nobody would come out to the home...we had to do it in one of the facilities in the city"* (parent)	
Full citation May, K. M., Searching for normalcy: mothers' caregiving for low birth weight infants, Pediatric Nursing, 23, 17-20, 1997 **Ref Id**	**Sample size** N=14 mothers of infants born premature **Characteristics** Maternal: Age of mothers was 21-41 years	**Setting** Mothers were contacted through a follow-up clinic for high risk infants Interviews were at a location of the mothers' choice: home, place of employment or a restaurant **Data collection**	**Themes/categories** **Burden of care at home (After discharge)/coping with preterm infant (barrier)** Mothers expressed the burden of care when bringing their infants home from hospital (physical and emotional strain) and changes to lifestyle "*I think an important time for people to be reached*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Roles of the researchers were not clearly described regarding analysis of data

Study details	Participants	Methods	Findings	Comments
460582 **Country/ies where the study was carried out** USA **Study type** Descriptive/qualitative study **Aim of the study** To explore the process mothers use to seek help in providing care to low birth weight infants **Source of funding** BRSG Agency for Health Care Policy and Research	10/14 mothers were Anglo 4/14 mothers were Latina !3/14 mothers were married 1/14 mothers was divorced First child 7/14 Mean education was 14 years Infant: Gestational age ranged from 23 to 34 weeks At time of study, infants age ranged from 4-11 months **Inclusion criteria** Mothers providing care at home for low birth weight infants who had been in NICU and were enrolled in a follow up clinic **Exclusion criteria** Not reported	The nurse manager of the clinic facilitated authors contact with eligible parents Each semi-structured interview lasted 30-65 minutes, over a 6 month period All interviews were audio taped and transcribed Focus groups with public health nurses at 4 were carried out to understand their perceptions of mothers' care of LBW infants and the nurses' role **Data analysis** Open and selective coding of data followed by theoretical coding Theoretical saturation occurred when new data confirmed existing categories and subcategories	*when they have premature children is in the first week, because you're terrified and you have no idea"* (mother of preterm infant) **Health care professional (barrier)** Some mothers stated that they found some health care professionals practices and attitudes as barriers, which resulted in mothers caring for their infant alone "*It's clearly an unstable situation. I'm going to have to work out something, but I just don't know what it's going to be. I'm going to do it"* (mother of preterm infant) **Seeking help (barrier)** Mothers found that they recognised there was a need for assistance in obtaining information, assessment and treatment, respite caregiving and support *"One thing is that I wish there were more resources to rely on, to fall back on. I wish there were more studies done and more statistics"* (mother of preterm infant) **Seeking help (facilitator)** Mothers found that they could seek help with assessment and treatment when at home "*I'd call the home health nurses and say 'can you stop by today? I think he's got a cold in his lungs. Am I hearing things or do I need to take him to the doctors?' She would come out"* (mother of preterm infant) **Support network (barrier)** Mothers stated that a support network was not beneficial to them in caring for their infant *"..We worry a lot about what is happening. And everybody just tells us not to worry but we know there is something wrong and we don't know*	Unclear if data collection saturation was achieved Unclear if a theory or hypothesis was generated from the results/findings **Overall quality** Moderate quality **Other information**

Study details	Participants	Methods	Findings	Comments
			what to do about it. So I'd say that in our case the support network really hasn't worked out very well" (mother)	
Full citation Neu,M., Robinson,J., Early weeks after premature birth as experienced by Latina adolescent mothers, MCN, American Journal of Maternal Child Nursing, 33, 166-172, 2008 **Ref Id** 306937 **Country/ies where the study was carried out** USA **Study type** Qualitative study **Aim of the study** To examine early adaptation challenges and strengths of young mothers with preterm infants	**Sample size** N=12 adolescent mothers **Characteristics** Maternal Age was 16 to 19 years Mexican American origin 7/12 mothers were married and lived with their husbands (3/7 with husband only, 2/7 with husband and family, 2/7 with mothers family) 5/12 mothers lived with their own family (2/5 fathers were not involved, 3/5 fathers visited their infants on a daily basis and some stayed the night) Infants 32 to 35 weeks gestational age at birth Spent 1 to 4 weeks in hospital 7/12 infants required oxygen for several days All infants were 2 to 3 weeks postnatal age at the time of the first visit	**Setting** Mothers were recruited from five NICUs in a mid-sized city in western US **Data collection** Visits were conducted by the first author at the mothers home Visits lasted 45 to 60 minutes Notes of conversation, observations of the home, and the teen's interaction with family members and her infant were taken during each visit or immediately afterwards Participants comments were summarised during each visit for accuracy and interpretation Repeated information was recorded that was heard or observed during the 8 weeks of visitation An audit trail using raw data and field notes of observations of mothers and infants was assembled Themes were identified by both authors **Data analysis** Narrative and field notes were separated into sections, and labelled	**Themes/categories** **Family support (facilitator**) Family members were heavily involved in caring for the infant "*I have lots of cousins who live very close. In the evening we get together and play wit our babies and just talk"* (mother) **Fathers support (barrier)** Fathers did not frequently help with parent caregiving as they were *"..tired when they got home from work"* (mother) **Isolation from peers (barrier)** Mothers expressed that they had lost part of their life and their friends, but turned to their family or partner for companionship *"sometimes I feel lonely. I have one friend with a baby and we see each other, but it is not the same as before. Now my boyfriend is my best friend"* (mother)	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear saturation during data collection Unclear if sufficient data presented supported findings Unclear saturation during data analysis Unclear if analysis was validated independently **Overall quality** Low **Other information**

Study details	Participants	Methods	Findings	Comments
Source of funding National Institutes of Health National Institute of Child Health and Human Development General Clinical Research Centres Programme, NCRR, NIH	**Inclusion criteria** Mothers of first-born infants English or Spanish speaking No illicit drug use No serious illness Infants were 32 to 34 weeks of gestational age at birth Infants had minimal oxygen needs Infants had no physical anomalies Infants had no major surgeries **Exclusion criteria** Not reported	with a code word or phrase to convey meaning of the section Codes with common meaning were grouped into categories, and further into main themes Both authors reviewed the data and discussed and agreed on themes		
Full citation Nicolaou,M., Rosewell,R., Marlow,N., Glazebrook,C., Mothers' experiences of interacting with their premature infants, Journal of Reproductive and Infant Psychology, 27, 182-194, 2009 **Ref Id** 307296 **Country/ies where the study was carried out** UK	**Sample size** N=20 mothers who met the inclusion criteria and volunteered to participate in the study **Characteristics** Male:female (n): 9:11 Infant characteristics Median (range) weeks of gestation at birth: 27 (23-34) Median days in hospital (range): 78 (18-165) Median infant age at interview (range): 9.5 months (4-24)	**Setting** At hospital At home after discharge **Data collection** Semi-structured interviews were conducted Questions centred on early interactions that mothers had with their premature infants in hospital and then in their home Mothers were also asked about the amount of information that they were given regarding interactions with their premature infants	**Themes/categories** **Information support at preparation of discharge from NICU (barrier) for parent/child interaction** Mothers identified issues regarding lack of information given to them about interacting with their infant at discharge from NICU *"we were given preparation but it was all very medical. We had booklets and discussions about RSV, meningitis, all the things he could pick up, but in terms of how to actually care for him and what to do when we got him home there really wasn't anything"* **Improvement of parent/infant interaction over time (facilitator)** Mothers were concerned with problems initially, and found interacting with their	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear saturation in terms of analysis Unclear if analysis has been independently validated **Overall quality** Moderate

Study details	Participants	Methods	Findings	Comments
Study type Qualitative study **Aim of the study** To explore thoughts and experiences of mothers concerning their early interactions with their premature infants To explore the perceived support and information needs of mothers of premature infants **Source of funding** Not reported	Single birth (n,%): 19 (95%) Maternal characteristics Median age (range): 31 (24-40) Marital status (n, married/cohabiting): 18 Ethnicity (n, white european): 19 Education (n, GCSEs): 6 Education (n, BTEC national diploma): 2 Education (n, degree or above): 12 **Inclusion criteria** Not reported **Exclusion criteria** Not reported	All interviews were conducted over the telephone, recorded and transcribed verbatim once completed **Data analysis** A thematic analysis was conducted to develop themes from interviews Transcripts were read repeatedly so that the researcher became familiar with the data and initial ideas were noted Initial codes were generated for the data, which were reviewed, combined or discarded, so potential themes were identified	infants challenging, but improved over time because their infants growth "*Now she's actually a lot more playful because she's getting bigger"* **Support from health visitors (barrier)** Mothers raised concerns with the quality of support from health visitors *"I felt a little bit left alone with him. Health visitors would come around but would all say'oh he's too small'...they didn't know how to deal with a premature baby"* or "the health visitors have been very *sweet but they quite often have very little idea about practical issues with premature babies. Sometimes you feel abandoned"* Mothers expressed that they would have liked more support in the early days when they took their infants home "*Hospital is probably the place that knows that we're all mums with new babies. It would have been great if we could have had a support group"* From content analysis, mothers felt that they could have had more support when taking their infants home from hospital *"I think personally I did as much as I could do, but I think I could have done with some more support"*	**Other information**
Full citation Niela-Vilen, H., Axelin, A., Melender, H. L., Salantera, S., Aiming to be a breastfeeding mother in a neonatal intensive care unit and at home: A thematic analysis of peer-	**Sample size** N=30 mothers of preterm infants and 3 peer supporters **Characteristics**	**Setting** A Facebook breast feeding peer-support group for mothers that was used as part of a randomised trial was provided as support in the study during and after discharge from NICU Mothers received guidance on	**Themes/categories** **Nurse support (barrier)** Some mothers stated that they wished for individual and equal guidance and support (and counselling) from all nurses in order to maintain breastfeeding and its potential	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations**

Study details	Participants	Methods	Findings	Comments
support group discussion in social media, Maternal and Child Nutrition, 11, 712-726, 2015 **Ref Id** 413084 **Country/ies where the study was carried out** Finland **Study type** Qualitative study **Aim of the study** To explore mothers views and perceptions of issues and problems that were relevant to them when they were breastfeeding their preterm infants **Source of funding** Finnish Doctoral Network in NursingFinnish Doctoral Network in Nursing Finnish Doctoral Network in Nursing	Maternal Age of mothers was median 29 years (range 20 to 46 years) Infants Born at <35 weeks gestational age and transferred to NICU **Inclusion criteria** Mothers of preterm infants who were born at <35 weeks of gestation and transferred to NICU **Exclusion criteria** Not reported	how to join the support group during the first week postpartum, and further access for at least a year after birth of their infant. The peer support was provided by three voluntary mothers who had previous experience of breastfeeding preterm infants. They had no specialist training, and a midwife was available to answer any questions related to breastfeeding **Data collection** Postings from the peer-support group were analysed, and mothers agreed to have their postings analysed by the author **Data analysis** Thematic analysis was used to analyse the content of peer discussions Data was in the form of online messages posted by mothers, peer supporters and midwife Initial themes were identified, and codes formed for themes and sub themes	challenges at home *"..I was hoping for more information especially about how to manage at home, when the baby is used to the bottle, and what kind of problems may exist and how to manage them. Your are not able to ask all relevant questions in hospital when you are worried about the health of your baby and the main issue is that the baby is getting food, one way or another. In hindsight, I would have acted differently when we got home, but then, as a novice, I ruined my opportunity to exclusively breast feed"* (mother of preterm infant) **Kangaroo care for breast feeding support at home (facilitator)** Some mothers stated that as they were able to kangaroo in NICU, they did not need to practice kangaroo at home "*..we were able to kangaroo..they really encouraged us to do it. Both nurses and doctors..we hardly ever practiced kangaroo at home"* (mother of preterm infant) **Breast feeding support (barrier)** Mothers experienced that the breast feeding counselling provided in NICU was not sufficient for their needs at home "*after discharge, we tried to practice breast feeding by ourselves. It didn't work out at all..the baby's latch wasn't right..*" or *"they said no breast feeding at all before the weight is clearly increasing. Well, after a few weeks, the baby refused to suckle the breast and he only accepted the bottle"* (mother of preterm after discharge from NICU) Mothers did not receive support/instructions for breast feeding at home "they didn't provide much	Unclear if data collected according to a theoretical framework Unclear saturation was achieved during data collections Unclear if saturation was achieved during data analysis Unclear if the analysis was independently validated The first author was a midwife participating in the peer-support group, which may have some influence on her perception of breastfeeding. **Overall quality** Moderate quality **Other information**

Study details	Participants	Methods	Findings	Comments
			support or instructions for home. '*You can breastfeed once a day for a start', that was the only advice I got. It is purely based on my own persistence that she has been exclusively breastfed for 4 weeks"* (mother of preterm infant at home)	
Full citation Phillips-Pula, L., Pickler, R., McGrath, J. M., Brown, L. F., Dusing, S. C., Caring for a preterm infant at home: a mother's perspective, The Journal of perinatal & neonatal nursing, 27, 335-344, 2013 **Ref Id** 460616 **Country/ies where the study was carried out** USA **Study type** Qualitative study **Aim of the study** To examine the experiences of mothers of preterm infants during the first 6 months at	**Sample size** N=8 mothers **Characteristics** Maternal 5/8 mothers were married 1/8 mothers was single 2/8 mothers in a committed relationship 4/8 mothers had college degrees 3/8 mothers had some college education 1/8 mothers was studying for a general education diploma 1/8 mothers was living with parents 4/8 were first time mothers 3/8 mothers had other children Infants Birth weight ranged from 1lb 4oz to 6lb Days in NICU ranged from 60 to 150 days Time since discharge ranged from 2 to 5 months	**Setting** Mothers were recruited through advertisements in northern Virginia and flyers placed in the NICU of a large health centre Interviews were scheduled according to mothers' availability and took place either at home or another choice of place **Data collection** Interviews took place once, and lasted from 60 to 90 minutes Interviews were open dialogue between the participants and the researcher **Data analysis** Epoche process of setting aside a priori thoughts Phenomenological reduction (by identifying significant statements or horizons, identifying and organising themes from horizon statements) Imaginative variation of how participants experienced the phenomenon	**Themes/categories** **Spouse/Family support (barrier)** Mothers stated that their spouse or partner did not understand how difficult it was to provide the necessary care for their infants, and although family were supportive mothers felt that they were isolated *" I don't care how many friends you have and how many babies they've had, if you don't have a baby in the NICU, you don't get it"* **Family support (facilitator)** Mothers expressed that they were thankful for support from friends or through a formalised group *"whenever I get tired my mom will say 'bring him to mer and go take a nap or something' and that helps"* **Health care professional support (facilitator)** Mothers stated that at least one person worked with them and made a difference "*The NP at the apnea clinic was amazing..the best..she understood everything" or "the nurses and neonatologists always talked to us like humans"*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** The relationship between the researcher and the selected sample is unclear Unclear if data saturation achieved during data collections Not enough data to support findings Unclear if data saturation achieved during the analysis Unclear hypothesis, theory or model generated from findings **Overall quality** Moderate **Other information**

Study details	Participants	Methods	Findings	Comments
home following discharge from NICU **Source of funding** Not reported	**Inclusion criteria** Volunteers who were 18 years of age or older, who had given birth to a singleton infant born between 24 to 34 weeks gestation, without serious sequelae, and who had been discharged from a NICU to home for 1 to 6 months **Exclusion criteria** Multiple births, infants discharged from NICU for longer than 6 month			
Full citation Reyna, B. A., Pickler, R. H., Thompson, A., A descriptive study of mothers' experiences feeding their preterm infants after discharge, Advances in Neonatal Care, 6, 333-40, 2006 **Ref Id** 445827 **Country/ies where the study was carried out** USA	**Sample size** N=55 mothers consented N=27 mothers returned for interviews **Characteristics** Maternal <24 years of age First time mothers Black ethnicity Unmarried and unemployed Infants 24 were singleton infants 3 sets of twins	**Setting** Mothers were interviewed 2 to 3 weeks after the infants' hospital discharge. Interviews took place in the school of nursing and were conducted by one of 3 authors **Data collection** The interview focussed on mothers feeding experiences since discharge and reflecting on the feeding experiences before discharge, and was developed to address changes in infant feeding skills	**Themes/categories** <u>After discharge</u> **NICU support-feeding (barrier)** At discharge, mothers had difficulty understanding the discharge instructions and feeding schedule and were hesitant to liberalise their infant's intake after discharge as they were worried about how much formula they should give *"I'm afraid of missing a feeding...the hardest part is when she's 3 hours this time and then she doesn't eat for 4 hours the next time, and I'm thinking I'm late, I didn't feed her" or "they gave me instructions as every 3 to 4 hours ad lib. I didn't ask that right*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear if saturation was achieved during data collection Insufficient data to support results/findings Unclear if saturation was achieved during data analysis Unclear if the analysis was independently validated

Study details	Participants	Methods	Findings	Comments
Study type Qualitative study **Aim of the study** To explore mothers' perception of their experiences in feeding their preterm infants in the early weeks after hospital discharge **Source of funding** National institute of Nursing research, National Institutes of Health	Age at birth was 35 weeks gestation (range 33 to 38 weeks) Age at time of interviews was 38 weeks gestation (range 35-40 weeks) **Inclusion criteria** Infants were participants in a lager study of feeding readiness in preterm infants Infants born at <32 weeks gestational age Medically stable (by 32 weeks post menstrual age) to allow oral feedings **Exclusion criteria** Not reported	Interviews were audiotapes and transcribed verbatim **Data analysis** Phenomenological analysis Transcripts were read initially by one author to obtain overall sense of information Transcripts were reread several times to extract themes Similar themes from transcripts were grouped The teems were defined by reviewing transcripts and formed consensus about results	*now she's on 2 ounces, when do I take her to 3 or 2.5 ounces"* Mothers also expressed the need to know how to prevent hiccups and how to encourage their babies to burp more often *"how many burps is she supposed to have?"* **Anxiety at discharge (barrier)** Mothers expressed their anxiety and apprehension about their infants after discharge "the only concern I have is, I don't want them to choke, I'm fearful of choking" However, concerns lessened as the infant's feeding patterns became clearer *"I was scared the first few days, but now it's like second nature. I pick her up, and I don't even think about anything anymore"* **Family support (barrier)** Although mothers found husband or family support was helpful, they were the primary care givers for the infants and were uncomfortable with other people feeding their infants *"the other people in the house, if they put the bottle in her mouth and she doesn't automatically suck it, then they thin she doesn't want it. I can't leave my baby alone, she'll starve to death"* **NICU support -feeding (facilitator)** Mothers responded that while their infant was in NICU, frequent visits and opportunities to feed before discharge led them to being more comfortable about the feeding process once at home "on the day she went home, I fed her 3 or 4 times that day. Every time I could get there, I got to feed her. I think they prepared me very well"	Unclear hypothesis, theory or model generated **Overall quality** Low quality **Other information** Phenomenological approach used in the analysis

Study details	Participants	Methods	Findings	Comments
Full citation Sommer, C. M., Cook, C. M., Disrupted bonds - parental perceptions of regionalised transfer of very preterm infants: a small-scale study, Contemporary nurse, 50, 256-266, 2015 **Ref Id** 461097 **Country/ies where the study was carried out** New Zealand **Study type** Qualitative study **Aim of the study** To investigate parents' perceptions of preterm infants transfer, to provide neonatal clinicians with insights to facilitate optimal service provision **Source of funding** Not reported	**Sample size** N=6 parents (5 mothers and 1 father) **Characteristics** Infants Ranged from 23+6 to 29 weeks gestational age Duration of NICU stay ranged from 3 to 12 weeks Two parents' infants were transferred to one regional special care baby unit Four parents' infants were transferred to another regional special care baby unit **Inclusion criteria** Mothers or fathers who were domiciled for two metropolitan hospitals Whose baby was born <29 weeks of gestation The infant received care in the NICU and later transferred to their local hospital, within the last 3 years	**Setting** Four interviews took place in parents' homes, and one interview was conducted at the parent's workplace **Data collection** Semi structured interviews conducted by the first author All interviews were audio taped and transcribed verbatim **Data analysis** Inductive approach (using detailed iterative readings of raw data to derive initial categories or codes) was used to analyse data and interpret meaningful themes The analysis was undertaken by the authors independently, followed by cross-checking for consistency. Subsequent to transcription, participants were offered to revise and amend their transcripts	**Themes/categories** **NICU support- Anxiety and uncertainty about regional transfer (barrier)** Parents who had adapted to NICU routine surrounding care of their infants found that transfer to another unit felt like they were being abandoned *"..feeling like you're kind of whisked out a back door and it's like that abandonment" or "it would have been reassuring to know that NICU hadn't washed their hands completely"* **Special baby care unit support - disruption to parental identity (barrier)** Mothers expressed the disruption to maternal identity through protocols that excluded parental input *"I got there and she (nurse) wouldn't let me hold him until the next shift came on and I just sat there in tears...whereas in NICU I was getting him out of the incubator myself, I could do all that"* Parents generally stated that in the special baby care unit, they were not valued, leaving them feeling like spare accessories rather than parents *"over at SCBU parents are surplus...they don't involve you in medical rounds"*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear relationship between researcher and selected sample Data collection procedure not clearly described and not according to a theoretical framework Roles of the researchers are not clearly described Unclear saturation during data collection Analysis description is vague Partial explanation of thematic analysis used Saturation during data analysis unclear Unclear if researcher managed pre-understanding in relation to the analysis Unclear if data was independently validated in the analysis **Overall quality** Very low quality

Study details	Participants	Methods	Findings	Comments
	Exclusion criteria Not reported			**Other information**
Full citation Thomas, J., Feeley, N., Grier, P., The perceived parenting self-efficacy of first-time fgathers caring for very-low-birth-weight infants self-efficacy in fathers of VLBW infants, Issues in Comprehensive Pediatric Nursing, 32, 180-199, 2009 **Ref Id** 445884 **Country/ies where the study was carried out** Canada **Study type** Qualitative study **Aim of the study** To explore the factors that first time fathers of a very low birth weight infant perceive to influence their parenting self-efficacy beliefs	**Sample size** N=5 **Characteristics** Fathers Age ranged from 32-47 years Educational background included high school (n=1), college (n=1), bachelors (n=1), masters (n=1), PhD (n=1) Cultural background included English (n=1), Greek (n=1), Iranian (n=1), Turkish (n=1), Hiatian (n=1) Linguistic grow included English (n=3) and French (n=2) Married (n=4) Living with partner (n=1) **Inclusion criteria** Fathers included: Had become a father of a very low birth weight infant (<1500g) within the last 2 years Above 19 years age Speak English or French	**Setting** Participants were recruited through convenience sampling from a neonatal follow up clinic in a large urban setting in Canada All participants were interviewed at a time and place most convenient to them **Data collection** A nurse clinician at the neonatal clinic identified fathers who matched the inclusion criteria, and were contacted via telephone Semi structured interviews lasted approximately 1 hour Interviews were audiotaped and transcribed verbatim **Data analysis** Conducted throughout the data collection period Content analysis was used to analyse data Each transcript was examined for statements concerning fathers' parenting self-efficacy	**Themes/categories** **NICU support at discharge (barrier)** Some fathers expressed that they did not have any role models to follow in order to deal with sudden responsibility for their infant *"when you have a premature baby...it comes home, you have so many questions because you are so scared...[but] you don't have a number to call. You are on your own"* **Family support (facilitator)** Fathers found that their mother -in -law was helpful in parenting *"she's extremely capable..feeding, teaching my mother tongue [language] and manners, how to handle a baby physically..in some ways through her caring for our baby, it was for us a kind of training"* **Personal beliefs (facilitator)** Some fathers reflected how personal belief supported them to care for their infant *" you develop a tough skin from the experience of being able to take up challenges in a situation where you might not have support or there is uncertainty or your future is unknown"* (immigrant)	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** The relationship between the researcher and selected sample not clearly described Roles of the researcher not clearly described Unclear saturation during data collection Unclear saturation during data analysis Unclear if analysis validated independently **Overall quality** Low quality **Other information**

Study details	Participants	Methods	Findings	Comments
Source of funding Not reported	Have no other children living in or outside of the household **Exclusion criteria** Infant and/or mother were not yet discharged from hospital Infant was born with birth defects Infant suffered intraventricular haemorrhage grades III and IV	Recurring concepts within and across transcripts were grouped and themed using an open-ended method Themes were continuously compared, confirmed and refined throughout the data collection process, independently by another researcher Coding was compared and a consensus was reached		
Full citation Turner,M., Winefield,H., Chur-Hansen,A., The emotional experiences and supports for parents with babies in a neonatal nursery, Advances in Neonatal Care, 13, 438-446, 2013 **Ref Id** 325142 **Country/ies where the study was carried out** Australia **Study type**	**Sample size** N= 9 mothers who consented to first interview at NICU and second after discharge **Characteristics** Maternal Mean age was 32.5 years (range 20 to 40 years) Infant Mean gestational age at birth was 25 weeks (range 24 to 31 weeks) Singleton birth (n=7) Twin birth (n=2) All participants attended the support group, with 8	**Setting** After discharge of the infant from NICU for a minimum of 12 weeks by the time of the interview **Data collection** Semi structured and employed open-ended prompts Interviews tool place via telephone, ranging from 45 to 70 minutes All interviews were digitally recorded with participant's permission All interviews were transcribed verbatim by the interviewer Data collection continued until saturation was achieved and no new themes were identified	**Themes/categories** **Anxiety at discharge from NICU-coping without assistance (barrier)** Mothers described anxiety about being able to cope with their infants without assistance and managing complications that may arise after discharge *"..they taught us..[cardiopulmonary resuscitation] CPR and stuff like that..and in my head it was like 'well what if something goes wrong and I don't know how to do the CPR?' "* **Family support at discharge from NICU-stress (barrier)** Parents distress at discharge increased du to family and friends input about their concerns regarding the infants' health *"..one of my girlfriends was bombarding me the day before we actually picked her up..My head was*	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear saturation during data analysis Unclear if researcher managed own pre-understanding in relation to analysis Unclear if analysis was independently validated **Overall quality** Low

Study details	Participants	Methods	Findings	Comments
Qualitative study **Aim of the study** To explore emotional reactions during the transition to home from the NICU for parents who participated in a support group **Source of funding** Royal Australian and New Zealand College of Psychiatrists (Young Investigators Grant Scheme)	participants attending more than one session **Inclusion criteria** Parents of infants who had been in NICU, who attended the NICU support group session during hospitalisation **Exclusion criteria** Not reported	**Data analysis** Data was analysed for themes using the Pope and Mays method An audit trail was maintained throughout the research and was examined The first author compared themes between and within interviews to produce codes Codes were compared against raw data by the second and third authors Consensus was reached by discussion of themes and subthemes	*spinning..I got in the car and said to my partner, 'I'm not going to cope. This is too much' "* **Precautions after discharge to prevent illness -parents** PArents were more vigilant regarding their infants health *"since our NICU graduate baby [was ill], we've been really conscious of keeping him away from other kids who are sick, and I took my other son out of childcare. If friends invite us over, we ask if their kids are going to be sick, and if they are, we don't go"* **Coping with on going medical support after discharge-support from NICU (barrier)** Parents were given an introduction to using oxygen at home by nursery staff but they felt unprepared for the change in mobility and lifestyle that it would mean for life at home " we're limited in where we can take him in the house without moving the oxygen cylinder. We're limited on what we can do, we sort of keep him away from any stuff where he's likely to catch a cold" **Feeding support at home after discharge from NICU (barrier)** Parents reported that it was a challenge to learn how to care for a feeding tube and how to gradually teach the baby to feed (breast or bottle) *"she still had the feeding tube in..we had to slowly increase the sucking feeds to slowly remove the gavage..so we were juggling"* **Caring for infant at home after discharge (barrier)**	**Other information**

Study details	Participants	Methods	Findings	Comments
			Parents stated that they needed to change their roles to responsibility and caretaking as this was a change from NICU *"it's just a really big adjustment..having to care for her 24/7, and not have the nurses guide me.."* **Parent and infant bonding after discharge from NICU** Parents described that they had a positive relationship with their infants after discharge in the home environment *"he's obviously more dependent upon me now...even though I think he knew who I was in hospital, he's more aware of what's going on. So that makes our relationship a little bit stronger"* **Peer support group for infant (facilitator)** Parents found it helpful for them to attend baby playgroup as it was a place where some parents reconnected after discharge from the hospital *" the support is carrying on now...having a kid who's..nearly 6 months old, but only 4 months corrected...I'm starting to think about solids...and that's something that I'll..go to the playgroup"* **Support group in NICU-after discharge (facilitator)** Parents expressed that the support group provided information (friendship and emotional support) was helpful when they were at home after discharge "..definitely [found information and educational content useful]"	

Study details	Participants	Methods	Findings	Comments
Full citation Vasquez, E., Creating paths: living with a very-low-birth-weight infant, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 24, 619-624, 1995 **Ref Id** 460686 **Country/ies where the study was carried out** USA **Study type** Qualitative study **Aim of the study** To describe parents' method of adaptation to the problems of caring for a very low birth weight infant at home **Source of funding** American Nurses' association mental health clinical traineeship	**Sample size** N=14 parents **Characteristics** Parents 10 couples and 4 single mothers Mean age of parents was 33 years (range 21 to 60 years) infants Very low birth weight <1500g **Inclusion criteria** Very low birth weight infants discharged from hospital Infants not requiring complex home care (dependent on oxygen, ventilator or both) Parents participate voluntarily and be willing to take part in three interviews **Exclusion criteria** Not reported	**Setting** After hospital discharge **Data collection** Parents participated in three interview sessions held at 1, 4 and 5 months after discharge from hospital Data was gathered using a formal interview guide Interviews were audiotaped and transcribed verbatim **Data analysis** Data analysis involved transcribing interviews in order to identify themes as they emerged from data Data was coded, compared with other data, and assigned to categories Data was analysed using the constant comparison method, which allowed continued integration of accumulated knowledge Categories were constantly modified as successive data demanded	**Themes/categories** <u>Coping with infants after discharge</u> **Isolation** Parents provide protection to their infant from germs, strangers, friends and close family members, and to avoid unintentional insults from them about the infants size and fragility *"when people come over...mostly relatives...I did tell them that they couldn't touch the baby" or "we didn't go to restaurants until 3 months after discharge...we didn't take him out much those first couple of months. And we still don't go out much" (parents)* **Parent and infant interaction (Facilitator)** Parents acknowledge changes in behaviour of their infants as they mature *"Once he starts smiling and listening to your voice, you're getting something back"* **Family and infant interaction (barrier) (parents perspective)** Parents felt angered by some remarks that people made about their infant "they're afraid of him, some people are afraid to touch him...he's so small. I'm talking about relatives, the people that I expect to love him. They love him...but don't show it. They haven't celebrated his birth yet..it's been 7 months" **Developmental concerns of infant (parent perspective)** Parents were concerned with public exposure with the infants actual age	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** The relationship between researcher and selected sample not clearly described Roles of the researcher not clearly described Unclear if saturation achieved during data collection Unclear if sufficient data supported findings Unclear if saturation achieved during data analysis Unclear if analysis independently validated **Overall quality** Low quality **Other information**

Study details	Participants	Methods	Findings	Comments
			being a difficult concept to address *"..we were talking about celebrating her birthday. When she turns 1..will she really be 1? Developmentally, she will be a little behind. We'll just do it on her real birthday, the day she should have been born"*	
Full citation Whittingham,Koa, Boyd,Roslyn N., Sanders,Matthew R., Colditz,Paul, Parenting and prematurity: Understanding parent experience and preferences for support, Journal of Child and Family Studies, 23, 1050-1061, 2014 **Ref Id** 325120 **Country/ies where the study was carried out** Australia **Study type** Qualitative study **Aim of the study**	**Sample size** N=18 parents of children born very preterm (≤32 weeks gestation) **Characteristics** Parents 16/18 were mothers 2/18 were fathers 15/18 were married 1/18 was single 2/18 were living together 10/18 had university degree 3/18 had vocational education/college 2/18 had trade/apprenticeship 3/18 had 12 years education 1/18 had <10 years education Infant Gestational age of preterm infant 26.33 (range 24.0 to 32.57)	**Setting** Hospital setting Parents were given draft copies of the Prem Baby Triple P workbooks to use before and during the focus group discussion **Data collection** Four focus groups were conducted with participants divided into small groups Each focus group lasted 2 hours and were moderated by the first and second author Focus group discussions were recorded and transcribed verbatim **Data analysis** Descriptive thematic analysis was used to analyse data Themes were identified from the data, until saturation was reached	**Themes/categories** <u>At home, after discharge</u> **Parenting habits (barrier)** Parents stated that as their infant grew into toddlerhood, they had difficulty judging appropriate developmental expectations. As a result, they were concerned that they had not sufficiently encouraged independence and appropriate behaviour *"..with behaviour..you tend to let them go because they are a bit more special...it's like there's a whole different behavioural pattern that you let them get with [them] because they can" (parents)* **Isolation (barrier)** Parents felt that they were isolated in order to protect their preterm infant from infection *"we didn't go out for 3 months. We came home and we didn't go out. We came home at the beginning of winter and stayed home and every single doctor said it, stay home"* **Family support (barrier)**	**Adapted from the CASP and the Swedish council on Health Technology Assessment.** **Limitations** Unclear if saturation achieved during data collection Unclear if analysis was independently validated **Overall quality** Moderate **Other information**

Study details	Participants	Methods	Findings	Comments
To identify from the parents' own perspective the unique aspects of parenting an infant born very preterm To asses parental preferences for support including opinions of a new tailored parenting intervention **Source of funding** Not reported	Current age of preterm infant (uncorrected) 22.28 months (range 10.5 to 48.0) Preterm infant sex 8/18 male, 10/18 female Professional assistance sought for preterm child for social, emotional, or behavioural problems (psychologist, psychiatrist, counsellor, or social worker): None: 10/18 Psychologist: 3/18 Paediatrician: 1/18 Counsellor: 1/18 Child health nurse: 1/18 Occupational therapist: 1/18 School counsellor: 1/18 **Inclusion criteria** Parents of an infant born very preterm (<32 weeks gestation) who had presented at a community health centre in the Royal Children's Hospital and Health Service District within the past 6 months **Exclusion criteria** Not reported		Parents also felt isolated because of the lack of understanding from friends and family "they just can't wrap their heads around it...some of our friends were watching a video [of the baby] because she was still in special care and they're like oh, she's pretty big, she's pretty big. Then my hand comes in and blocks her out completely. Oh, no she's not. That's just the start of it, the rest of it: they can't wrap their heads around it" **Community support -developmental expectations (barrier)** Parents found it difficult to judge if a specific issue was a result of prematurity, a sign of a disorder or part of normal development "you're always looking. Is that normal behaviour or is that premie behaviour?" **Feeding advice -community services (barrier)** Parents were confused by variation of support provided by community nurses compared with special care unit "*my community nurse at the community health clinic told me I should be starting her on solids at her six months real age and then I rang special care and they said probably, we normally go corrected age but whatever the baby wants so I gave up and just ant with whatever she told me. But when I went back to the community nurse a couple of months later she was into me because this baby should be on mashed ...and you should fast track this baby through all of this and I just went you know, how am I supposed to know what I'm supposed to do?"*	

Study details	Participants	Methods	Findings	Comments
			Information support at prior to discharge from NICU Parents felt it would be important to be able to debrief close to time of discharge *" ..I felt emotionally I don't think that I would take it in at that stage. Maybe at the special care or close to the end..to be in the ICU and have that emotional weight [parenting support] would just be an extra weight added..."*	

Developmental follow up of pre-term babies

Identification of problems and disorders

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Full citation Blaggan, S., Guy, A., Boyle, E. M., Spata, E., Manktelow, B. N., Wolke, D.,	**Sample size** N=219 **Characteristics**	**Screening strategies/tools** Screening tool: PARCA-R, cutoff scores of < 49 aned	**Methods** Parents of 219 children born late and moderately preterm completed the PARCA-R questionnaire and the Brief	**Results** **Diagnostic Accuracy of PARCA-R Cutoff Scores for Identifying Developmental Delay (language and cognitive) in Children Born Late and Moderately Preterm (32-36wks) and assessed at 25 months CA:**	**Other information** **Study quality - QUADAS 2 checklist** **Patient selection** Was a consecutive or

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Johnson, S., A parent questionnaire for developmental screening in infants born late and moderately preterm, Pediatrics, 134, e55-62, 2014

Ref Id

397054

Country/ies where the study was carried out

UK

Study type

Cross sectional study

Aim of the study</td>
<td>
<table>
<tr><th>Characteristics</th><th>Recruited, n = 253</th><th>Rest of Cohort, n = 860</th><th>Final Sample, n= 219</th></tr>
<tr><td>Boy, n (%)</td><td>133 (53)</td><td>467 (54)</td><td>114 (52)</td></tr>
<tr><td>Gestational age, wk, n(%)</td><td>14 (6)</td><td>52 (6)</td><td>10 (5)</td></tr>
<tr><td>32 wk</td><td>17 (7)</td><td>69 (8)</td><td>16 (7)</td></tr>
<tr><td>33 wk</td><td>38 (15)</td><td>147 (17)</td><td>35 (16)</td></tr>
<tr><td>34 wk</td><td>69 (27)</td><td>213 (25)</td><td>58 (26)</td></tr>
<tr><td>35 wk</td><td>115 (45)</td><td>379 (44)</td><td>100 (46)</td></tr>
<tr><td>36 wk</td><td>35 (1.2)</td><td>35 (1.2)</td><td>35 (1.2)</td></tr>
<tr><td>Mean (SD)</td><td>35 (32–36)</td><td>35 (32–36)</td><td>35 (32–36)</td></tr>
<tr><td>Birth weight, g, n (%)</td><td></td><td></td><td></td></tr>
</table>
</td>
<td>< 44 taken from 2 previously published UK studies; Diagnosis tool: Bayley Scales of Infant and Toddler Development. Third edition (Bayley - III)</td>
<td>Infant Social and Emotional Assessment when children were 24 months corrected at (range 24-27 mths), 7 to 14 days before their child reached 2 year corrected age as part of Late and Moderately Preterm Birth Study (LAMBS). The children were subsequently assessed by using the cognitive and language scales of the Bayley Scales of Infant and Toddler Development, Third Edition. The cognitive and language scales of the Bayley-III were administered as the criterion</td>
<td>
<table>
<tr><th>PARCA-R Cutoff</th><th>Bayley Criterion</th><th>Sensitivity %, (95% CI)</th><th>Specificity %, (95% CI)</th><th>PPV %, (95% CI)</th><th>NPV %, (95% CI)</th></tr>
<tr><td>PRC <49</td><td>CB-III <80</td><td>35 (16–56)</td><td>90 (86–94)</td><td>27 (12–45)</td><td>93 (54–94)</td></tr>
<tr><td>PRC <44</td><td>CB-III <80</td><td>35 (16–57)</td><td>94 (91–98)</td><td>39 (18–62)</td><td>93 (89–96)</td></tr>
<tr><td>PRC <73</td><td>CB-III <80</td><td>90 (75–100)</td><td>76 (70–82)</td><td>28 (17–39)</td><td>99 (97–100)</td></tr>
<tr><td>PRC <49</td><td>MDI <70</td><td>38 (22–55)</td><td>91 (86–95)</td><td>43 (26–62)</td><td>89 (84–94)</td></tr>
</table>
</td>
<td>random sample of patients enrolled? Yes, participants were from Late and Moderately Preterm Birth Study (LAMBS) Was a case-control design avoided? Yes Did the study avoid inappropriate exclusions? Yes
1.A Could the selection of patients have introduced bias? No
1.B Is there concern that the included patients do not match the review question? Low risk

Index Test
Were the index test results</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>To assess the clinical utility of the PARCA-R as a first line screening tool for identifying developmental delay in children born late and moderate preterm.

Study dates
Not reported

Source of funding
Not reported</td>
<td>
<table>
<tr><td><1500</td><td>8 (3)</td><td>21 (2)</td><td>6 (3)</td></tr>
<tr><td>1501–2000</td><td>38 (15)</td><td>157 (18)</td><td>31 (14)</td></tr>
<tr><td>2001–2500</td><td>91 (36)</td><td>314 (36)</td><td>79 (36)</td></tr>
<tr><td>2501–3000</td><td>81 (32)</td><td>273 (32)</td><td>71 (33)</td></tr>
<tr><td>>3001</td><td>32 (13)</td><td>91 (11)</td><td>29 (13)</td></tr>
<tr><td>Mean (SD)</td><td>2460 (519)</td><td>2414 (495)</td><td>2482 (523)</td></tr>
<tr><td>Median (range)</td><td>2460 (1150–4960)</td><td>2400 (1098–4380)</td><td>2460 (1150–4960)</td></tr>
<tr><td>Missing</td><td>3 (1)</td><td>4 (1)</td><td>3 (1)</td></tr>
<tr><td>Multiple birth, n (%)</td><td></td><td></td><td></td></tr>
<tr><td>Singletons</td><td>227 (90)</td><td>681 (79)</td><td>205 (93)</td></tr>
</table>
</td>
<td></td>
<td>measure from which standardised composite scores were derived. Bayley-III scores < 80 was used to classify moderate/severe development delay rather than the conventional cutoff of Bayley-III scores < 70. Psychologists were blind to parents' PARCA responses when conducting Bayley - assessment.</td>
<td>
<table>
<tr><td>PRC <44</td><td>MDI <70</td><td>25 (9–43)</td><td>91 (87–95)</td><td>26 (9–44)</td><td>90 (86–94)</td></tr>
<tr><td>PRC <73</td><td>MDI <70</td><td>56 (43–68)</td><td>88 (82–93)</td><td>65 (52–77)</td><td>83 (77–88)</td></tr>
</table>
PRC<73 was the optimum cut-off of PARCA scores
Area under the curve (AUC): 0.863

Due to the information reported in the study, only sens, specs, PPV, NPV, LR+ and LR - for the accuracy of PRC < 73 (MDI < 70) could be calculated:
PRC < 73,
MDI < 70 among children born at 32-36 wks GA and assessed at 25 months corrected age:

Sensitivity: 0.90 (0.77-1.03)
Specificity: 0.76 (0.70-0.82)
PPV: 0.27 (0.17-0.38)
NPV: 0.99 (0.97-1.00)
LR+: 3.73 (2.80-4.97)
LR-: 0.13 (0.04-0.49)
</td>
<td>interpreted without knowledge of the results of the reference standard? Yes
If a threshold was used, was it pre-specified? Yes, from previously published studies
2.A Could the conduct or interpretation of the index test have introduced bias? Unclear

2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?
Low risk

Reference Standard
Is the reference</td>
</tr>
</table>

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
	<table><tr><td>Multiples</td><td>26 (10)</td><td>179 (21)</td><td>14 (7)</td></tr><tr><td>Socioeconomic deprivation,a mean (SD)</td><td>22.4 (16.5)</td><td>27.9 (17.2)</td><td>21.9 (16.52)</td></tr></table> **Inclusion criteria** The child would be between 24 months 0 days and 27 months 30 days at the time of the development test; **Exclusion criteria** Not reported				standard likely to correctly classify the target condition? Yes Were the reference standard results interpreted without knowledge of the results of the index test? Yes, psychologists were blinded to the screening test results **3.A Could the reference standard, its conduct, or its interpretation have introduced bias?** low risk **3.B Is there concern that the target condition as defined by the reference standard does not**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					match the review question? Low risk **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Yes, 7 to 14 days Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes **4. A Could the patient flow have introduced bias?** Low risk Were all patients included in the analysis? Yes

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td>Overall quality: moderate (limited information were reported therefore 2x2 Tables for the majority of cut-offs could not be tabulated)</td></tr>
<tr><td>Full citation

Cuttini, M., Ferrante, P., Mirante, N., Chiandotto, V., Fertz, M., Dall'Oglio, A. M., Coletti, M. F., Johnson, S., Cognitive assessment of very preterm infants at 2-year corrected age: performance of the Italian</td><td>Sample size

N=120 Italian children

Characteristics

Characteristics of the study sample (n = 120).
n %
<table><tr><td>Gender</td><td></td><td></td></tr><tr><td>Male</td><td>70</td><td>58.3</td></tr><tr><td>Female</td><td>50</td><td>41.7</td></tr><tr><td>Gestational age (weeks)</td><td></td><td></td></tr></table></td><td>Screening strategies/tools

-The PARCA-R (Parent Report of Children's Abilities Revised for very premature infants);

The concurrent validity of the Italian PARCA-R was assessed</td><td>Methods

120 consecutive Italian very preterm children (mean GA 28.8 wks, SD 2.1) were assessed in 4 hospitals through the MDI of the Bayley Scales of Infant Development (BSID-II). The parents were mailed the PARCA-R questionnaire in advance of the scheduled hospital examination</td><td>Results

Children born at 22-31 wks' GA, assessed at 2-year corrected age:
PARCA-R < 46;
BSID-II MDI < 70:

sensitivity: % (95%CI): 0.73 (0.46-0.99)
specificity: % (95%CI): 0.77 (0.69-0.85)
positive predictive value (PPV)*: % (95%CI): 0.24 (0.09-0.39)
negative predictive value (NPV)*: % (95%CI): 0.96 (0.93-1.00)
positive likelihood ratio (LR+): (95% CI)*: 3.17 (1.92-5.22)
negative likelihood ratio (LR-): (95% CI)*: 0.35 (0.13-0.93)
* calculated by NGA technical team

PARCA-R < 44;
BSID-II MDI < 70: < 70 assessed at 2-year corrected age:

sensitivity: % (95%CI): 0.64 (0.35-0.92)
specificity: % (95%CI): 0.79 (0.71-0.87)
positive predictive value (PPV)*: % (95%CI): 0.23 (0.08-0.38)</td><td>Other information

Study quality - QUADAS 2 checklist
Patient selection
Was a consecutive or random sample of patients enrolled? Yes
Was a case-control design avoided? Yes
Did the study avoid inappropriate exclusions? Yes
1.A Could the selection of patients have</td></tr>
</table>

Study details	Participants			Screening strategies/tools	Methods	Outcomes and results	Comments
version of the PARCA-R parent questionnaire, Early Human Development, 88, 159-63, 2012 **Ref Id** 397142 **Country/ies where the study was carried out** Italy **Study type** Cross-sectional study **Aim of the study** To validate the Italian version of the PARCA-R parent	24–25	11	9.1	using as gold standard the BSID-II MDI	together with instructions for completion, and were asked to return it at the time of the visit. BSID - II < 70 (below 2SD) is conventionally used to indicate moderate/severe cognitive delay; score < 85 (below 1 SD) include also mildly delayed cases.	negative predictive value (NPV)*: % (95%CI): 0.96 (0.91-0.99) positive likelihood ratio (LR+): (95% CI)*: 3.01 (1.69-5.36) negative likelihood ratio (LR-): (95% CI)*: 0.46 (0.21-1.01) ** calculated by NGA technical team* **PARCA-R < 68;** **BSID-II MDI < 70: < 85 assessed at 2-year corrected age:** sensitivity: % (95%CI): 0.85 (0.71-0.98) specificity: % (95%CI): 0.64 (0.54-0.73) positive predictive value (PPV)*: % (95%CI): 0.39 (0.26-0.52) negative predictive value (NPV)*: % (95%CI): 0.94 (0.88-0.99) positive likelihood ratio (LR+): (95% CI)*: 2.34 (1.71-3.20) negative likelihood ratio (LR-): (95% CI)*: 0.24 (0.09-0.60) ** calculated by NGA technical team* ***Area under the curve of PRC to predict MDI scores:*** Area under of the curve (AUC) of the PARCA-R to predict an MDI score < 70: 0.83; with optimal PRC cut-off 46 points to maximize both the test sensitivity and specificity; AUC of the PARCA-R to predict an MDI score < 85: 0.77 and the optimal PRC cut-off 68 points to maximize both the test sensitivity and specificity	**introduced bias?** No **1.B Is there concern that the included patients do not match the review question?** Low risk **Index Test** Were the index test results interpreted without knowledge of the results of the reference standard? Yes If a threshold was used, was it pre-specified? Unclear **2.A Could the conduct or interpretation of the index test have introduced bias?** Unclear **2.B Is there concern that the index test,**
	26–27	20	16.7				
	28–29	30	25.0				
	30–31	59	49.2				
	Birth weight (g)						
	< 1000	39	32.5				
	1000–1499	61	50.8				
	≥1500	20	16.7				
	Presence of cerebral palsy						
	No	109	90.8				
	Yes	11	9.2				

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>questionnaire and test its clinical effectiveness in assessing cognitive development (measured by BSID-II) of very preterm children at 2 years of corrected age.

Study dates

Not reported

Source of funding

Italian Ministry of Health</td>
<td>
<table>
<tr><td>Severe neuromotor/sensorial disability</td><td></td><td></td></tr>
<tr><td>None</td><td>113</td><td>94.2</td></tr>
<tr><td>Neuromotor</td><td>5</td><td>4.2</td></tr>
<tr><td>Hearing</td><td>1</td><td>0.8</td></tr>
<tr><td>Vision</td><td>0</td><td>0.0</td></tr>
<tr><td>Mixed[a]</td><td>1</td><td>0.8</td></tr>
</table>
Inclusion criteria

Children from four of the participating hospitals routinely use BSID-II to assess very preterm infants; Children born at 22-31 wks of GA;

Exclusion criteria

For this analysis, 39 children were excluded because of a non-Italian mother, 5 because of missing date of completion in the PARCA-R, and 32 because of a gap between the BSID-II examination and the PARCA-R larger than 15 days. In case of twins, only one
</td>
<td></td><td></td><td></td>
<td>its conduct, or interpretation differ from the review question?
Low risk

Reference Standard
Is the reference standard likely to correctly classify the target condition? Yes
Were the reference standard results interpreted without knowledge of the results of the index test? Unclear, not clearly reported
3.A Could the reference standard, its conduct, or its interpretation have</td>
</tr>
</table>

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
	randomly selected child was included in the analyses, leading to the exclusion of 10 additional children. Thus, the final sample included 120 Italian children.				**introduced bias?** Low risk **3.B Is there concern that the target condition as defined by the reference standard does not match the review question?** Low risk **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Yes, 15 days Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes Were all

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td>patients included in the analysis? Yes
4. A Could the patient flow have introduced bias? Low risk
Were all patients included in the analysis? Yes
Overall quality: Moderate</td></tr>
<tr><td>Full citation

Dewey, D., Creighton, D. E., Heath, J. A., Wilson, B. N., Anseeuw-Deeks, D., Crawford, S. G., Sauve, R., Assessment of developmental</td><td>Sample size

N= 103 after 48 out of 199 were lost to follow-up, and 44 of 199 were excluded;

Characteristics
<table><tr><td>Variable</td><td>ELBW (≤1,000 g) N =</td></tr><tr><td>No. of males, % (n)</td><td>48.5 (50)</td></tr><tr><td>Birth weight in grams (SD)</td><td>817.27 (120.61); rang 1,000 g</td></tr></table></td><td>Screening strategies/tools

Score ≤ 15th percentile on the DCDQ as screening tool;
Score ≤ 15th percentile on the Movement ABC as</td><td>Methods

-103 children participated in the study at 5 years of age at the Perinatal Follow-up Clinic, Alberta Children's Hospital, Calgary, Developmental Coordination Disorder Questionnaire (DCDQ) was part of the</td><td>Results

Developmental Coordination Disorder assessed at 5-year of age:
Screened by Developmental Coordination Disorder Questionnaire (DCDQ), score ≤ 15th percentile on the DCDQ as impaired;
Diagnosed by Movement ABC, a score ≤ 15th percentile on the Movement ABC as impaired;
Children born at mean 27 wks' GA (range: 24-35wks):

DCDQ cut-off score <15th percentile:
sensitivity: % (95%CI): 0.37 (0.25-0.48)
specificity: % (95%CI): 0.91 (0.83-1.00)
positive predictive value (PPV): % (95%CI): 0.89 (0.77-1.01)
negative predictive value (NPV): % (95%CI): 0.45 (0.34-0.56)</td><td>Other information

Study quality - QUADAS 2 checklist
Patient selection
Was a consecutive or random sample of patients enrolled? Yes
Was a case-control design avoided? Yes</td></tr>
</table>

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
coordination disorder in children born with extremely low birth weights, Developmental Neuropsychology, 36, 42-56, 2011 **Ref Id** 397168 **Country/ies where the study was carried out** Canada **Study type** Cross-sectional study **Aim of the study** To examine the	Gestational age in weeks (SD) 27.07 (2.02); range 24 to 32 wks **Inclusion criteria** 5-year old children born pre-term; **Exclusion criteria** Children diagnosed with cerebral palsy, significant developmental delay (IQ < 70) and/or visual impairment, which precluded them from participating in the standardized assessments. (n=44 out of 199)	diagnosis standard;	follow-up check up **-For assessment on movement ABC:** Participants were assessed by occupational therapists that were unaware of the perinatal history of the child or the child's performance on any assessments conducted by the Perinatal Follow-up Clinic.	positive likelihood ratio (LR+): (95% CI): 4.49 (1.45-13.9) * negative likelihood ratio (LR-): (95% CI): 0.69 (0.56-0.85) * ** calculated by NGA technical team*	Did the study avoid inappropriate exclusions? Yes **1.A Could the selection of patients have introduced bias?** No **1.B Is there concern that the included patients do not match the review question?** Low risk **Index Test** Were the index test results interpreted without knowledge of the results of the reference standard? Yes If a threshold was used, was it pre-specified? No **2.A Could the conduct or interpretation of the index**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
prevalence of motor problems identified in a regional population cohort of 5-year-old children with birth weights ≤ 1,000 g, using various methods including standardized motor assessment measures, an established clinic protocol and parent report. **Study dates** 2001-2005 **Source of funding**					**test have introduced bias?** Low risk **2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** Low concern **Reference Standard** Is the reference standard likely to correctly classify the target condition? Yes Were the reference standard results interpreted without knowledge of the results of the index test? Yes **3.A Could the reference**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Alberta Children's Hospital Foundation					**standard, its conduct, or its interpretation have introduced bias?** Low risk **3.B Is there concern that the target condition as defined by the reference standard does not match the review question?** Low risk **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Not reported Did all patients receive a reference standard? Yes

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					Did patients receive the same reference standard? Yes Were all patients included in the analysis? Yes **4. A Could the patient flow have introduced bias?** Low risk Were all patients included in the analysis? Yes Overall quality: Moderate
Full citation Halbwachs, M., Muller, J. B., Nguyen The Tich, S., de La Rochebrochard, E.,	**Sample size** N=452 children born preterm < 35 wks' GA **Characteristics** 2003-2004	**Screening strategies/tools** ASQ Diagnosis tool: WPPSI-III	**Methods** -First, trained psychologists in our follow-up network evaluated the children with a French version of the standardized	**Results** **ASQ score 285; IQ lower than score 85 on WPPSI-III at age 5-years, born at ≤ 35 wks GA:** The optimal cut-off ASQ score value for identifying children with full-scale IQ scores<85 was 285, with a Sensitivity: 0.80 (95% CI: 0.71–0.87)	**Other information** **tudy quality - QUADAS 2 checklist** **Patient selection** Was a consecutive or

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Gascoin, G., Branger, B., Rouger, V., Roze, J. C., Flamant, C., Usefulness of parent-completed ASQ for neurodevelopmental screening of preterm children at five years of age, PLoS ONE [Electronic Resource], 8, e71925, 2013 **Ref Id** 397287 **Country/ies where the study was carried out** France **Study type**	**Inclusion criteria** All surviving children born ≤35 weeks of gestational age (GA) between January 2003 and December 2004 and enrolled in the regional "Loire Infant Follow-up Team" (LIFT) network program at discharge were included **Exclusion criteria** Not reported		WPPSI-III test for children aged between four years and seven years and three months. This test covers two major areas that are evaluated with two scales: verbal capacity and performance capacity. Next, the Full-Scale Intelligence Quotient (Full-scale IQ) is defined as the composite of verbal and performance IQ scores. -A full-scale IQ score < 85 was considered to define neurodevelopmental impairment and a full-scale IQ score < 70 was considered to define severe	Specificity: 0.54 (95% CI: 0.48–0.60) PPV*: 0.31 (0.25-0.36) NPV*: 0.92 (0.88-0.95) LR+*: 1.74 (1.50-2.02) LR-*: 0.37 (0.24-0.56) AUC: 0.73±0.03 **ASQ score 270; IQ lower than score 70 on WPPSI-III at age 5-years** (**no data for 2x2 Table**): Sensitivity: 0.85 (95% CI: 0.68–0.94)	random sample of patients enrolled? Yes Was a case-control design avoided? Yes Did the study avoid inappropriate exclusions? Yes **1.A Could the selection of patients have introduced bias?** No **1.B Is there concern that the included patients do not match the review question?** Low risk **Index Test** Were the index test results interpreted without knowledge of the results of the reference standard? Yes

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Follow-up study with cross sectional analysis **Aim of the study** To examine use of the parent-completed Ages and Stages Questionnaire (ASQ) as a screening tool for neurodevelopmental disabilities in preterm infants at five years of age. **Study dates** 2003-2004			mental retardation. -The ASQ was completed before the psychological assessment, so that the WPPSI test would not influence the parents' evaluation. The pediatric psychologists in the regional network were blinded to the children's ASQ results.	Specificity: 0.81 (95% CI: 0.77–0.85) PPV*: 0.22 (0.14-0.30) NPV*: 0.98 (0.98-0.99) LR+*: 4.46 (3.47-5.7) LR-*: 0.18 (0.07-0.45) AUC: 0.90 ±0.04 * calculated by NGA technical team	If a threshold was used, was it pre-specified? No **2.A Could the conduct or interpretation of the index test have introduced bias?** No **2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** Low risk **Reference Standard** Is the reference standard likely to correctly classify the target condition? Yes Were the reference standard results interpreted

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Source of funding No support of funding					without knowledge of the results of the index test? Yes **3.A Could the reference standard, its conduct, or its interpretation have introduced bias?** low risk **3.B Is there concern that the target condition as defined by the reference standard does not match the review question?** Low risk **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Uncl

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					ear, not reported Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes **4. A Could the patient flow have introduced bias?** Yes (the study did not clearly report the interval between 2 tests) Were all patients included in the analysis? Yes Overall quality: High
Full citation Indredavik, M. S., Vik, T.,	**Sample size** N=56 adolescents born preterm and with very low birth weight	**Screening strategies/tools**	**Methods** A follow-up study of VLBW adolescents who had been	**Results** **Children born at 28.8 wks' GA (range 24-36 wks, very low birth weight < 1000g), assessed at 14-year of age:**	**Other information** **Study quality - QUADAS 2 checklist**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Heyerdahl, S., Kulseng, S., Brubakk, A. M., Psychiatric symptoms in low birth weight adolescents, assessed by screening questionnaires, European Child & Adolescent Psychiatry, 14, 226-36, 2005 **Ref Id** 397325 **Country/ies where the study was carried out** Norway **Study type** Follow-up study with	**Characteristics** Children born pre-term during 1986-1988; Mean GA: 28.8 wks (range: 24-35) **Inclusion criteria** Birth weight ≤ 1500g and admitted to the NICU in the period of 1986-1989.; **Exclusion criteria** Child with trisomi 21;	- Screening: SDQ (rated separately by mother, father, and teacher) - Diagnosis assessed by psychiatric in-depth interview;	admitted to the Neonatal Intensive Care Unit (NICU) at the University Hospital in Trondheim (the referral hospital) in the period 1986–1988. A 10 % random sample of women (with one or two previous pregnancies) was selected for follow-up during pregnancy. The present study was carried out between November 2000 and October 2002, and included a psychiatric assessment, an evaluation of cognitive abilities and a neuropaediatric examination. The Strengths and Difficulties	**Mother's report on SDQ > 90th percentile (screening); and** **Any psychiatric diagnosis (symptoms and problems) assessed by in-depth interview** **sensitivity:** % (95%CI): 0.85 (0.67-1.04) **specificity**: % (95%CI): 0.58 (0.42-0.74) positive predictive value (PPV)*: % (95%CI): 0.43 (0.25-0.61) negative predictive value (NPV)*: % (95%CI): 0.92 (0.81-1.02) **positive likelihood ratio (LR+)**: (95% CI)*: 2.04 (0.32-3.12) **negative likelihood ratio (LR-)**: (95% CI)*: 0.25 (0.06-0.92) **Area under the curve (AUC)** reported by the study: 0.81 (0.67-0.94) ** calculated by NGA technical team* **Father's report on SDQ > 90th percentile (screening); and** **Any psychiatric diagnosis (symptoms and problems) assessed by in-depth interview** **sensitivity:** % (95%CI): 0.50 (0.24-0.76) **specificity**: % (95%CI): 0.75 (0.61-0.90) positive predictive value (PPV)*: % (95%CI): 0.47 (0.21-0.72) negative predictive value (NPV)*: % (95%CI): 0.78 (0.64-0.93) **positive likelihood ratio (LR+)**: (95% CI)*: 2.06 (0.93-4.59) **negative likelihood ratio (LR-)**: (95% CI)*: 0.66 (0.38-1.15) **Area under the curve (AUC)** reported by the study: 0.70 (0.49-0.92)	**Patient selection** Was a consecutive or random sample of patients enrolled? Yes Was a case-control design avoided? Yes Did the study avoid inappropriate exclusions? Yes **1.A Could the selection of patients have introduced bias?** no **1.B Is there concern that the included patients do not match the review question?** Low concern **Index Test** Were the index test results interpreted without knowledge of

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
cross sectional analysis **Aim of the study** To explore psychiatric symptoms in low birth weight adolescents, and the usefulness of questionnaires compared with psychiatric interview. **Study dates** 2000-2002 **Source of funding** Department of Child and Adolescent			Questionnaire (SDQ), age 4–16 years, was completed by the adolescents, mothers, fathers and teachers. Then results on SDQ were compared with the results of in-depth interview psychiatric assessment.	** calculated by NGA technical team* **Teacher's report on SDQ > 90th percentile (screening); and** **Any psychiatric diagnosis (symptoms and problems) assessed by in-depth interview** **sensitivity:** % (95%CI): 0.57 (0.31-0.83) **specificity**: % (95%CI): 0.88 (0.78-0.98) positive predictive value (PPV)*: % (95%CI): 0.62 (0.35-0.88) negative predictive value (NPV)*: % (95%CI): 0.86 (0.76-0.96) **positive likelihood ratio (LR+)**: (95% CI)*: 4.80 (1.88-12.28) **negative likelihood ratio (LR-)**: (95% CI)*: 0.49 (0.26-0.90) **Area under the curve (AUC)** reported by the study: 0.80 (0.65-0.96) ** calculated by NGA technical team*	the results of the reference standard? Unclear, the study did not clearly reported it If a threshold was used, was it pre-specified? Unclear **2.A Could the conduct or interpretation of the index test have introduced bias?** Yes, high risk of bias **2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** Yes **Reference Standard** Is the reference standard likely

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Psychiatry, Norwegian University of Science and Technology					to correctly classify the target condition? Yes Were the reference standard results interpreted without knowledge of the results of the index test? Unclear, not clearly reported **3.A Could the reference standard, its conduct, or its interpretation have introduced bias?** Yes, high risk of bias **3.B Is there concern that the target condition as defined by the reference standard does not match the**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					review question? No **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Unclear Did all patients receive a reference standard? No Did patients receive the same reference standard? Yes Were all patients included in the analysis? Yes **4. A Could the patient flow have introduced bias?** Unclear Were all patients included in the analysis? No, some children

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					(25%) were lost to follow-up. Overall quality: Low The study did not clearly report whether the assessors of SDQ or psychiatric diagnosis were blind to the results of the other test.
Full citation Johnson, S., Hollis, C., Kochhar, P., Hennessy, E., Wolke, D., Marlow, N., Psychiatric Disorders in Extremely Preterm Children: Longitudinal Finding at	**Sample size** N= 219 **Characteristics** Not reported **Inclusion criteria** All babies born at < 26 wks gestation and admitted for neonatal intensive care in the UK and Ireland from March through December 1995;	**Screening strategies/tools** n/a	**Methods** -To obtain behavioral data, parents and teachers competed questionnaires, and parents participated a structured psychiatric interview regarding their child's behavior.	**Results** **Predictors of psychiatric disorders (assessed by DWAB) in extremely preterm children at 11 years of age:** **pervasive attentional problems measured by SDQ at 6 years:** Adjusted OR (95%CI): 3.07 (1.13-8.31) **Pervasive conduct problems measured by SDQ at 6 years:** Adjusted OR (95%CI): 10.3 (2.87-37.3) The forward step-wise model controlled for internalizing behavior at 2.5 years, serious functional disability at 6	**Other information** Based on the NICE manual 2012 checklist for prognostic studies and QUIPS. **Participants:** low risk of bias **Attrition:** moderate risk of bias parents of 77 (25%) babies did not provide

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Age 11 Years in the EPICure Study, Journal of the American Academy of Child and Adolescent Psychiatry, 49, 453-463.e1, 2010 **Ref Id** 410768 **Country/ies where the study was carried out** UK **Study type** prospective longitudinal study **Aim of the study**	**Exclusion criteria** Not reported		• SDQ: at 6 years, parents and teachers completed the Strengths and Difficulties Questionnaire (SDQ) from which scores above the 90th percentile have been previously proposed to best identif	years, NEC, and internalizing behavioral problems at 2.5 years.	consent to take part in the study; **Prognostic factor measurement:** low risk of bias **Outcome measurement:** low risk of bias **Confounding:** moderate risk of bias **Analysis and reporting:** low risk of bias. Overall quality: moderate

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
to investigate the prevalence, correlates, and precursors of psychiatric disorders in a whole population of extremely preterm children at 11 years of age. **Study dates** Cohort of extremely preterm babies born in 1995 and followed up at 2.5 year, 6 year, and 11 year of age. **Source of funding**			• y children with clinically significant problem • outcome measure: The Development And Well Being Assessment (DAWBA), from which information required for assigning ICD-10 and DSM-IV-		

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Medical Research Council, UK			TR diagnoses of childhood psychiatric disorders was obtaine Statistical methods: Neonatal and neurodevelopmental outcome variables at 2.5 and 6 years were used in univariate logistic regression to predict psychiatric diagnoses. A multivariate forward stepwise procedure was applied to identify independent factors		

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
			associated with psychiatric diagnoses (adjusted OR) at three time points: neonatal, outcomes at 2.5 years, outcomes at 6 years		
Full citation Johnson, S., Hollis, C., Marlow, N., Simms, V., Wolke, D., Screening for childhood mental health disorders using the Strengths and Difficulties Questionnaire: The validity of multi-informant	**Sample size** N = 219 **Characteristics** at age 11 years, 219 (71% of survivors) children were assessed at a median age of 131 months (range 121–145mo); 118 females, 101 males; 93 (42%) were born at 23–24 weeks' gestation and 126 (58%) at 25 weeks. **Inclusion criteria** All infants born extremely preterm (< 26wks) from March to December 1995 were recruited at birth and followed up at 2 years 6 months and 6 years of age. Data for this study were obtained from follow-up of this cohort at 11 years of age (n=219; 71%).	**Screening strategies/tools** SDQ; Diagnostic evaluation tool: DAWBA	**Methods** Parents completed the SDQ which was about their child's health and behaviour, and were asked to participate in a semi-structured diagnostic interview about their child's mental health. Each child's teacher also	**Results** **Among children born preterm (GA < 26wks):** **Abnormal parent SDQ and abnormal teacher SDQ** **Psychiatric disorder assessed at age 11 years:** **Emotional disorders** **Parent SDQ: value (95% CI)** **Teacher SDQ: value (95% CI)** Sensitivity: 0.67 (0.43–0.85) 0.29 (0.12–0.53) Specificity: 0.80 (0.78–0.82) 0.90 (0.88–0.93) PPV: 0.25 (0.12-0.36) 0.24 (0.10-0.43 NPV: 0.96 0.93– (0.98 0.92) 0.92 (0.91-0.95) LR+: 3.29 (2.13-5.09) 2.37 (1.01-5.52) LR-: 0.41 (0.22-0.80) 0.81 (0.61-1.09) * calculated by NGA team **Conduct disorders** **Parent SDQ: value (95% CI)** **Teacher SDQ: value (95%CI)** Sensitivity: 0.67 (0.37–0.88) 0.33 (0.12–0.60) Specificity: 0.90 (0.89–0.92) 0.95 (0.94– 0.97) PPV: 0.30 (0.16–0.39) 0.31 (0.11–0.55)	**Other information** **Study quality - QUADAS 2 checklist** **Patient selection** Was a consecutive or random sample of patients enrolled? Yes Was a case-control design avoided? Yes Did the study avoid inappropriate exclusions? Yes

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
reports, Developmental Medicine and Child Neurology, 56, 453-459, 2014 **Ref Id** 445673 **Country/ies where the study was carried out** UK **Study type** Follow-up study with cross-sectional analysis **Aim of the study** To investigate the diagnostic	**Exclusion criteria** Not reported		completed the SDQ about the child's behaviour and mental health; Combined (either the parent or the teacher rating resulted in an abnormal screen);	NPV: 0.98 (0.96–0.99) 0.96 (0.94–0.97) LR+: 6.91 (3.84-12.41) 6.89 (2.48-19.16) LR-: 0.37 (0.16-0.82) 0.70 (0.47-1.05)	**1.A Could the selection of patients have introduced bias?** No **1.B Is there concern that the included patients do not match the review question?** Low risk **Index Test** Were the index test results interpreted without knowledge of the results of the reference standard? Yes If a threshold was used, was it pre-specified? No, no threshold used in this study **2.A Could the conduct or interpretation of the index test have introduced**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
accuracy of the Strengths and Difficulties Questionnaires (SDQ) in a population of children born extremely preterm (< 26 wks gestation) **Study dates** 1995-2016 **Source of funding** Medical Research Council, UK					**bias?** Unclear (No threshold used) **2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** Low risk **Reference Standard** Is the reference standard likely to correctly classify the target condition? Yes Were the reference standard results interpreted without knowledge of the results of the index test? Yes, psychiatrists had no previous

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					knowledge of the children **3.A Could the reference standard, its conduct, or its interpretation have introduced bias?** low risk **3.B Is there concern that the target condition as defined by the reference standard does not match the review question?** Low risk **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Unclear, not reported

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes **4. A Could the patient flow have introduced bias?** Low risk Were all patients included in the analysis? No [the numbers of children's parents (n=209) or teacher (n=197)s completing the SDQ were different from the number of children finally assessed by the DAWBA (n=201)]

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					Overall quality: Moderate
Full citation Johnson, S., Wolke, D., Marlow, N., Developmental assessment of preterm infants at 2 years: Validity of parent reports, Developmental medicine and child neurology, 50, 58-62, 2008 **Ref Id** 433235 **Country/ies where the**	**Sample size** N=164 children born at < 32 wk's GA and their parents; participants were from an earlier RCT performed to enhance parental support during the neonatal period **Characteristics** Characteristics of study sample Infant characteristics Study sample, n (%) Total 164 Males 82 (50) Females 82 (50) Gestational age: median (range) wks: 29 (23–31) 23–24 8 (5) 25–26 18 (11) 27–28 43 (26) 29–30 95 (58) Birthweight: median (range) g: 1200 (478–1954) <1000 48 (29) >1500 116 (71) Corrected age at BSID-II: mean (range) mo 24 (23–28) *BSID-II, Bayley Scales of Infant Development – 2nd edn*	**Screening strategies/tools** PARCA-R: the Parent Report of Children's Abilities	**Methods** Parents were contacted to arrange a home visit when their child was 2 years' corrected age, during which one of two psychologists formally assessed the child's development using the BSID-II. Parents were sent the PARCA-R to complete 1 week before the home visit so that their observation of their child's responses on	**Results** PARCA-R, PRC cut-off scoares for prediction of MDI scores < 70, BSID-II: **In infants born < 32wks and aged 2 (corrected age):** **PRC cut-off score <44:** sensitivity: % (95%CI): 0.85 (0.58-0.96) specificity: % (95%CI): 0.87 (0.81-0.92) positive predictive value (PPV): % (95%CI): 0.37 (0.22-0.54) negative predictive value (NPV): % (95%CI): 0.98 (0.95-1) positive likelihood ratio (LR+): (95% CI): 6.72 (4.16-10.8) * negative likelihood ratio (LR-): (95% CI): 0.18 (0.05-0.63) * * *calculated by NGA technical team* **PRC cut-off score <49:** sensitivity: % (95%CI): 0.85 (0.58-0.96) specificity: % (95%CI): 0.83 (0.77-0.88) positive predictive value (PPV): % (95%CI): 0.31 (0.18-0.47) negative predictive value (NPV): % (95%CI): 0.98 (0.95-0.99) positive likelihood ratio (LR+): (95% CI): 5.11 (3.36-7.82) * negative likelihood ratio (LR-): (95% CI): 0.18 (0.05-0.66) * * *calculated by NGA technical team* **In infants born <31 wks GA and aged 2 (corrected age):** **PRC cut-off score < 49:**	**Other information** **Study quality - QUADAS 2 checklist** **Patient selection** Was a consecutive or random sample of patients enrolled? Unclear (participants were from an earlier RCT performed to enhance parental support during the neonatal period) Was a case-control design avoided? Yes Did the study avoid inappropriate

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
study was carried out UK **Study type** Cross-sectional study **Aim of the study** To investigate the validity and diagnostic utility of the PARCA-R in a sample of 2-year-old children born at < 32wks' GA. **Study dates** July 2002-Jan 2003; May 2003-Nov 2003;	**Inclusion criteria** Infants born at < 32 wk's GA were recruited to the support during the neonatal period. **Exclusion criteria** Children not assessed at corrected age of 2 years was excluded from data analysis; One randomly selected child from each set of twins was also excluded from data analysis;		the BSID-II did not influence responses on the questionnaire.	sensitivity: % (95%CI): 0.81 (0.57-0.93) specificity: % (95%CI): 0.81 (0.68-0.90) positive predictive value (PPV): % (95%CI): 0.59 (0.39-0.77) negative predictive value (NPV): % (95%CI): 0.91 (0.81-0.98) positive likelihood ratio (LR+): (95% CI): 4.26 (2.94-6.16) * negative likelihood ratio (LR-): (95% CI): 0.24 (0.13-0.47) * ** calculated by NGA technical team*	exclusions? Yes **1.A Could the selection of patients have introduced bias?** low risk **1.B Is there concern that the included patients do not match the review question?** low concern **Index Test** Were the index test results interpreted without knowledge of the results of the reference standard? Yes If a threshold was used, was it pre-specified? Yes **2.A Could the conduct or interpretation of the index test have introduced bias?** low risk

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Source of funding The Health Foundation					**2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** low concern **Reference Standard** Is the reference standard likely to correctly classify the target condition? Yes Were the reference standard results interpreted without knowledge of the results of the index test? Yes **3.A Could the reference standard, its conduct, or its interpretation have**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					introduced bias? low risk **3.B Is there concern that the target condition as defined by the reference standard does not match the review question?** low concern **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Yes Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes Were all patients included in the analysis? Yes

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					4.A Could the patient flow have introduced bias? LOW Overall quality: Moderate
Full citation Martin, A. J., Darlow, B. A., Salt, A., Hague, W., Sebastian, L., McNeill, N., Tarnow-Mordi, W., Performance of the Parent Report of Children's Abilities-Revised (PARCA-R) versus the Bayley Scales of Infant Developme	**Sample size** N=204 **Characteristics** The median birthweight of the 204 infants in the study was 911 g (IQR: 718–1163); The median gestational age at birth was 27 (IQR: 25–30) weeks and 100 (49.0%) were girls **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Screening strategies/tools** Screening: PARCA-R; Diagnosis: BSID-III	**Methods** The children in this study comprised a sample of participants in the International Neonatal Immunotherapy Study (INIS), an RCT; -An assessment with PARCA-R was completed in 204/206 (99%) infants that received the BSID III. -The parent questionnaire (comprising the PARCA-R) was	**Results** Using the standard normative scoring for the BSID, 9 infants (4.4%, 95% CI 1.6% to 7.2%) met the criteria for at least moderate cognitive delay (BSID cognitive composite score <70), and 16 (8.4%, 95% CI 4.5% to 12.4%) met the criteria for at least moderate language delay (BSID language composite score<70). **PARCA-R cognitive score ≤19 on the cognitive component,** **Bayley III cognition scale score < 70, at least 2SD below the norm of 100, children born at 27wk median GA, when assessed at age 5-year** sensitivity: % (95%CI): 0.89 (0.68-1.09) specificity: % (95%CI): 0.89 (0.84-0.94) positive predictive value (PPV)*: % (95%CI): 0.28 (0.11-0.44) negative predictive value (NPV)*: % (95%CI): 0.99 (0.98-1.00) positive likelihood ratio (LR+): (95% CI)*: 8.25 (5.18-13.14) negative likelihood ratio (LR-): (95% CI)*: 0.12 (0.02-0.79) ** calculated by NGA technical team*	**Other information** **Study quality - QUADAS 2 checklist** **Patient selection** Was a consecutive or random sample of patients enrolled? Unclear, the study was a follow-up of an earlier RCT Was a case-control design avoided? Yes Did the study avoid inappropriate

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
nt III, Archives of Disease in Childhood, 98, 955-8, 2013 **Ref Id** 411096 **Country/ies where the study was carried out** Australia **Study type** Follow-up of RCT with cross-sectional analysis **Aim of the study** To compare the PARCA-R as an indicator of developmen t in high-risk			mailed to parents for completion approximately 4 weeks before the child reached 24 months of age (corrected for any prematurity). -The BSID III was administered by a certified psychologist, or other trained assessor, at the time of the scheduled 24 month INIS follow-up visit. -The interval between the administration of the two assessments was less than 1 month for 70.1% of the sample, and less than 2 months for 82% of the sample. -Complete PARCA-R data	The PARCA–R cognitive component identified the cases of cognitive delay accurately achieving an **AUC of 0.96 (95% CI 0.90 to 1.00**; a cut-point of ≤19 on the cognitive component had a sensitivity of 0.89 and specificity of 0.89). **PARCA-R language score ≤23 on the language component,** **Bayley III cognition scale score < 70, at least 2SD below the norm of 100, children born at 27wk median GA (range 25-30wks), when assessed at age 5-year** sensitivity: % (95%CI): 0.75 (0.54-0.96) specificity: % (95%CI): 0.79 (0.74-0.85) positive predictive value (PPV)*: % (95%CI): 0.26 (0.12-0.35) negative predictive value (NPV)*: % (95%CI): 0.97 (0.95-0.99) positive likelihood ratio (LR+): (95% CI)*: 3.62 (2.42-5.30) negative likelihood ratio (LR-): (95% CI)*: 0.32 (0.13-0.74) ** calculated by NGA technical team* The PARCA-R language component likewise identified the cases of language delay accurately achieving an **AUC of 0.97 (95% CI 0.94 to 0.99**; a cut-point of ≤23 on the language component had a sensitivity of 0.75 and specificity of 0.79).	exclusions? Un clear, in/exclusion criteria not reported **1.A Could the selection of patients have introduced bias?** No **1.B Is there concern that the included patients do not match the review question?** Lo w risk **Index Test** Were the index test results interpreted without knowledge of the results of the reference standard? Yes If a threshold was used, was it pre-specified? Yes **2.A Could the conduct or interpretation of the index**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
infants against the latest version of the BSID (BSID III), given that instrument's potential to gain acceptance as a new criterion approach to developmental assessment. **Study dates** Not reported **Source of funding** National Health and Medical Research Council of Australia			were available for 186/204 (91%) infants, and no infant had more than five missing item responses.		**test have introduced bias?** No **2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** Low risk **Reference Standard** Is the reference standard likely to correctly classify the target condition? Yes Were the reference standard results interpreted without knowledge of the results of the index test? Unclear, the study did not clearly report whether BSID-

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					III assessors were blinded to the results of PARCA-R **3.A Could the reference standard, its conduct, or its interpretation have introduced bias?** high risk **3.B Is there concern that the target condition as defined by the reference standard does not match the review question?** Low risk **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Yes,

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					most were tested within 1 month Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes **4. A Could the patient flow have introduced bias?** Yes Were all patients included in the analysis? Yes Overall quality: Low
Full citation Schonhaut, L., Armijo, I., Schonstedt, M., Alvarez, J., Cordero, M., Validity	**Sample size** The current study was part of a larger national validation study of the ASQ-3 in a representative sample of the Chilean population in which agreement between ASQ-3 AND Bayley-III in term children with low biological and social risk factors. The current sample was composed of children who attended a well-child clinic in Santiago, Chile.	**Screening strategies/tools** Screening: on the ASQ-3, the presence	**Methods** -Data were collected from 306 term and preterm children ages 8, 18, and 30 months' CGA	**Results** **ASQ-3 Psychometric Values (< 2 SD) Compared With Bayley-III (1 ≥ 1 SD) according to GA, assessed at age 8-mth, 18-mth, and 30-mth corrected age:** **ASQ < 2SD below the mean;** **Developmental delay measured by: Bayley -III: Bayley III ≥ 1 SD below the mean**	**Other information** **Study quality - QUADAS 2 checklist Patient selection**

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>of the ages and stages questionnaires in term and preterm infants, Pediatrics, 131, e1468-74, 2013

Ref Id

397695

Country/ies where the study was carried out

Chile

Study type

Cross-sectional study

Aim of the study

To assess the concurrent validity of the parent-</td>
<td>N= 124 late preterm (GA 32-36wks); 63 extremely preterm (< 32wks GA or weight < 1500g)

Characteristics

<table>
<tr><th>Characteristic</th><th>Age Group
8 Months (n= 110)</th><th>18 Months (n= 100)</th><th>30 Mon (n =</th></tr>
<tr><td>Gestational age</td><td></td><td></td><td></td></tr>
<tr><td>37–41 wk</td><td>43 (39)</td><td>39 (39)</td><td>37 (</td></tr>
<tr><td>32–36 wk</td><td>44 (40)</td><td>41 (41)</td><td>39 (</td></tr>
<tr><td><32 wk or <1500 g</td><td>23 (21)</td><td>20 (20)</td><td>20 (</td></tr>
<tr><td>Gender</td><td></td><td></td><td></td></tr>
<tr><td>Female</td><td>45 (41)</td><td>47 (47)</td><td>53 (</td></tr>
</table>
</td>
<td>of any domain screened <2 SDs below the mean area score was considered a positive screen (indicating failure or delay).

Diagnosis: A Bayley-III score less than ≤1 SD indicated mild or severe delay.</td>
<td>recruited from an ambulatory well-child clinic in Santiago, Chile.
-Parents completed the ASQ-3 in their homes, and afterward a trained professional administered the Bayley-III in a clinic setting.
-The time interval between both measures was no more than 2 weeks;
-Development was assessed at 8, 18, or 30 months corrected corrected gestational age.</td>
<td>
<table>
<tr><th>Value</th><th>Term (n = 119)</th><th>Late Preterm: 32-36 wks GA, (n = 124)</th></tr>
<tr><td>Sensitivity</td><td>59 (36–78)</td><td>80 (61–91)</td></tr>
<tr><td>Specificity</td><td>87 (79–92)</td><td>73 (63–81)</td></tr>
<tr><td>PPV</td><td>44 (26–63)</td><td>43 (30–57)</td></tr>
<tr><td>NPV</td><td>93 (86–96)</td><td>94 (86–97)</td></tr>
<tr><td>Positive LR</td><td>4.6 (2.4–8.8)</td><td>2.9 (2.0–4.3)</td></tr>
<tr><td>Negative LR</td><td>0.4 (0.27–0.83)</td><td>0.27 (0.1–0.6)</td></tr>
</table>
Data are presented as % (95% CI) or n (95% CI). NPV, negative predictive value; PPV, positive predictive value.
</td>
<td>Was a consecutive or random sample of patients enrolled? Yes (part of a national validation study)
Was a case-control design avoided? Yes
Did the study avoid inappropriate exclusions? Yes
1.A Could the selection of patients have introduced bias? No
1.B Is there concern that the included patients do not match the review question? Low risk

Index Test
Were the index test results interpreted</td>
</tr>
</table>

Study details	Participants				Screening strategies/tools	Methods	Outcomes and results	Comments
completed developmental screening measure Ages and Stages Questionnaires, Third Edition (ASQ-3) compared with the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III) in children born term, late preterm, or extremely preterm at 8, 18, or 30 months of corrected gestational ages (CGA). **Study dates**	Male	65 (59)	53 (53)	43 (45)*				without knowledge of the results of the reference standard? Yes If a threshold was used, was it pre-specified? Yes **2.A Could the conduct or interpretation of the index test have introduced bias?** Unclear **2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** Low risk **Reference Standard** Is the reference standard likely to correctly classify the
	Multiple pregnancies	34 (31)	31 (31)	35 (37)	NS			
	Maternal age, mean ± SD, y	32.9 ± 3.6	34.2 ± 3.3	35.3 ± 4.2	< .05**			
	Mother's years of education	17.7 ± 2.6	17.4 ± 2.3	17.6 ± 2.6	NS			
	Maternal occupation				NS			
	Paid work	71	77	74				
	Homemaker	29	23	26				
	Family income eighth and ninth deciles of income	95	95	100	NS			
	Inclusion criteria							

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
2008-2011 **Source of funding** Clinica Alemana Research Grants Program	-306 term and preterm children ages 8, 18, and 30 months' CGA recruited from an ambulatory well-child clinic in Santiago, Chile. **Exclusion criteria** Not reported				target condition? Yes Were the reference standard results interpreted without knowledge of the results of the index test? Yes, the study did not clearly reported on that **3.A Could the reference standard, its conduct, or its interpretation have introduced bias? moderate risk** **3.B Is there concern that the target condition as defined by the reference standard does not match the review**

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					question? Low risk **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Yes, no more than 2 weeks Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes **4. A Could the patient flow have introduced bias?** Low risk Were all patients included in the analysis? Yes Overall quality: moderate

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td>Other information: Population screened with the ASQ-3 represented only those middle-class parents who attended private medical clinics in Chile.</td></tr>
<tr><td>Full citation

Simard, M. N., Luu, T. M., Gosselin, J., Concurrent validity of ages and stages questionnaires in preterm infants, Pediatrics, 130, e108-14, 2012</td><td>Sample size

Participants were initially recruited as part of a larger longitudinal study on early neurocranial markers in preterm infants that involved a 2-year follow-up.
N= 142 infants born between 29 and 36 6/7 weeks of gestation were randomly selected and included if they had a birth weigth < 2500 g and were admitted for at least 24 hours at Sainte-Justine University Health Centre's NICU.

Characteristics</td><td>Screening strategies/tools

- Screening: at 12 and 24 months' CA, the child developmental status was assessed by using the ASQ, second</td><td>Methods

-Participants were initially recruited as part of a larger longitudinal study on early neurocranial markers in preterm infants that involved a 2-year follow-up;
-At 12 and 24 months' CA, the child developmental status was assessed at</td><td>Results

BSID-II MDI < 85 at 12 months Corrected age, among children born at 29-36 wks GA: N= 121
<table>
<tr><td></td><td>ASQ Cutoff Scoresa</td><td></td><td></td></tr>
<tr><td></td><td><1 SD</td><td><1.5 SD</td><td><2</td></tr>
<tr><td>Sensitivity</td><td>0.60 (0.39 to 0.81)</td><td>0.45 (0.23 to 0.67)</td><td>0.
0.</td></tr>
</table></td><td>Other information

Study quality - QUADAS 2 checklist
Patient selection
Was a consecutive or random sample of patients enrolled? Yes
Was a case-control design avoided? Yes
Did the study avoid</td></tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Ref Id

397717

Country/ies where the study was carried out

Canada

Study type

Cross sectional study

Aim of the study

To determine the ability of the ASQ at 12 and 24 months' corrected age (CA) to identify preterm children at higher risk of presenting mild</td>
<td>
<table>
<tr><th></th><th>Seen at 12 mo CA</th><th>Seen at 24 mo CA</th></tr>
<tr><td>Total, n</td><td>124</td><td>112</td></tr>
<tr><td>Median gestational age (range), wk</td><td>32 (29–36)</td><td>32 (29–36)</td></tr>
<tr><td>Gestational age, n (%)</td><td></td><td></td></tr>
<tr><td>29-31 6/7 wk</td><td>52 (42)</td><td>45 (40)</td></tr>
<tr><td>32-33 6/7 wk</td><td>51 (41)</td><td>49 (44)</td></tr>
<tr><td>34-36 6/7 wk</td><td>21 (17)</td><td>18 (16)</td></tr>
</table>
Inclusion criteria

Infants born between May 2004 and April 2006, between 29 and 36 6/7 weeks of gestation were randomly selected and included if they had a birth weight < 2500 g and were admitted for at least 24 hours at Sainte-Justine University Health Centre's NICU.
</td>
<td>edition, and the BSID-II.
-Then, the BSID-II was administered by 1 of 2 trained assessors who were blind to ASQ scores. In addition, independent assessors completed the assessments at the 12- and 24-month visits.</td>
<td>Sainte-Justine University Health Center over a 1-hour period by using the ASQ, second edition, and the BSID-II.
-The ASQ was first completed on site by the parents who were asked the questions by a research assistant. Then, the BSID-II was administered by 1 of 2 trained assessors who were blind to ASQ scores. In addition, independent assessors completed the assessments at the 12- and 24-month visits.
-To be considered at risk on the ASQ, the child</td>
<td>
<table>
<tr><td>Specificity</td><td>0.68 (0.59 to 0.77)</td><td>0.78 (0.71 to 0.87)</td><td>0.88 (0.82 to 0.95)</td></tr>
<tr><td>PPV</td><td>0.29 (0.16-0.42)</td><td>0.33 (0.16-0.80)</td><td>0.25 (0.03-0.46)</td></tr>
<tr><td>NPV</td><td>0.88 (0.81-0.95)</td><td>0.87 (0.80-0.94)</td><td>0.83 (0.76-0.90)</td></tr>
<tr><td>LR+</td><td>1.83 (1.17-2.87)</td><td>2.25 (1.23-4.11)</td><td>1.50 (0.53-4.21)</td></tr>
<tr><td>LR_</td><td>0.60 (0.36-1.01)</td><td>0.68 (0.46-1.01)</td><td>0.93 (0.75-1.15)</td></tr>
</table>
BSID-II PDI < 85 at 12 months Corrected age, among children born at 29-36 wks GA: N= 119
<table>
<tr><td></td><td>ASQ Cutoff Scoresa</td><td></td><td></td></tr>
<tr><td></td><td><1 SD</td><td><1.5 SD</td><td><2 SD</td></tr>
<tr><td>Sensitivity</td><td>0.52 (0.38–0.67)</td><td>0.39 (0.24–0.53)</td><td>0.25 (0.12–0.38)</td></tr>
<tr><td>Specificity</td><td>0.90 (0.83–0.96)</td><td>0.96 (0.92–1.00)</td><td>0.97 (0.94–1.00)</td></tr>
</table>
</td>
<td>inappropriate exclusions? Yes
1.A Could the selection of patients have introduced bias? Unclear
1.B Is there concern that the included patients do not match the review question? Low concern

Index Test
Were the index test results interpreted without knowledge of the results of the reference standard? Yes
If a threshold was used, was it pre-specified? Yes
2.A Could the conduct or interpretation of the index test have introduced</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>developmental delay that would justify additional developmental assessment. More specifically, concurrent validity was calculated by comparing the ASQ against the Bayley Scales of Infant Development, second edition (BSID-II).

Study dates

2004-2006

Source of funding

Canadian Institutes of</td>
<td>Exclusion criteria

Presence of chromosomal anomalies, congenital malformation, consanguinity, congenital infection, documented neonatal stroke, residing outside the metropolitan Montreal area, language spoken at home other than French or English, and significant social problems for 1 or both parents (drug addiction, alcoholism, mental illness, intellectual disability, or history of abuse, neglect, or family violence).</td>
<td></td>
<td>had to score below the failure cutoff threshold on any domain forming a category. There were 3 cutoff thresholds: 2 SD, 1.5 SD, and 1 SD. Using a lower cutoff (1 SD instead of 2 SD) is stricter and results in including more infants in the at-risk group. -Failure on any of the communication, problem-solving, or personal-social domains was then compared against an MDI <85. Similarly, being at risk on any the gross or fine motor domains was compared against a PDI <85. The study</td>
<td>
<table>
<tr><td>PPV</td><td>0.73 (0.58-0.89)</td><td>0.80 (0.62-0.98)</td><td>0.85 (0.65-1.04)</td></tr>
<tr><td>NPV</td><td>0.78 (0.69-0.86)</td><td>0.74 (0.65-0.82)</td><td>0.71 (0.61-0.79)</td></tr>
<tr><td>LR+</td><td>5.04 (2.46-10.3)</td><td>7.33 (2.62-20.5)</td><td>9.85 (2.29-42.4)</td></tr>
<tr><td>LR_</td><td>0.53 (0.38-0.74)</td><td>0.65 (0.51-0.83)</td><td>0.76 (0.64-0.91)</td></tr>
</table>
BSID-II MDI < 85 at 24 months Corrected age, among children born at 29-36 wks GA: N= 109
<table>
<tr><td></td><td>ASQ Cutoff Scoresa</td><td></td><td></td></tr>
<tr><td></td><td><1 SD</td><td><1.5 SD</td><td><2 SD</td></tr>
<tr><td>Sensitivity</td><td>0.92 (0.81–1.00)</td><td>0.88 (0.74–1.00)</td><td>0.75 (0.58–0.92)</td></tr>
<tr><td>Specificity</td><td>0.55 (0.45–0.66)</td><td>0.72 (0.63–0.82)</td><td>0.78 (0.69–0.87)</td></tr>
</table>
</td>
<td>bias? Low concern
2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?
Low concern

Reference Standard
Is the reference standard likely to correctly classify the target condition? Yes
Were the reference standard results interpreted without knowledge of the results of the index test? Yes
3.A Could the reference standard, its conduct, or</td>
</tr>
</table>

<table>
<tr><th>Study details</th><th>Participants</th><th>Screening strategies/tools</th><th>Methods</th><th>Outcomes and results</th><th>Comments</th></tr>
<tr>
<td>Health Research Grant 77617</td>
<td></td>
<td></td>
<td>used a cutoff of <85 on the BSID-II (1 SD below the mean) to include mild developmental delay</td>
<td>
<table>
<tr><td>PPV</td><td>0.39 (0.27-0.52)</td><td>0.51 (0.36-0.65)</td><td>0.53 (0.36-0.68)</td></tr>
<tr><td>NPV</td><td>0.95 (0.90-1.01)</td><td>0.95 (0.90-1.00)</td><td>0.90 (0.83-0.97)</td></tr>
<tr><td>LR+</td><td>2.07 (1.59-2.69)</td><td>3.34 (2.27-4.90)</td><td>3.46 (2.17-5.51)</td></tr>
<tr><td>LR_</td><td>0.14 (0.04-0.53)</td><td>0.16 (0.05-0.46)</td><td>0.33 (0.17-0.63)</td></tr>
</table>
BSID-II PDI < 85 at 24 months Corrected age, among children born at 29-36 wks GA: N= 107
<table>
<tr><td></td><td>ASQ Cutoff Scoresa</td><td></td><td></td></tr>
<tr><td></td><td><1 SD</td><td><1.5 SD</td><td><2</td></tr>
<tr><td>Sensitivity</td><td>0.50 (0.31 to 0.69)</td><td>0.50 (0.31 to 0.69)</td><td>0.
0.</td></tr>
<tr><td>Specificity</td><td>0.73 (0.64 to 0.83)</td><td>0.73 (0.64 to 0.83)</td><td>0.
0.</td></tr>
</table>
</td>
<td>its interpretation have introduced bias? Low risk
3.B Is there concern that the target condition as defined by the reference standard does not match the review question? Low risk

Flow and Timing Was there an appropriate interval between index test(s) and reference standard? Yes, 1-hour period Did all patients receive a reference standard? Yes Did patients receive the same</td>
</tr>
</table>

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
				PPV 0.39 (0.23-0.55) 0.39 (0.23-0.55) 0.57 (0.31-0.83) NPV 0.81 (0.71-0.90) 0.81 (0.71-0.90) 0.80 (0.71-0.88) **LR+** 1.82 (1.09-3.03) 1.82 (1.09-3.03) 3.95 (1.51-10.36) **LR_** 0.69 (0.47-1.02) 0.69 (0.47-1.02) 0.71 (0.59-0.97)	reference standard? Yes Were all patients included in the analysis? Yes **4. A Could the patient flow have introduced bias?** Low risk Were all patients included in the analysis? Yes Overall quality: high
Full citation Skellern, C. Y., Rogers, Y., O'Callaghan, M. J., A parent-completed developmental questionnaire: follow up of ex-premature	**Sample size** N= 147 children born at less than 31wks' GA and assessed at 18-22 months corrected age **Characteristics** **12 months *n* = 56 (%)** **18 months *n* = 24 (%)** **24 month 43 (%)** Sex distribution:	**Screening strategies/tools** Screening: ASQ Diagnosis: Bayley Scales of Infant Development MID scale at 18	**Methods** -One hundred and sixty-seven children who were ex-premature infants (less than 31 weeks gestation) attended the Growth and Development Clinic (Mater Children's Hospital,	**Results** Children born at < 31wks' GA, assessed at 18 months corrected age (within 4 weeks): **screening tool: ASQ, diagnosis tool: Bayely MDI scale < 1SD** **ASQ < 2SD:** sensitivity: % (95%CI): 0.50 (-0.19-1.19) specificity: % (95%CI): 0.91 (0.79-1.03) positive predictive value (PPV) *: % (95%CI): 0.33 (-0.20-0.86) negative predictive value (NPV)*: % (95%CI): 0.95 (0.86-1.04) positive likelihood ratio (LR+)*: (95% CI): 5.5 (0.81-37.2) negative likelihood ratio (LR-)*: (95% CI): 0.55 (0.14-2.2) ** calculated by NGA technical team*	**Other information** **Study quality - QUADAS 2 checklist** **Patient selection** Was a consecutive or random sample of patients enrolled? Yes

Study details	Participants			Screening strategies/tools	Methods		Outcomes and results	Comments
infants, Journal of Paediatrics & Child Health, 37, 125-9, 2001 **Ref Id** 397723 **Country/ies where the study was carried out** Australia **Study type** cross-sectional study **Aim of the study** The study aimed to explore the test characteristics of the 'Ages and Stages	Male	27 (48)	12 (50)	months corrected age.	30 (70)	Brisbane) from June 1998 to July 1999 for follow up at corrected ages of 12, 18, 24, and 48 months. -Parents of children born preterm completed the age-appropriate ASQ before their children attended the clinics, visit to the clinic coincided with the above corrected ages (CA) ± 4 weeks. -The study children were also assessed by a multidisciplinary team during the clinic visit; those performing the psychometric assessments	7 (54)	Was a case-control design avoided? Yes Did the study avoid inappropriate exclusions? Yes **1.A Could the selection of patients have introduced bias?** No **1.B Is there concern that the included patients do not match the review question?** Low risk **Index Test** Were the index test results interpreted without knowledge of the results of the reference standard? Yes If a threshold was used, was it pre-specified? Yes
	Female	29 (52)	12 (50)		13 (30)		6 (46)	
	Maternal education:							
	Secondary–incomplete	15 (27)	5 (21)		9 (21)		4 (31)	
	Secondary–completed	19 (34)	9 (37)		7 (16)		4 (31)	
	Secondary + further education	14 (25)	3 (13)		11 (26)		3 (23)	
	Tertiary complete	8 (14)	7 (29)		16 (37)		2 (15)	
	Birthweight (g)							
	mean	904	854		897		785	

Study details	Participants			Screening strategies/tools	Methods	Outcomes and results	Comments
Questionnaires' (ASQ) as a screening tool in an Australian population of children who were born prematurely, to detect those with developmental delay when compared to standard psychometric assessments. The ASQ have been in other populations demonstrated to be valid, economical and culturally sensitive **Study dates**	(SD)	183	118	184	were blinded to the results of the questionnaire score and perinatal details. The standardized psychometric assessments for each age group were at 18 months corrected age by the 'Bayley Scales of Infant Development'Mental Development Intelligence' (MDI) scale;	106	**2.A Could the conduct or interpretation of the index test have introduced bias?** no **2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** Low risk **Reference Standard** Is the reference standard likely to correctly classify the target condition? Yes Were the reference standard results interpreted without knowledge of the results of the index
	Gestational age (weeks)						
	mean	27	26	27		26	
	(SD)	1.7	1.5	1.4		1.3	
	Major disability (*n*)	7	5	7		2	
	Cerebral palsy	5	4	4		2	
	Hearing impairment	1	0	1		0	
	Visual impairment	0	1	2		0	
	Mixed disability	1	0	0		0	
	Inclusion criteria criteria: premature < 31 weeks, CA ± 4 weeks of study age groups						

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
1998-1999 **Source of funding** Not reported	**Exclusion criteria** children who couldn't be assessed by the multidisciplinary team; children with incomplete questionnaires				test? Unclear, the study did not clearly report on this **3.A Could the reference standard, its conduct, or its interpretation have introduced bias?** high risk **3.B Is there concern that the target condition as defined by the reference standard does not match the review question?** Low risk **Flow and Timing** Was there an appropriate interval between index test(s) and reference standard? Yes

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes **4. A Could the patient flow have introduced bias?** Low risk Were all patients included in the analysis? Yes Overall quality: moderate
Full citation Woodward, B. J., Papile, L. A., Lowe, J. R., Laadt, V. L., Shaffer, M. L., Montman, R.,	**Sample size** N = 228 extremely low birth weight infants enrolled after parental consent into the PROPHET study and who survived to hospital discharge. **Characteristics** Characteristics for the 228 children in this study included: mean birth weight - 738.5 g (500-997 g.);	**Screening strategies/tools** Screening tool: ASQ Parents were asked to complete an ASQ	**Methods** Neurodevelopmental evaluation of infants enrolled in the PROPHET study included administration of the BSID-II and neurologic	**Results** Children born at 25.4 weeks GA (range: 23.0-31.0 weeks), screened by at 18-22 months corrected age, outcome **assessed by BSID-II (> 2SD below the mean, either MDI or PDI):** **ASQ > 2 SD below the mean:** sensitivity: % (95%CI): 0.73 (0.60-0.84) specificity: % (95%CI): 0.65 (0.55-0.73) positive predictive value (PPV): % (95%CI)*: 0.524 (0.41-0.63)	**Other information** **Study quality - QUADAS 2 checklist** **Patient selection** Was a consecutive or random

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
Watterberg, K. L., Use of the Ages and Stages Questionnaire and Bayley Scales of Infant Development-II in neurodevelopmental follow-up of extremely low birth weight infants, Journal of Perinatology, 31, 641-6, 2011 **Ref Id** 445924 **Country/ies where the study was carried out** USA **Study type**	**mean gestational age - 25.4 weeks (23.0-31.0 weeks);** gender - males 121 (53.1%), females 107 (46.9%); ethnicity - Non-Hispanic white 117 (51.3%), Black 73 (32.0%), Hispanic 27 (11.8%), Other 11(4.8%); median total household income was $30,000 - $40,000. **Inclusion criteria** Eligibility criteria for that study included birth weight between 500-999 grams and the need for mechanical ventilation at 12-48 hours of age. **Exclusion criteria** Not reported	when their child was 4, 8, 12 and 18-22 months corrected age. A score of 2 standard deviations or more below the mean in any one of the domains is considered a "fail" on the ASQ Development assessment tool: BSID-II, for this study, a standard score of 70 or below, which is 2 standard deviations	examination by certified examiners at 18 – 22 months corrected age. Families were separately consented for the ancillary ASQ study and were asked to complete an ASQ when their child was 4, 8, 12 and 18-22 months corrected age. Approximately 2 weeks prior to an infant turning 4, 8, 12 and 18-22 months corrected age, an age-appropriate ASQ form was mailed to the home. Completed ASQs were either mailed back to the center (families were provided with stamped	negative predictive value (NPV): % (95%CI)*: 0.816 (0.73-0.90) positive likelihood ratio (LR+): (95% CI)*: 2.05 (1.58-2.76) negative likelihood ratio (LR-): (95% CI)*: 0.42 (0.27-0.65) ** calculated by NGA technical team* Children born at 25.4 weeks GA (range: 23.0-31.0 weeks), screened by at 18-22 months corrected age, outcome **assessed by BSID-II (> 2SD below the mean, either MDI or PDI):** **ASD > 1SD below the mean** sensitivity: % (95%CI): 0.94 (0.89-1.00) specificity: % (95%CI): 0.32 (0.23-0.40) positive predictive value (PPV): % (95%CI)*: 0.43 (0.34-0.51) negative predictive value (NPV): % (95%CI)*: 0.92 (0.834-1.00) positive likelihood ratio (LR+): (95% CI)*: 1.39 (1.21-1.60) negative likelihood ratio (LR-): (95% CI)*: 0.16 (0.05-0.49) ** calculated by NGA technical team* Children born at 25.4 weeks GA (range: 23.0-31.0 weeks), screened by at 18-22 months corrected age, outcome **assessed by BSID-II (> 1SD below the mean, either MDI or PDI):** **ASD > 2SD below the mean** sensitivity: % (95%CI): 0.63 (0.53-0.72) specificity: % (95%CI): 0.76 (0.64-0.85) positive predictive value (PPV): % (95%CI)*: 0.81 (0.72-0.89) negative predictive value (NPV): % (95%CI)*: 0.54 (0.44-0.64) positive likelihood ratio (LR+): (95% CI)*: 2.47 (1.58-3.86) negative likelihood ratio (LR-): (95% CI)*: 0.50 (0.38-0.67) ** calculated by NGA technical team*	sample of patients enrolled? unclear, the study was the follow-up of an RCT Was a case-control design avoided? Yes Did the study avoid inappropriate exclusions? Yes **1.A Could the selection of patients have introduced bias?** Unclear **1.B Is there concern that the included patients do not match the review question? Unclear** **Index Test** Were the index test results interpreted without knowledge of the results of

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
cross sectional study (follow-up of an earlier RCT, cross-sectional analysis) **Aim of the study** 1) to assess correlation between results on the Ages and Stages Questionnaire (ASQ), and the Bayley Scales of Infant Development II (BSID-II) at 18-22 months corrected age; 2) to assess the degree to which earlier ASQ assessments predict		below the mean, was considered a "fail" on either the Mental or Psychomotor Scale of the BSID-II.	and addressed envelopes) or the research coordinator called the family and obtained the answers to the ASQ by phone. If the family had not completed the 18 – 22 month ASQ prior to the professional neurodevelopmental evaluation, the family was asked to complete the ASQ on site. ***The Bayley Scales of Infant Development*** includes Mental (MDI) and Psychomotor (PDI) Scales, as well as a Behavior Rating Scale. Raw scores on the BSID-II are		the reference standard? Yes If a threshold was used, was it pre-specified? Yes **2.A Could the conduct or interpretation of the index test have introduced bias?** No **2.B Is there concern that the index test, its conduct, or interpretation differ from the review question?** Low risk **Reference Standard** Is the reference standard likely to correctly classify the target condition? Yes Were the reference standard

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
later BSID-II results; **Study dates** Not reported **Source of funding** National institute of Child Health and Human Development			converted to standardized scores with a mean of 100 and a standard deviation of 15. For this study, a standard score of 70 or below, which is 2 standard deviations below the mean, was considered a "fail" on either the Mental or Psychomotor Scale of the BSID-II		results interpreted without knowledge of the results of the index test?Unclear, the study did not clearly reported on this **3.A Could the reference standard, its conduct, or its interpretation have introduced bias?** unclear **3.B Is there concern that the target condition as defined by the reference standard does not match the review question?** Low risk **Flow and Timing** Was there an

Study details	Participants	Screening strategies/tools	Methods	Outcomes and results	Comments
					appropriate interval between index test(s) and reference standard? Yes Did all patients receive a reference standard? Yes Did patients receive the same reference standard? Yes **4. A Could the patient flow have introduced bias?** Low risk Were all patients included in the analysis? Yes Overall quality: low

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Developmental follow up of pre-term babies

Delivering enhanced developmental support and surveillance

There were no evidence tables for this review.

Sharing information

Study details	Participants	Methods	Findings	Comments
Full citation Johnson, S., Gilmore, C., Gallimore, I., Jaekel, J., Wolke, D., The long-term consequences of preterm birth: what do teachers know?, Developmental Medicine & Child Neurology, 57, 571-7, 2015 **Ref Id** 460926 **Country/ies where the study was carried out** UK **Study type** A cross-sectional survey study	**Sample size** n=585 teachers n=212 educational psychologists **Characteristics** Of the 585 teachers who completed the survey, 65% (381) were employed by the community, voluntary aided, or controlled schools; 24% (142) in academies or free schools; and 11% (62) in independent schools. These teachers were teaching children of varied ages, 36% were teaching children aged 3 to 5 years; 46% teaching children aged 5 to 7 years; 48% teaching children aged 7 to 11 years; 37% teaching children aged 11 to 14 years; 36$ teaching children 14 to 16 years; and 24% teaching children aged 16 to 18 years. Compared to the national data for staff in publicly funded school, the respondents were significantly more likely to be female, to be teachers rather than teaching assistants, and to be employed in special schools.	**Setting** Online survey for teaching staff and educational psychologists in England/UK. **Data collection** All teaching staff in every school in England were invited to participate via an email sent to the head teacher of each school requesting them to distribute it to their staff. The email contained information about the survey and a hyperlink to the online survey. All members of the Association for Educational Psychologists (the professional organisation for educational psychologists in the UK) were invited via email including information about the survey and a hyperlink to the online survey. In addition, posters	**Relevant findings** Mean knowledge score for teaching staff was 14.7 (SD 5.5, range 0-27), corresponding to 45% accuracy (SD 17%). 12% responded with <25% accuracy, 2.6% (n=15) scored zero. Mean knowledge score for educational psychologists was 17.1 (SD 5.0, range 1-28), corresponding to 52% (SD15%) accuracy. 5.2% responded with <25% accuracy. Teaching staff had significantly lower scores than educational psychologists (p<0.001). Teaching staff: Teaching staff in schools for children with special educational needs (SEN) scores significantly higher than staff in mainstream schools, 15.8 versus 14.5 (p=0.024).	**Limitations** 1. Research question and design Was there a clear research question, and was this important and sensible? **YES.**Was a questionnaire the most appropriate research design for this question? **YES.** 2. Sampling What was the sampling frame and was it sufficiently large and representative? **NO. No sampling as such was done. The survey was targeting all teaching staff and educational staff in England (from 24 000 schools in England), however, only 585 teachers and 212 educational psychologists responded by completing the PB-KS. Of the 679 teaching staff who responded to the PB-KS, 80% completed all 33 items (20% were thus excluded). Compared with national data for staff in publicly funded schools, the respondents (teaching staff) were more likely to be female (86% versus 83%, p=0.031); be teachers instead of teaching assistants (93%**

Study details	Participants	Methods	Findings	Comments
Aim of the study To assess the knowledge and information needs of education professionals relating to the developmental and educational consequences of preterm birth. **Source of funding** Nuffield Foundation grant; Royal Society Dorothy Hodgkin Fellowship.	Most of the 212 educational psychologists who completed the survey were female, qualified, and employed in the local government. Compared with national data, respondents were significantly more likely to be female and full members versus trainees/affiliate/retired. **Inclusion criteria** All teaching staff in every school in England were eligible to participate. All educational psychologists were eligible to participate. **Exclusion criteria** Non-teaching staff; respondents with missing demographic information; incomplete responses on PB-KS.	and social media were used to recruit teachers and educational psychologists to participate in the survey. The survey used was the Preterm Birth-Knowledge Scale (PB-KS), which comprises 33 statements with forced choice responses ('true', 'false', 'don't know'). Each statement is evidence-based and developed from a literature review relating to outcomes after preterm birth. The accuracy and validity of the statements were reviewed by experts in the field during the development of the survey. Responses on individual statement were scored for accuracy based upon current knowledge ('don't know' or incorrect=0; correct=1) and a total knowledge score (range 0-33) was computed (higher scores indicate greater knowledge). The survey also explored opinions about who is likely to be responsible for supporting preterm children and the value of disclosing a child's preterm birth status. Self-perceived competence in supporting a preterm child, adequacy of training received and information needs were also assessed with responses recorded on	Teaching staff with SEN coordinator role scores significantly higher than non-SEN coordinators, 16.4 versus 14.0 (p<0.001). Teaching staff who had worked for at least 16 years scored significantly higher than respondents with less work experience (p=0.003). Female teaching staff scored significantly higher than male teaching staff, 15.1 versus 12.9 (p=0.005). Teaching staff who felt they were equipped to support preterm children scored significantly higher than those who felt they were ill-equipped to support preterm children, 16.4 versus 13.7 (p<0.001). Teaching staff who felt they received sufficient training about prematurity scored significantly higher than those who felt they received insufficient training on prematurity, 16.9 versus 14.4 (p<0.001). Educational psychologists: No difference in scoring in relation to sex; being fully qualified or being a trainee/affiliate/retried; years of employment; feeling of receiving sufficient/insufficient training in relation to prematurity.	**versus 58%, p<0.001); be employed in special schools (18% versus 7%, p<0.001). Compared with national data, the educational psychologists who responded in the survey were more likely to be female (86% versus 79%, p=0.01) and full members versus trainees/affiliate/retired (91% versus 85%, p=0.02). Therefore, because of low response rate and the sample showing different characteristics than national data on school staff, it is likely that the sample is not representative of the target population.** Did all participants in the sample understand what was required of them, and did they attribute the same meaning to the terms in the questionnaire? **YES.** 3. Instrument What claims for reliability and validity have been made, and are these justified? **YES. The PB-KS questionnaire has been validated and has good internal reliability (Cronbach's alpha=0.82).** Did the questions cover all relevant aspects of the problem in a non-threatening and non-directive way? **YES.** Were open-ended (qualitative) and closed-ended (quantitative) questions used appropriately? **UNCLEAR. Only close-ended questions were used. Open-ended questions would perhaps catch more meaningful and rich data but are impractical in a large survey like this.**

Study details	Participants	Methods	Findings	Comments
		a 5-point Likert scale ('strongly disagree'; 'disagree'; 'neither agree not disagree'; 'agree'; 'strongly agree'). Additionally, demographic information of the respondent were collected. **Data analysis** Differences between teachers and educational psychologists in PB-KS scores were assessed using independent samples Student's t-tests. To assess the effects of demographic characteristics on knowledge levels, the association between demographic variables and PB-KS scores were analysed separately for teaching staff and educational psychologists using independent Student's t-test or linear regression, as appropriate. Multivariable linear regression was used to assess the independent effect of demographic variables on knowledge scores. Data was analysed using SPSS v20.	Educational psychologists who felt they were equipped to support preterm children scored significantly higher than those who felt they were ill-equipped to support preterm children, 17.9 versus 15.8 (p=0.003). Both both groups, the greatest accuracy was demonstrated on items related to neurosensory sequelae such as cerebral palsy and the need for assistance with activities of daily living. Only 8% of the teachers knew that maths difficulties are a particular deficit after preterm birth. Only 11% to 18% of all respondents knew that very preterm children are likely to be inattentive and have poorer peer relationship skills than term-born children. Information needs More than 90% of all respondents felt they were likely to come into contact with a preterm child. Most respondents felt that educational management was the responsibility of the class teacher. About 3/4 of the respondents felt that disclosure of preterm birth status would be beneficial for the child and would not lead	Was a pilot version administered to participants representative of those in the sampling frame, and the instrument modified accordingly? **NO. No report about pilot test.** 4. Response What was the response rate and have non-responders been accounted for? **There was no clear sampling frame but overall the response rate low. Only 585 teaching staff members completed the survey although the invitation to participate was sent to all head teachers in all the 24 000 schools in England. The respondents' characteristics were compared to the national data of the target population (please see point 2. above for more information).** 5. Coding and analysis Was the analysis appropriate (e.g. statistical analysis for quantitative answers, qualitative analysis for open-ended questions) and were the correct techniques used? **YES.** Were adequate measures in place to maintain accuracy of data? **YES.** 6. Presentation of results Have all relevant results ('significant' and 'non-significant') been reported? **YES.** Is there any evidence of 'data dredging' (i.e. analyses that were not 'hypothesis driven')? **NO.** **Overall quality of evidence: low**

Study details	Participants	Methods	Findings	Comments
			to negative labeling of the child. Only 38% of the teaching staff felt adequately equipped to support a preterm born child. Only 14% of the teaching staff felt the had received sufficient training on prematurity. Over 80% of all the respondents requested more information about preterm birth.	The checklist for quality assessment: Greenhalgh et al. (2005) Diffusion of Innovations in Health Service Organisations: A Systematic Literature Review. Appendix 2. Box A.4 Quality checklist for questionnaire surveys.

Appendix K and L: Evidence tables and supplementary tables- developmental follow-up of preterm babies

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Appendix L: Supplementary tables

Table 1: Neurodevelopmental assessment at two years of age as recommended by the British Association of Perinatal Medicine (information in this table compiled from BAPM, 2008).

Neurodevelopmental outcomes	Definition for severe neurodevelopmental disability	Definition for moderate neurodevelopmental disability	Suggested assessment instruments
Motor	Cerebral palsy with GMFCS level 3, 4 or 5	Cerebral palsy with GMFCS level 2	Development scales which place heavy reliance on motor items or by neurological examination (using e.g. the scheme developed by Amiel-Tison and Grenier); GMFCS to be used to quantify motor function in children with cerebral palsy
Cognitive function	Score <-3 standard deviations below norm (DQ <55)	Score -2SD to -3SD below norm (DQ 55-70)	The working group recommends that all neonatal services plan to develop their follow-up service to include a formal developmental assessment using Bayley-3 cognitive scale. In the short term, a quantifiable standardised scale (e.g. Bayley Scales or Griffiths Scales) or a quantifiable screening test (e.g. PARCA-R, Bayley Screener) is recommended.
Hearing	No useful hearing even with aids (profound >90dBHL)	Hearing loss corrected with aids (usually moderate 40-70dBHL); or some hearing but loss not corrected by aids (usually severe 70-90dBHL)	-
Speech and language	No meaningful words/signs; or unable to comprehend cued command (i.e. commands only understood in a familiar situation or with visual cues e.g. gestures)	Some but fewer than 5 words or signs; or unable to comprehend un-cued command but able to comprehend a cued command	-
Vision	Blind; or can only perceive light or light reflecting objects	Seems to have moderately reduced vision but better thasn severe visual	-

Neurodevelopmental outcomes	Definition for severe neurodevelopmental disability	Definition for moderate neurodevelopmental disability	Suggested assessment instruments
		impairment; or blind in one eye with good vision in the contralateral eye	
Seems to have moderately reduced vision but better thasn severe visual impairment; or blind in one eye with good vision in the contralateral eye	Seems to have moderately reduced vision but better thasn severe visual impairment; or blind in one eye with good vision in the contralateral eye	Seems to have moderately reduced vision but better thasn severe visual impairment; or blind in one eye with good vision in the contralateral eye	Seems to have moderately reduced vision but better thasn severe visual impairment; or blind in one eye with good vision in the contralateral eye

1 *GMFCS Gross Motor Function Classification System; DQ developmental quotient; SD standard deviation; dbHL desibels hearing level; PARCA-R Parent Report of Children's Abilities-Revised*

2 **Table 2: The choices for neurodevelopmental follow-up: assessment beyond two years of age (Salt and Redshaw, 2006)**

Which aspects or domains of development?	When?	By whom?
• Cognitive ability • Neuropsychological functioning • Executive function • Non-verbal learning • Visual-motor skills • Speech and language • Sensory impairment • Academic achievement • Behavioural adjustment • Motor development • Disability • Quality of life • Social skills and adjustment	• Infancy ○ 2 years • Preschool ○ 3-4 years • Junior/middle school ○ 5-6 years ○ 7 years • Senior school ○ 12 years ○ 14-15 years	• Clinician/paediatrician • Neurologist • Clinical psychologist • Educational psychologist • Physiciotherapist • Parent • Teacher • Child/teenager

1 **Table 3: Measures used for neurodevelopmental follow-up after two years of age (Salt and Redshaw, 2006)**

Area of behaviour/outcome	Measure	Other details	Age range	Most recent revision
Cognition	Bayley scales of infant development (BSID-II)	Mental, motor, and behaviour rating scale	Birth-4 years	1993
	Griffiths scales of mental development	6 subscales	Birth to 8 years	2005 Birth to 2 years
				2005 2 to 8 years
	McCarthy Scale (cognitive abilities)	6 scales: verbal, perceptual-performance, quantitative, composite (general cognitive, memory, motor	2.5 – 8.5 years	1972
		General Cognitive Index (GCI) is derived from the verbal, quantitative and perceptual performance scales.		
	Stanford binet intelligence scale 4th edition	5 subscales	2 years-adult	2003
		Verbal and non-verbal		
	Wechsler preschool and primary scale of intelligence (WPPSI-III)	Four core subtests (2.6 to 3.11) – 2 verbal, 2 performance	2 years 6 months – 7 years 3 months	2004
		Seven core subtests (4.0 to 7.3) – 3 verbal, 3 performance, 1 processing speed		
	Kaufman assessment battery of childhood	Global Scales: sequential processing, simultaneous processing, mental processing composite, achievement, nonverbal	2 years 6 months – 12 years 6 months	1983
	Wechsler Intelligence Scale for Children (WISC-Iv)	10 core subtests: 3 verbal comprehension, 3 perceptual reasoning, 2 working memory, 2 processing speed and 5 supplemental tests	6 – 16 years	2005
	British ability scales 2nd edition	2.6 to 3.5 Four core scales – general cognitive ability and diagnostic scales	Early years – 2.5 years – 7 years 11 months	1996
		3.5 to 5.11 – 6 core scales and 6 diagnostic scales	School age — 5.0 years to 17 years 11 months	
		6.0 to 17.11 – 6 core and 5 diagnostic		

Area of behaviour/outcome	Measure	Other details	Age range	Most recent revision
	Ages and Stages questionnaires (ASQ)	A screening tool for parents and caregivers: on communication, gross motor, fine motor, problem solving, and personal-social aspects of behaviour.	4 months – 5 years	1989, Different language editions available
	Parent report of children's abilities (PARCA)	3 subscales; non-verbal cognition, linguistic skills and expressive vocabulary	2 years of age	2004
	Leiter international performance scale: revised edition	20 subtests measuring non-verbal intelligence — 10 visualisation and reasoning and 10 attention and memory	2 years – 20 years 11 months	1997
	NEPSY — neuropsychological assessment	5 domains: attention/executive functions, language, sensorimotor function visuospatial processing and memory and learning	3 – 12 years	1997
	Behaviour rating of executive function BRIEF-P BRIEF	3 indexes: inhibitory self-control, flexibility and emergent metacognition	2 – 5 years 11 months	2003
		2 indexes: behavioural regulation and metacognition and Global Executive Composite Score	5 – 18 years	2000
Language	Preschool Language Scale (PLS3/4)	Total language, auditory, comprehension, expression	0 – 6.11	2002
		Communication	0 – 3 years, 5 – 11 years	
	Peabody picture vocabulary test-R	Receptive vocabulary	2.5 years-adulthood	1981
	Reynell Developmental Language Scales	2 scales: Comprehension and Expression Standardised on different populations.	15 months – 7.5 years	Different language editions available
	British picture vocabulary scale; 2nd and 3rd editions	Receptive vocabulary (no reading, speaking or writing required, pointing only) (UK and North American editions)	3 – 15 years 8 months	Different editions available

Area of behaviour/outcome	Measure	Other details	Age range	Most recent revision
Behaviour	Child behaviour checklist (CBCL)	Preschool and school-age editions: a wide range of scales and teacher/parent report forms	1.5 – 5 years	2003
			6 – 18 years	
	Conners Rating Scale (CRS-R)	Parent and Teacher rating scales and Conners and Wells adolescent Self Report Scale	3 – 17 years	1996
	Vineland adaptive behaviour scales II	Professional interview, areas of assessment include: communication, daily living, socialization, and motor skills.	Birth-19 years	2003/4
	Goodman strengths and difficulties	Parent/teachers/self completion for adolescents: 25 attributes, emotional, conduct, hyperactivity — inattention, peer relationships and prosocial behaviour	4 – 16 years (3 years modified)	1997
	Rutter child behaviour scale questionnaire	Parent and teacher scales	Pre-school children	1993
			School age children	1993
Motor skills and fine motor coordination	Movement ABC	Normative and qualitative measures: movement competence, manual dexterity, ball skills, static and dynamic balance	4 – 12 years	1992
	Movement ABC Checklist	Teacher/parent completion, topics as above	4 – 12 years	1992
	Beery VMI 5th Edition	Test of visual motor Integration with supplementary tests for visual perception and motor coordination	2 – 18.11 years	2004
	Beery Buktenica			

1 **Table 4: Test batteries chosen by the SwissNeoNet for the two milestone ages of 2 and 5-6 years (Adams et al., 2014)**

18-24 months corrected age	5-6 years chronological age
• Bayley Scales of Infant Development Third Edition (cognition, language, motor) for all children born at <28 weeks of gestation or who developed moderate to severe encephalopathy due to asphyxia; for all other high-risk children Griffith's Test (if Bayley-III is not available or time restriction)	• Intellectual examination using Kaufmann Assessment Battery for Children (K-ABC) • Neurological examination including cerebral palsy classification according to SCPE and Palisano's gross motor function classification • Motor examination using Zurcher Neuromotor Assessment • Behaviour assessment using Strengths and Difficulties Questionnaire (SDQ)

18-24 months corrected age	5-6 years chronological age
• Neurological examination including classification of cerebral palsy according to Surveillance of Cerebral Palsy in Europe (SCPE) and Palisano's gross motor function classification • Visual examination (including Lang test) • Hearing examination	• Visual examination • Hearing examination

1 **Table 5: Child and family outcomes to be considered at different ages (Doyle et al., 2014)**

	Ages at assessment											
	2-6 w	3-4 m	8 m	12 m	15-18 m	24 m	36 m	4-5 y*	6-8 y†	12-14 y	Transition to adult	Adult
Child												
Physical Health												
General health	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++
Growth	+++	+++	+++	+++	++	++	++	++	++	+++‡	++§	++§
Feeding problems	+++	++	++	++	+	+	+	0	0	0	0	0
Special senses	+++	++	++	+	+	+	+	+	+	+	+	+
Neurological	+++	+++	+++	+++	+++	+++	++	++	+	+	+	+
Motor skills	+	++	++	+++	+++	+++	+++	+++	+++	++	+	+
Blood pressure/CVS	UR	UR	UR	UR	UR	+/-	+/-	++	+++	+++	+++	+++
Respiratory health	+++	+++	+++	+++	+++	+++	++	++	+++	+++	+++	+++
Metabolic/endocrine	0	0	0	0	0	0	0	0	+	++	+++	+++
Reproduction	0	0	0	0	0	0	0	0	0	+	++	+++
Learning and cognition												
Development/ cognitive function	++	++	++	++	+++	+++	+++	+++	+++	+++	++	++
Language	+	++	+++^	+++^	+++^	+++^	+++	+++	+++	+	0	0
Pre-academic skills	0	0	0	0	0	0	+	+++	++	0	0	0
Academic progress	0	0	0	0	0	0	0	0	+++	+++	+++	++¶

	Ages at assessment											
Mental Health												
Behaviour	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++
Social skills	+	+	++^	+++^	+++^	+++^	+++^	+++	+++	+++	+++	+++
Psychopathology	0	0	0	+^	+^	++^	++^	++	+++	+++	+++	+++
risk-taking behaviour	0	0	0	0	0	0	0	0	0	++	+++	+++
Quality of Life												
Daily functioning	++	++	++	++	++	++	+++	+++	+++	+++	+++	+++
Quality of life	0	0	0	0	0	0	+	++	+++	+++	+++	+++
Family												
Parents' mental health	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++
Carer-child interaction	+++	+++	+++	+++	+++	+++	+++	++	+	+	+	0
Family function	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++
Siblings	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++	+++

*0 = does not apply; + to +++ reflects relative importance; +/– = of dubious value. w weeks; m months; y years; CVS cardiovascular system; UR unreliable *prior to school entry; †1-2 years after starting school; ‡growth 12–14 years includes normal pubertal development; §overweight/obesity an ongoing issue; ¶ongoing life learning; ^relevant to early presentation of autism spectrum disorder. Shaded areas represent a suggested minimal checklist for busy clinicians.*

Table 6: Assessment tools for follow-up of high risk children recommended by Doyle et al. (2014)

Outcome	**Tool**
Feeding problems	Parent-completed questionnaire
Neurological problems, e.g. cerebral palsy	Neurological examination with particular emphasis on motor function, tone and tendon reflexes
Motor skills	Alberta Infant Motor Scale (AIMS); Neuro-Sensory Motor Development Assessment (NSMDA); motor scales of Bayley Scales of Infant and Toddler Development (BSID-3); Movement Assessment Battery for Children – Second Edition (M-ABC-2); Bruininks-Oseretsky Test of Motor Proficiency, Second Edition (BOT-2).
General development	BSID-3; Griffiths Mental Development Scales-extended/revised
Cognitive functioning	General: Wechsler scales; Stanford-Binet Intelligence Scales; Differential Ability Scales; Kaufman Assessment Battery for Children (K-ABC)

Outcome	Tool
	Specific cognitive domains: NEPSY-II; Test of Everyday Attention for Children (TEACh); Children's Memory Scale; Automated Working Memory Assessment; Delis-Kaplan Executive Function System; Behaviour Rating Inventory of Executive Function (BRIEF)
Language development	Rosetti Infant-Toddler Language Scale; MacArthur-Bates Communicative Development Inventories (CDI-II); Preschool Language Scale (PLS4); Clinical Evaluation of Language Fundamentals – Preschool (CELF-P2); Clinical Evaluation of Language Fundamentals – Fourth Edition (CELF-4); Test of Language Competence – Expanded Edition (TLC-Expanded); Comprehensive Assessment of Spoken Language (CASL)
Pre-academic skills	Subtests from the Pre-school Screening Test; Early Math Diagnostic Assessment; Early Reading Diagnostic Assessment (ERDA-II); Process Assessment of the Learner (PAL-II)
Academic skills at school age	Wechsler Individual Achievement Test (WIAT); WIAT-II Abbreviated; Wide Range Achievement Test (WRAT4); Teacher Assessment of Academic Skills
Behavioural problems	NICU Network Neurobehavioural Scale; Einstein Neonatal Neurobehavioural Assessment Scale; Infant-Toddler Social and Emotional Assessment; Child Behaviour Checklist (CBCL); Behavioural Assessment System for Children (BASC-2); Tester's Raring of Child Behaviour; Strengths and Difficulties Questionnaire (SDQ)
Mental health diagnoses	Preschool Age Psychiatric Assessment (PAPA); Development and Well-Being Assessment (DAWBA); Diagnostic Interview for Children and Adolescents (DICA-IV); Children's Interview for Psychiatric Syndromes (ChIPS); Structured Clinical Interview for DSM Disorders (SCID)
Autism screeners	Modified Checklist for Autism in Toddlers (MCHAT); Gilliam Autism Rating Scale (GARS-2); Social Communication Questionnaire (SCQ); Social Responsiveness Scale (SRS)
ADHD screeners	Brown Attention Deficit Disorder Scales for Children and Adolescents; Conners 3rd Edition (Conners 3)
Daily functioning skills	Vineland Adaptive Behaviour Scales
Well-being and self-esteem	Health Utility Index Mark; Coopersmith Self-Esteem Inventory

1 **Table 7: Follow-up for very preterm born children in the 1st year of life in Estonia (Toome et al., 2008).**

	40 pma	2 m CA	4 m CA	6 m CA	9 m CA	12 m CA
Paediatrician at FU clinic	x	x	x	x	x	x
Physiotherapist at FU clinic	x	x	x	x	x	x
Family practitioner (immunisation, prophylaxis, acute disease)		x	x	x	x	x
Child neurologist at FU clinic	By requirement (decided by paediatrician)					x

	40 pma	2 m CA	4 m CA	6 m CA	9 m CA	12 m CA
Psychologist/ Speech therapist						x
Hearing	OAE					
Vision	ROP	By requirement (decided by ophthalmologist or paediatrician)				
Hips		US	X-ray			
	Orthopaedist by requirement					

FU follow up; pma postmenstrual age; m months; CA corrected age; OAE Otoacoustic Emissions Test; ROP retinopathy of prematurity; US ultrasound

Table 8: Follow-up for very preterm born children in the 2nd year of life in Estonia (Toome et al., 2008).

	18 m CA	24 m CA
Child neurologist at FU clinic	x (if 12 m abnormal)	x (if 12 or 18 m abnormal or sent by paediatrician)
Physiotherapist	x	x
Hearing screening	x	
Clinical psychologist		x (BSID-III)
Speech therapist		x (Reynell-III)
Paediatrician at FU clinic		x

FU follow up; m months; CA corrected age; BSID-III Bayley Scales of Infant Development Third Edition

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