National Institute for Health and Care Excellence

Draft for Consultation

Specialist neonatal respiratory care for babies born preterm

[F] Evidence reviews for involving and supporting parents and carers

NICE guideline <TBC at publication>

Evidence reviews

October 2018

Draft for Consultation

These evidence reviews were developed by the National Guideline Alliance, hosted by the Royal College of Obstetricians and Gynaecologists

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Involving and supporting parents and carers

This evidence report contains information on 3 reviews relating to involving and supporting parents and carers.

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Review question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

Introduction

Preterm babies receiving respiratory support on a neonatal unit, particularly over a prolonged period, require attention to their ongoing developmental needs. While high-quality medical management and the use of specialised equipment is important for mortality and morbidity, these can also be influenced by the way in which the baby is cared for ex-utero. Attention to positioning, opportunities for contact, particularly skin to skin holding, appropriate progression of feeding and interaction all contribute to optimum neurodevelopmental outcomes. Parents are their baby's best advocates and carers, a fact that is recognised by the growing implementation of programmes and philosophies of care such as the Newborn Individualised Developmental Care and Assessment Programme (NIDCAP®) and Family Integrated Care (FIC). Staff training and education in behavioural cues is also necessary in order to support parents and optimise the effectiveness of their involvement in their baby's care, including maximising opportunities for interaction.

This review aims to explore the effectiveness of parent and carer involvement in the care of preterm babies who are receiving respiratory support and aims to identify which types of involvement can have a positive effect on factors such as length of stay, oxygen dependency and neurodevelopmental outcomes.

Summary of the protocol

See Table 1 for a summary of the population, intervention, comparison and outcome (PICO) characteristics of this review.

Table 1: Summary of the protocol (PICO table)

Population	Preterm babies receiving respiratory support: **Exclusions:** • Preterm babies with any congenital abnormalities except patent ductus arteriosus • Preterm babies who are ventilated solely due to a specific non-respiratory comorbidity, such as sepsis, necrotising enterocolitis, neurological disorders

Intervention	Parent carer involvement:
	• Kangaroo care
	• Skin to skin
	• Early parent/carer interaction
	  ○ positive touch
	  ○ comfort holding
	  ○ non-nutritive sucking
	• Family integrated care
	• NIDCAP®
	• Verbal interaction:
	  ○ reading
	  ○ singing to babies

	○ talking to babies • Involvement of parents/carers early on in feeding, including: ○ Tube feeding ○ Bottle feeding ○ Expressing ○ Breastfeeding • Specially trained healthcare professionals guiding parents/carers on their involvement in the care of their preterm babies
Comparison	Intervention versus conventional care
Outcomes	**Critical outcomes:** • Days in hospital during initial admission • Bronchopulmonary dysplasia (oxygen dependency at 36 weeks post menstrual age or 28 days of age) • Neurodevelopmental outcomes at ≥18 months: ○ Cerebral palsy (reported as presence or absence of condition, not severity of condition) ○ Neurodevelopmental delay (reported as dichotomous outcomes, not continuous outcomes such as mean change in score) - Severe (score of >2 SDs below normal on validated assessment scales, or on Bayley assessment scale of mental developmental index (MDI) or psychomotor developmental index (PDI) <70 or complete inability to assign score due to CP or severe cognitive delay) - Moderate (score of 1-2 SDs below normal on validated assessment scales, or on Bayley assessment scale of MDI or PDI 70-84) ○ Neurosensory impairment (reported as presence or absence of condition) - Severe hearing impairment (for example, deaf) - Severe visual impairment (for example, blind) **Important outcomes:** • Number of episodes of confirmed or suspected sepsis during initial hospitalisation • Mortality prior to discharge • Infant growth defined as changes in z scores at 3, 6, 12 and 24 months of age: ○ Weight ○ Height ○ Head circumference • Parent/carer satisfaction using validated scales

CP: cerebral palsy; MDI: mental development index; PDI: psychomotor developmental index; RCT: randomised controlled trial; SD: standard deviation; NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme

For full details see review protocol in appendix A.

Clinical evidence

Included studies

Sixteen publications of randomised controlled trials (RCTs) were included in this review (Als 1994, Als 2003, Als 2004, Buehler 1995, Fleisher 1995, Harding 2014, Maguire 2009a, Maguire 2009b, McAnulty 2010, McAnulty 2009, O'Brien 2018, Peters 2009, Roberts 2000, Rojas 2003, Westrup 2000, Westrup 2004).

One was a multicentre international study (O'Brien 2018), 9 were performed in the USA (Als 1994, Als 2003, Als 2004, Buehler 1995, Fleisher 1995, Harding 2014, McAnulty 2010, McAnulty 2009, Rojas 2003), 2 in Sweden (Westrup 2000, Westrup 2004), 2 in the Netherlands (Maguire 2009a, Maguire 2009b), 1 in Canada (Peters 2009) and 1 in the UK (Roberts 2000).

Two RCTs examined kangaroo care and skin to skin contact compared to conventional cuddling and traditional holding (Roberts 2000 and Rojas 2003).

One RCT examined non-nutritive sucking prior to and at onset of nasogastric tube feeding compared to no non-nutritive sucking intervention (Harding 2014).

One cluster RCT examined Family Integrated Care (FIC) compared to standard neonatal intensive care unit care (O'Brien 2018)

The remaining publications were RCTs (Als 1994, Als 2003, Als 2004, Buehler 1995, Fleisher 1995, Maguire 2009a, Maguire 2009b, Peters 2009, Westrup 2000, Westrup 2004), follow up studies at longer follow up periods (Als 1994 [McAnulty 2010]; Maguire 2009a [Maguire 2009b]) or secondary publications of additional outcomes from previously published data (Als 1994 and 2003 [McAnulty 2009]) that examined NIDCAP® compared to standard neonatal intensive care unit care.

There was no RCT or cohort study evidence for positive touch, comfort holding, verbal interaction, early feeding involvement or guided participation.

Most of the included studies reported length of hospital stay for the initial admission and some also reported bronchopulmonary dysplasia (BPD), neurodevelopmental and neurosensory outcomes, sepsis and Mortality prior to discharge. None of the included studies reported parent/carer satisfaction outcomes.

See literature search strategy in appendix B and the study selection flow chart in appendix C.

Excluded studies

Studies not included in this review, and their reasons for exclusion, are provided in appendix K

Summary of clinical studies included in the evidence review

Table 2 provides a brief summary of the included studies.

Table 2: Summary of included studies

Study	Population	Intervention/ Comparison	Outcomes	Comments
Als 2004 USA RCT	N= 30 Infants of 28^{+4} weeks to 33^{+3} GA at birth	NIDCAP® versus Standard Care Follow up at 2 weeks and 9 months corrected age	• Days in hospital duration initial admission • BPD	=<72 hours of respiratory support (ventilation or CPAP) and vasopressor medication Infants were healthier than in other Als studies

Study	Population	Intervention/ Comparison	Outcomes	Comments
Als 2003 USA RCT	N= 92 Infants with birth weight < 1250g and GA at birth < 28 weeks who had received mechanical ventilation starting within the first 3 hours after birth (which had lasted longer than 24 hours in the first 48 hours	NIDCAP® versus standard care Follow up at 2 weeks	• Days in hospital duration initial admission • BPD	Results from 3 hospitals are presented – those from Brigham Woman's Hospital are also presented by McAnulty 2009
Als 1994 USA RCT	N= 38 Infants inborn at the study site with birthweight < 1250 g and GA < 30 weeks and > 24 weeks who had received mechanical ventilation starting within the first 3 hours after birth and lasting longer than 24 hours in the first 48 hours	NIDCAP® versus standard care Follow up at 2 weeks and 9 months corrected age	• Days in hospital duration initial admission • BPD	Followed up in McAnulty 2010
Buehler 1995 USA RCT	N= 24 Infants inborn at study site with birth weight of 2500 g or less GA at birth between 30 and 34 weeks inclusive and who were not receiving mechanical	NIDCAP® versus standard care Follow up at 2 weeks	• Days in hospital duration initial admission •	

Study	Population	Intervention/ Comparison	Outcomes	Comments
	ventilation at 48 hours			
Cruz 2018 Canada, Australia and New Zealand Multicentre cluster RCT	N= 1786 Infants born at 33 weeks GA or less, who had no or low-level respiratory support. Parents needed to commit to being present for at least 6 hours/day in FIC groups.	FIC versus standard NICU care Follow up 3 weeks	• Days in hospital duration initial admission • BPD • Mortality prior to dischage	Respiratory support defined as 'oxygen by cannula or mask or non-invasive ventilation such as CPAP, biphasic CPAP and NIPAP ventilation'.
Fleisher 1995 USA RCT	N= 40 Infants with a birthweight of <1250g and GA <30 weeks at birth	NIDCAP® versus standard care Follow up prior to discharge	• Days in hospital duration initial admission • No of episodes of confirmed or suspected sepsis during intial hospitalisation	
Harding 2014 USA RCT	N= 59 Infants born at 26-35 weeks GA and were recruited from level 1 inner city neonatal unit	Non-nutritive sucking (NNS) prior to NGT feeds versus NNS on onset of NGT feeds versus normal developmental care Follow up at 6 months	• Days in hospital duration initial admission	
Maguire 2009a The Netherlands RCT	Infants born < 32 weeks GA	NIDCAP® versus standard care Follow up at 36 weeks	• Days in hospital duration initial admission • BPD • No of episodes of confirmed or suspected sepsis during intial hospitalisation • Mortality prior to discharge	
Maguire 2009b The Netherlands	Follow up of Maguire 2009a	NIDCAP® versus standard care	• Neurodevelopmental outcomes – Neurodevelopmental delay	

Study	Population	Intervention/ Comparison	Outcomes	Comments
RCT		Follow up 2 years		
McAnulty 2010 USA RCT	Follow up of AIs 1994	NIDCAP® versus standard care Follow up at 8 years corrected age	• Neurodevelopmental delay - Cerebral palsy; hearing loss	
McAnulty 2009 USA RCT	See AIs 1994 and 2003	NIDCAP® versus standard care Follow up at 2 weeks and 9 months	• Days in hospital duration initial admission • BPD • Neurodevelopmental outcomes – Neurodevelopmental delay; psychomotor delay	Synthesis of the results of three RCTs performed at Brigham's Womens Hospital, 2 of which were already reported and one of which was unreported
Peters 2009 Canada RCT	N= 120 Infants with birth weight 500 to 1250 g and of <32 weeks GA	NIDCAP® versus standard care Follow up at 18 months	• Days in hospital duration initial admission • BPD • No of episodes of confirmed or suspected sepsis during intial hospitalisation • Neurodevelopmental outcomes – Neurodevelopmental delay; cerebral palsy • Mortality prior to discharge	
Roberts 2000 UK RCT	N= 30 Premature or small for gestational age infants born at 30 or more weeks' gestation or corrected age, medically stable, and who may have received nasal	Kangaroo care versus conventional cuddling care Follow up at 6 weeks after discharge or 3 months of age; and 6 months	• Days in hospital duration initial admission	

Study	Population	Intervention/ Comparison	Outcomes	Comments
	continuous positive airway pressure in place or a nasal cannula			
Rojas 2003 UK RCT	N= 60 Infants of 32 weeks or less of gestation, birthweight 1500 g or less and who were receiving minimal ventilatory support	Skin to skin contact versus traditional holding Follow up prior to discharge	• No of episodes of confirmed or suspected sepsis during intial hospitalisation • Mortality prior to discharge	
Westrup 2004 Sweden RCT	Follow up of Westrup 2000	NIDCAP® versus control Follow up at 5 years	• Neurodevelopmental outcomes – Cerebral palsy; severe hearing impairment; severe visual impairent	
Westrup 2000 Sweden RCT	N= 25 Infants inborn at study site with GA <32 weeks and had need of ventilatory support 24 hours after birth, at least in the form of continuous positive airway pressure (CPAP)	NIDCAP® versus control Follow up at 36 weeks	• BPD • No of episodes of confirmed or suspected sepsis during intial hospitalisation • Mortality prior to discharge	

BPD: bronchopulmonary dysplasia; CP: cerebral palsy; CPAP: continuous positive airways pressure; FIC: family integrated care; GA: gestational age; MDI: mental development index; NGT: nasogastric tube; NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme; NICU: neonatal intensive care unit; NIPAP: nasal intermittent positive pressure ventilation; RCT: randomised controlled trial

See appendix D for clinical evidence tables.

Quality assessment of clinical studies included in the evidence review

See appendix F for full GRADE tables.

E Economic evidence

E.2 Existing economic evidence

No existing economic evidence on the cost effectiveness of interventions with a focus on parent carer involvement in the care of preterm babies requiring respiratory support was identified by the literature searches of the economic literature undertaken for this guideline.

E.3 Economic model

A decision analytical model was developed to assess the relative cost-effectiveness of parent/carer interventions for preterm babies requiring respiratory care. The rationale for economic modelling, the methodology adopted, the results and the conclusions from this economic analysis are described in detail in appendix J. Completed methodology checklist of guideline economic analysis is provided in appendix M. Economic evidence profile is presented in appendix I. This section provides a summary of the methods employed and the results of the guideline economic analysis.

E.3.1 Overview of methods

A decision-analytic model in the form of a simple Markov model was constructed to evaluate the relative cost-effectiveness of interventions with a focus on parent/carer involvement in the care of preterm babies requiring respiratory support. The interventions assessed were NIDCAP® (in addition to standard care) compared with standard care only. The choice of interventions assessed in the economic analysis was determined by the availability of respective clinical data included in the guideline systematic literature review. The economic analysis considered effective interventions, as demonstrated by the systematic review of clinical evidence. The study population comprised of preterm babies requiring respiratory care (<27 weeks' gestation). Clinical data were derived from 2 studies included in the guideline systematic review of clinical evidence and other published literature.

The measure of outcome in the economic analysis was the number of quality-adjusted life years (QALYs) gained. The perspective of the analysis was that of NHS and PSS. Resource use and cost data was based on the published literature and where necessary supplemented with the committee's expert opinion. National UK unit costs were used. The cost year was 2017. Two methods were employed for the analysis of input parameter data and the presentation of the results. First, a deterministic analysis was undertaken, where data were analysed as point estimates and results were presented in the form of incremental cost-effectiveness ratios (ICERs) following the principles of incremental analysis. A probabilistic analysis was subsequently performed in which most of the model input parameters were assigned probability distributions. Subsequently, 10,000 iterations were performed, each drawing random values out of the distributions fitted onto the model input parameters. Mean costs and QALYs for each treatment option were calculated by averaging across the 10,000 iterations. This approach allowed more comprehensive consideration of the uncertainty characterising the input parameters and captured the non-linearity characterising the economic model structure. Results of the probabilistic analysis were also summarised in the form of cost-effectiveness acceptability curves, which express the probability of NIDCAP® being cost-effective at various at various cost-effectiveness thresholds. Various deterministic sensitivity analyses were undertaken to test the robustness of the conclusions. Sub-group analysis was undertaken to explore the cost-effectiveness of NIDCAP® in preterm babies 27-34 weeks' gestation. Also, a secondary analysis was undertaken where the cost-effectiveness of NIDCAP® was explored using a wider public sector perspective.

Findings of the base-case economic analysis

According to deterministic analysis, from an NHS and PSS perspective in preterm babies <27 weeks' gestation NIDCAP® (in addition to standard care) was a cost-effective option with a cost per QALY of £14,380 (versus standard care) that is below the lower threshold of £20,000 per QALY. According to the deterministic sensitivity analyses, the results were sensitive to the risk ratio of neurodevelopmental problems for NIDCAP® with a potential for the ICER to increase above the threshold of £30,000 per QALY when using the upper confidence interval value for the risk ratio of neurodevelopmental problems (cognitive domain). The results were also sensitive to the utility value for moderate neurodevelopmental problems with a potential for the ICER of NIDCAP® to be above £20,000 per QALY threshold. The conclusions wree robust to changes in other model inputs including cost inputs and baseline rates.

The conclusions of the probabilistic analysis were similar to those of deterministic analysis. At the lower threshold of £20,000 per QALY (NICE, 2008b) the probability of NIDCAP® (in addition to standard care) being cost-effective was 0.673 and it increased to 0.843 at the threshold of £30,000 per QALY. NIDCAP® (in addition to standard care) became dominant in preterm babies <27 weeks' gestation from a wider public sector perspective.

The results of the sub-group analysis indicated that from an NHS and PSS perspective and also a wider public sector perspective NIDCAP® (in addition to standard care) was unlikely to be cost-effective in preterm babies >27 weeks' gestation.

A threshold analysis was undertaken which indicated that for NIDCAP® to be cost-effective in preterm babies >27 weeks' gestation at the threshold of £20,000 per QALY the public sector costs per child with neurodevelopmental problems would need to be substantially higher than expected and as a result, NIDCAP® is unlikely to be cost-effective in this sub-group of babies even from a wider public sector perspective. Although, the cost-effectiveness of NIDCAP® in preterm babies >27 weeks' gestation may be improved when condsidering a longer lifetime horizon. However, clinical and cost data was insufficient to inform such analysis.

Strengths and limitations

This analysis attempted to estimate the cost-effectiveness of NIDCAP® (in addition to standard care) in preterm babies requiring respiratory support with clinical data from the guideline systematic review. Clinical data on NIDCAP® was limited and focused only on the neurodevelopmental mental delay. However, the effectiveness of NIDCAP® in terms of reduction in neurodevelopmental mental delay was judged by the committee to be very important. Due to the lack of suitable data the NIDCAP® intervention cost was based on the committee expert opinion. Also, there was a lack of cost data in children with neurodevelopmental problems.

Clinical evidence statements

Comparison 1. Kangaroo care or skin to skin contact versus conventional care

Critical outcomes

Initial hospital admission duration

- Low quality evidence from 1 RCT (number of participants, n=30) showed that there is no clinically significant difference in initial hospital admission duration between kangaroo care and conventional cuddling care.

Bronchopulmonary dysplasia

- No evidence was found for this critical outcome.

Neurodevelopmental outcomes at ≥18 months:

- No evidence was found for this critical outcome.

Important outcomes

Sepsis

- Low quality evidence from 1 RCT (n=60) showed that there is no clinically significant difference in sepsis incidence between skin to skin contact and traditional holding.

Mortality prior to discharge

- Low quality evidence from 1 RCT (n=60) showed that there is no clinically significant difference in Mortality prior to discharge between skin to skin contact and traditional holding.

Infant growth defined as changes in z scores at 3, 6, 12 and 24 months of age

- No evidence was found for this important outcome.

Parental/ carer satisfaction using validated scales

- No evidence was found for this important outcome.

Comparison 2. Non-nutritive sucking (NNS) versus no NNS

Critical outcomes

Initial hospital admission duration

- Moderate quality evidence from 1 RCT (n=39) showed that there may be a clinically significant reduction in initial hospital admission duration with pre-nasogastric tube (NGT) feeding NNS compared to no NNS but there is uncertainty around the estimate
- Moderate quality evidence from 1 RCT (n=40) showed that there is a clinically significant reduction in initial hospital admission duration with NNS at onset of NGT feeding compared to no NNS.

Bronchopulmonary dysplasia

- No evidence was found for this critical outcome.

Neurodevelopmental outcomes at ≥18 months:

- No evidence was found for this critical outcome.

Important outcomes

Sepsis

- No evidence was found for this important outcome.

Mortality prior to discharge

- No evidence was found for this important outcome.

Infant growth defined as changes in z scores at 3, 6, 12 and 24 months of age

- No evidence was found for this important outcome.

Parental/ carer satisfaction using validated scales

- No evidence was found for this important outcome.

Comparison 3. Family Integrated Care (FIC) versus standard care

Critical outcomes

Initial hospital admission duration

- Moderate quality evidence from one cluster RCT with a low risk of bias (n=26 sites, n=1786 babies) showed a clinically significant longer initial hospital admission duration with FIC compared to standard care for preterm babies of 33 weeks gestational age or less. When the analysis was adjusted for baseline characteristics however, there was no clinically significant difference.

Bronchopulmonary dysplasia

- Low quality evidence from one cluster RCT (n=26 sites, n=1786 babies) showed that there is no clinically significant difference in bronchopulmonary dysplasia with FIC compared to standard care for preterm babies of 33 weeks gestational age or less

Neurodevelopmental outcomes at ≥18 months:

- No evidence was found for this critical outcome.

Important outcomes

Sepsis

- No evidence was found for this important outcome.

Mortality prior to discharge

- Low quality evidence from one cluster RCT (n=26 sites, n=1786 babies) showed that there is no clinically significant difference in Mortality prior to discharge with FIC compared to standard care for preterm babies of 33 weeks gestational age or less.

Infant growth defined as changes in z scores at 3, 6, 12 and 24 months of age

- No evidence was found for this important outcome.

Parental/ carer satisfaction using validated scales

- No evidence was found for this important outcome.

Comparison 4. NIDCAP® versus standard care

Critical outcomes

Initial hospital admission duration

- Low quality evidence from 8 RCTs (n=506) showed that there is no clinically significant difference in initial hospital admission duration with NIDCAP® compared to standard care for preterm babies overall.
- Very low quality evidence from 3 RCTs (n=162) showed that there is no clinically significant difference in initial hospital admission duration with NIDCAP® compared to standard care for preterm babies <28 weeks gestational age.
- Low quality evidence from 1 RCT (n=35) showed that there may be a clinically significant reduction in initial hospital admission duration with NIDCAP® compared to standard care for preterm babies <30 weeks gestational age but there is uncertainty around the estimate.
- Moderate quality evidence from 2 RCTs (n=255) showed that there is no clinically significant difference in initial hospital admission duration with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age.

- Low quality evidence from 1 RCT (n=30) showed that there is no clinically significant difference in initial hospital admission duration with NIDCAP® compared to standard care for preterm babies 28-34 weeks gestational age.
- Very low quality evidence from 1 RCT (n=24) showed that there is no clinically significant difference in initial hospital admission duration with NIDCAP® compared to standard care for preterm babies 30-34 weeks gestational age.

Bronchopulmonary dysplasia

- Very low quality evidence from 7 RCTs (n=487) showed that there may be a clinically significant reduction in bronchopulmonary dysplasia with NIDCAP® compared to standard care for preterm babies overall but there is uncertainty around the estimate.
- Low quality evidence from 3 RCTs (n=164) showed that there is no clinically significant difference in bronchopulmonary dysplasia with NIDCAP® compared to standard care for preterm babies <28 weeks gestational age.
- Very low quality evidence from 3 RCTs (n=293) showed that there is no clinically significant difference in bronchopulmonary dysplasia with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age.
- Very low quality evidence from 1 RCT (n=30) showed that there is no clinically significant difference in bronchopulmonary dysplasia with NIDCAP® compared to standard care for preterm babies 28-32 weeks gestational age.

Cerebral palsy

- Very low quality evidence from 3 RCTs (n=149) showed that there is no clinically significant difference in cerebral palsy with NIDCAP® compared to standard care for preterm babies overall
- Very low quality evidence from 1 RCT (n=22) showed that there is no clinically significant difference in cerebral palsy with NIDCAP® compared to standard care for preterm babies <28 weeks gestational age
- Very low quality evidence from 2 RCTs (n=127) showed that there is no clinically significant difference in cerebral palsy with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age

Neurodevelopmental outcomes at ≥18 months: neurodevelopmental mental delay

- Low quality evidence from 2 RCTs (n=240) showed that there is a clinically significant reduction in moderate or severe neurodevelopmental mental delay (assessed using Bayley Scales of Infant Development [BSID], MDI sub-scale, followed up at between 18 months and 2 years corrected age) with NIDCAP® compared to standard care for preterm babies
- Low quality evidence from 1 RCT (n=101) showed that there is a clinically significant reduction in severe neurodevelopmental mental delay (assessed using BSID, MDI sub-scale, followed up at 18 months) with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age
- Very low quality evidence from 1 RCT (n=139) showed that there is no difference in moderate or severe neurodevelopmental mental delay (assessed using BSID, MDI sub-scale, followed up at 2 years corrected age) with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age

Psychomotor delay

- Very low quality evidence from 1 RCT (n=139) showed that there is no clinically significant difference in moderate or severe psychomotor delay (assessed using BSID at 1 and 2 years) with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age

Severe hearing impairment

- Very low quality evidence from 3 RCTs (n=149) showed that there is no clinically significant difference in severe hearing impairment (followed up at between 18 months and 8 years corrected age) with NIDCAP® compared to standard care for preterm babies overall
- Very low quality evidence from 1 RCT (n=22) showed that there is no clinically significant difference in severe hearing impairment (followed up at 8 years corrected age) with NIDCAP® compared to standard care for preterm babies <30 weeks gestational age
- Very low quality evidence from 2 RCTs (n=127) showed that there is no clinically significant difference in severe hearing impairment (followed up at 18 months and 5 years) with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age

Severe visual impairment

- Very low quality evidence from 1 RCT (n=26) showed that there is no clinically significant difference in severe visual impairment (followed up at 5 years) with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age

Important outcomes

Sepsis

- Low quality evidence from 4 RCTs (n=329) showed that there is no clinically significant difference in sepsis incidence with NIDCAP® compared to standard care for preterm babies overall
- Very low quality evidence from 1 RCT (n=33) showed that there is no clinically significant difference in sepsis incidence with NIDCAP® compared to standard care for preterm babies <30 weeks gestational age
- Low quality evidence from 3 RCTs (n=296) showed that there is no clinically significant difference in sepsis incidence with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age

Mortality prior to discharge

- Very low quality evidence from 3 RCTs (n=309) showed that there is no clinically significant difference in Mortality prior to discharge with NIDCAP® compared to standard care for preterm babies <32 weeks gestational age.

Infant growth defined as changes in z scores at 3, 6, 12 and 24 months of age

- No evidence was found for this important outcome.

Parental/ carer satisfaction using validated scales

- No evidence was found for this important outcome.

See appendix E for Forest plots.

Economic evidence statements

- Guideline economic analysis indicated that NIDCAP® (in addition to standard care) compared with standard care is cost-effective in preterm babies <27 weeks' gestation from an NHS and PSS perspective. At the threshold of £20,000 per QALY the probability of NIDCAP® being cost-effective was 0.673 and it increased to 0.843 at the threshold of £30,000 per QALY. NIDCAP® (in addition to standard care) is unlikely to be cost-effective in preterm babies >27 weeks' gestation from NHS & PSS perspective and also from a wider public sector perspective. This evidence was directly applicable to the NICE decision-making context and was characterised by minor methodological limitations.

- No existing economic evidence on the cost-effectiveness of interventions with a focus on parent carer involvement in the care of preterm babies requiring respiratory support was available.

Recommendations

F1.1 Explain to the parents and carers of preterm babies on respiratory support that non-nutritive sucking (using a dummy):

- is beneficial during nasogastric tube feeds if the baby is awake, because it can reduce the length of the baby's hospital stay and
- can help soothe the baby between feeds.

F1.2 Consider providing the Newborn individualized developmental care and assessment program (NIDCAP®) to improve cognitive development in babies born at less than 27 weeks.

F1.3 Tell parents and carers about the benefits of using touch to communicate with their baby, for example, through skin-to-skin contact.

Research recommendations

What is the impact of parental involvement as part of Family integrated care (FIC) or the Newborn individualised developmental care and assessment programme (NIDCAP®) on the incidence of bronchopulmonary dysplasia and length of hospital stay in preterm babies?

Rationale and impact

Why the committee made the recommendations

There was good evidence that using a dummy (non-nutritive sucking) during nasogastric feeds reduces the length of the baby's hospital stay. In addition, there was some evidence that the Newborn individualized developmental care and assessment program (NIDCAP®) improved neurodevelopmental outcomes relating to cognitive development and was a cost-effective intervention in babies born at less than 27 weeks. Although the evidence for skin-to-skin contact did not show any benefit, there was no evidence of harm. There was no evidence that Family integrated care (FIC) provided any additional benefits compared to standard care.

Based on their experience and the clinical evidence, the committee recommended explaining to parents and carers about the potential benefits of interacting with their baby because early social development and relationship-forming are key to successful emotional and behavioural development.

Because of the limited evidence available on FIC and NIDCAP®, the committee made it a priority to recommend that further research be done to investigate the potential impact of NIDCAP® and FIC on length of stay and BPD.

Impact of the recommendations on practice

The committee agreed that the recommendations on non-nutritive sucking and using positive touch (such as containment holding or skin-to-skin contact) would not result in a major change in practice, but will help improve consistency in best practice.

Although there are cost implications for units to train professionals in NIDCAP®, the recommendation to consider NIDCAP® would lead to a more consistent approach across

neonatal care networks to practice linked with neurodevelopmental care. It would also improve parent access to this neurodevelopmental care.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The committee agreed that the aims of involving parents and carers in caring for preterm babies on respiratory support were to reduce the length of hospital stay and the incidence of BPD, and to improve neurodevelopmental outcomes, and the committee therefore prioritised these as critical outcomes. The committee agreed that neurodevelopmental outcomes were the most important of these because of the life-long impact on the affected baby and their parents or carers.

The committee were keen to see if there was evidence that parent and carer involvement reduced Mortality prior to discharge and rates of sepsis and so these were chosen as important outcomes. Infant growth (defined as changes in z scores for weight, height or head circumference) was prioritised as an important outcome as this would be a more immediate marker of the potential benefit of the involvement of parents and carers in a baby's care. Finally, parental satisfaction was chosen as an important outcome to determine if involvement was felt to be of benefit to the parents and carers too.

Evidence from RCTs was available for four of the interventions stipulated in the protocol - kangaroo or skin to skin care, non-nutritive sucking, FIC and NIDCAP®. Evidence was assessed using GRADE methodology.

For kangaroo care or skin to skin care no evidence was found for the critical outcomes BPD and neurodevelopmental outcome and for the important outcomes infant growth and parent/carer satisfaction.

For non-nutritive sucking no evidence was found for the critical outcomes BPD and neurodevelopmental outcome and for the important outcomes sepsis, Mortality prior to discharge, infant growth and parent/carer satisfaction.

For FIC no evidence was found for the critical outcome neurodevelopmental outcome and for the important outcomes sepsis, infant growth and parent/carer satisfaction.

For NIDCAP® no evidence was found for the important outcomes infant growth and parent/carer satisfaction.

The quality of the evidence

The quality of evidence ranged from moderate to very low. It was most often downgraded because of the uncertainty around the risk estimate or because of risk of bias introduced by a high risk of contamination across treatment groups. This was due to the fact that blinding of parents and NICU staff to treatment allocation was not feasible for the NIDCAP® intervention. There was heterogeneity within some meta-analyses. In most cases subgroup analysis according to gestational age accounted for this heterogeneity but otherwise a random effects model was used.

Meta-analysis and stratification of results by gestational age was performed for some NIDCAP® outcomes although stratification as specified in the protocol was not possible from the available data.

Due to the lack of data for some interventions and outcomes the committee made a research recommendation, prioritising the need for more evidence on the impact of Family Integrated Care and parental involvement as part of NIDCAP® on length of hospital stay and BPD.

Benefits and harms

The evidence that was included for kangaroo care and skin to skin care was limited to two small RCTs, creating uncertainty around the risk estimate for the three relevant outcomes presented. However, in combination with their own experience, the committee were aware of a large body of RCT evidence from developing world settings (mainly South America) that had established the benefits of this type of care, and of evidence from observational studies conducted in UK settings examining surrogate outcomes such as heart rate. The committee were also aware of other studies examining the mechanisms underlying the benefits of care, for example, the positive effect of kangaroo care in reducing cortisol levels and raising oxytocin levels, which aided breastfeeding and improved babies' digestion. Therefore, although some of this evidence was for a different population, and not for preterm babies receiving respiratory support in a NHS setting, the committee considered that there would be very little risk of harm associated with this practice and it would be difficult to justify a "no treatment" comparison group in further research on kangaroo or skin to skin care in preterm babies receiving respiratory care in UK hospital settings. The committee identified that in their clinical experience the only risk from kangaroo or skin to skin care was the risk of accidently extubating a baby, but that this was extremely rare. The committee therefore made a recommendation to support parents and carers by advising them about the potential benefits of interacting with their baby using practices such as skin-to-skin or kangaroo care.

Evidence from one small RCT demonstrated that there was a clinically significant reduction in length of hospital stay when non-nutritive sucking was offered at the onset of nasogastric tube feeding. The committee made a recommendation to explain the benefits of non-nutritive sucking to parents based on the evidence, the physiological rationale of feeding reinforcing the sucking reflex as these actions are simultaneous, and because they believed there would be no associated harm. However, a weak recommendation was made to consider non-nutritive sucking opportunities in between feeds if the baby showed an interest in sucking. The committee believed this might also improve feeding, but the evidence did not demonstrate a parallel reduction in length of hospital stay and the physiological rationale did not directly support a stronger recommendation.

Evidence from a large cluster randomised trial demonstrated no additional benefit with FIC compared to standard care for two critical outcomes and one important outcome. The committee discussed the limitations of the contributing study and the feasibility for and impact on parents and carers of a commitment to participate in the care of their baby for 6 hours in the neonatal unit on a daily basis. Although the committee agreed with the principles forming the basis of FIC, they chose not to make a clinical recommendation believing that these principles underlie many of the clinical recommendations made across the guideline.

NIDCAP® is an intervention comprising a detailed neurobehavioural observation of the baby with recommendations then made for individualised care and interaction based on the baby's cues of challenge or competence. This is delivered by a neonatal professional extensively trained over two years in neuro-behaviour. Whilst the evidence did not demonstrate clear benefit for most of the outcomes that were prioritised for review, there was no evidence of harm – and benefit was demonstrated for one of the componemnts of the key outcome of neurodevelopment at 18 months and subsequent follow-up, when used with infants under 27 weeks. The committee acknowledged the considerable expense of NIDCAP® training but also noted that few NIDCAP® professionals are required per unit and that being part of a NIDCAP® network or having access to a NIDCAP® professional to ensure the use of the NIDCAP® approach would have beneficial effects.

Cost effectiveness and resource use

There was no published economic evidence available for this review. The committee agreed that interventions such as skin to skin care or kangaroo care are cheap to deliver and would not require additional NHS resources.

The committee further discussed that offering parents and carers information and support is an integral part of services in most centres and any supplementary advice on the potential benefits of interacting with their baby (for example skin-to-skin care) would have only modest resource implications, if any.

The committee agreed that offering non-nutritive sucking would not require additional NHS resources.

The guideline economic analysis indicated that from an NHS & PSS perspective in preterm babies <27 weeks' gestation NIDCAP® (in addition to standard care) was a cost-effective option with a cost per QALY of £14,380 (versus standard care) that is below the threshold of £20,000 per QALY. At the threshold of £20,000 per QALY (NICE, 2008b) the probability of NIDCAP® (in addition to standard care) being cost-effective was 0.673 and it increased to 0.843 at the threshold of £30,000 per QALY. NIDCAP® (in addition to standard care) became dominant in preterm babies <27 weeks' gestation from a wider public sector perspective.

The results of the sub-group analysis indicated that from an NHS & PSS and also a wider public sector perspective NIDCAP® (in addition to standard care) was unlikely to be cost-effective in preterm babies >27 weeks' gestation. A threshold analysis indicated that the public sector cost would need to be substantially higher than expected for NIDCAP® to be cost-effective in preterm babies >27 weeks' gestation at the threshold of £20,000 per QALY.

The committee noted the additional cost of providing NIDCAP® in comparison to other developmental care approaches - the initial training is more costly. However, only a few neonatal staff within a centre would need to be trained to deliver NIDCAP®. Also, the apportioned cost of training per preterm baby is likely to be negligible. In addition, there are also important additional benefits for family members, caregivers and society as the likelihood of looking after a child with long-term developmental problems is reduced. Particularly so, since infants with neurodevelopmental problems are likely to incur higher education costs once they start school; if NIDCAP reduces neurodevelopmental mental delay, it could reduce education costs later in life.

Other factors the committee took into account

The committee considered the fact that some families found it difficult to be present on the neonatal unit every day or for long periods of time, and for these parents and carers these recommendations might be more difficult to implement, but the committee agreed that parents/carers should be encouraged to be present on the neonatal unit with their baby for as long as possible and as often as possible, depending on their individual circumstances.

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Review question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

Introduction

For parents, having a premature baby who requires respiratory support is an extremely stressful experience, and can be overwhelming. As well as being an emotionally difficult time, the practical difficulties families might face in being with, and caring for, their baby can cause additional stress and upset. Some families find it difficult to visit their baby consistently, and while many neonatal units offer some practical support to families (like overnight accommodation or help with travel costs), access to support varies between units. Needing respiratory support can also present unique challenges to parent and carers being involved in their baby's care as well. The baby's face may be covered making it more difficult to take part in certain aspects of their care because of this, for example feeding, changing or holding their baby.

This review aims to explore the different types of support that parents and carers value when their baby requires respiratory support in neonatal care. It also aims to assess how parents and carers would like to receive support, and to determine ways to improve the parent and carer experience through supporting their presence and involvement in their baby's care.

Summary of the protocol

See Table 3 for a summary of the population, intervention/context and outcome characteristics of this review.

Table 3: Summary of the protocol

Population	• Parents or carers of preterm babies who require respiratory support • Studies of parents or carers whose baby is born below 37 weeks gestation **Exclusions:** • Parents or carers of preterm babies with any congenital abnormalities other than patent ductus arteriosus • Parents or carers of preterm babies who are ventilated solely due to a specific non-respiratory comorbidity, such as sepsis, necrotising enterocolitis, neurological disorders • Quantitative data
Intervention/ context	Type of support for parents and carers with regards to preterm babies requiring respiratory support on the neonatal unit.

Outcomes	**Themes**
	Themes will be identified from the literature, but expected themes are:
	• Psychological and social support:
	  ○ Counselling
	  ○ Crisis intervention
	  ○ Emotional support
	  ○ Stress management
	  ○ Vulnerable families, safeguarding
	  ○ Support groups
	• Support from staff:
	  ○ Parental participation in decision-making, including participation in ward rounds

- Parental presence and participation in care-giving
- Hospital design and supportive spaces:
  - Facilities to support family presence in the neonatal unit e.g. comfortable reclining chairs
  - Accommodation, food
  - Parking and public transport links
  - Design of physical space that take into account infants', families', and staff members' needs
- Financial support
  - Transportation to and from hospital, parking
  - Child care

1 For full details see review protocol in appendix A.

2 Clinical evidence

3 A single search was conducted to look for systematic reviews and qualitative studies.

4 Included studies

5 15 qualitative studies were identified (Ardal 2011; Cescuti-Butler 2003; Falck 2016; Feeley
6 2013; Flacking 2016; Gibbs 2016; Guillaume 2013; Heinemann 2013; Holditch-Davis 2000;
7 Jackson 2003; MacDonald 2007; Neu 1999; Pohlman 2009; Smith 2012; Wigert 2014).

8 Two studies focused on the perspective of mothers with preterm babies requiring respiratory
9 support in the neonatal intensive care unit (NICU) (Holditch-Davis 2000; MacDonald 2007).
10 Two studies focused on the perspective of fathers with preterm babies requiring respiratory
11 support in the NICU (Feeley 2013; Pohlman 2009). 11 studies focused on the perspective of
12 parents with preterm babies requiring respiratory support in the NICU (Ardal 2011; Cescuti-
13 Butler 2003; Falck 2016; Flacking 2016; Gibbs 2016; Guillaume 2013; Heinemann 2013;
14 Jackson 2003; Neu 1999; Smith 2012; Wigert 2014).

15 The majority of included studies collected data by semi-structured interviews or unstructured
16 interviews. The most common data analysis method employed across studies was thematic
17 analysis. With regard to the setting of studies:

18 • 3 studies took place in Canada (Ardal 2011; Feeley 2013; MacDonald 2007)
19 • 1 study took place in France (Guillaume 2013)
20 • 3 studies took place in Sweden (Heinemann 2013; Jackson 2003; Wigert 2014)
21 • 2 studies took place in the UK (Cescutti-Butler 2003; Gibbs 2016)
22 • 5 studies took place in the US (Falck 2016; Holditch-Davis 2000; Neu 1999; Pohlman
23 2009; Smith 2012).

24 Risk of bias was assessed using the Cochrane checklist for qualitative studies (see methods
25 chapter). The risk of bias in the included studies ranged from low to high (3 studies with low
26 risk of bias; 6 studies with moderate risk of bias; 1 with high risk of bias).

27 See the literature search strategy in appendix B and study selection flow chart in appendix C.

28 Excluded studies

29 Studies not included in this review with reasons for their exclusions are provided in appendix
30 K.

Summary of qualitative studies included in the evidence review

2 Table 4 provides a brief summary of the included studies.

3 **Table 4: Summary of included studies**

Study details	Participants	Methods	Themes
Ardal 2011 Canada	**Study parents** Mothers, n=8 Age, median (IQR) years: 30 (27-39) **Study infants** n=9 (7 singletons, 1 set twin boys) Birth weight (mean)= 981.11g Gestational age (mean)=26.8 weeks Major diagnoses: respiratory distress syndrome, apnoea of prematurity, retinopathy of prematurity, chronic lung disease, anaemia, sepsis, feeding intolerance, intraventricular haemorrhage, patent ductus arteriosis Requiring support for breathing, n (%)= 9 (100)	**Data Collection** The study used an exploratory, qualitative design based on grounded theory. Interviews were conducted with an in-depth semi-structured interview guide with open-ended questions. Interviews conducted, transcribed, and translated by trained bilingual research assistants who were linguistically matched with the mothers. **Data Analysis** Similar themes were clustered into conceptual categories, and excerpts from the mothers' narratives were then selected by the team to illustrate the themes in each of the categories.	**Social support** -Family and friends **Parent-to-Parent support** -Shared experiences
Cescutti-Butler 2003 UK	**Study parents** Parents, n = 8	**Data Collection** Participants were interviewed by using unstructured tape-recorded interviews. **Data Analysis** Interpretations and findings were compared with the literature as the data collection and analysis progressed.	**Staff support** -Facilitating parents in participating in care -Facilitating transition into parenting role -Interpersonal relationships
Falck 2016 USA	**Study parents** Mothers, n= 6 Gestational age, weeks, mean (SD): 28.7 (6.8) **Study infants** n= 6 Gestational age, weeks, mean (SD): 29.8 (3.13) Birth weight, g, median (IQR): 770 (460-1830) On ventilator n = 6 Days on ventilator, median (IQR): 33 (6-187)	**Data Collection** Data was collected through the use of a semi-structured interview guide. Probes were utilized to obtain details and specific descriptions of participant's experiences. **Data Analysis** Concurrent data analysis occurred during data collection. Researchers coded interview transcripts and data extrapolated from medical record review concurrently with recruitment and resolved discrepancies through repeated discussions. Emerging categories	**Social support** -Counselling **Staff support** -Communication to reduce stress -Continuity of care **Hospital environment** -Need for privacy -Feelings of security or insecurity

		were used to refine interview questions and themes were generated.	
Feeley 2013 Canada	**Study parents** Fathers, n= 18 **Study infants** n= 21 Medical treatments, n (%) Mechanical ventilation/high-frequency ventilation= 15 (71.4) CPAP/HFNC= 18 (85.7) Intravenous or central line= 21 (100) Isolation= 0 (0) Chest tube= 1 (4.8) Gavage/TPN= 18 (85.7)	**Data Collection** Semi-structured interviews were conducted by a female interviewer in a private room adjacent to the NICU with no other persons present. Interviews were audio recorded and lasted between 45–90 minutes. Participants completed a demographic questionnaire, and data pertaining to the infant's condition were gathered from the medical record. **Data Analysis** The interview data were subjected to inductive content analysis. Analysis and interviews occurred concurrently. First, transcripts of the interviews were verified for accuracy, and notes recorded following the interview were inserted into the transcripts. These codes were further examined and compared between transcripts as data collection continued.	**Social support** -Friends and family -counselling -Partners **Staff support** -Facilitating transition into parenting role **Parent-to-Parent support** -Observational learning **Hospital design** -Friendly, homelike environment -Feelings of security or insecurity **Financial support**
Flacking 2016 Sweden, Finland, England	**Study parents** Swedish parents, n= 8 English parents, n= 6 Finnish parents, n= 9	**Data Collection** Parents answered an emotional closeness form. **Data Analysis** Data from completed forms was typed into word documents. Authors independently inductively analysed the data using thematic network analysis. Text segments were organised into themes. Finally, an over-arching global theme was determined.	**Social support** -Partners **Staff support** -Communication to reduce stress **Hospital environment** -Need for privacy -Participating in care
Gibbs 2016 UK	**Study parents** n=6 Mothers, n (%)= 3 (50) Fathers, n (%)= 3 (50) **Study infants** n=3 Gestational age, median (IQR)= 28^{+6} (24^{+1} to 29^{+4}) Birth weight, g, median (IQR)= 1070 (620 to 1450)	**Data Collection** The participants engaged in a semi-structured in-depth interview. All participants elected to be interviewed as couples in their home. The interviews, lasting between 60 and 90 min, were digitally recorded and transcribed verbatim the first author. **Data Analysis** Paradigmatic data analysis was conducted manually with a	**Staff support** -Facilitating parents in participating in care -Facilitating transition into parenting role -Communication to reduce stress -Interpersonal relationships

	Length of NICU stay, days, median (IQR)= 76 (62 to 117) Days on ventilation, median (IQR)= 3 (1 to 29) Days on CPAP, median (IQR)= 8 (7 to 76)	process similar to inductive content coding. The transcripts were openly code, this initial coding structure then underwent two further stages of refinement as the codes were grouped into larger categories. The summary categories developed from each interview were then compared across transcripts to identify common or recurrent experiences.	-Continuity of care **Parent-to-parent support** -Shared experiences **Hospital environment** -Participating in care
Guillaume 2013 France	**Study parents** n= 60 Fathers, n (%)= 30 (50) Age mother, years, mean (SD): 30.7 (6.6) Age father, years, mean (SD): 33.5 (6.8) **Study infants** n= 49 Female, n (%)= 29 (59) Gestational age, weeks, mean (SD)= 27 (2) Birth weight, g, mean (SD)= 965 (206) Ventilation type at time of interview, n (%) Spontaneous ventilation= 8 (16) Nasal ventilation= 30 (61) Endotracheal ventilation= 11 (22)	**Data Collection** Semi-directive interviews lasting 60-90 minutes were conducted by a social psychologist trained in research and not involved in a NICU. Audio recordings of the interviews were made. Fathers and mothers were interviewed separately. **Data Analysis** The interviews were analysed using discourse analysis. Researchers performed a horizontal analysis, with immersion and manual coding of themes, and a vertical analysis that compared themes throughout.	**Staff support** -Facilitating parents in participating in care -Facilitating transition into parenting role -Communication to reduce stress Continuity of care **Hospital environment** -Feelings of security or insecurity
Heinemann 2013 Sweden	**Study parents** Mothers, n= 7 Fathers, n= 6 **Study infants** n=7 n requiring ventilator support= 7 Gestational age at birth, weeks, median (IQR)= 25 + 4 (23 + 5 to 27 + 6) Range of birth weights, g= 492 – 1044	**Data Collection** Data was collected through interviews with parents that took place at least 1 week after the infant's transfer from a NICU room to another room in the hospital. Interviews were conducted by the first author using a conversation guide. **Data Analysis** Analysis of the data took place continuously throughout the interview period. The authors read the text and used qualitative content analysis - first they identified meaning units, secondly they condensed these units into codes and further subcategories.	**Social support** -Partners **Staff support** -Facilitating parents in participating in care -Communication to reduce stress -Interpersonal relationships **Hospital environment** -Need for privacy -Friendly, homelike environment
Holditch-Davis 2000 USA	**Study parents** Mothers, n = 31 Age, mean (SD)= 29.1 (5.4)	**Data Collection** Data was collected through semi-structured interviews in which the mother was given the chance to fully share her experiences and	**Staff support** -Communication to reduce stress -Interpersonal relationships

	Study infants Female, n= 18 Male, n= 28 Gestation at birth, weeks, mean (SD)= 30.4 (2.7) Birth weight, g, mean (SD)= 1437 (543) Mechanical ventilation, n= 27 Supplemental oxygen when off the ventilator, n= 22 Length of ventilation, days, mean (SD)= 6.7 (7.8) Length of supplemental oxygen, days, mean (SD)= 10.6 (12.7)	feelings about her infant and the NICU. Interviews lasted approximately an hour, were audiotaped, and were transcribed verbatim. **Data Analysis** Each interview was read and coded based on an a priori conceptual framework. The quotes were edited to remove identifying information and to improve clarity.	**Hospital environment** -Feelings of security or insecurity
Jackson 2003 Sweden	**Study parents** n= 7 Mother's age, years, median (IQR)= 32.5 (28-37) Father's age, years, median (IQR)= 32.5 (31-39) **Study infants** n=8 Male= 5 Female= 3 Birth weight, g, median (range)= 1467.5 (660 to 2385) Length of gestation, weeks, median (range)= 30 (25-34) Major diagnoses, n Hyperbilirubinaemia= 7 Sepsis= 3 Respiratory distress syndrome= 2 Transient tachypnoea= 4 Medical technology, n CPAP= 4 Ventilator support= 2	**Data Collection** Parents were interviewed as dyadic mother-father units (with the exception of 2 pairs who were interviewed separately). Each new interview was based on the findings from the previous interview. 30 interviews were conducted in total by one author, each one lasted between 45-90 minutes and were audiotaped and transcribed verbatim. **Data Analysis** Analysis was conducted in systematic steps, which included: reading the interview transcripts to understand the content as a whole; dividing the text into meaning units; transforming the meaning units into a nursing perspective; condensing the units into four syntheses; integrating the four themes into the structure of the phenomenon of parenthood; validating the structure by the second author	**Staff support** -Interpersonal relationships **Hospital environment** -Need for privacy **Financial support**
MacDonald 2007 Canada	**Study parents** Mothers, n= 8 Average age= 33 **Study infants** n=14 Singletons, n= 3 Twins, n=4 Triplets, n= 1 Gestational age, weeks, median (IQR)= 25 + 5 (23 + 4 to 29 +6)	**Data Collection** Interviews took place in person with open-ended questions. Responses were audio-recorded. Follow-up weekly visits were used to observe, photograph and document the mothers' interactions with their infant(s). Mothers were then asked to questions about the images. **Data Analysis**	**Social support** -Partners **Staff support** -Continuity of care **Hospital environment** -Participating in care

	Birth weight, g, median (IQR)= 718.5 (480 to 1577)	Data was analysed using the constant comparative method developed in grounded theory. The researchers developed a provisional hypothesis and then verified it by reviewing the data and clarifying with the participants to validate the researchers' interpretations. Data were then organised into recurring common themes.	
Neu 1999 USA	**Study parents** n= 9 Mothers, n= 8 Maternal age, years, mean= 25.9 Singleton birth, n= 9 First time parents, n = 4 **Study infants** n= 9 n on assisted ventilation= 9 Female, n= 6 Birth weight, g, mean (SD)= 1064 (423) Gestational age, weeks, mean (SD)= 27.2 (2.0)	**Data Collection** The research design incorporated two interviews, one conducted immediately after two skin-to-skin care session and a follow-up interview conducted several months later. The investigator or research assistant took videos lasting 8 -10 minutes as well as field notes. **Data Analysis** The investigator transcribed the open-ended telephone interviews verbatim. The researchers applied codes, which were grouped into subthemes and main themes. Content from the videotaped segments were compiled and pooled with parent/infant behavioural data from the field notes and the parent narrative to provide a more complete description of the parent's experience.	**Staff support** -Facilitating transition into parenting role **Hospital environment** -Need for privacy
Pohlman 2009 USA	**Study parents** Fathers, n= 9 Age, years, median (IQR)= 36 (22-39) **Study infants** n= 9 Gestational age, weeks, median (IQR)= 28 (25-32) Birth weight, g, median (IQR)= 933 (515-2196)	**Data Collection** Interviews were conducted every 2-3 weeks and lasted 60-90 minutes. Interviews were audio-recorded and transcribed verbatim. Interview guides were used to initiate conversation and encourage dialogue. **Data Analysis** Data was analysed using an interpretive approach, which involved a systematic and circular process including reading of the narrative text; coding; and creating interpretive files	**Social support** -Partners **Staff support** -Communication to reduce stress -Continuity of care
Smith 2012 USA	**Study parents** n=29 Parent, n (%) Mother= 20 (69) Father= 9 (31) Parental age at delivery, n (%) 18-24 y= 3 (10)	**Data Collection** One researcher conducted all interviews in person or by telephone, using the interview script and appropriate probing as needed. The in-person interviews were conducted either in the infant's room in the NICU, in one	**Social support** -Friends and family -Partners **Staff support**

	24-34 y= 10 (34) >/= 35 y= 2 (7) Missing/declined= 2 (7) **Study infants** n= 40 Infant gestational age at delivery, n (%) </= 28 wk= 15 (37) 29-33 wk= 19 (48) >/= 11 (28) Complications, n (%) Respiratory distress syndrome treated with surfactant= 29 (72) Patent ductus arteriosis treated either medically or surgically= 14 (35) Retinopathy of prematurity= 5 (13)	of the NICU parent rooms, or in a researcher's office, depending on family's preference. The interviews lasted 21 to 80 minutes, with the average being 45 minutes. All interviews were digitally recorded and transcribed. **Data Analysis** Researchers identified and organised key themes that described parental coping strategies used to handle the NICU experience and the ways that staff supported them. Authors developed a codebook, which was then refined the codebook by reviewing the remaining interviews until they had reached thematic saturation. The relevant subthemes were then organized, and freshly coded all of the interviews using the finalized codebook.	-Facilitating transition into parenting role -Interpersonal relationships **Parent-to-parent support** -Shared experiences
Wigert 2014 Sweden	**Study parents** n= 27 Fathers, n= 11 Mothers, n=16 Mother's age, mean= 33 Fathers age, mean= 34 **Study infants** n= 22 Number of days in the NICU, median (IQR)= 33 (11 to 120) Infants born prematurely, n= 17 Infants born at full term, n= 5 Mechanical ventilation, n= 13 Nasal CPAP, n= 13 RDS, n= 18 Cerebral haemorrhage or neonatal stroke, n= 8 Congenital anomaly, n= 3	**Data Collection** Open-ended interviews were conducted and recorded digitally in the parent's home. Interviews lasted between 23 and 70 minutes. **Data Analysis** The interviews were transcribed verbatim. No predetermined hypotheses or theories were used. The meanings in the text were condensed, compared and grouped in clusters, which were compared and contrasted.	**Staff support** -Facilitating parents in participating in care -Facilitating transition into parenting role -Communication to reduce stress -Interpersonal relationships -Continuity of care

1 *CPAP: continuous positive airway pressure; HFNC: high flow nasal cannula; IQR: inter-quartile range; NICU: neonatal intensive*
2 *care unit; SD: standard deviation; TPN: total parenteral nutrition*

3 See appendix D for full evidence tables and appendix N for the qualitative quotes and
4 excerpts extracted from the studies.

Quality assessment of clinical studies included in the evidence review

6 See appendix F for full GRADE-CERqual tables.

Economic evidence

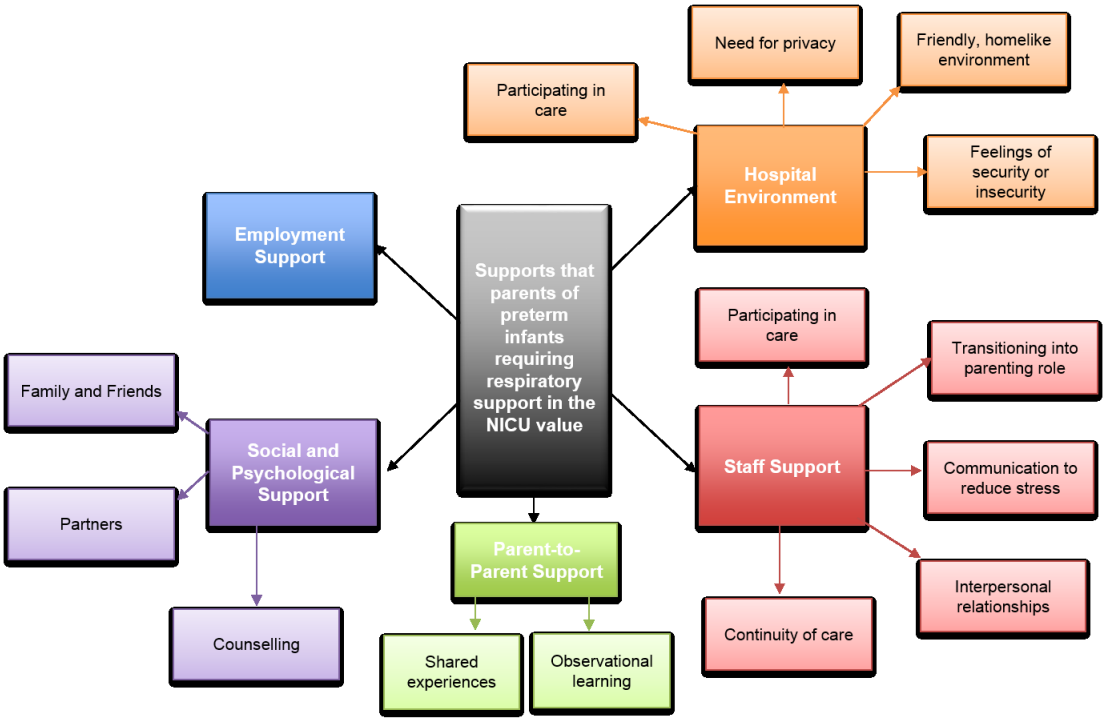
No economic evidence on the cost effectiveness of aspects of care that parents and carers value when their baby requires respiratory care was identified by the literature searches of the economic literature undertaken for this guideline.

Economic model

No economic modelling was undertaken for this review because the committee agreed that the topic was unsuitable for the economic modelling.

Qualitative evidence statements

Figure 1: Thematic map



Theme 1: Social and Psychological Support

Friends and family

- High quality evidence from 3 qualitative studies carried out among fathers and parents of preterm infants requiring respiratory support in the NICU found that practical support, including meal preparation, assistance with household tasks, and child care, from friends and family assisted the parents in involving themselves with their preterm infant in the NICU. Parents also found that family and friends who were familiar with the NICU and demonstrated empathy and understanding of the parents' anxieties reduced the stress over the burden of educating and reassuring those in the social support network who were not familiar with the situation.

Counselling

- Moderate quality evidence from 2 qualitative studies carried out among parents and fathers of preterm infants requiring respiratory support in the NICU found that an interdisciplinary NICU team with professionals who are able to provide psychological and spiritual support was valuable and some fathers utilised online chat rooms with similar parents in order to guide their involvement in their child's care.

Partners

- High quality evidence from 6 qualitative studies carried out among parents and fathers of preterm infants requiring respiratory support in the NICU found that being able to talk about the NICU experience with their partner and developing a routine around caregiving activities supported parents in coping with having their infant in the NICU.

Theme 2: Staff Support

Facilitating parents in participating in care

- High quality evidence from 5 qualitative studies carried out among parents of preterm infants requiring respiratory support in the NICU found that staff acted as gatekeepers to their participation in their infant's care. Participating in ward rounds, hearing information about their child, and caring behaviour facilitate and support parents in becoming involved with their infant's care.

Facilitating the transition into the parenting role

- High quality evidence from 7 qualitative studies carried out among parents and fathers of preterm infants requiring respiratory support in the NICU found that parents felt more confident transitioning into the parenting role when staff provided encouragement and the parents felt they had the freedom to care for their child with the staff present to help if needed. Staff who provided informal and formal training on providing care and who acted as role models that the parents could observe were also welcome supports.

Communication to reduce stress

- High quality evidence from 8 qualitative studies carried out among parents and mothers of preterm infants requiring respiratory support in the NICU found that communication with staff was crucial for developing a trusting relationship with staff and minimising parental anxiety. Elements such as using transparent communication methods to provide personalised information, family meetings to facilitate shared decision making, and regular phone updates when the parents are not in the NICU, assisted the parents and mothers to reduce stress. Parents need to feel that their beliefs and concerns are respected and that the information they receive is shared at the appropriate time and is not too medical.

Interpersonal relationships

- High quality evidence from 7 qualitative studies carried out among parents and mothers of preterm infants requiring respiratory support in the NICU found that feeling a sense of rapport with staff gave the parents both self-confidence in their parenting role and that their infant was being cared for well in the NICU. Parents found it beneficial when staff facilitated friendships with other parents and NICU graduate parents, through activities such as coffee hours or scrapbooking sessions, as enjoyed interacting with people whose child was or had been receiving the same care.

Continuity of care

- High quality evidence from 6 qualitative studies carried out among parents of preterm infants requiring respiratory support in the NICU found that having continuity in the staff caring for their infant facilitated a sense of trust and confidence in the care the nurses were providing. Parents felt that lack of consistency in care meant that staff did not always

know the infant and would have different opinions on the type of care that was needed. Parents felt supported by having a contact or designated nurse or doctor.

Theme 3: Parent-to-Parent Support

Shared experiences

- High quality evidence from 3 qualitative studies carried out among parents of preterm infants requiring respiratory support in the NICU found that having a parent-buddy who spoke the same language, was from the same ethno-cultural background, and had the same experience with an infant in the NICU enabled them to communicate their feelings and concerns and understand the preterm birth experience. Engaging with other NICU parents helped parents to cope because it provided them with information and perspective.

Observational learning

- Moderate quality evidence from 1 qualitative study carried out among fathers of preterm infants requiring respiratory support in the NICU found that being able to watch other parents in open-spaced NICUs as they cared for their own infants helped them to become more involved with their infant.

Theme 4: Hospital Environment

Need for privacy

- High quality evidence from 5 qualitative studies carried out among parents of preterm infants requiring respiratory support in the NICU found that the lack of privacy, noise, and business in the NICU prevented parents from engaging in skin-to-skin care and feeling comfortable expressing emotions.

Friendly, homelike environment

- Moderate quality evidence from 2 qualitative studies carried out among parents and fathers of preterm infants requiring respiratory support in the NICU found that allowing 24 hour visiting access and an NICU environment with décor and furniture that resembled a home environment facilitated involvement in their infant's care.

Feelings of security or insecurity

- High quality evidence from 4 qualitative studies carried out among parents, fathers, and mothers of preterm infants requiring respiratory support in the NICU found that in order to feel secure in the NICU environment they had to understand the different medical equipment and monitors. An open-room design made some mothers feel safer and more secure as they were in close proximity to medical staff.

Participating in care

- Moderate quality evidence from 3 qualitative study carried out among parents of preterm infants requiring respiratory support in the NICU found that the presence of respiratory equipment and lines in the NICU environment highlighted the severity of their infant's health condition and limited their involvement in nurturing their infant. The cultural environment of the NICU, including policies, restricted visiting hours, and prevention from joining in ward rounds, hindered parents from being able to engage with their infant.

Theme 5: Employment Support

- Low quality evidence from 2 qualitative studies carried out among parents and fathers of preterm infants requiring respiratory support in the NICU found that having employers who

provided paternity leaves enabled them to participate more in their infant's care and visit the NICU more frequently.

Economic evidence statements

- No economic evidence on the cost effectiveness of aspects of care that parents and carers value when their baby requires respiratory care was available.

Recommendations

The recommendations from this evidence review have been combined with the recommendations for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies requiring respiratory support. The recommendations are listed after the evidence review for question 6.3. The committee's discussion of the evidence in this section pertains only to the evidence and recommendations relating to 'support'.

Rationale and impact

Why the committee made the recommendations

There was good evidence that parents value emotional, psychological and practical support from staff, friends and family, peers (such as other parents of preterm babies) and employers when caring for a preterm baby receiving respiratory support. Parents also value professional support and counselling.

There was also evidence that parents value being partners in their baby's care, want to be supported by staff in caring for their baby, and need to be able to develop good communication and relationships with the staff caring for their baby.

There was evidence that parents value a comfortable, homely environment on the neonatal unit that is conducive to being involved in planning and providing care for their baby. Parents also value having 24-hour access to the neonatal unit, with private areas and privacy when needed.

Impact of the recommendations on practice

The committee agreed that the recommendations would not result in a major change in practice, but will help improve consistency in best practice.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The committee agreed that the support valued by parents or carers of preterm babies receiving respiratory support had thematic outcomes relating to social and psychological elements, parent-to-parent relationships, staff interactions, hospital environment and employment. All of these thematic outcomes were considered useful once the evidence had been appraised. These thematic outcomes reflect what service users value as the evidence was identified from interviews with parents themselves.

The committee prioritised psychological support for parents or carers of preterm babies receiving respiratory support as being of primary importance due to the large effect that poor mental health can have on both the wellbeing of the baby and the rest of the family. The

committee noted that it would have been beneficial to have had more specific evidence regarding the type of psychological support and counselling that parents valued.

The quality of the evidence

Evidence was available from 15 qualitative studies, with 2 focusing on the perspective of mothers, 2 focusing on the perspective of fathers, and 11 focusing on the perspectives of both mothers and fathers. No studies were identified that investigated the perspectives of other carers of babies receiving respiratory support. Evidence was found for all of the thematic categories identified in the protocol. The quality of the evidence in this review ranged from low to high, but the majority of the evidence was moderate to high, which meant that the committee could make strong recommendations.

The quality of evidence was most often downgraded because of methodological limitations affecting the risk of bias, inadequacy of the evidence and relevance of the findings.

Methodological limitations affecting the risk of bias were generally attributed to some studies not clearly reporting the sampling method or relationship between the researcher and participants.

The confidence of the adequacy of the evidence was downgraded in some instances as a result of data saturation not being reached. In these instances, the themes were under-developed and analysing further data would likely reveal new data and concepts.

The confidence in the relevance of the findings was downgraded due to indirectness in the study population with some babies not being preterm.

Benefits and harms

In considering the evidence presented, the committee acknowledged the principles set out in the NICE Quality Standard 4 (QS4) on Specialist Neonatal Care. Quality statement 5 of this document covers ‘Encouraging parental involvement in care’ and states ‘Parents of babies receiving specialist neonatal care are encouraged and supported to be involved in planning and providing care for their baby, and regular communication with clinical staff occurs throughout the care pathway.’

The committee noted that there was evidence that parents valued having friends and family who were informed of the realities of having a preterm baby and who provided practical support, such as meal preparation and caring for older children. There was also evidence that parents valued psychological support and counselling, and although there was no specific evidence about who should deliver this care the committee agreed that it should be a qualified professional.

There was evidence that parents wanted to be supported by staff in caring for their baby, and this again was in-line with quality statement 5. There was evidence that parents value participating in ward round discussions about their baby, help transitioning into a parenting role and being recognised as partners in their baby’s care. Parents also expressed the need for clear, consistent, timely communication, the development of good interpersonal relationships and continuity of care.

The evidence showed that parents valued having the opportunity to engage with graduate parents of preterm babies or to have parent-buddies that could help them cope and understand the experience of being a parent of a preterm baby.

Finally, there was evidence regarding the hospital environment, showing that parents valued having 24-hour access to the neonatal unit, a homely environment with comfortable furniture and that private areas to facilitate skin-to-skin care and difficult conversations were required.

Employment support (such as paternity leave) was valued by parents but recommendations were not made in this area as any recommendations would be beyond the remit of this guideline and would rely instead on the parental leave policies of parents' employers.

The evidence identified potential benefits of implementing support valued by parents or carers of preterm babies receiving respiratory support, including improving the parent's experience and family relationships and better breastfeeding rates. Although the purpose of the review was to identify support valued by parents, it was also noted that improved support to parents had a beneficial effect on staff too, with fewer staff absences. The committee noted that in some units the professionals providing support to parents also provided support to the staff.

The committee identified several potential harms associated with implementing these recommendations, including issues of confidentiality arising with parents participating in ward rounds (and who may therefore be present on the ward when other babies are being discussed), conflict between staff and parents who have been given more decision-making power and feelings of exclusion by parents who are not able to visit their baby. However, overall the committee did not think these harms were a major problem.

The committee agreed that the benefits of implementing the support valued by parents outweighed the harms. The committee noted that there are solutions to the potential harms. For example, some units already give headphones to parents to maintain confidentiality during ward rounds, and parents who are not able to visit their baby (for example mothers who are too ill to attend the neonatal unit) can still receive updates on their baby's care through phone calls from the medical team or by receiving videos or photos of their baby from nurses, although the committee recognised that this was not as good as participating in care by being present with their baby. Enabling and supporting parents to participate in their baby's care, and fostering a culture where parents are regarded as partners in their baby care, is key to reducing conflict and tension between parents and staff.

While there was evidence that parents and carers expressed the need for maintaining continuity amongst the health care professionals caring for their baby, the committee did not make a recommendation based on this evidence because they did not think that such a recommendation could be implemented given ongoing staff turnover.

Cost effectiveness and resource use

There was no economic evidence on the cost-effectiveness of aspects of care that parents and carers value when their baby requires respiratory care.

The committee expressed the view that providing psychological support for parents and carers of all babies who require respiratory support may incur additional healthcare resources (that is, the time required to provide such support and care). The committee agreed that psychological support could be provided by members of the existing healthcare team (most neonatal units will already have access to trained staff who are able to deliver this type of support), and would not always require employment of additional staff. Therefore, the committee considered the costs of providing such support and care to be modest and would be worthwhile when taking into account the potential improvement in babies' outcomes. Poor mental health in parents can have a negative effect on both the wellbeing of the baby and the rest of the family that may require more expensive later intervention.

The committee was of the view that staff support and training in providing effective support to parents and carers should already be routinely undertaken by professionals (including medical staff) working with babies requiring respiratory support and was unlikely to incur significant extra resource implications. The committee expressed the view that the cost of providing training for professionals is relatively small, taking into account that it has the

potential to significantly change the behaviour of professionals in meaningful and positive ways. For example, staff would be better placed to facilitate parents' involvement in care, to minimise parental anxiety, act as role models that the parents could observe, be better able to communicate with family and carers and to make their overall interactions more efficient when dealing with parents and carers.

The committee agreed that there was evidence that better equipped staff provide better care, may increase the potential for babies to be discharged earlier and reduce the number of staff absences. Overall, the committee was therefore of a view that well-trained staff may lead to cost savings in the NHS.

Other factors the committee took into account

The committee agreed that support should be provided in an accessible format – for example in different languages. Parents with low-literacy may struggle to participate in interventions that involve reading or writing their baby's notes or accessing other written information. The committee discussed the use of parent-buddies, particularly those that speak the same first language as the parents.

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Review question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

Introduction

Parents and carers of preterm babies who require respiratory support in a neonatal unit see their babies undergoing a range of medical procedures, investigations and treatments. This involves the use of various types of specialist equipment, for example to supply supplemental oxygen or for ventilatory support. They also meet a range of healthcare professionals with varied roles. They may encounter difficulties with caring for their baby, for example associated with the use of face masks, nasal prongs, endotracheal tubes or occasionally a tracheostomy. In general, having a preterm baby receiving respiratory support on a neonatal unit can be a major challenge for parents and carers.

This review will aim to identify information that is valued by parents (for example on equipment, prognosis, treatments, infant health and care, bonding, and parent/carer support), and in what format this information should be provided.

Summary of the protocol

See Table 5 for a summary of the population, intervention/context and outcome characteristics of this review.

Table 5: Summary of the protocol

Population	• Parents or carers of preterm babies who require respiratory support • Studies of parents or carers whose baby is born below 37 weeks gestation **Exclusions:** • Parents or carers of preterm babies with any congenital abnormalities other than patent ductus arteriosus • Parents or carers of preterm babies who are ventilated solely due to a specific non-respiratory comorbidity, such as sepsis, necrotising enterocolitis, neurological disorders • Quantitative data
Intervention/ context	Information content with regards to preterm babies who are receiving respiratory support during their stay on the neonatal unit
Outcomes	**Themes** Themes will be identified from the literature, but expected themes are: • Formats o In person - Presentations - Health care professionals - Peer support groups - Neonatal groups o Print - Pamphlets, books, magazines - Parent information binder o Online - Videos

- Webinars
- Condition-specific organisations

- Internet resources
- Technology
  - Television
  - DVD
  - Mobile applications
  - Call line
  - Audio recordings
  - Webcams
  - Baby diaries/journey boxes

- Qualities
  - Availability of different languages
  - Equality of access e.g. vision impairment
  - Timing of access
  - Frequency of accessibility. For example is a particular format really valuable, but very hard to get access to?

- Types of information
  - Clinical Information
    - Equipment
    - Prognosis
    - Participation in ward rounds
    - Risks
    - Medication
    - Medical options
    - Infant's health and care
      - Feeding and weight gain
      - Behavioural cues and developmental stages
  - Parent/carer-infant bonding information
    - Positive touch techniques, including kangaroo care (skin-to-skin contact with the baby against the parent/carer's chest) and comfort holding (cradling baby with still touch)
    - Infant care - breastfeeding, feeding, changing
    - Behavioural cues
  - Coping information
    - Support groups
    - Stress education

1 *DVD: digital video disc*

2 For full details see review protocol in appendix A.

Clinical evidence

4 A single search was conducted to look for systematic reviews and qualitative studies.

Included studies

6 Ten qualitative studies were identified (Calam 1999; Feeley 2013; Gibbs 2016; Guillaume
7 2013; Heinemann 2013; Kavanaugh 2005; Neu 1999; Pohlman 2009; Smith 2012; Wigert
8 2014).

Two studies focused on the perspective of fathers with preterm babies requiring respiratory support in the neonatal intensive care unit (NICU) (Feeley 2013; Pohlman 2009), 8 studies focused on the perspective of parents with preterm babies requiring respiratory support in the NICU (Calam 1999; Gibbs 2016; Guillaume 2013; Heinemann 2013; Kavanaugh 2005; Neu 1999; Smith 2012; Wigert 2014).

The majority of included studies collected data by semi-structured interviews or unstructured interviews. The most common data analysis method employed across studies was thematic analysis. With regard to the setting of studies:

- 3 studies took place in Canada (Feeley 2013)
- 1 study took place in France (Guillaume 2013)
- 2 studies took place in Sweden (Heinemann 2013; Wigert 2014)
- 1 study took place in the UK (Gibbs 2016)
- 4 studies took place in the US (Kavanaugh 2005; Neu 1999; Pohlman 2009; Smith 2012).

Assessment of risk of bias was completed using the Cochrane checklist for qualitative studies (see Methods chapter). The risk of bias in the included studies ranged from low to high (3 studies with low risk of bias; and 7 studies with moderate risk of bias).

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of qualitative studies included in the evidence review

Table 6 provides a brief summary of the included studies.

Table 6: Summary of included studies

Study details	Participants	Methods	Themes
Calam 1999 UK	**Study parents** Mothers, n= 76 Median age, median (IQR)= 25 (17 to 40) **Study infants** n= 76 Male, n= 44 Gestational age, weeks, median (IQR)= 28 (23-34) Birth weight, g, median (IQR)= 1185 (661-2230) Days on NICU, median (IQR)= 61 (8-251) Intracranial haemorrhage, n =34	**Data Collection** Mothers were interviewed using a semi-structured interview format 12-24 weeks after birth. Mothers also completed a Malaise Inventory to assess current emotional well-being. **Data Analysis** Data generated from interviews were categorised and coded. Researchers applied numerical codes according to the degree of recall, understanding or satisfaction to the prediction for the future and assessment of maternal mental health.	**Prenatal and Postnatal Information** -Difficulty absorbing prenatal information -Postnatal care
Feeley 2013 Canada	**Study parents** Fathers, n= 18 **Study infants** n= 21 Medical treatments, n (%)	**Data Collection** Semi-structured interviews were conducted by a female interviewer in a private room adjacent to the NICU with no other persons present. Interviews were audio	**Infant's Health Status** -Understanding the medical condition

Study details	Participants	Methods	Themes
	Mechanical ventilation/high-frequency ventilation= 15 (71.4) CPAP/HFNC= 18 (85.7) Intravenous or central line= 21 (100) Isolation= 0 (0) Chest tube= 1 (4.8) Gavage/TPN= 18 (85.7)	recorded and lasted between 45–90 minutes. Participants completed a demographic questionnaire, and data pertaining to the infant's condition were gathered from the medical record. **Data Analysis** The interview data were subjected to inductive content analysis. Analysis and interviews occurred concurrently. First, transcripts of the interviews were verified for accuracy, and notes recorded following the interview were inserted into the transcripts. These codes were further examined and compared between transcripts as data collection continued.	**Caring for the Infant** -Parenting activities **For the Future** -Decision making
Gibbs 2016 UK	**Study parents** n=6 Mothers, n (%)= 3 (50) Fathers, n (%)= 3 (50) **Study infants** n=3 Gestational age, median (IQR)= 28 + 6 (24 +1 to 29 + 4) Birth weight, g, median (IQR)= 1070 (620 to 1450) Length of NICU stay, days, median (IQR)= 76 (62 to 117) Days on ventilation, median (IQR)= 3 (1 to 29) Days on CPAP, median (IQR)= 8 (7 to 76)	**Data Collection** The participants engaged in a semi-structured in-depth interview. All participants elected to be interviewed as couples in their home. The interviews, lasting between 60 and 90 min, were digitally recorded and transcribed verbatim the first author. **Data Analysis** Paradigmatic data analysis was conducted manually with a process similar to inductive content coding. The transcripts were openly code, this initial coding structure then underwent two further stages of refinement as the codes were grouped into larger categories. The summary categories developed from each interview were then compared across transcripts to identify common or recurrent experiences.	**Infant's Health Status** -Understanding the medical condition **Caring for the Infant** -Parenting activities
Guillaume 2013 France	**Study parents** n= 60 Fathers, n (%)= 30 (50) Age mother, years, mean (SD): 30.7 (6.6) Age father, years, mean (SD): 33.5 (6.8) **Study infants** n= 49 Female, n (%)= 29 (59) Gestational age, weeks, mean (SD)= 27 (2) Birth weight, g, mean (SD)= 965 (206)	**Data Collection** Semi-directive interviews lasting 60-90 minutes were conducted by a social psychologist trained in research and not involved in a NICU. Audio recordings of the interviews were made. Fathers and mothers were interviewed separately. **Data Analysis** The interviews were analysed using discourse analysis. Researchers performed a horizontal analysis, with immersion and manual coding	**Infant's Health Status** -Receiving updates -Recall of information **Caring for the Infant** -Changes in care -Behavioural cues

Study details	Participants	Methods	Themes
	Ventilation type at time of interview, n (%) Spontaneous ventilation= 8 (16) Nasal ventilation= 30 (61) Endotracheal ventilation= 11 (22)	of themes, and a vertical analysis that compared themes throughout.	**Understanding the NICU environment** **Formats** -Telephone
Heinemann 2013 Sweden	**Study parents** Mothers, n= 7 Fathers, n= 6 **Study infants** n=7 n requiring ventilator support= 7 Gestational age at birth, weeks, median (IQR)= 25 + 4 (23 + 5 to 27 + 6) Range of birth weights, g= 492 – 1044	**Data Collection** Data was collected through interviews with parents that took place at least 1 week after the infant's transfer from a NICU room to another room in the hospital. Interviews were conducted by the first author using a conversation guide. **Data Analysis** Analysis of the data took place continuously throughout the interview period. The authors read the text and used qualitative content analysis - first they identified meaning units, secondly they condensed these units into codes and further subcategories.	**Infant's Health Status** -Recall of information **Caring for the Infant** -Parenting activities
Kavanaugh 2005 USA	**Study parents** Mothers, n= 6 Fathers, n=2 Mother's age, years, mean (SD)= 28 (5.09) Father's age, years= 21 and 31 Years of education, mean (SD)= 12.87 (1.64) **Study infants** Birth weight, g, range= 597-723 Receiving ventilatory support at the end of data collection period, n= 2	**Data Collection** Prenatal interviews were performed in person and audio-recorded and maternal and infant hospital records were reviewed. The co-investigator conducted interviews with the physicians and nurses. Parents were contacted weekly until the 25th week of gestation of the infant to ascertain life support decisions. Postnatal interviews were conducted. An end-of-life interview was conducted with the mother of the infant who died **Data Analysis** Interviews were transcribed verbatim and data from interviews were combined with medical records and demographic forms to acquire an overall picture of the participants' experiences. The Ottawa Framework was used as the organising framework for data management. Data were coded as per the framework and were compared within and across each case.	**Prenatal and Postnatal** -Inability to absorb information prenatally -Prenatal maternal and infant health -Postnatal **Caring for the infant** -Breastfeeding **For the Future** -Plans for future pregnancies -Decision making **Formats** -Nurses -Physician or neonatologist -Timing and consistency
Neu 1999 USA	**Study parents** n= 9 Mothers, n= 8 Age, mean= 25.9	**Data Collection** The research design incorporated two interviews, one conducted immediately after two skin-to-skin	**Caregiving information** -Skin to skin care

Study details	Participants	Methods	Themes
	Singleton birth, n= 9 First time parents, n = 4 **Study infants** n= 9 n on assisted ventilation= 9 Female, n= 6 Birth weight, g, mean (SD)= 1064 (423) Gestational age, weeks, mean (SD)= 27.2 (2.0)	care session and a follow-up interview conducted several months later. The investigator or research assistant took videos lasting 8 -10 minutes as well as field notes. **Data Analysis** The investigator transcribed the open-ended telephone interviews verbatim. The researchers applied codes, which were grouped into subthemes and main themes. Content from the videotaped segments were compiled and pooled with parent/infant behavioural data from the field notes and the parent narrative to provide a more complete description of the parent's experience.	
Pohlman 2009 US	**Study parents** Fathers, n= 9 Age, years, median (IQR)= 36 (22-39) **Study infants** n= 9 Gestational age, weeks, median (IQR)= 28 (25-32) Birth weight, g, median (IQR)= 933 (515-2196)	**Data Collection** Interviews were conducted every 2-3 weeks and lasted 60-90 minutes. Interviews were audio-recorded and transcribed verbatim. Interview guides were used to initiate conversation and encourage dialogue. **Data Analysis** Data was analysed using an interpretive approach, which involved a systematic and circular process including reading of the narrative text; coding; and creating interpretive files	**Caring for the Infant** -Parenting activities **Understanding the NICU Environment**
Smith 2012 USA	**Study parents** n=29 Parent, n (%) Mother= 20 (69) Father= 9 (31) Parental age at delivery, n (%) 18-24 y= 3 (10) 24-34 y= 10 (34) >/= 35 y= 2 (7) Missing/declined= 2 (7) **Study infants** n= 40 Infant gestational age at delivery, n (%) </= 28 wk= 15 (37) 29-33 wk= 19 (48) >/= 11 (28) Complications, n (%)	**Data Collection** One researcher conducted all interviews in person or by telephone, using the interview script and appropriate probing as needed. The in-person interviews were conducted either in the infant's room in the NICU, in one of the NICU parent rooms, or in a researcher's office, depending on family's preference. The interviews lasted 21 to 80 minutes, with the average being 45 minutes. All interviews were digitally recorded and transcribed. **Data Analysis** Researchers identified and organised key themes that described parental coping strategies used to handle the NICU experience and the ways that staff	**Prenatal and Postnatal Information** -Inability to absorb information prenatally **Caring for Infant** -Parenting activities **Formats** -Telephone -Medical team -Nurses -Physician or neonatologist -Timing and Consistency

Study details	Participants	Methods	Themes
	Respiratory distress syndrome treated with surfactant= 29 (72) Patent ductus arteriosis treated either medically or surgically= 14 (35) Retinopathy of prematurity= 5 (13)	supported them. Authors developed a codebook, which was then refined the codebook by reviewing the remaining interviews until they had reached thematic saturation. The relevant subthemes were then organized, and freshly coded all of the interviews using the finalized codebook.	-Other resources
Wigert 2014 Sweden	**Study parents** n= 27 Fathers, n= 11 Mothers, n=16 Mother's age, mean= 33 Fathers age, mean= 34 **Study infants** n= 22 Number of days in the NICU, median (IQR)= 33 (11 to 120) Infants born prematurely, n= 17 Infants born at full term, n= 5 Mechanical ventilation, n= 13 Nasal CPAP, n= 13 RDS, n= 18 Cerebral haemorrhage or neonatal stroke, n= 8 Congenital anomaly, n= 3	**Data Collection** Open-ended interviews were conducted and recorded digitally in the parent's home. Interviews lasted between 23 and 70 minutes. **Data Analysis** The interviews were transcribed verbatim. No predetermined hypotheses or theories were used. The meanings in the text were condensed, compared and grouped in clusters, which were compared and contrasted.	**Prenatal and Postnatal Information** -Postnatal **Understanding the Infant's Health Status** -Understanding the medical condition **Caring for the Infant** -Parenting activities

CPAP: continuous positive airway pressure; g: grams; HFNC: high flow nasal cannula; IQR: inter-quartile range; NICU: neonatal intensive care unit; RDS: respiratory distress syndrome; SD: standard deviation; TPN: total parenteral nutrition; y: years

See appendix D for full evidence tables and appendix N for the qualitative quotes and excerpts extracted from the studies.

Quality assessment of clinical studies included in the evidence review

See appendix F for full GRADE-CERqual tables.

Economic evidence

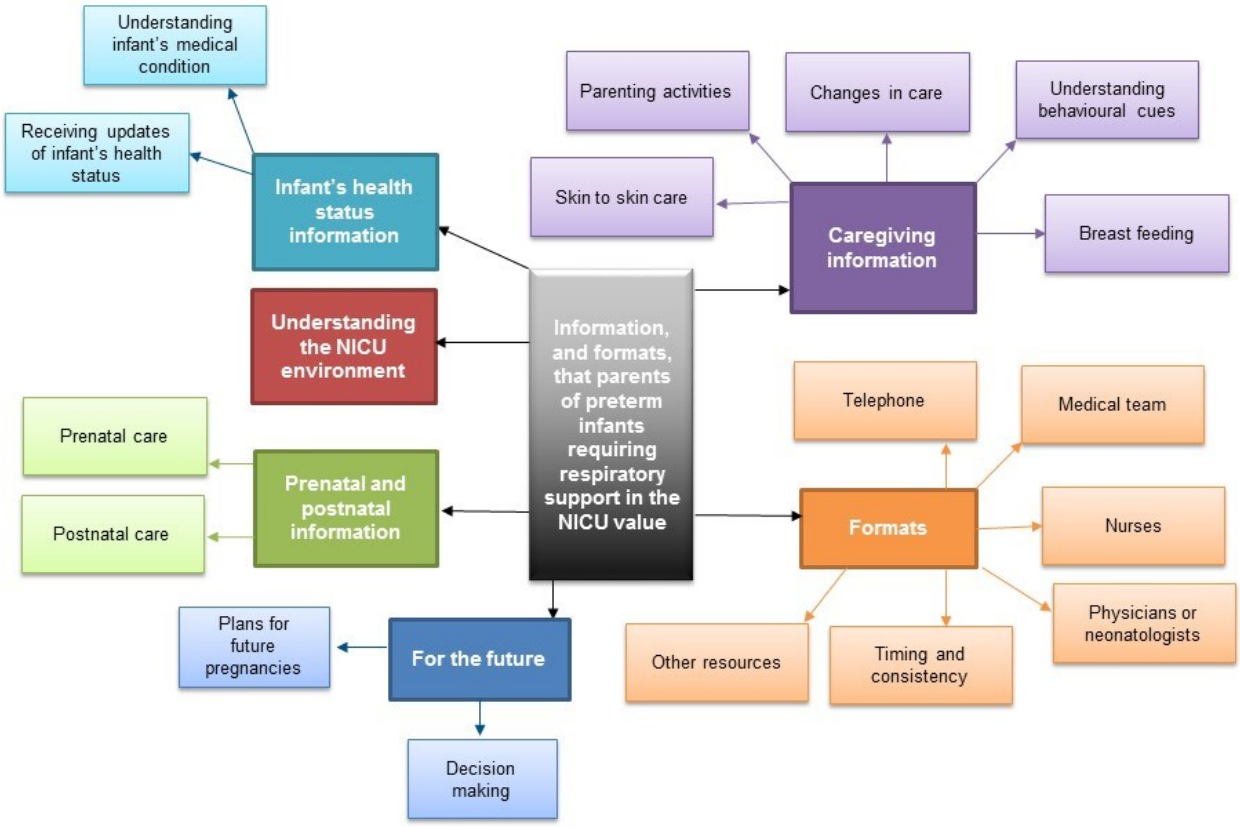
No economic evidence on the cost effectiveness of information provision to parents and carers of preterm babies requiring respiratory support was identified by the literature searches of the economic literature undertaken for this review.

Economic model

No economic modelling was undertaken for this review because the committee agreed that this topic was not suitable for de-novo economic modelling.

Qualitative evidence statements

Figure 2: Thematic map



Theme 1. Prenatal and postnatal information

Prenatal maternal and infant health

- Low quality evidence from 1 qualitative study carried out among parents of preterm infants requiring respiratory support in the NICU found that parents were given information, including morbidity and mortality for preterm infants born at different gestational ages. However, parents wanted more specific information on the treatments their infants would likely need after delivery.

Postnatal information

- Low quality evidence from 3 qualitative studies carried out among parents of preterm infants requiring respiratory support in the NICU found that staff provided the most information at the beginning of the infant's hospitalisation, but parents would have liked a delayed postnatal review of what happened prenatally and during the birth, as many mothers were still recovering from the birth when they received the majority of the information.

Theme 2. Infant's health status information

Understanding the infant's medical condition

- High quality evidence from 3 qualitative studies carried out among fathers and parents of preterm infants requiring respiratory support in the NICU found that understanding their infant's medical condition and care was crucial. However, parents found that staff did not always fully explain complex medical issues or would leave parents waiting for information about their infant's illness, which caused them anxiety.

Receiving updates of the infant's health status

- High quality evidence from 1 qualitative study carried out among parents of preterm infants requiring respiratory support in the NICU found that parents appreciated receiving clear information about their infant's health status immediately after exam results or tests. Mothers did not like when they had to receive information from their husbands and would have preferred to receive updates from a physician.

Theme 3: Caregiving information

Parenting activities

- High quality evidence from 6 qualitative studies carried out among parents and fathers of preterm infants requiring respiratory support in the NICU found that nurses were crucial in providing information in regards to caregiving practices, such as feeding and nappy changes. Informal and formal training provided by patient staff assisted parents in developing the confidence to participate in their child's care.

Changes in care

- Moderate quality evidence from 1 qualitative study carried out among parents of preterm infants requiring respiratory support in the NICU found that parents insisted on receiving information in regards to changes in the infant's medical treatment, such as changes in intubation, catheter, and location in the hospital. Parents preferred to receive this information from the neonatologist as opposed to the nurse.

Understanding behavioural cues

- Moderate quality evidence from 1 qualitative study carried out parents of preterm infants requiring respiratory support in the NICU found that mothers, more often than fathers, wanted explanations of the infant's reactions and behaviours.

Breast feeding

- Low quality evidence from 1 qualitative study carried out among parents of preterm infants requiring respiratory support in the NICU found that mothers perceived information provided in breast-feeding programs as useful, as it helped them make decisions in regards to feeding their infant.

Skin to skin care

- Moderate quality evidence from 1 qualitative study carried out among parents of preterm infants requiring respiratory support in the NICU found that parents were reluctant and lacked confidence to engage in skin to skin care when nurses did not provide them with information on how to hold and transfer the infant without dislodging tubes and ventilator equipment.

Theme 4: Future information

Plans to have children in the future

- Low quality evidence from 1 qualitative study carried out among parents of preterm infants requiring respiratory support in the NICU found that one mother whose infant had died wanted more information on the cause of death and advice for pregnancies in the future. Mothers who knew someone who had an extremely premature infant who survived found that this information gave them hope for their child.

Decision making

- Low evidence from 2 qualitative studies carried out among fathers and parents of preterm infants requiring respiratory support in the NICU found that staff sharing information and providing opportunities to ask questions facilitated parents becoming involved in decision-making about the infant's care. Adequate and clear information enabled parents to feel confident when physicians asked them to make a decision about their infant's care.

Theme 5: Neonatal unit environment information

- Moderate quality evidence from 2 qualitative studies carried out among parents and fathers of preterm infants requiring respiratory support in the NICU found that having regular explanations of the medical equipment, upper and lower limits of monitors and the meaning of different alarms and buzzers would prevent frightening experiences and feelings of helplessness.

Theme 6: Information formats

Telephone

- Moderate quality evidence from 2 qualitative studies carried out among parents of preterm infants requiring respiratory support in the NICU found that regular and ritualised phone calls were appreciated. Parents reported feeling reassured and linked to their child by receiving regular phone calls when they were at home and the infant was still in the neonatal unit. In contrast, receiving routine information at home through an unexpected phone call caused alarm, as it was assumed that an unplanned call was linked to bad news.

Medical team (member not specified)

- Moderate quality evidence from 2 qualitative studies study carried out among parents and fathers of preterm infants requiring respiratory support in the NICU found that information should be shared by staff members who are adequately trained to provide tailored medical information that is tailored to their emotional needs and technical knowledge and who provide parents with the opportunity to ask questions and recommend additional resources.

Nurses

- Low quality evidence from 2 qualitative studies carried out among parents and mothers of preterm infants requiring respiratory support in the NICU found that nurses assisted parents in understanding complex medical concepts and reduced feelings of anxiety. Due to nurses' regular interactions with the infant, parents felt that primary nurses were most adept at providing day-to-day information and was the best source of information about changes in their baby's medical condition.

Physicians or neonatologists

- Low quality evidence from 2 qualitative studies carried out among parents and mothers of preterm infants requiring respiratory support in the NICU found that the neonatologist was

the preferred source of information for technical or complex information, even if parents required additional explanations from nurses afterwards. Physicians should provide as much information as is required to convey the complexities of the situation and allow the parents to ask as many questions as needed.

Timing and consistency

- High quality evidence from 4 qualitative studies carried out among parents of preterm infants requiring respiratory support in the NICU found that parents, especially mothers, struggled to absorb and understand information that was shared with them during prenatal consultations when they learned their infant would be premature. Many parents were overwhelmed by the amount of information they received during this emotional experience, which later prevented them from being able to recall information. Parents stated that their preferred time to receive information would be during clinical rounds as opposed to during the prenatal consultation, immediately after delivery or before discharge. Parents would be interested in receiving information at a time separate from rounds. Additionally, it is crucial for parents to receive honest information that is shared consistently by all the members of the care team to avoid having parents receive confusing and varying messages.

Other resources (including books, internet resources, friends and family)

- Moderate quality evidence from 1 qualitative study carried out among parents of preterm infants requiring respiratory support in the NICU found that the majority of parents received information from staff and the medical care team, although sources such as printed materials, friends and family or the internet were also consulted.

Economic evidence statements

- No economic evidence on the cost effectiveness of information provision to parents and carers of preterm babies requiring respiratory support was available.

Recommendations

The recommendations from this evidence review have been combined with the recommendations for Question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support. The combined recommendations from these 2 reviews are given below. The committee's discussion of the evidence in this section pertains only to the evidence relating to 'information'.

Supporting parents and carers while their preterm baby is on respiratory support

F2.1 Recognise parents and carers as partners in their baby's care, and support them in this role.

F2.2 Encourage and support parents and carers to:

- be involved in planning and providing their baby's day-to-day care, for example, feeding and nappy changing
- participate in discussions and decisions about their baby during ward rounds, providing input into planning and providing care.

F2.3 Provide regular opportunities and time for parents and carers to discuss their baby's care, ask questions about the information they have been given and discuss concerns.

F2.4 Give parents and carers the time, support and encouragement they need to become confident in caring effectively for their baby.

F2.5 Offer parents and carers psychological support from a professional who is trained to deliver this type of help and advice.

Providing information to parents and carers while their preterm baby is on respiratory support

F2.6 Ask parents and carers about how and when they would like to receive information about their baby's treatment and progress.

F2.7 Support discussions with parents and carers using written information. Ensure that information is up to date, relevant, appropriate to the parents' and carers' needs and preferences, and consistent between healthcare professionals. For more guidance on communication (ncluding different formats and languages),providing information, and shared decision-making see the NICE guideline on patient experience in adult NHS services.

F2.8 Ensure that information for parents and carers is delivered by an appropriate healthcare professional, and information for hospitalised mothers who cannot visit their baby is delivered by a senior healthcare professional, for example, a neonatologist or specialist registrar, face-to-face whenever possible.

F2.9 Be sensitive about the timing of discussions with parents and carers. In particular, discuss significant perinatal events without delay, providing the mother has sufficiently recovered from the birth.

F2.10 Provide information for parents and carers that includes:

- explanations and regular updates about their baby's condition and treatment, especially if there are any changes
- what happens in the neonatal unit, and the equipment being used to support their baby
- what respiratory support is being provided for their baby
- how to get involved in their baby's day-to-day care, interact with their baby and interpret the baby's neurobehavioural cues
- the roles and responsibilities of different members of their baby's healthcare team, and key contacts
- information about caring for a premature baby to share with family and friends, and practical suggestions about how to get help and support from family and friends
- opportunities for peer support from neonatal unit graduate parents or parent buddies
- details of local support groups, online forums and national charities, and how to get in touch with them.

Neonatal services for preterm babies on respiratory support

F2.11 Those responsible for planning and delivering neonatal services should ensure that neonatal units:

- are welcoming and friendly
- foster positive and supportive relationships by providing parents and carers with 24-hour access to their baby
- provide privacy for skin-to-skin contact and feeding
- have private areas for difficult conversations
- have comfortable furniture and provide a relaxing environment for families.

F2.12 Ensure that healthcare professionals in neonatal units can support parents and carers by being competent in:

- communicating complex and sensitive information clearly
- tailoring information and support to the person's individual needs and circumstances.

Rationale and impact

Why the committee made the recommendations

There was good evidence that parents and carers value high-quality, relevant, consistent information about their baby's health and care, including regular updates on their baby's progress. Parents and carers value information that is appropriate for their needs and explained clearly to them, and value the opportunity to ask questions. There was evidence that the appropriate timing of information is important to parents. The evidence also showed that parents and carers prefer information to be provided by an appropriate healthcare professional, and for it to be backed up by written information.

Parents value information on a range of topics, including how to interpret their baby's neurobehavioural cues, breastfeeding, skin-to-skin contact, the medical equipment used, who to contact, and other sources of information they could access themselves.

There was evidence that parents and carers value having 24-hour access to the neonatal unit, which should be a homely environment with comfortable furniture and private areas. In a number of the support and information themes, parents and carers agreed that healthcare professionals who provide information and support should be trained and competent in this, so the committee made an overarching recommendation.

Impact of the recommendations on practice

The committee agreed that the recommendations would not result in a major change in practice, but will help improve consistency in best practice.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The committee agreed that the information valued by parents or carers of preterm babies receiving respiratory support had thematic outcomes relating to prenatal and postnatal information, caregiving information, information about the baby's health status, information for the future and understanding the neonatal unit environment. In addition, the committee agreed that it was important to know the preferred format of this information. All of these thematic outcomes were considered useful once the evidence had been appraised. These thematic outcomes reflect what service users value, as the evidence was identified from interviews with parents themselves.

The committee prioritised the consistency, clarity and timely nature of information, as the evidence highlighted the importance of the adequate pacing of information, regardless of the type of information.

The committee noted that there was no evidence on formats of information using modern technology, such as apps, online resources or Facebook groups that many parents may utilise. However it was decided this was not a priority for a research recommendation.

The quality of the evidence

Evidence was available from 10 qualitative studies, with 2 focusing on the perspective of fathers, and 8 focusing on the perspectives of both mothers and fathers. No studies investigated the perspective of other caregivers responsible for babies requiring respiratory support. Evidence was not found for all of the thematic categories identified in the protocol, specifically formats including print, online resources or technology. The quality of the evidence in this review ranged from low to high, but the majority of the evidence was moderate to high, which meant that the committee could make strong recommendations.

The quality of evidence was most often downgraded because of methodological limitations affecting the risk of bias, inadequacy of the evidence, and relevance of the findings.

Methodological limitations affecting the risk of bias were generally attributed to some studies not clearly reporting the sampling method or relationship between the researcher and participants.

The confidence of the adequacy of the evidence was downgraded in some instances as a result of data saturation not being reached. In these instances, the themes were under-developed and analysing further data would likely reveal new data and concepts.

The confidence in the relevance of the findings was downgraded due to indirectness in the study population with some babies not being preterm.

Benefits and harms

The evidence showed that parents valued information on prenatal health issues (for both mother and baby) which included the likely morbidity and mortality at different gestational ages. However, parents had difficulty understanding some information about their baby's prognosis and the birth of the baby if information was provided immediately after stressful events or if it was not given in a clear manner. The timing of information giving was therefore important, with some parents wanting it deferred in such circumstances.

Parents valued information about their baby's medical condition and their medical care, and this should be provided in a timely fashion and delayed only where circumstances demanded it.

Parents valued information about how to care for their baby, as well as how to interpret their baby's behavioural cues. Parents also valued information on breastfeeding and on providing skin-to-skin contact as part of the baby's care, and information from the nurses on these areas greatly increased their confidence and willingness to be involved in their baby's care. Parents valued receiving information that was tailored to their needs and that was delivered by the appropriate member of staff, with some parents valuing more technical information about changes in care coming from medical staff rather than nursing staff. Parents valued consistent information, and the committee agreed that it was important that whoever was delivering the information (nurse, doctor or other healthcare professional) should deliver it clearly and check for the parents' understanding, and not rely on the information having to be re-explained by another member of the team later. Staff should however be aware that it may take time for parents to absorb information and they may require repeated encouragement before becoming confident in caring for their baby with reduced input from staff. The evidence also described how having an understanding of the medical equipment (for example, its purposes, and what alarms and buzzers meant) and being able to ask questions regarding their baby's health and care enabled parents to become comfortable caring for their baby.

Parents valued information regarding the future (such as hereditary issues) and having sufficient information to be involved in decision-making.

The evidence addressed the importance parents placed on the format, timing and consistency of information provided, and the committee discussed the need for the medical and nursing teams to agree with parents the method of delivery and frequency of information. The evidence demonstrated that parents value information that is consistent between healthcare professionals so as to avoid confusion and mistrust.

Due to the complexity of medical information, the committee agreed that information shared with parents and carers should where appropriate be followed-up by high-quality written and online resources, and that parents are aware of key contacts on the neonatal unit.

The committee agreed that the potential benefits of the recommendations would include more accurate and consistent information, enabling parents and carers to feel more confident and improving relationships between staff and parents/carers.

The committee did not identify any harms related to these recommendations.

The committee discussed the value placed by parents on information for the future (such as hereditary issues) but did not make any recommendations as they felt this may require specialist information provision, would be on a case-by-case basis, and did not apply to the majority of babies requiring respiratory support.

Cost effectiveness and resource use

There was no economic evidence on the cost-effectiveness of information provision to parents and carers of preterm babies requiring respiratory support.

However, the committee noted that there would be costs associated with implementing these recommendations, including costs in terms of the time needed to share information and the costs of translating or interpreting information that needed to be provided in languages other than English.

The committee expressed the view that providing prenatal and postnatal information, caregiving information, infant's health status information and making sure that neonatal unit environment is supportive and friendly are integral parts of most services and providing such supplementary advice would have only modest resource implications, if any, which are justifiable as these principles and factors are deemed essential in ensuring the success of care in preterm babies requiring respiratory care.

Similarly, the committee was of the view that staff training in providing effective support to parents and carers should be routinely undertaken by professionals (including medical staff) working with babies requiring respiratory support and would not incur significant extra resource implications. The committee expressed the view that the cost of providing training of professionals is relatively small, taking into account that it has the potential to significantly change the behaviour of professionals in meaningful and positive ways (for example, being better placed to facilitate parents' involvement in care and minimising parental anxiety, acting as role models that the parents could observe, better ability to communicate with family and carers and the potential to reduce their burden) and make their overall interactions more efficient when dealing with parents and carers. Overall, the committee considered that such staff training is expected to lead to savings to the NHS.

Other factors the committee took into account

The committee agreed that information should be available in different languages and that print materials should be easily readable and accessible to parents with lower levels of literacy.

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Appendices

Appendix A – Review protocols

Review protocol for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

Field (based on PRISMA-P	Content
Review question in SCOPE	What involvement do parents, carers and family members value in the care of babies who are receiving respiratory support?
Review question in guideline	What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?
Type of review question	Intervention
Objective of the review	To determine the impact of parent and carer involvement on short and long- term outcomes for preterm babies receiving respiratory support such as comfort, feeding, and neurodevelopmental outcomes.
Eligibility criteria – population/disease/condition/issue/domain	Preterm babies receiving respiratory support Exclusions: • Preterm babies with any congenital abnormalities excluding patent ductus arteriosus • Preterm babies who are ventilated solely due to a specific non-respiratory comorbidity, such as sepsis, NEC, neurological disorders • RCTs with <15 participants in each arm will not routinely be included. Consideration will be given to their inclusion if the evidence from larger RCTs is judged not to be sufficient – in quality or quantity. • Studies where >2/3 of preterm babies receive respiratory support will be included in the review

Field (based on PRISMA-P	Content
	• RCTs with <15 participants in each arm was chosen as a minimum number in order for an analysis that is based on normal distribution (e.g. t-test) to be reasonably valid.
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Parent carer involvement: 1) Kangaroo Care 2) Skin to skin 3) Early parent/carer interaction - positive touch - comfort holding - non-nutritive sucking 4) Family integrated care 5) NIDCAP® (Newborn Individualised Developmental Care and Assessment Programme) 6) Verbal Interaction: - reading - singing to babies - talking to babies 7) Involvement of parents/carers early on in feeding e.g. - Tube feeding - Bottle feeding - Expressing - Breastfeeding 8) Specially trained healthcare professionals in guiding parents/carers on their involvement in the care of their preterm babies
Eligibility criteria – comparator(s)/control or reference (gold) standard	Comparisons: Intervention versus conventional care

Field (based on PRISMA-P	Content

Outcomes and prioritisation	Critical outcomes:
	• Days in hospital during initial admission
	• Bronchopulmonary dysplasia (oxygen dependency at 36 weeks post menstrual age or 28 days of age)
	• Neurodevelopmental outcomes at >18 months:
	  ○ Cerebral palsy (reported as presence or absence of condition, not severity of condition)
	  ○ Neurodevelopmental delay (reported as dichotomous outcomes, not continuous outcomes such as mean change in score)
	  ○ Severe (score of >2 SD below normal on validated assessment scales, or on Bayleys assessment scale of mental developmental index (MDI) or psychomotor developmental index (PDI) <70 or complete inability to assign score due to CP or severe cognitive delay)
	  ○ Moderate (score of 1-2 SD below normal on validated assessment scales, or on Bayleys assessment scale of MDI or PDI 70-84)
	  ○ Neurosensory impairment (reported as presence or absence of condition)
	  ○ Severe hearing impairment (e.g deaf)
	  ○ Severe visual impairment (e.g blind)
	Important outcomes:
	• Number of episodes of confirmed or suspected sepsis during initial hospitalisation
	• Mortality prior to discharge
	• Infant growth defined as changes in z scores for at 3, 6, 12 and 24 months of age:
	  ○ Weight

Field (based on PRISMA-P	Content
	○ Height ○ Head circumference • Parental/ carer satisfaction using validated scales
Eligibility criteria – study design	Systematic reviews of RCTs RCTs If insufficient RCTs: prospective cohort studies If insufficient prospective cohort studies: retrospective cohort studies
Other inclusion exclusion criteria	Inclusion: English language Developed countries with a neonatal care system similar to the UK (e.g. OECD countries) Studies conducted post 1990
Proposed sensitivity/sub-group analysis, or meta-regression	Stratified analyses based on the following sub-groups: Gestational age: <26+6 weeks 27-31+6 weeks 32-36+6 weeks A sensitivity analysis will be conducted if there is sufficient heterogeneity in the analyses.
Selection process – duplicate screening/selection/analysis	Sifting, data extraction, appraisal of methodological quality and GRADE assessment will be performed by the systematic reviewer. Resolution of any disputes will be with the senior systematic reviewer and the Topic Advisor. Quality control will be performed by the senior systematic reviewer. Dual sifting and data extraction will not be undertaken for this question.
Data management (software)	Pairwise meta-analyses will be performed using Cochrane Review Manager (RevMan5).

Field (based on PRISMA-P	Content
	'GRADEpro' will be used to assess the quality of evidence for each outcome. NGA STAR software will be used for study sifting, data extraction, recording quality assessment using checklists and generating bibliographies/citations.
Information sources – databases and dates	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase Limits (e.g. date, study design): Apply standard animal/non-English language exclusion Limit to RCTs and systematic reviews in first instance but download all results Dates: from 1990 Studies conducted post 1990 will be considered for this review question, as the GC felt that significant advances have occurred in ante-natal and post-natal respiratory management since this time period and outcomes for preterm babies prior to 1990 are not the same as post 1990.
Identify if an update	Not an update
Author contacts	Developer: NGA
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual
Search strategy	For details please see appendix B
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) or H (economic evidence tables).
Data items – define all variables to be collected	For details please see evidence tables in appendix D (clinical evidence tables) or H (economic evidence tables).
Methods for assessing bias at outcome/study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual Appraisal of methodological quality:

Field (based on PRISMA-P	Content
	The methodological quality of each study will be assessed using an appropriate checklist: • AMSTAR for systematic reviews • Cochrane risk of bias tool for RCTs • Cochrane risk of bias tool for non-randomised studies The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/
Criteria for quantitative synthesis (where suitable)	For details please see section 6.4 of Developing NICE guidelines: the manual
Methods for analysis – combining studies and exploring (in)consistency	The quality of the evidence for an outcome (i.e. across studies) will be assessed using GRADE. Synthesis of data: Pairwise meta-analysis will be conducted where appropriate When meta-analysing continuous data, final and change scores will be pooled and if any studies reports both, the method used in the majority of studies will be analysed. Inconsistency: Inconsistency in pairwise meta-analyses will be assessed through the I2 statistic and through visual analysis of the forest plot generated. A sensitivity analysis will be conducted where significant heterogeneity is identified. Minimally important differences: Default values will be used of: 0.8 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes from mean baseline for both groups, unless more appropriate values are identified by the guideline committee or in the literature. Mortality – any change (statistically significant)

Field (based on PRISMA-P	Content
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual. If sufficient relevant RCT evidence is available, publication bias will be explored using RevMan software to examine funnel plots. Trial registries will be examined to identify missing evidence: Clinical trials.gov, NIHR Clinical Trials Gateway
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual
Rationale/context – Current management	For details please see the introduction to the evidence review in the full guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by The National Guideline Alliance and chaired by Dr Janet Rennie in line with section 3 of Developing NICE guidelines: the manual. Staff from The National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the full guideline.
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds The National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England
PROSPERO registration number	Not registered

Review protocol for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

Field (based on PRISMA-P	Content
Review question in SCOPE	What are the benefits and risks of involving parents, carers and family members in the care of babies who are receiving respiratory support?
Review question in guideline	What support is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?
Type of review question	Qualitative
Objective of the review	To determine what support is valued by parents and carers of preterm babies who are receiving respiratory support in the neonatal unit. Three objectives have been set up: 1. Explore the areas of support that would benefit parents and carers of preterm babies who are receiving respiratory support on the neonatal unit and assess the means through which parents and carers would like to receive support 2. Explore the areas of support that parents and carers have found acceptable and effective 3. Determine ways to improve parent and carers' experience of having a baby who is receiving respiratory support through supporting their presence and involvement in their baby's care during their stay on the neonatal unit
Eligibility criteria – population/disease/condition/issue/domain	Inclusions: • Parents or carers of preterm babies who require respiratory support • Studies of parents or carers whose baby is born below 37 weeks gestation Exclusions:

Field (based on PRISMA-P	Content
	• Parents or carers of preterm babies with any congenital abnormalities excluding PDA • Parents or carers of preterm babies who are ventilated solely due to a specific non-respiratory comorbidity, such as sepsis, NEC, neurological disorders • Studies where >2/3 of preterm babies receive respiratory support will be included in the review • Quantitative data
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Context: Type of support for parents and carers with regards to preterm babies requiring respiratory support on the neonatal unit.
Eligibility criteria – comparator(s)/control or reference (gold) standard	N/A

Outcomes and prioritisation	**Themes**
	Themes will be identified from the literature, but expected themes are:
	• Psychological and Social support:
	  ○ Counselling
	  ○ Crisis intervention
	  ○ Emotional support
	  ○ Stress management
	  ○ Vulnerable families, safeguarding
	  ○ Support groups
	• Support from staff:
	  ○ Parental participation in decision-making, including participation in ward rounds
	  ○ Parental presence and participation in care-giving
	• Hospital design and supportive spaces:

Field (based on PRISMA-P	Content
	○ Facilities to support family presence in the neonatal unit e.g. comfortable reclining chairs ○ Accommodation, food ○ Parking and public transport links ○ Design of physical space that take into account infants', families', and staff members' needs • Financial support ○ Transportation to and from hospital, parking ○ Child care
Eligibility criteria – study design	Qualitative methods: Semi-structured and structured interviews, focus groups, observations Quantitative designs: Surveys (from which only qualitative data will be included)
Other inclusion exclusion criteria	Inclusion: • English language • Developed countries with a neonatal care system similar to the UK (e.g. OECD countries) • Studies conducted post 1990
Proposed sensitivity/sub-group analysis, or meta-regression	Stratified analyses based on the following sub-groups: Gestational age: • <26+6 weeks • 27-31+6 weeks • 32-36+6 weeks
Selection process – duplicate screening/selection/analysis	Sifting, data extraction, appraisal of methodological quality and GRADE-CERQual assessment will be performed by the systematic reviewer. Resolution of any disputes will be with the senior

Field (based on PRISMA-P	Content
	systematic reviewer and the Topic Advisor. Quality control will be performed by the senior systematic reviewer. Dual sifting and data extraction will not be undertaken for this question.
Data management (software)	NGA STAR software will be used for study sifting, data extraction, recording quality assessment using checklists and generating bibliographies/citations. Microsoft Excel will be used to organise data into themes
Information sources – databases and dates	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycINFO, CINAHL Limits (e.g. date, study design): Apply standard animal/non-English language exclusion Dates: from 1990 Studies conducted post 1990 will be considered for this review question, as the GC felt that significant advances have occurred in antenatal and postnatal respiratory management that would influence the supports available to parents and carers of preterm babies, and thus what they might value, post-1990 that are not the same as prior to 1990.
Identify if an update	Not an update
Author contacts	Developer: NGA
Highlight if amendment to previous protocol	N/A
Search strategy	For details please see appendix B.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) and H (economic evidence tables).
Data items – define all variables to be collected	For details please see evidence tables in appendix D (clinical evidence tables) and H (economic evidence tables).

Field (based on PRISMA-P	Content
Methods for assessing bias at outcome/study level	The methodological quality of each study will be assessed using the NICE checklists for evaluating the quality of qualitative research
Criteria for quantitative synthesis (where suitable)	N/A
Methods for analysis – combining studies and exploring (in)consistency	Appraisal of methodological quality: The quality of the evidence for a theme (i.e. across studies) will be assessed using GRADE-CERQual, a process like GRADE that is adapted for qualitative information Synthesis of data: Thematic content analysis will be used to synthesise the qualitative data. It is a qualitative analytic method that identifies and reports recurrent themes. Thematic analysis is used in qualitative research to focus on examining themes within data and goes beyond counting phrases or words to identifying implicit and explicit ideas within the data. A theme map may also be presented if there is sufficient information identified in the search.
Meta-bias assessment – publication bias, selective reporting bias	N/A
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
Rationale/context – Current management	For details please see the introduction to the evidence review in the full guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by The National Guideline Alliance and chaired by Dr Janet Rennie in line with section 3 of Developing NICE guidelines: the manual. Staff from The National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the full guideline.

Field (based on PRISMA-P	Content
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds The National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England
PROSPERO registration number	Not registered

1

2 **Review protocol for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies**
3 **who are receiving respiratory support on the neonatal unit?**

Field (based on PRISMA-P	Content
Review question in SCOPE	What information, and in what format, is valued by parents and carers of babies who are receiving respiratory support in hospital, both during admission and at discharge?
Review question in guideline	What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?
Type of review question	Qualitative
Objective of the review	To determine what information, and in what format, parents and carers of preterm babies who are receiving respiratory support on the neonatal unit value Two objectives have been set up: 1. To explore the type of information that parents and carers of preterm babies who are receiving respiratory support on the neonatal unit find valuable

Field (based on PRISMA-P	Content
	2. To assess the formats through which parents and carers would like to receive information
Eligibility criteria – population/disease/condition/issue/domain	Parents or carers of preterm babies who require respiratory support on the neonatal unit Inclusions: • Parents or carers of preterm babies who require respiratory support • Studies of parents or carers of preterm babies born below 37 weeks gestation Exclusions: • Parents or carers of preterm babies with any congenital abnormalities except PDA • Parents or carers of preterm babies who are ventilated solely due to a specific non-respiratory comorbidity, such as sepsis, NEC, neurological disorders Studies where >2/3 of preterm babies receive respiratory support will be included in the review Quantitative data
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Context: Information content with regards to preterm babies who are receiving respiratory support during their stay on the neonatal unit
Eligibility criteria – comparator(s)/control or reference (gold) standard	N/A

Outcomes and prioritisation	**Themes – information and format**
	Themes will be identified from the literature, but expected themes are:
	• Formats
	  ○ In person
	  ▪ Presentations
	  ▪ Health care professionals

Field (based on PRISMA-P	Content
	▪ Peer support groups ▪ Neonatal groups o Print ▪ Pamphlets, books, magazines ▪ Parent information binder o Online ▪ Videos ▪ Webinars ▪ Condition-specific organisations ▪ Internet resources o Technology ▪ Television ▪ DVD ▪ Mobile applications ▪ Call line ▪ Audio recordings ▪ Webcams ▪ Baby diaries/journey boxes • Qualities o Availability of different languages o Equality of access e.g. vision impairment o Timing of access o Frequency of accessibility e.g. is a particular format really valuable, but very hard to get access to? • Types of information o Clinical Information ▪ Equipment ▪ Prognosis ▪ Participation in ward rounds

Field (based on PRISMA-P	Content
	▪ Risks ▪ Medication ▪ Medical options ▪ Infant's health and care • Feeding and weight gain • Behavioural cues and developmental stages o Parent/carer-infant bonding information ▪ Positive touch techniques, including kangaroo care (skin-to-skin contact with the baby against the parent/carer's chest) and comfort holding (cradling baby with still touch) ▪ Infant care - breastfeeding, feeding, changing ▪ Behavioural cues o Coping information ▪ Support groups ▪ Stress education
Eligibility criteria – study design	Qualitative methods: Semi-structured and structured interviews, focus groups, observations Quantitative methods: Surveys (from which only qualitative data will be extracted)
Other inclusion exclusion criteria	Inclusion: • English language • Developed countries with a neonatal care system similar to the UK (e.g. OECD countries) • Studies conducted post 1990
Proposed sensitivity/sub-group analysis, or meta-regression	Stratified analyses based on the following sub-groups: Gestational age: • <26+6 weeks

Field (based on PRISMA-P	Content
	• 27-31+6 weeks • 32-36+6 weeks
Selection process – duplicate screening/selection/analysis	Sifting, data extraction, appraisal of methodological quality and GRADE-CERQual assessment will be performed by the systematic reviewer. Resolution of any disputes will be with the senior systematic reviewer and the Topic Advisor. Quality control will be performed by the senior systematic reviewer. Dual sifting and data extraction will not be undertaken for this question.
Data management (software)	NGA STAR software will be used for study sifting, data extraction, recording quality assessment using checklists and generating bibliographies/citations. Microsoft Excel will be used to organise data into themes
Information sources – databases and dates	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycINFO, CINAHL Limits (e.g. date, study design): Apply standard animal/non-English language exclusion Dates: from 1990 Studies conducted post 1990 will be considered for this review question, as the GC felt that significant advances have occurred in antenatal and postnatal respiratory management that would influence the information that parents and carers of preterm babies might value post-1990 that are not the same as prior to 1990.
Identify if an update	Not an update
Author contacts	Developer: NGA
Highlight if amendment to previous protocol	N/A
Search strategy	For details please see appendix B.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) and H (economic evidence tables).

Field (based on PRISMA-P	Content
Data items – define all variables to be collected	For details please see evidence tables in appendix D (clinical evidence tables) or H (economic evidence tables).
Methods for assessing bias at outcome/study level	N/A The methodological quality of each study will be assessed using the NICE checklists for evaluating the quality of qualitative research
Criteria for quantitative synthesis (where suitable)	N/A
Methods for analysis – combining studies and exploring (in)consistency	Appraisal of methodological quality: The quality of the evidence for a theme (i.e. across studies) will be assessed using GRADE-CERQual, a process like GRADE that is adapted for qualitative information Synthesis of data: Thematic content analysis will be used to synthesise the qualitative data. It is a qualitative analytic method that identifies and reports recurrent themes. Thematic analysis is used in qualitative research to focus on examining themes within data and goes beyond counting phrases or words to identifying implicit and explicit ideas within the data. A theme map may also be presented if there is sufficient information identified in the search.
Meta-bias assessment – publication bias, selective reporting bias	N/A
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual
Rationale/context – Current management	For details please see the introduction to the evidence review in the full guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by The National Guideline Alliance and chaired by Dr Janet Rennie in line with section 3 of Developing NICE guidelines: the manual.

Field (based on PRISMA-P	Content
	Staff from The National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the full guideline.
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds The National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England
PROSPERO registration number	Not registered

1

2

Appendix B – Literature search strategies

Literature search strategies for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

Systematic reviews and RCTs

Date of initial search: 18/10/2017

Database(s): Embase 1980 to 2017 Week 41, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

Date of updated search: 26/06/2018

Database(s): Embase 1980 to 2018 Week 26, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	or/1-10
12	exp Intensive Care, Neonatal/ use ppez
13	newborn intensive care/ use emez
14	exp Intensive Care Units, Neonatal/ use ppez
15	neonatal intensive care unit/ use emez
16	Neonatal Nursing/ use ppez
17	exp newborn nursing/ use emez
18	newborn care/ use emez
19	(special and care and baby and unit*).tw.
20	((newborn or neonatal or neo-natal) adj ICU*1).tw.
21	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
22	(SCBU or NICU).tw.
23	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
24	or/12-23
25	11 and 24
26	exp Family/ use ppez
27	exp family/ use emez
28	Caregivers/ use ppez
29	caregiver/ use emez
30	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
31	(sibling* or brother* or sister*).tw.
32	or/26-31
33	25 and 32
34	Professional-Family Relations/
35	Object Attachment/
36	Infant Care/
37	Kangaroo-Mother Care Method/
38	exp Parent-Child Relations/
39	Touch/ or Touch Perception/
40	Facilitated Tucking/
41	Sucking Behavior/
42	Pacifiers/
43	exp Voice/ or Speech/

#	Searches
44	Acoustic Stimulation/
45	Reading/
46	Singing/
47	Music Therapy/
48	Patient Participation/
49	Enteral Nutrition/
50	Bottle Feeding/
51	exp Breast Feeding/
52	Rooming-in Care/
53	or/34-52 use ppez
54	human relation/
55	family centered care/
56	exp emotional attachment/
57	infant care/
58	kangaroo care/
59	exp child parent relation/
60	exp touch/ or tactile stimulation/
61	facilitated tucking/ or body position/
62	sucking/
63	pacifier/
64	voice/ or speech/
65	maternal voice intervention/
66	exp sensory stimulation/
67	reading/
68	singing/
69	music therapy/
70	patient participation/
71	enteric feeding/
72	bottle feeding/
73	exp breast feeding/
74	rooming in/
75	or/54-74 use emez
76	(family?centred or family?centered or family?integrat*).tw.
77	(involv* or interact* or participat* or support* or satisf* or dissatisf* or well being or well?being).tw.
78	development* care.tw.
79	(caregiving or caring or nurtur*).tw.
80	NIDCAP.tw.
81	((skin adj2 skin) or (kangaroo adj2 (care or interact* or position* or support*))).tw.
82	(bond or bonding or attachment).tw.
83	(hold or holding or cuddl* or rock* or swaddl* or touch* or tactile).tw.
84	(suck* or dummy or dummies or pacifier*).tw.
85	(read or reading or sing* or song* or lullab* or talk* or voice* or vocal).tw.
86	((auditory or acoustic or noise) adj2 stimulat*).tw.
87	(tubefeed* or (tube adj feed*) or (enter* adj feed*) or (enter* adj nutrition)).tw.
88	(breastfeed* or (breast adj milk) or breastmilk or breastfed or (breast adj feed*) or (breast adj fed)).tw.
89	(express* adj2 milk).tw.
90	or/76-89
91	53 or 75 or 90
92	33 and 91
93	limit 92 to english language
94	limit 93 to yr="1990 -Current"
95	Letter/ use ppez
96	letter.pt. or letter/ use emez
97	note.pt.
98	editorial.pt.
99	Editorial/ use ppez
100	News/ use ppez
101	exp Historical Article/ use ppez
102	Anecdotes as Topic/ use ppez
103	Comment/ use ppez
104	Case Report/ use ppez
105	case report/ or case study/ use emez
106	(letter or comment*).ti.
107	or/95-106
108	randomized controlled trial/ use ppez
109	randomized controlled trial/ use emez
110	random*.ti,ab.
111	or/108-110
112	107 not 111

#	Searches
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	exp Animals, Laboratory/ use ppez
117	exp Animal Experimentation/ use ppez
118	exp Animal Experiment/ use emez
119	exp Experimental Animal/ use emez
120	exp Models, Animal/ use ppez
121	animal model/ use emez
122	exp Rodentia/ use ppez
123	exp Rodent/ use emez
124	(rat or rats or mouse or mice).ti.
125	or/112-124
126	94 not 125
127	Meta-Analysis/
128	Meta-Analysis as Topic/
129	systematic review/
130	meta-analysis/
131	(meta analy* or metanaly* or metaanaly*).ti,ab.
132	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
133	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
134	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
135	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
136	(search* adj4 literature).ab.
137	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
138	cochrane.jw.
139	((pool* or combined) adj2 (data or trials or studies or results)).ab.
140	or/127-128,131,133-138 use ppez
141	or/129-132,134-139 use emez
142	or/140-141
143	clinical Trials as topic.sh. or (controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or (placebo or randomi#ed or randomly).ab. or trial.ti.
144	143 use ppez
145	(controlled clinical trial or pragmatic clinical trial or randomized controlled trial).pt. or drug therapy.fs. or (groups or placebo or randomi#ed or randomly or trial).ab.
146	145 use ppez
147	crossover procedure/ or double blind procedure/ or randomized controlled trial/ or single blind procedure/ or (assign* or allocat* or crossover* or cross over* or ((doubl* or singl*) adj blind*) or factorial* or placebo* or random* or volunteer*).ti,ab.
148	147 use emez
149	144 or 146
150	148 or 149
151	142 or 150
152	126 and 151
153	remove duplicates from 152

1 **Observational studies**

2 Date of initial search: 18/10/17

3 Database(s): Embase 1980 to 2017 Week 41, Ovid MEDLINE(R) Epub Ahead of Print, In-
4 Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)
5 1946 to Present

6 Date of updated search: 26/06/2018

7 Database(s): Embase 1980 to 2018 Week 26, Ovid MEDLINE(R) Epub Ahead of Print, In-
8 Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)
9 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.

#	Searches
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	or/1-10
12	exp Intensive Care, Neonatal/ use ppez
13	newborn intensive care/ use emez
14	exp Intensive Care Units, Neonatal/ use ppez
15	neonatal intensive care unit/ use emez
16	Neonatal Nursing/ use ppez
17	exp newborn nursing/ use emez
18	newborn care/ use emez
19	(special and care and baby and unit*).tw.
20	((newborn or neonatal or neo-natal) adj ICU*1).tw.
21	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
22	(SCBU or NICU).tw.
23	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
24	or/12-23
25	11 and 24
26	exp Family/ use ppez
27	exp family/ use emez
28	Caregivers/ use ppez
29	caregiver/ use emez
30	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
31	(sibling* or brother* or sister*).tw.
32	or/26-31
33	25 and 32
34	Professional-Family Relations/
35	Object Attachment/
36	Infant Care/
37	Kangaroo-Mother Care Method/
38	exp Parent-Child Relations/
39	Touch/ or Touch Perception/
40	Facilitated Tucking/
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51	exp Breast Feeding/
52	Rooming-in Care/
53	or/34-52 use ppez
54	human relation/
55	family centered care/
56	exp emotional attachment/
57	infant care/
58	kangaroo care/
59	exp child parent relation/
60	exp touch/ or tactile stimulation/
61	facilitated tucking/ or body position/
62	sucking/
63	pacifier/
64	voice/ or speech/
65	maternal voice intervention/
66	exp sensory stimulation/
67	reading/
68	singing/
69	music therapy/
70	patient participation/
71	enteric feeding/
72	bottle feeding/

#	Searches
73	exp breast feeding/
74	rooming in/
75	or/54-74 use emez
76	(family?centred or family?centered or family?integrat*).tw.
77	(involv* or interact* or participat* or support* or satisf* or dissatisf* or well being or well?being).tw.
78	development* care.tw.
79	(caregiving or caring or nurtur*).tw.
80	NIDCAP.tw.
81	((skin adj2 skin) or (kangaroo adj2 (care or interact* or position* or support*))).tw.
82	(bond or bonding or attachment).tw.
83	(hold or holding or cuddl* or rock* or swaddl* or touch* or tactile).tw.
84	(suck* or dummy or dummies or pacifier*).tw.
85	(read or reading or sing* or song* or lullab* or talk* or voice* or vocal).tw.
86	((auditory or acoustic or noise) adj2 stimulat*).tw.
87	(tubefeed* or (tube adj feed*) or (enter* adj feed*) or (enter* adj nutrition)).tw.
88	(breastfeed* or (breast adj milk) or breastmilk or breastfed or (breast adj feed*) or (breast adj fed)).tw.
89	(express* adj2 milk).tw.
90	or/76-89
91	53 or 75 or 90
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93	limit 92 to english language
94	limit 93 to yr="1990 -Current"
95	Letter/ use ppez
96	letter.pt. or letter/ use emez
97	note.pt.
98	editorial.pt.
99	Editorial/ use ppez
100	News/ use ppez
101	exp Historical Article/ use ppez
102	Anecdotes as Topic/ use ppez
103	Comment/ use ppez
104	Case Report/ use ppez
105	case report/ or case study/ use emez
106	(letter or comment*).ti.
107	or/95-106
108	randomized controlled trial/ use ppez
109	randomized controlled trial/ use emez
110	random*.ti,ab.
111	or/108-110
112	107 not 111
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	exp Animals, Laboratory/ use ppez
117	exp Animal Experimentation/ use ppez
118	exp Animal Experiment/ use emez
119	exp Experimental Animal/ use emez
120	exp Models, Animal/ use ppez
121	animal model/ use emez
122	exp Rodentia/ use ppez
123	exp Rodent/ use emez
124	(rat or rats or mouse or mice).ti.
125	or/112-124
126	94 not 125
127	Epidemiologic Studies/
128	Case Control Studies/
129	Retrospective Studies/
130	Cohort Studies/
131	Longitudinal Studies/
132	Follow-Up Studies/
133	Prospective Studies/
134	Cross-Sectional Studies/
135	or/127-134 use ppez
136	clinical study/
137	case control study/
138	family study/
139	longitudinal study/
140	retrospective study/
141	prospective study/

#	Searches
142	cohort analysis/
143	or/136-142 use emez
144	((retrospective$ or cohort$ or longitudinal or follow?up or prospective or cross section$) adj3 (stud$ or research or analys$)).ti.
145	135 or 143 or 144
146	126 and 145
147	remove duplicates from 146

1 **Health economics**

2 Date of initial search: 18/10/17

3 Database(s): Embase 1980 to 2017 Week 41, Ovid MEDLINE(R) Epub Ahead of Print, In-
4 Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)
5 1946 to Present

6 Date of updated search: 26/06/2018

7 Database(s): Embase 1980 to 2018 Week 26, Ovid MEDLINE(R) Epub Ahead of Print, In-
8 Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)
9 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	or/1-10
12	exp Intensive Care, Neonatal/ use ppez
13	newborn intensive care/ use emez
14	exp Intensive Care Units, Neonatal/ use ppez
15	neonatal intensive care unit/ use emez
16	Neonatal Nursing/ use ppez
17	exp newborn nursing/ use emez
18	newborn care/ use emez
19	(special and care and baby and unit*).tw.
20	((newborn or neonatal or neo-natal) adj ICU*1).tw.
21	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
22	(SCBU or NICU).tw.
23	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
24	or/12-23
25	11 and 24
26	exp Family/ use ppez
27	exp family/ use emez
28	Caregivers/ use ppez
29	caregiver/ use emez
30	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
31	(sibling* or brother* or sister*).tw.
32	or/26-31
33	25 and 32
34	Professional-Family Relations/
35	Object Attachment/
36	Infant Care/
37	Kangaroo-Mother Care Method/
38	exp Parent-Child Relations/
39	Touch/ or Touch Perception/
40	Facilitated Tucking/
41	Sucking Behavior/
42	Pacifiers/

#	Searches
43	exp Voice/ or Speech/
44	Acoustic Stimulation/
45	Reading/
46	Singing/
47	Music Therapy/
48	Patient Participation/
49	Enteral Nutrition/
50	Bottle Feeding/
51	exp Breast Feeding/
52	Rooming-in Care/
53	or/34-52 use ppez
54	human relation/
55	family centered care/
56	exp emotional attachment/
57	infant care/
58	kangaroo care/
59	exp child parent relation/
60	exp touch/ or tactile stimulation/
61	facilitated tucking/ or body position/
62	sucking/
63	pacifier/
64	voice/ or speech/
65	maternal voice intervention/
66	exp sensory stimulation/
67	reading/
68	singing/
69	music therapy/
70	patient participation/
71	enteric feeding/
72	bottle feeding/
73	exp breast feeding/
74	rooming in/
75	or/54-74 use emez
76	(family?centred or family?centered or family?integrat*).tw.
77	(involv* or interact* or participat* or support* or satisf* or dissatisf* or well being or well?being).tw.
78	development* care.tw.
79	(caregiving or caring or nurtur*).tw.
80	NIDCAP.tw.
81	((skin adj2 skin) or (kangaroo adj2 (care or interact* or position* or support*))).tw.
82	(bond or bonding or attachment).tw.
83	(hold or holding or cuddl* or rock* or swaddl* or touch* or tactile).tw.
84	(suck* or dummy or dummies or pacifier*).tw.
85	(read or reading or sing* or song* or lullab* or talk* or voice* or vocal).tw.
86	((auditory or acoustic or noise) adj2 stimulat*).tw.
87	(tubefeed* or (tube adj feed*) or (enter* adj feed*) or (enter* adj nutrition)).tw.
88	(breastfeed* or (breast adj milk) or breastmilk or breastfed or (breast adj feed*) or (breast adj fed)).tw.
89	(express* adj2 milk).tw.
90	or/76-89
91	53 or 75 or 90
92	33 and 91
93	limit 92 to english language
94	limit 93 to yr="1990 -Current"
95	Letter/ use ppez
96	letter.pt. or letter/ use emez
97	note.pt.
98	editorial.pt.
99	Editorial/ use ppez
100	News/ use ppez
101	exp Historical Article/ use ppez
102	Anecdotes as Topic/ use ppez
103	Comment/ use ppez
104	Case Report/ use ppez
105	case report/ or case study/ use emez
106	(letter or comment*).ti.
107	or/95-106
108	randomized controlled trial/ use ppez
109	randomized controlled trial/ use emez
110	random*.ti,ab.
111	or/108-110

#	Searches
112	107 not 111
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	exp Animals, Laboratory/ use ppez
117	exp Animal Experimentation/ use ppez
118	exp Animal Experiment/ use emez
119	exp Experimental Animal/ use emez
120	exp Models, Animal/ use ppez
121	animal model/ use emez
122	exp Rodentia/ use ppez
123	exp Rodent/ use emez
124	(rat or rats or mouse or mice).ti.
125	or/112-124
126	94 not 125
127	Economics/
128	Value of life/
129	exp "Costs and Cost Analysis"/
130	exp Economics, Hospital/
131	exp Economics, Medical/
132	Economics, Nursing/
133	Economics, Pharmaceutical/
134	exp "Fees and Charges"/
135	exp Budgets/
136	or/127-135 use ppez
137	health economics/
138	exp economic evaluation/
139	exp health care cost/
140	exp fee/
141	budget/
142	funding/
143	or/137-142 use emez
144	budget*.ti,ab.
145	cost*.ti.
146	(economic* or pharmaco?economic*).ti.
147	(price* or pricing*).ti,ab.
148	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
149	(financ* or fee or fees).ti,ab.
150	(value adj2 (money or monetary)).ti,ab.
151	or/144-149
152	136 or 143 or 151
153	126 and 152
154	remove duplicates from 153

1 **Systematic reviews, RCTs and Health economics**

2 Date of initial search: 18/10/2017

3 Databases: The Cochrane Library, issue 10 of 12, October 2017

4 Date of updated search: 27/06/2018

5 Databases: The Cochrane Library, issue 6 of 12, June 2018

ID	Search
#1	MeSH descriptor: [Infant, Newborn] explode all trees
#2	(infan* or neonat* or neo-nat* or newborn* or baby or babies or preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie or premies or low birth weight or very low birth weight):ti,ab,kw
#3	(LBW or VLBW):ti,ab
#4	MeSH descriptor: [Respiratory Distress Syndrome, Newborn] explode all trees
#5	MeSH descriptor: [Intensive Care, Neonatal] explode all trees
#6	MeSH descriptor: [Intensive Care Units, Neonatal] explode all trees
#7	MeSH descriptor: [Neonatal Nursing] explode all trees
#8	((newborn or neonat* or neo-nat*) near/2 (unit or care or department* or facilit* or hospital* or ICU*)):ti,ab,kw
#9	(special near baby next unit*)
#10	(SCBU or NICU):ti,ab

ID	Search
#11	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie* or premies) near/2 (unit* or care or department* or facilit* or hospital*)):ti,ab,kw
#12	{or #1-#11}
#13	MeSH descriptor: [Family] explode all trees
#14	MeSH descriptor: [Caregivers] explode all trees
#15	(famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*):ti,ab,kw
#16	{or #13-#15}
#17	#12 and #16 Publication Year from 1990 to 2017
#18	MeSH descriptor: [Professional-Family Relations] this term only
#19	MeSH descriptor: [Object Attachment] this term only
#20	MeSH descriptor: [Infant Care] explode all trees
#21	MeSH descriptor: [Parent-Child Relations] explode all trees
#22	MeSH descriptor: [Touch Perception] explode all trees
#23	MeSH descriptor: [Touch] this term only
#24	MeSH descriptor: [Sucking Behavior] explode all trees
#25	MeSH descriptor: [Pacifiers] this term only
#26	MeSH descriptor: [Voice] explode all trees
#27	MeSH descriptor: [Speech] this term only
#28	MeSH descriptor: [Acoustic Stimulation] this term only
#29	MeSH descriptor: [Reading] this term only
#30	MeSH descriptor: [Singing] this term only
#31	MeSH descriptor: [Music Therapy] this term only
#32	MeSH descriptor: [Patient Participation] this term only
#33	MeSH descriptor: [Enteral Nutrition] explode all trees
#34	MeSH descriptor: [Bottle Feeding] this term only
#35	MeSH descriptor: [Breast Feeding] explode all trees
#36	("family centred" or "family centered" or "family integrat*"):ti,ab
#37	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (involv* or participat*)):ti,ab,kw
#38	"development* care"
#39	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (caregiving or caring or nurtur*)):ti,ab,kw
#40	NIDCAP
#41	("skin to skin" or "kangaroo care" or "kangaroo position*" or "kangaroo support*"):ti,ab
#42	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (bond or bonding or attachment)):ti,ab
#43	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (hold or holding or cuddl* or rock* or swaddl* or touch* or tactile)):ti,ab
#44	"non-nutriti* suck*" or pacifier* or dummy or dummies:ti,ab
#45	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (read or reading or sing* or song* or lullab* or talk* or vocal or voice*)):ti,ab
#46	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (auditory or acoustic or noise or stimulat*)):ti,ab
#47	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (tubefeed* or (tube near feed*) or (enter* near feed*) or (enter* near nutrition))):ti,ab
#48	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (breastfeed* or (breast adj milk) or breastmilk or breastfed or (breast adj feed*) or (breast adj fed))):ti,ab
#49	((famil* or parent or parents or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) near (express* near milk*)):ti,ab
#50	{or #18-#49} Publication Year from 1990 to 2017
#51	#17 and #50 Publication Year from 1990 to 2017

1

2 **Literature search strategies for question 6.2 What support is valued by parents**
3 **and carers of preterm babies requiring respiratory support?**

4 Date of search: 25/09/2017

1 Database(s): Embase 1980 to 2017 Week 39, Ovid MEDLINE(R) Epub Ahead of Print, In-
2 Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)
3 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	or/1-10
12	exp Intensive Care, Neonatal/ use ppez
13	newborn intensive care/ use emez
14	exp Intensive Care Units, Neonatal/ use ppez
15	neonatal intensive care unit/ use emez
16	Neonatal Nursing/ use ppez
17	exp newborn nursing/ use emez
18	newborn care/ use emez
19	(special and care and baby and unit*).tw.
20	((newborn or neonatal or neo-natal) adj ICU*1).tw.
21	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
22	(SCBU or NICU).tw.
23	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
24	or/12-23
25	11 and 24
26	exp Family/ use ppez
27	exp family/ use emez
28	Caregivers/ use ppez
29	caregiver/ use emez
30	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
31	(sibling* or brother* or sister*).tw.
32	or/26-31
33	25 and 32
34	Stress, Psychological/ use ppez
35	exp stress/ use emez
36	(stress* or anxious or anxiet* or worry or worri* or concern*).tw.
37	exp Adaptation, Psychological/ use ppez
38	psychological adjustment/ use emez
39	exp coping behavior/ use emez
40	exp Social Support/ use ppez
41	caregiver support/ use emez
42	self help/ use emez
43	Self-Help Groups/ use ppez
44	Counseling/ use ppez
45	exp counseling/ use emez
46	counsel*.tw.
47	Crisis Intervention/ use ppez
48	crisis intervention/ use emez
49	Vulnerable Populations/ use ppez
50	vulnerable population/ use emez
51	exp Emotions/ use ppez
52	exp Emotion/ use emez
53	((psychological or psychosocial or emotion* or social* or self or crisis) adj2 (support* or adjust* or intervention*)).tw.
54	(family?centred or family?centered or family?integrat*).tw.
55	(ward round* or involv* or support* or satisf* or dissatisf* or well being or well?being).tw.
56	(caregiving or caring or nurtur*).tw.
57	exp Choice Behavior/ use ppez
58	Decision Support Techniques/ use ppez
59	exp Decision Making/ use ppez
60	decision making/ use emez
61	family decision making/ use emez
62	shared decision making/ use emez
63	Professional-Family Relations/ use ppez

#	Searches
64	human relation/ use emez
65	(choice* or choose* or request* or prefer* or decide* or decision* or seek*).tw.
66	"Hospital Design and Construction"/ use ppez
67	hospital design/ use emez
68	hospital building/ use emez
69	((hospital* or clinic*1 or unit* or department* or facilit*) adj2 (design* or environment* or comfort*)).tw.
70	Rooming-in Care/ use ppez
71	rooming in/ use emez
72	(accommodat* or residen* or living or room*).tw.
73	exp Food/ use ppez
74	exp food/ use emez
75	(food or eat* or drink*).tw.
76	Parking Facilities/ use ppez
77	exp "traffic and transport"/ use emez
78	(parking or transport*).tw.
79	Financial Support/ use ppez
80	(financ* or cost* or money or expense*).tw.
81	exp Child Rearing/ use ppez
82	exp child care/ use emez
83	(child care or childcare).tw.
84	or/34-83
85	33 and 84
86	limit 85 to english language
87	limit 86 to yr="1990-current"
88	Letter/ use ppez
89	letter.pt. or letter/ use emez
90	note.pt.
91	editorial.pt.
92	Editorial/ use ppez
93	News/ use ppez
94	exp Historical Article/ use ppez
95	Anecdotes as Topic/ use ppez
96	Comment/ use ppez
97	Case Report/ use ppez
98	case report/ or case study/ use emez
99	(letter or comment*).ti.
100	or/88-99
101	randomized controlled trial/ use ppez
102	randomized controlled trial/ use emez
103	random*.ti,ab.
104	or/101-103
105	100 not 104
106	animals/ not humans/ use ppez
107	animal/ not human/ use emez
108	nonhuman/ use emez
109	exp Animals, Laboratory/ use ppez
110	exp Animal Experimentation/ use ppez
111	exp Animal Experiment/ use emez
112	exp Experimental Animal/ use emez
113	exp Models, Animal/ use ppez
114	animal model/ use emez
115	exp Rodentia/ use ppez
116	exp Rodent/ use emez
117	(rat or rats or mouse or mice).ti.
118	or/105-117
119	87 not 118
120	Qualitative Research/ use ppez
121	qualitative research/ use emez
122	Interview/ use ppez
123	exp interview/ use emez
124	(theme* or thematic).mp.
125	qualitative.af.
126	Nursing Methodology Research/ use ppez
127	nursing methodology research/ use emez
128	questionnaire*.mp.
129	ethnological research.mp.
130	ethnograph*.mp.
131	ethnonursing.af.
132	phenomenol*.af.

#	Searches
133	(grounded adj (theor* or study or studies or research or analys?s)).af.
134	(life stor* or women* stor* or men* stor* or people* stor* or person* stor*).mp.
135	(emic or etic or hermeneutic* or heuristic* or semiotic*).af. or (data adj1 saturat*).tw. or participant observ*.tw.
136	(social construct* or (postmodern* or post-structural*) or (post structural* or poststructural*) or post modern* or post-modern* or feminis* or interpret*).mp.
137	(action research or cooperative inquir* or co operative inquir* or co-operative inquir*).mp.
138	(humanistic or existential or experiential or paradigm*).mp.
139	(field adj (study or studies or research)).tw.
140	human science.tw.
141	biographical method.tw.
142	theoretical sampl*.af.
143	((purpos* adj4 sampl*) or (focus adj group*)).af.
144	(account or accounts or unstructured or open-ended or open ended or text* or narrative*).mp.
145	(life world or life-world or conversation analys?s or personal experience* or theoretical saturation).mp.
146	((lived or life) adj experience*).mp.
147	cluster sampl*.mp.
148	observational method*.af.
149	content analysis.af.
150	(constant adj (comparative or comparison)).af.
151	((discourse* or discurs*) adj3 analys?s).tw.
152	narrative analys?s.af.
153	heidegger*.tw.
154	colaizzi*.tw.
155	spiegelberg*.tw.
156	(van adj manen*).tw.
157	(van adj kaam*).tw.
158	(merleau adj ponty*).tw.
159	husserl*.tw.
160	foucault*.tw.
161	(corbin* adj2 strauss*).tw.
162	glaser*.tw.
163	or/120-162
164	Meta-Analysis/
165	Meta-Analysis as Topic/
166	systematic review/
167	meta-analysis/
168	(meta analy* or metanaly* or metaanaly*).ti,ab.
169	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
170	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
171	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
172	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
173	(search* adj4 literature).ab.
174	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
175	cochrane.jw.
176	((pool* or combined) adj2 (data or trials or studies or results)).ab.
177	or/162-163,166,168-173 use ppez
178	or/164-167,169-174 use emez
179	or/177-178
180	163 or 179
181	119 and 180
182	remove duplicates from 181

1 Date of search: 25/09/2017

2 Database(s): AMED (Allied and Complementary Medicine) 1985 to September 2017, Health
3 and Psychosocial Instruments 1985 to July 2017, Maternity & Infant Care Database
4 (MIDIRS) 1971 to August 2017, PsycINFO 1806 to September Week 3 2017

#	Searches
1	Premature Birth/ or Neonatal Period/ or Birth Weight/
2	1 use psyh
3	exp Infant Newborn/ use amed
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	(low adj3 birth adj3 weigh$).tw.
7	(LBW or VLBW).tw.
8	or/2-7
9	Neonatal Intensive Care/ use psyh

#	Searches
10	Intensive Care Neonatal/ use amed
11	(special and care and baby and unit*).tw.
12	((newborn or neonatal or neo-natal) adj ICU*1).tw.
13	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
14	(SCBU or NICU).tw.
15	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
16	or/9-14
17	8 and 16
18	exp Family/ or exp Family Members/ or exp Family Relations/ or Caregivers/
19	18 use psyh
20	exp Family/ use amed
21	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
22	(sibling* or brother* or sister*).tw.
23	or/19-22
24	17 and 23
25	Psychological Stress/ or exp Stress Reactions/ or exp Anxiety/ or Emotional Trauma/
26	25 use psyh
27	Stress Psychological/ use amed
28	(stress* or anxious or anxiet* or worry or worri* or concern*).tw.
29	"Stress and Coping Measures"/ or Coping Behavior/
30	29 use psyh
31	Adaptation Psychological/ use amed
32	Social Support/ or Caregiver Burden/
33	32 use psyh
34	Social Support/ use amed
35	exp Counseling/ use psyh
36	Counseling/ use amed
37	counsel*.tw.
38	exp Crisis Intervention/ or exp Crisis Intervention Services/
39	38 use psyh
40	exp Emotions/ use psyh
41	exp Emotion/ use amed
42	((psychological or emotion* or social* or self or crisis) adj2 (support* or adjust* or intervention*)).tw.
43	Parent Perceptions/ or Parental Expectations/ or Parental Involvement/ or Parental Role/ or Parenting/
44	43 use psyh
45	Family-Centered Care/ use psyh
46	(family?centred or family?centered or family?integrat*).tw.
47	(ward round* or involv* or support* or satisf* or dissatisf* or well being or well?being).tw.
48	(caregiving or caring or nurtur*).tw.
49	((professional? or staff* or personnel or doctor? or physician? or consultant? or nurse?) adj3 (relation* or interact* or involv* or meet* or collaborat* or rapport*)).tw.
50	Nurse-Parent Interaction/ use psyh
51	exp Choice Behavior/ use psyh
52	Decision Making/ use psyh
53	Shared Decision Making/ use psyh
54	exp Decision Making/ use amed
55	Professional Family Relations/ use amed
56	(choice* or choose* or request* or prefer* or decide* or decision* or seek*).tw.
57	exp Health Facilities/ use amed
58	exp Facility Environment/ use psyh
59	((hospital* or clinic*1 or unit* or department* or facilit*) adj2 (design* or environment* or comfort*)).tw.
60	(accommodat* or residen* or living or room*).tw.
61	exp Eating Behavior/ or exp Drinking Behavior/
62	61 use psyh
63	exp Food/ and Beverages/ use amed
64	(food or eat* or drink*).tw.
65	(parking or transport*).tw.
66	Financial Strain/ use psyh
67	exp Financing Personal/ use amed
68	(financ* or cost* or money).tw.
69	exp Child Care/ use psyh
70	exp Child Care/ use amed
71	(child care or childcare).tw.
72	or/26-28,30-31,33-37,39-42,44-60,62-71
73	24 and 72
74	Qualitative Research/ use psyh
75	qualitative.tw.

#	Searches
76	interview*.tw.
77	(theme* or thematic).tw.
78	questionnaire*.tw.
79	(ethnological research or ethnograph* or ethnonursing or phenomenol*).tw.
80	(grounded adj (theor* or study or studies or research or analys?s)).tw.
81	(life stor* or women* stor* or men* stor* or people* stor* or person* stor*).tw.
82	(emic or etic or hermeneutic* or heuristic* or semiotic*).af. or (data adj1 saturat*).tw. or participant observ*.tw.
83	(social construct* or (postmodern* or post-structural*) or (post structural* or poststructural*) or post modern* or post-modern* or feminis* or interpret*).tw.
84	(action research or cooperative inquir* or co operative inquir* or co-operative inquir*).tw.
85	(humanistic or existential or experiential or paradigm*).tw.
86	(field adj (study or studies or research)).tw.
87	(human science or biographical method or theoretical sampl*).tw.
88	((purpos* adj4 sampl*) or (focus adj group*)).tw.
89	(account or accounts or unstructured or open-ended or open ended or text* or narrative* or life world or life-world or conversation analys?s or personal experience* or theoretical saturation).tw.
90	((lived or life) adj experience*).tw.
91	(cluster sampl* or observational method* or content analysis or (constant adj (comparative or comparison))).tw.
92	(((discourse* or discurs*) adj3 analys?s) or narrative analys?s).tw.
93	or/74-92
94	Meta Analysis/ use psyh
95	Meta Analysis/ use amed
96	(meta analy* or metanaly* or metaanaly*).tw.
97	((systematic* or evidence*) adj2 (review* or overview*)).tw.
98	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
99	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
100	(search* adj4 literature).ab.
101	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
102	cochrane.jw.
103	((pool* or combined) adj2 (data or trials or studies or results)).ab.
104	or/94-103
105	93 or 104
106	73 and 105
107	limit 106 to english language [Limit not valid in MWIC; records were retained]
108	limit 107 to yr="1990 -Current"
109	remove duplicates from 108

1

2 Date of search: 25/09/2017

3 Database(s): CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature) 1937-
4 current, EBSCO Host

#	Query
S101	S53 AND S100
S100	S87 OR S99
S99	S88 OR S89 OR S90 OR S91 OR S92 OR S93 OR S94 OR S95 OR S96 OR S97 OR S98
S98	AB ((pool* or combined) N2 (data or trials or studies or results))
S97	(MH "Cochrane Library")
S96	AB (medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit)
S95	AB (search* N4 literature)
S94	AB (search strategy or search criteria or systematic search or study selection or data extraction)
S93	AB (reference list* or bibliograph* or hand search* or manual search* or relevant journals)
S92	TX ((systematic* or evidence*) N2 (review* or overview*))
S91	TX ((systematic or evidence) N2 (review* or overview*))
S90	TX (meta analy* or metanaly* or metaanaly*)
S89	(MH "Meta Analysis")
S88	(MH "Systematic Review")
S87	S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86
S86	TX (constant N1 (comparative or comparison))
S85	TX ((discourse* or discurs or narrative)* N3 analys?s)
S84	TX (cluster sampl* or theme* or thematic or observational method* or questionnaire* or content analysis)
S83	TX (life world or life-world or conversation analys?s or personal experience* or theoretical saturation or lived experience* or life experience*)

#	Query
S82	TX (focus group or account or accounts or unstructured or open-ended or open ended or text* or narrative* or life world or life-world or conversation analys?s or personal experience* or theoretical saturation)
S81	TX (biographical method or theoretical sampl* or (purpos* N4 sampl*))
S80	TX (field N (study or studies or research))
S79	TX (action research or cooperative inquir* or co operative inquir* or co-operative inquir* or humanistic or existential or experiential or paradigm*)
S78	TX (social construct* or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or interpret*)
S77	TX ((emic or etic or hermeneutic* or heuristic* or semiotic*) or (data near saturat*) or participant observ*)
S76	TX (life stor* or women* stor* or men* stor* or people* stor* or person* stor*)
S75	TX (grounded N (theor* or study or studies or research or analys?s))
S74	TX (ethnonursing or ethnograph* or phenomenol*)
S73	(MH "Cluster Sample+")
S72	(MH "Life Experiences+")
S71	(MH "Phenomenological Research")
S70	(MH "Theoretical Sample")
S69	(MH "Field Studies")
S68	(MH "Purposive Sample")
S67	(MH "Qualitative Validity+")
S66	(MH "Constant Comparative Method")
S65	(MH "Ethnonursing Research")
S64	(MH "Ethnological Research")
S63	(MH "Ethnographic Research")
S62	(MH "Content Analysis")
S61	(MH "Discourse Analysis")
S60	(MH "Observational Methods+")
S59	(MH "Focus Groups")
S58	(MH "Questionnaires+")
S57	(MH "Research, Nursing")
S56	(MH "Grounded Theory")
S55	(MH "Interviews+")
S54	(MH "Qualitative Studies+")
S53	S20 AND S52
S52	S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51
S51	TX (child care or childcare)
S50	(MH "Child Care+")
S49	TX (financ* or cost* or money or expense*)
S48	(MH "Financial Support")
S47	TX (parking or transport*)
S46	TX (food or eat* or drink*)
S45	(MH "Food Preferences")
S44	TX (accommodat* or residen* or living or room*)
S43	(MH "Rooming In")
S42	TX ((hospital* or clinic or clinics or unit* or department* or facilit*) N (design* or environment* or comfort*))
S41	(MH "Interior Design and Furnishings+")
S40	(MH "Family Attitudes+")
S39	(MH "Professional-Family Relations")
S38	TX (choice* or choose* or request* or prefer* or decide* or decision* or seek*)
S37	(MH "Decision Making+")
S36	TX (caregiving or caring or nurtur*)
S35	TX (ward round* or involv* or support* or satisf* or dissatisf* or well being)
S34	TX (family centred or family centered or family integrat*)
S33	TX ((psychological or psychosocial or emotion* or social* or self or crisis) near (support* or adjust* or intervention*))
S32	TX ((psychological or psychosocial or emotion* or social* or self or crisis) near2 (support* or adjust* or intervention*))
S31	(MH "Emotions+")
S30	TX (counsel* or psychotherap* or family theray)
S29	(MH "Crisis Intervention") OR (MH "Special Populations")
S28	(MH "Crisis Intervention")
S27	(MH "Counseling+")
S26	(MH "Support Groups")
S25	(MH "Coping+")
S24	(MH "Support, Psychosocial")
S23	(MH "Adaptation, Psychological+")
S22	TX (stress* or anxious or anxiet* or worry or worri* or concern*)
S21	(MH "Stress, Psychological+")
S20	S15 AND S19

#	Query
S19	S16 OR S17 OR S18
S18	TX (famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*)
S17	(MH "Caregivers")
S16	(MH "Family+")
S15	S6 AND S14
S14	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
S13	TX ((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie or premies) N (unit* or care or department* or facilit* or hospital*))
S12	TX (SCBU or NICU)
S11	TX ((newborn or neonat* or neo-nat*) near (unit or care or department* or facilit* or hospital* or ICU*))
S10	TX (special and care and baby and unit*)
S9	(MH "Neonatal Nursing+")
S8	(MH "Intensive Care Units, Neonatal")
S7	(MH "Intensive Care, Neonatal+")
S6	S1 OR S2 OR S3 OR S5
S5	S1 AND S4
S4	(MH "Respiratory Distress Syndrome+")
S3	TX (low birth weight or very low birth weight)
S2	TX (infan* or neonat* or neo-nat* or newborn* or baby or babies or preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie or premies)
S1	(MH "Infant, Newborn+")

1 Date of search: 25/09/2017

2 Database(s): Wiley Web of Science Social Science Citation Index (SSCI) 1900 to present

#	Searches
#40	#39 AND #26 DocType=All document types; Language=All languages;
#39	#38 OR #35 DocType=All document types; Language=All languages;
#38	#37 OR #36 DocType=All document types; Language=All languages;
#37	TS=((reference list* or bibliograph* or hand search* or manual search* or relevant journals or search strategy or search criteria or systematic search or study selection or data extraction or medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit) or (search* NEAR literature)) DocType=All document types; Language=All languages;
#36	TS=((meta analy* or metanaly* or metaanaly*) or ((systematic* or evidence*) NEAR (review* or overview*)) or ((pool* or combined) NEAR (data or trials or studies or results))) DocType=All document types; Language=All languages;
#35	#34 OR #33 OR #32 OR #31 OR #30 OR #29 OR #28 OR #27 DocType=All document types; Language=All languages;
#34	TS=((constant NEAR (comparative or comparison)) or ((discourse* or discurs*) NEAR analys?s)) DocType=All document types; Language=All languages;
#33	TS=((lived or life) NEAR experience*) DocType=All document types; Language=All languages;
#32	TS=((purpos* NEAR sampl*) or (focus NEAR group*)) DocType=All document types; Language=All languages;
#31	TS=(field NEAR (study or studies or research)) DocType=All document types; Language=All languages;
#30	TS=(social construct* or (postmodern* or post-structural*) or (post structural* or poststructural*) or post modern* or post-modern* or feminis* or interpret*) DocType=All document types; Language=All languages;
#29	TS=((emic or etic or hermeneutic* or heuristic* or semiotic*) or (data NEAR saturat*) or participant observ*) DocType=All document types; Language=All languages;
#28	TS=(grounded NEAR (theor* or study or studies or research or analys?s)) DocType=All document types; Language=All languages;
#27	TS=(qualititative or interview* or questionnaire* or theme* or thematic or ethnograph* or ethnonurs* or phenomenol* or action research or cooperative inquir* or co operative inquir* or co-operative inquir* or humanistic or existential or experiential or paradigm* or human science or biographical method or theoretical sampl* or account or accounts or unstructured or open-ended or open ended or text* or narrative* or life world or life-world or conversation analys?s or personal experience* or theoretical saturation or cluster sampl* or observational method* or content analysis or narrative analys?s) DocType=All document types; Language=All languages;
#26	#25 AND #12 DocType=All document types; Language=All languages;
#25	#24 OR #23 OR #22 OR #21 OR #20 OR #19 OR #18 OR #17 OR #16 OR #15 OR #14 OR #13 DocType=All document types; Language=All languages;

#	Searches
#24	TS=(childcare or child care) DocType=All document types; Language=All languages;
#23	TS=(financ* or cost* or money or expense*) DocType=All document types; Language=All languages;
#22	TS=(parking or transport*) DocType=All document types; Language=All languages;
#21	TS=(food or eat* or drink*) DocType=All document types; Language=All languages;
#20	TS=((hospital* or clinic or clinics or unit* or department* or facilit*) NEAR (design* or environment* or comfort*)) DocType=All document types; Language=All languages;
#19	TS=(choice* or choose* or request* or prefer* or decide* or decision* or seek*) DocType=All document types; Language=All languages;
#18	TS=(caregiving or caring or nurtur*) DocType=All document types; Language=All languages;
#17	TS=(ward round* or involv* or support* or satisf* or dissatisf* or well being or well-being or wellbeing) DocType=All document types; Language=All languages;
#16	TS=(family centred or family-centred or family centered or family-centered or family integrat* or family-integrat*) DocType=All document types; Language=All languages;
#15	TS=((psychological or psychosocial or emotion* or social* or self or crisis) NEAR (support* or adjust* or intervention*)) DocType=All document types; Language=All languages;
#14	TS=(counsel* or self help or support group* or crisis intervention or vulnerable) DocType=All document types; Language=All languages;
#13	TS=(stress* or anxious or anxiet* or worry or worri* or concern* or coping) DocType=All document types; Language=All languages;
#12	#11 AND #10 DocType=All document types; Language=All languages;
#11	TS=(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) DocType=All document types; Language=All languages;
#10	#9 AND #4 DocType=All document types; Language=All languages;
#9	#8 OR #7 OR #6 OR #5 DocType=All document types; Language=All languages;
#8	TS=((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie or pre?mies) NEAR (unit* or care or department* or facilit* or hospital*)) DocType=All document types; Language=All languages;
#7	TS=(SCBU or NICU) DocType=All document types; Language=All languages;
#6	TS=((newborn or neonat* or neo-nat*) NEAR (unit or care or department* or facilit* or hospital* or ICU*)) DocType=All document types; Language=All languages;
#5	TS=(special and care and baby and unit*) DocType=All document types; Language=All languages;
#4	#3 OR #2 OR #1 DocType=All document types; Language=All languages;
#3	TS=(low birth weight) DocType=All document types; Language=All languages;
#2	TS=(preterm or pre-term or prematur* or pre-matur* or pre?mie or pr?emies) DocType=All document types; Language=All languages;
#1	TS=(infan* or neonat* or neo-nat* or newborn* or baby or babies) DocType=All document types; Language=All languages;

1 **Health economics**

2 Date of search: 25/09/2017

3 Database(s): Embase 1980 to 2017 Week 39, Ovid MEDLINE(R) Epub Ahead of Print, In-
4 Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)
5 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez

#	Searches
10	neonatal respiratory distress syndrome/ use emez
11	or/1-10
12	exp Intensive Care, Neonatal/ use ppez
13	newborn intensive care/ use emez
14	exp Intensive Care Units, Neonatal/ use ppez
15	neonatal intensive care unit/ use emez
16	Neonatal Nursing/ use ppez
17	exp newborn nursing/ use emez
18	newborn care/ use emez
19	(special and care and baby and unit*).tw.
20	((newborn or neonatal or neo-natal) adj ICU*1).tw.
21	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
22	(SCBU or NICU).tw.
23	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
24	or/12-23
25	11 and 24
26	exp Family/ use ppez
27	exp family/ use emez
28	Caregivers/ use ppez
29	caregiver/ use emez
30	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
31	(sibling* or brother* or sister*).tw.
32	or/26-31
33	25 and 32
34	Stress, Psychological/ use ppez
35	exp stress/ use emez
36	(stress* or anxious or anxiet* or worry or worri* or concern*).tw.
37	exp Adaptation, Psychological/ use ppez
38	psychological adjustment/ use emez
39	exp coping behavior/ use emez
40	exp social support/ use ppez
41	caregiver support/ use emez
42	self help/ use emez
43	Self-Help Groups/ use ppez
44	Counseling/ use ppez
45	exp counseling/ use emez
46	counsel*.tw.
47	Crisis Intervention/ use ppez
48	crisis intervention/ use emez
49	Vulnerable Populations/ use ppez
50	vulnerable population/ use emez
51	exp Emotions/ use ppez
52	exp Emotion/ use emez
53	((psychological or emotion* or social* or self or crisis) adj2 (support* or adjust* or intervention*)).tw.
54	(family?centred or family?centered or family?integrat*).tw.
55	(involv* or support* or satisf* or dissatisf* or well being or well?being).tw.
56	(caregiving or caring or nurtur*).tw.
57	exp Choice Behavior/ use ppez
58	Decision Support Techniques/ use ppez
59	exp Decision Making/ use ppez
60	decision making/ use emez
61	family decision making/ use emez
62	shared decision making/ use emez
63	Professional-Family Relations/ use ppez
64	human relation/ use emez
65	(choice* or choose* or request* or prefer* or decide* or decision* or seek*).tw.
66	"Hospital Design and Construction"/ use ppez
67	hospital design/ use emez
68	hospital building/ use emez
69	((hospital* or clinic*1 or unit* or department* or facilit*) adj2 (design* or environment* or comfort*)).tw.
70	Rooming-in Care/ use ppez
71	rooming in/ use emez
72	(accommodat* or residen* or living or room*).tw.
73	exp Food/ use ppez
74	exp food/ use emez
75	(food or eat* or drink*).tw.
76	Parking Facilities/ use ppez

#	Searches
77	exp "traffic and transport"/ use emez
78	(parking or transport*).tw.
79	Financial Support/ use ppez
80	(financ* or cost* or money).tw.
81	exp Child Rearing/ use ppez
82	exp child care/ use emez
83	(child care or childcare).tw.
84	or/34-83
85	33 and 84
86	limit 85 to english language
87	limit 86 to yr="1990-current"
88	Letter/ use ppez
89	letter.pt. or letter/ use emez
90	note.pt.
91	editorial.pt.
92	Editorial/ use ppez
93	News/ use ppez
94	exp Historical Article/ use ppez
95	Anecdotes as Topic/ use ppez
96	Comment/ use ppez
97	Case Report/ use ppez
98	case report/ or case study/ use emez
99	(letter or comment*).ti.
100	or/88-99
101	randomized controlled trial/ use ppez
102	randomized controlled trial/ use emez
103	random*.ti,ab.
104	or/101-103
105	100 not 104
106	animals/ not humans/ use ppez
107	animal/ not human/ use emez
108	nonhuman/ use emez
109	exp Animals, Laboratory/ use ppez
110	exp Animal Experimentation/ use ppez
111	exp Animal Experiment/ use emez
112	exp Experimental Animal/ use emez
113	exp Models, Animal/ use ppez
114	animal model/ use emez
115	exp Rodentia/ use ppez
116	exp Rodent/ use emez
117	(rat or rats or mouse or mice).ti.
118	or/105-117
119	87 not 118
120	Economics/
121	Value of life/
122	exp "Costs and Cost Analysis"/
123	exp Economics, Hospital/
124	exp Economics, Medical/
125	Economics, Nursing/
126	Economics, Pharmaceutical/
127	exp "Fees and Charges"/
128	exp Budgets/
129	or/120-128 use ppez
130	health economics/
131	exp economic evaluation/
132	exp health care cost/
133	exp fee/
134	budget/
135	funding/
136	or/130-135 use emez
137	budget*.ti,ab.
138	cost*.ti.
139	(economic* or pharmaco?economic*).ti.
140	(price* or pricing*).ti,ab.
141	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
142	(financ* or fee or fees).ti,ab.
143	(value adj2 (money or monetary)).ti,ab.
144	or/137-142
145	129 or 136 or 144

#	Searches
146	119 and 145
147	remove duplicates from 146

Date of search: 25/09/2017

Database(s): The Cochrane Library, issue 9 of 12, September 2017

ID	Search
#1	MeSH descriptor: [Infant, Newborn] explode all trees
#2	(infan* or neonat* or neo-nat* or newborn* or new-born* or baby or babies or preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie or premies)
#3	((low adj3 birth near/3 weigh*) or (LBW or VLBW))
#4	MeSH descriptor: [Respiratory Distress Syndrome, Newborn] explode all trees
#5	MeSH descriptor: [Intensive Care, Neonatal] explode all trees
#6	MeSH descriptor: [Intensive Care Units, Neonatal] explode all trees
#7	(special care baby unit* or ((newborn or neonatal) near ICU*1) or (SCBU or NICU))
#8	{or #1-#7}
#9	MeSH descriptor: [Family] explode all trees
#10	MeSH descriptor: [Caregivers] this term only
#11	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandmother* or grandfather* or caregiver* or carer*)
#12	{or #9-#11}
#13	#8 and #12
#14	MeSH descriptor: [Stress, Psychological] this term only
#15	(stress* or anxious or anxiet* or worry or worri* or concern*)
#16	MeSH descriptor: [Adaptation, Psychological] explode all trees
#17	MeSH descriptor: [Social Support] explode all trees
#18	MeSH descriptor: [Self-Help Groups] this term only
#19	MeSH descriptor: [Counseling] explode all trees
#20	(counsel* or crisis or crises) .tw.
#21	MeSH descriptor: [Crisis Intervention] this term only
#22	MeSH descriptor: [Vulnerable Populations] explode all trees
#23	MeSH descriptor: [Emotions] explode all trees
#24	((psychological or psychosocial or emotion* or social* or self or crisis) near/2 (support* or adjust* or intervention*))
#25	(family centred or family centered or family integrat* or ward round* or involv* or support* or satisf* or dissatisf* or well being or wellbeing or caregiving or caring or nurtur*)
#26	MeSH descriptor: [Choice Behavior] explode all trees
#27	MeSH descriptor: [Decision Support Techniques] explode all trees
#28	MeSH descriptor: [Decision Making] explode all trees
#29	(choice* or choose* or request* or prefer* or decide* or decision* or seek*)
#30	Professional-Family Relations
#31	MeSH descriptor: [Hospital Design and Construction] this term only
#32	(((hospital* or clinic*1 or unit* or department* or facilit*) near/2 (design* or environment* or comfort*)) or (accommodat* or residen* or living or room*))
#33	MeSH descriptor: [Rooming-in Care] explode all trees
#34	(food or eat* or drink*)
#35	MeSH descriptor: [Parking Facilities] this term only
#36	(parking or transport*)
#37	MeSH descriptor: [Financial Support] this term only
#38	(financ* or cost* or money)
#39	MeSH descriptor: [Child Rearing] explode all trees
#40	(child care or childcare)
#41	{or #14-#40}
#42	#13 and #41 Publication Year from 1990 to 2017

Literature search strategies for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

Date of initial search: 09/10/2017

Database(s): Embase 1980 to 2017 Week 41, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh*).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	or/1-10
12	exp Intensive Care, Neonatal/ use ppez
13	newborn intensive care/ use emez
14	exp Intensive Care Units, Neonatal/ use ppez
15	neonatal intensive care unit/ use emez
16	Neonatal Nursing/ use ppez
17	exp newborn nursing/ use emez
18	newborn care/ use emez
19	(special and care and baby and unit*).tw.
20	((newborn or neonatal or neo-natal) adj ICU*1).tw.
21	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
22	(SCBU or NICU).tw.
23	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
24	or/12-23
25	11 and 24
26	exp Family/ use ppez
27	exp family/ use emez
28	Caregivers/ use ppez
29	caregiver/ use emez
30	(famil* or parent* or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
31	(sibling* or brother* or sister*).tw.
32	or/26-31
33	25 and 32
34	Health Education/mt
35	exp Consumer Health Information/
36	Patient Education as Topic/
37	Patient Education Handout/
38	Communication/
39	Health Communication/
40	Health Promotion/
41	Information Dissemination/
42	exp Access to Information/
43	Professional-Family Relations/
44	Self-Help Groups/
45	exp Peer Group/
46	Charities/
47	Hotlines/
48	Publications/
49	Pamphlets/
50	Video-Audio Media/
51	exp Educational Technology/
52	exp Telephone/
53	exp Internet/
54	Webcasts/
55	exp Videoconferencing/
56	Electronic Mail/
57	Text Messaging/
58	Social Networking/
59	"Instructional Films and Videos"/
60	Computer-Assisted Instruction/
61	or/34-60 use ppez
62	health education/
63	health promotion/
64	breast feeding education/
65	parenting education/
66	patient education/
67	information/

#	Searches
68	information dissemination/
69	consumer health information/
70	patient information/
71	medical information/
72	access to information/
73	interpersonal communication/
74	doctor patient relation/
75	nurse patient relationship/
76	self help/
77	support group/
78	peer group/ or peer counseling/
79	hotline/
80	publication/
81	technology/
82	videotape/
83	television/
84	telephone/
85	exp mobile phone/
86	Internet/
87	webcast/
88	e-mail/
89	text messaging/
90	blogging/
91	social media/
92	videoconferencing/
93	or/62-92 use emez
94	patient education handout.pt.
95	(pamphlet* or leaflet* or book*1 or booklet* or diary or diaries or manual* or brochure* or publication* or handout* or magazine* or binder* or journey box* or video* or dvd* or audio* or "face to face" or "in person").tw.
96	((information* or educat* or neonatal) adj3 (model* or group* or program* or need* or requirement* or support* or seek* or access* or disseminat*)).tw.
97	(learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*).ti.
98	((language* or age* or gender* or cultur* or person* or ethnic*) adj3 (information* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*)).ti.
99	((timing or frequency or access* or availab* or equal*) and (inform* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or consult* or involvement or support* or counsel* or discuss*)).tw.
100	charit*.tw.
101	(hotline* or call line or helpline* or telephone* or phone* or smartphone* or mobile* or email* or texting or messaging or skype or facetime or teleconferenc* or videoconferenc*).tw.
102	(electronic* or online or on-line or internet or website* or web site* or web page* or webpage* or app*1 or social network* or social media* or facebook* or twitter or blog* or webinar* or webcast* or podcast* or youtube or webcam*).tw.
103	or/94-102
104	61 or 93 or 103
105	33 and 104
106	limit 105 to english language
107	limit 106 to yr="1990 -Current"
108	Letter/ use ppez
109	letter.pt. or letter/ use emez
110	note.pt.
111	editorial.pt.
112	Editorial/ use ppez
113	News/ use ppez
114	exp Historical Article/ use ppez
115	Anecdotes as Topic/ use ppez
116	Comment/ use ppez
117	Case Report/ use ppez
118	case report/ or case study/ use emez
119	(letter or comment*).ti.
120	or/108-119
121	randomized controlled trial/ use ppez
122	randomized controlled trial/ use emez
123	random*.ti,ab.
124	or/121-123
125	120 not 124
126	animals/ not humans/ use ppez

#	Searches
127	animal/ not human/ use emez
128	nonhuman/ use emez
129	exp Animals, Laboratory/ use ppez
130	exp Animal Experimentation/ use ppez
131	exp Animal Experiment/ use emez
132	exp Experimental Animal/ use emez
133	exp Models, Animal/ use ppez
134	animal model/ use emez
135	exp Rodentia/ use ppez
136	exp Rodent/ use emez
137	(rat or rats or mouse or mice).ti.
138	or/125-137
139	107 not 138
140	Meta-Analysis/
141	Meta-Analysis as Topic/
142	systematic review/
143	meta-analysis/
144	(meta analy* or metanaly* or metaanaly*).ti,ab.
145	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
146	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
147	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
148	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
149	(search* adj4 literature).ab.
150	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
151	cochrane.jw.
152	((pool* or combined) adj2 (data or trials or studies or results)).ab.
153	or/140-141,144,146-151 use ppez
154	or/142-145,147-152 use emez
155	or/153-154
156	Qualitative Research/ use ppez
157	qualitative research/ use emez
158	Interview/ use ppez
159	exp interview/ use emez
160	(theme* or thematic).mp.
161	qualitative.af.
162	Nursing Methodology Research/ use ppez
163	nursing methodology research/ use emez
164	questionnaire*.mp.
165	ethnological research.mp.
166	ethnograph*.mp.
167	ethnonursing.af.
168	phenomenol*.af.
169	(grounded adj (theor* or study or studies or research or analys?s)).af.
170	(life stor* or women* stor* or men* stor* or people* stor* or person* stor*).mp.
171	(emic or etic or hermeneutic* or heuristic* or semiotic*).af. or (data adj1 saturat*).tw. or participant observ*.tw.
172	(social construct* or (postmodern* or post-structural*) or (post structural* or poststructural*) or post modern* or post-modern* or feminis* or interpret*).mp.
173	(action research or cooperative inquir* or co operative inquir* or co-operative inquir*).mp.
174	(humanistic or existential or experiential or paradigm*).mp.
175	(field adj (study or studies or research)).tw.
176	human science.tw.
177	biographical method.tw.
178	theoretical sampl*.af.
179	((purpos* adj4 sampl*) or (focus adj group*)).af.
180	(account or accounts or unstructured or open-ended or open ended or text* or narrative*).mp.
181	(life world or life-world or conversation analys?s or personal experience* or theoretical saturation).mp.
182	((lived or life) adj experience*).mp.
183	cluster sampl*.mp.
184	observational method*.af.
185	content analysis.af.
186	(constant adj (comparative or comparison)).af.
187	((discourse* or discurs*) adj3 analys?s).tw.
188	narrative analys?s.af.
189	heidegger*.tw.
190	colaizzi*.tw.
191	spiegelberg*.tw.
192	(van adj manen*).tw.
193	(van adj kaam*).tw.

#	Searches
194	(merleau adj ponty*).tw.
195	husserl*.tw.
196	foucault*.tw.
197	(corbin* adj2 strauss*).tw.
198	glaser*.tw.
199	or/156-198
200	155 or 199
201	139 and 200
202	remove duplicates from 201

1 Date of initial search: 09/10/2017

2 Database(s): AMED (Allied and Complementary Medicine) 1985 to September 2017,
3 Maternity & Infant Care Database (MIDIRS) 1971 to September 2017, PsycINFO 1806 to
4 October Week 1 2017

#	Searches
1	Premature Birth/ or Neonatal Period/ or Birth Weight/
2	1 use psyh
3	exp Infant Newborn/ use amed
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	(low adj3 birth adj3 weigh*).tw.
7	(LBW or VLBW).tw.
8	or/2-7
9	Neonatal Intensive Care/ use psyh
10	Intensive Care Neonatal/ use amed
11	(special and care and baby and unit*).tw.
12	((newborn or neonatal or neo-natal) adj ICU*1).tw.
13	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
14	(SCBU or NICU).tw.
15	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
16	or/9-15
17	8 and 16
18	exp Family/ or exp Family Members/ or exp Family Relations/ or Caregivers/
19	18 use psyh
20	exp Family/ use amed
21	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
22	(sibling* or brother* or sister*).tw.
23	or/18-22
24	17 and 23
25	exp Health Education/ use psyh
26	exp health education/ use amed
27	Client Education/ use psyh
28	exp Communication/ use psyh
29	exp Communication/ use amed
30	exp Health Complaints/ use psyh
31	exp Health Promotion/ use psyh
32	Health Promotion/ use amed
33	Information Dissemination/ use psyh
34	Information Seeking/ use psyh
35	Professional-Family Relations/ use amed
36	Self-Help Groups/ use amed
37	Support Groups/ use psyh
38	Peers/ use psyh

#	Searches
39	Peer Group/ use amed
40	Charities/ use amed
41	Organizations/ use psyh
42	Hot Line Services/ use psyh
43	Hotlines/ use amed
44	exp Communications Media/ use psyh
45	exp Communications Media/ use amed
46	Internet/ or Websites/ or Blog/ or exp Social Media/
47	46 use psyh
48	Text Messaging/ or exp Mobile Devices/
49	48 use psyh
50	Instructional Media/ or Audiovisual Instruction/ or Computer-Assisted Instruction/
51	50 use psyh
52	Computer Assisted Instruction/ use amed
53	Parent Training/ or Parenting Skills/
54	53 use psyh
55	Patient Education/ use amed
56	or/25-45,47,49,51-52,54-55
57	(pamphlet* or leaflet* or book*1 or booklet* or diary or diaries or manual* or brochure* or publication* or handout* or magazine* or binder* or journey box* or video* or dvd* or audio* or "face to face" or "in person").tw.
58	((information* or educat* or neonatal) adj3 (model* or group* or program* or need* or requirement* or support* or seek* or access* or disseminat*)).tw.
59	(learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*).ti.
60	((language* or age* or gender* or cultur* or person* or stage* of life or life stage* or lifestyle* or leisure) adj3 (information* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*)).ti.
61	((timing or frequency or access* or availab* or equal*) and (inform* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or consult* or involvement or support* or counsel* or discuss*)).tw.
62	charit*.tw.
63	(hotline* or call line or helpline* or telephone* or phone* or smartphone* or mobile* or texting or messaging or skype or facetime or videoconferenc*).tw.
64	(electronic* or online or on-line or internet or website* or web site* or web page* or webpage* or app*1 or social network* or social media* or facebook* or twitter or blog* or webinar* or webcast* or podcast* or youtube or webcam*).tw.
65	or/57-64
66	56 or 65
67	24 and 66
68	limit 67 to english language [Limit not valid in MWIC; records were retained]
69	limit 68 to yr="1990 -Current"
70	Qualitative Research/ use psyh
71	qualitative.tw.
72	interview*.tw.
73	(theme* or thematic).tw.
74	questionnaire*.tw.
75	(ethnological research or ethnograph* or ethnonursing or phenomenol*).tw.
76	(grounded adj (theor* or study or studies or research or analys?s)).tw.
77	(life stor* or women* stor* or men* stor* or people* stor* or person* stor*).tw.
78	(emic or etic or hermeneutic* or heuristic* or semiotic*).af. or (data adj1 saturat*).tw. or participant observ*.tw.
79	(social construct* or (postmodern* or post-structural*) or (post structural* or poststructural*) or post modern* or post-modern* or feminis* or interpret*).tw.
80	(action research or cooperative inquir* or co operative inquir* or co-operative inquir*).tw.
81	(humanistic or existential or experiential or paradigm*).tw.
82	(field adj (study or studies or research)).tw.

#	Searches
83	(human science or biographical method or theoretical sampl*).tw.
84	((purpos* adj4 sampl*) or (focus adj group*)).tw.
85	(account or accounts or unstructured or open-ended or open ended or text* or narrative* or life world or life-world or conversation analys?s or personal experience* or theoretical saturation).tw.
86	((lived or life) adj experience*).tw.
87	(cluster sampl* or observational method* or content analysis or (constant adj (comparative or comparison))).tw.
88	(((discourse* or discurs*) adj3 analys?s) or narrative analys?s).tw.
89	or/70-88
90	Meta Analysis/ use psyh
91	Meta Analysis/ use amed
92	(meta analy* or metanaly* or metaanaly*).tw.
93	((systematic* or evidence*) adj2 (review* or overview*)).tw.
94	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
95	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
96	(search* adj4 literature).ab.
97	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
98	cochrane.jw.
99	((pool* or combined) adj2 (data or trials or studies or results)).ab.
100	or/90-99
101	89 or 100
102	69 and 101
103	remove duplicates from 102

1 Date of initial search: 10/10/2017

2 Database(s): EBSCO Host CINAHL Plus

#	Query
S63	S41 AND S62
S62	S54 OR S61
S61	S55 OR S56 OR S57 OR S58 OR S59 OR S60
S60	AB ((pool* or combined) N2 (data or trials or studies or results))
S59	(MH "Cochrane Library")
S58	AB (reference list* or bibliograph* or hand search* or manual search* or relevant journals) OR (search* N4 literature) OR (search strategy or search criteria or systematic search or study selection or data extraction) or (medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit)
S57	TX ((systematic or evidence) N2 (review* or overview*))
S56	TX (meta analy* or metanaly* or metaanaly*)
S55	(MH "Systematic Review") OR (MH "Meta Analysis")
S54	S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53
S53	TX (constant N1 (comparative or comparison))
S52	TX ((discourse* or discurs or narrative)* N3 analys?s)
S51	TX (focus group or account or accounts or unstructured or open-ended or open ended or text* or narrative* or life world or life-world or conversation analys?s or personal experience* or theoretical saturation or life world or life-world or conversation analys?s or personal experience* or theoretical saturation or lived experience* or life experience* or cluster sampl* or theme* or thematic or observational method* or questionnaire* or content analysis)
S50	TX (biographical method or theoretical sampl* or (purpos* N4 sampl*))
S49	TX (field N1(study or studies or research))
S48	TX (social construct* or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or interpret* or action research or cooperative inquir* or co operative inquir* or co-operative inquir* or humanistic or existential or experiential or paradigm*)
S47	TX ((emic or etic or hermeneutic* or heuristic* or semiotic*) or (data near saturat*) or participant observ*)
S46	TX (life stor* or women* stor* or men* stor* or people* stor* or person* stor*)
S45	TX (ethnonursing or ethnograph* or phenomenol* or (grounded N1 (theor* or study or studies or research or analys?s))
S44	(MH "Grounded Theory") OR (MH "Research, Nursing") OR (MH "Field Studies") OR (MH "Theoretical Sample") OR (MH "Phenomenological Research") OR (MH "Life Experiences+") OR (MH "Cluster Sample+")
S43	(MH "Interviews+") OR (MH "Questionnaires+") OR (MH "Focus Groups") OR (MH "Observational Methods+") OR (MH "Discourse Analysis") OR (MH "Content Analysis") OR (MH "Ethnographic Research") OR (MH "Ethnological Research") OR (MH "Ethnonursing Research") OR (MH "Constant Comparative Method") OR (MH "Qualitative Validity+") OR (MH "Purposive Sample")
S42	(MH "Qualitative Studies+")

#	Query
S41	S19 AND S40
S40	S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39
S39	TI (electronic* or online or on-line or internet or website* or web site* or web page* or webpage* or app or apps or social network* or social media* or facebook* or twitter or blog* or webinar* or webcast* or podcast* or youtube or webcam*)
S38	TI (charit* or hotline* or call line or helpline* or telephone* or phone* or smartphone* or mobile* or email* or texting or messaging or skype or facetime or teleconferenc* or videoconferenc*)
S37	TI ((timing or frequency or access* or availab* or equal*) and (inform* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or consult* or involvement or support* or counsel* or discuss*))
S36	TI ((language* or age* or gender* or cultur* or person* or ethnic*) N (information* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*))
S35	TI (learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*)
S34	TI ((information* or educat* or neonatal) N (model* or group* or program* or need* or requirement* or support* or seek* or access* or disseminat*))
S33	TI (pamphlet* or leaflet* or book*1 or booklet* or diary or diaries or manual* or brochure* or publication* or handout* or magazine* or binder* or journey box* or video* or dvd* or audio* or "face to face" or "in person")
S32	(MH "Computer Assisted Instruction")
S31	(MH "Communications Media") OR (MH "Audiorecording") OR (MH "Videorecording") OR (MH "Social Media") OR (MH "Webcasts") OR (MH "Telecommunications+") OR (MH "Audiovisuals")
S30	(MH "Information Resources+")
S29	(MH "Telephone Information Services")
S28	(MH "Support Groups") or (MH "Peer Group") or (MH "Charities")
S27	(MH "Professional-Family Relations")
S26	(MH "Information Needs")
S25	(MH "Access to Information+")
S24	(MH "Selective Dissemination of Information")
S23	(MH "Parental Notification") OR (MM "Communication")
S22	(MM "Patient Education")
S21	(MM "Consumer Health Information")
S20	(MM "Health Education")
S19	S14 AND S18
S18	S15 OR S16 OR S17
S17	TX (famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*)
S16	(MH "Caregivers")
S15	(MH "Family+")
S14	S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
S13	TX TX ((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie or premies) N (unit* or care or department* or facilit* or hospital*))
S12	TX (SCBU or NICU)
S11	TX ((newborn or neonat* or neo-nat*) near (unit or care or department* or facilit* or hospital* or ICU*))
S10	TX (special and care and baby and unit*)
S9	(MH "Intensive Care Units, Neonatal")
S8	(MH "Intensive Care, Neonatal+")
S7	S1 OR S2 OR S3 OR S4 OR S6
S6	S1 AND S5
S5	(MH "Respiratory Distress Syndrome+")
S4	TX (low birth weight or very low birth weight)
S3	(MH "Infant, Low Birth Weight+")
S2	TX (infan* or neonat* or neo-nat* or newborn* or baby or babies or preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie or premies)
S1	(MH "Infant, Newborn+")

1 Date of initial search: 10/10/2017

2 Database(s): Wiley Web of Science Social Science Citation Index (SSCI) 1900 to present

#	Searches
#35	#34 AND #21 DocType=All document types; Language=English;
#34	#33 OR #30 DocType=All document types; Language=English;
#33	#32 OR #31 DocType=All document types; Language=English;

#	Searches
#32	TS=((reference list* or bibliograph* or hand search* or manual search* or relevant journals or search strategy or search criteria or systematic search or study selection or data extraction or medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit) or (search* NEAR literature)) DocType=All document types; Language=English;
#31	TS=((meta analy* or metanaly* or metaanaly*) or ((systematic* or evidence*) NEAR (review* or overview*)) or ((pool* or combined) NEAR (data or trials or studies or results))) DocType=All document types; Language=English;
#30	#29 OR #28 OR #27 OR #26 OR #25 OR #24 OR #23 OR #22 DocType=All document types; Language=English;
#29	TS=((constant NEAR (comparative or comparison)) or ((discourse* or discurs*) NEAR analys?s)) DocType=All document types; Language=English;
#28	TS=((lived or life) NEAR experience*) DocType=All document types; Language=English;
#27	TS=((purpos* NEAR sampl*) or (focus NEAR group*)) DocType=All document types; Language=English;
#26	TS=(field NEAR (study or studies or research)) DocType=All document types; Language=English;
#25	TS=(social construct* or (postmodern* or post-structural*) or (post structural* or poststructural*) or post modern* or post-modern* or feminis* or interpret*) DocType=All document types; Language=English;
#24	TS=((emic or etic or hermeneutic* or heuristic* or semiotic*) or (data NEAR saturat*) or participant observ*) DocType=All document types; Language=English;
#23	TS=(grounded NEAR (theor* or study or studies or research or analys?s)) DocType=All document types; Language=English;
#22	TS=(qualititative or interview* or questionnaire* or theme* or thematic or ethnograph* or ethnonurs* or phenomenol* or action research or cooperative inquir* or co operative inquir* or co-operative inquir* or humanistic or existential or experiential or paradigm* or human science or biographical method or theoretical sampl* or account or accounts or unstructured or open-ended or open ended or text* or narrative* or life world or life-world or conversation analys?s or personal experience* or theoretical saturation or cluster sampl* or observational method* or content analysis or narrative analys?s) DocType=All document types; Language=English;
#21	#20 AND #12 DocType=All document types; Language=English;
#20	#19 OR #18 OR #17 OR #16 OR #15 OR #14 OR #13 DocType=All document types; Language=English;
#19	TS=(electronic* or online or on-line or internet or website* or web site* or web page* or webpage* or app*1 or social network* or social media* or facebook* or twitter or blog* or webinar* or webcast* or podcast* or youtube or webcam*) DocType=All document types; Language=English;
#18	TS=(charit* or hotline* or call line or helpline* or telephone* or phone* or smartphone* or mobile* or email* or texting or messaging or skype or facetime or teleconferenc* or videoconferenc*) DocType=All document types; Language=English;
#17	TS=((timing or frequency or access* or availab* or equal*) and (inform* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or consult* or involvement or support* or counsel* or discuss*)) DocType=All document types; Language=English;
#16	TI=((language* or age* or gender* or cultur* or ethnic*) NEAR (information* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*)) DocType=All document types; Language=English;
#15	TI=(learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*) DocType=All document types; Language=English;
#14	TS=((information* or educat* or neonatal) NEAR (model* or group* or program* or need* or requirement* or support* or seek* or access* or disseminat*)) DocType=All document types; Language=English;
#13	TS=(pamphlet* or leaflet* or book or books or booklet* or diary or diaries or manual* or brochure* or publication* or handout* or magazine* or periodical* or binder* or journey box* or video* or dvd* or audio* or "face to face" or "in person") DocType=All document types; Language=English;
#12	#11 AND #10 DocType=All document types; Language=English;

#	Searches
#11	TS=(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer* or sibling* or brother* or sister*) DocType=All document types; Language=English;
#10	#9 AND #4 DocType=All document types; Language=English;
#9	#8 OR #7 OR #6 OR #5 DocType=All document types; Language=English;
#8	TS=((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie or pre?mies) NEAR (unit* or care or department* or facilit* or hospital*)) DocType=All document types; Language=English;
#7	TS=(SCBU or NICU) DocType=All document types; Language=English;
#6	TS=((newborn or neonat* or neo-nat*) NEAR (unit or care or department* or facilit* or hospital* or ICU*)) DocType=All document types; Language=English;
#5	TS=(special and care and baby and unit*) DocType=All document types; Language=English;
#4	#3 OR #2 OR #1 DocType=All document types; Language=English;
#3	TS=(low birth weight) DocType=All document types; Language=English;
#2	TS=(preterm or pre-term or prematur* or pre-matur* or pre?mie or pr?emies) DocType=All document types; Language=English;
#1	TS=(infan* or neonat* or neo-nat* or newborn* or baby or babies) DocType=All document types; Language=English;

1 **Qualitative and health economics**

2 Date of initial search: 09/10/2017

3 Database(s): The Cochrane Library, issue 10 of 12, October 2017

ID	Search
#1	MeSH descriptor: [Infant, Newborn] explode all trees
#2	(infan* or neonat* or neo-nat* or newborn* or new-born* or baby or babies or preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie or premies)
#3	((low adj3 birth near/3 weigh*) or (LBW or VLBW))
#4	MeSH descriptor: [Respiratory Distress Syndrome, Newborn] explode all trees
#5	MeSH descriptor: [Intensive Care, Neonatal] explode all trees
#6	MeSH descriptor: [Intensive Care Units, Neonatal] explode all trees
#7	(special care baby unit* or ((newborn or neonatal) near ICU*1) or (SCBU or NICU))
#8	{or #1-#7}
#9	MeSH descriptor: [Family] explode all trees
#10	MeSH descriptor: [Caregivers] this term only
#11	(famil* or parent? or parental or mother* or maternal or father* or paternal or grandparent* or grandmother* or grandfather* or caregiver* or carer*)
#12	{or #9-#11}
#13	#8 and #12
#14	MeSH descriptor: [Health Education] explode all trees and with qualifier(s): [Methods - MT]
#15	MeSH descriptor: [Consumer Health Information] explode all trees
#16	MeSH descriptor: [Patient Education as Topic] this term only
#17	MeSH descriptor: [Patient Education Handout] this term only
#18	MeSH descriptor: [Communication] this term only
#19	MeSH descriptor: [Health Communication] this term only
#20	MeSH descriptor: [Health Promotion] this term only
#21	MeSH descriptor: [Information Dissemination] this term only
#22	MeSH descriptor: [Access to Information] explode all trees
#23	MeSH descriptor: [Professional-Family Relations] this term only
#24	MeSH descriptor: [Self-Help Groups] this term only
#25	MeSH descriptor: [Peer Group] explode all trees

ID	Search
#26	MeSH descriptor: [Charities] explode all trees
#27	MeSH descriptor: [Hotlines] explode all trees
#28	MeSH descriptor: [Publications] explode all trees
#29	MeSH descriptor: [Pamphlets] this term only
#30	MeSH descriptor: [Video-Audio Media] explode all trees
#31	MeSH descriptor: [Educational Technology] explode all trees
#32	MeSH descriptor: [Telephone] explode all trees
#33	MeSH descriptor: [Internet] explode all trees
#34	MeSH descriptor: [Videoconferencing] explode all trees
#35	MeSH descriptor: [Computer-Assisted Instruction] explode all trees
#36	(pamphlet* or leaflet* or book or books or booklet* or diary or diaries or manual or manuals or brochure* or publication* or handout* or magazine* or periodical* or binder* or journey box* or video* or dvd* or audio* or "face to face" or "in person"):ti
#37	((information* or educat* or neonatal) next (model* or group* or program* or need* or requirement* or support* or seek* or access* or disseminat*)):ti
#38	(learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*):ti
#39	((language* or age* or gender* or cultur* or stage* of life or life stage* or lifestyle*) next (information* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*)):ti
#40	((timing or frequency or access* or availab* or equal*) and (inform* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or consult* or involvement or support* or counsel* or discuss*)):ti
#41	charit*
#42	(hotline* or call line or helpline* or telephone* or phone* or smartphone* or mobile* or texting or messaging or skype or facetime or teleconferenc* or videoconferenc*):ti
#43	(electronic* or online or on-line or internet or website* or web site* or web page* or webpage* or email* or app*1 or social network* or social media* or facebook* or twitter or blog* or webinar* or webcast* or podcast* or youtube or webcam*):ti
#44	{or #14-#43}
#45	#13 and #44 Publication Year from 1990 to 2017, in Cochrane Reviews (Reviews and Protocols), Other Reviews, Technology Assessments and Economic Evaluations

1 **Health economics**

2 Date of initial search: 09/10/2017

3 Database(s): Embase 1980 to 2017 Week 41, Ovid MEDLINE(R) Epub Ahead of Print, In-
4 Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R)
5 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh*).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	or/1-10
12	exp Intensive Care, Neonatal/ use ppez
13	newborn intensive care/ use emez
14	exp Intensive Care Units, Neonatal/ use ppez
15	neonatal intensive care unit/ use emez

#	Searches
16	Neonatal Nursing/ use ppez
17	exp newborn nursing/ use emez
18	newborn care/ use emez
19	(special and care and baby and unit*).tw.
20	((newborn or neonatal or neo-natal) adj ICU*1).tw.
21	((newborn or neonat* or neo-nat*) adj2 (unit or care or department* or facilit* or hospital*)).tw.
22	(SCBU or NICU).tw.
23	((infan* or baby or babies or preterm or pre-term or prematur* or pre?mie* or premie*1) adj2 (unit* or care or department* or facilit* or hospital*)).tw.
24	or/12-23
25	11 and 24
26	exp Family/ use ppez
27	exp family/ use emez
28	Caregivers/ use ppez
29	caregiver/ use emez
30	(famil* or parent* or mother* or maternal or father* or paternal or grandparent* or grandfather* or grandmother* or caregiver* or carer*).tw.
31	(sibling* or brother* or sister*).tw.
32	or/26-31
33	25 and 32
34	Health Education/mt
35	exp Consumer Health Information/
36	Patient Education as Topic/
37	Patient Education Handout/
38	Communication/
39	Health Communication/
40	Health Promotion/
41	Information Dissemination/
42	exp Access to Information/
43	Professional-Family Relations/
44	Self-Help Groups/
45	exp Peer Group/
46	Charities/
47	Hotlines/
48	Publications/
49	Pamphlets/
50	Video-Audio Media/
51	exp Educational Technology/
52	exp Telephone/
53	exp Internet/
54	Webcasts/
55	exp Videoconferencing/
56	Electronic Mail/
57	Text Messaging/
58	Social Networking/
59	"Instructional Films and Videos"/
60	Computer-Assisted Instruction/
61	or/34-60 use ppez
62	health education/
63	health promotion/
64	breast feeding education/
65	parenting education/
66	patient education/

#	Searches
67	information/
68	information dissemination/
69	consumer health information/
70	patient information/
71	medical information/
72	access to information/
73	interpersonal communication/
74	doctor patient relation/
75	nurse patient relationship/
76	self help/
77	support group/
78	peer group/ or peer counseling/
79	hotline/
80	publication/
81	technology/
82	videotape/
83	television/
84	telephone/
85	exp mobile phone/
86	Internet/
87	webcast/
88	e-mail/
89	text messaging/
90	blogging/
91	social media/
92	videoconferencing/
93	or/62-92 use emez
94	patient education handout.pt.
95	(pamphlet* or leaflet* or book*1 or booklet* or diary or diaries or manual* or brochure* or publication* or handout* or magazine* or binder* or journey box* or video* or dvd* or audio* or "face to face" or "in person").tw.
96	((information* or educat* or neonatal) adj3 (model* or group* or program* or need* or requirement* or support* or seek* or access* or disseminat*)).tw.
97	(learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*).ti.
98	((language* or age* or gender* or cultur* or person* or stage* of life or life stage* or lifestyle* or leisure) adj3 (information* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or involvement or support* or counsel*)).ti.
99	((timing or frequency or access* or availab* or equal*) and (inform* or educat* or learn* or train* or program* or advi?e* or instruct* or teach* or knowledge or understanding or misunderstanding or communicat* or miscommunicat* or consult* or involvement or support* or counsel* or discuss*)).tw.
100	charit*.tw.
101	(hotline* or call line or helpline* or telephone* or phone* or smartphone* or mobile* or texting or messaging or skype or facetime or videoconferenc*).tw.
102	(electronic* or online or on-line or internet or website* or web site* or web page* or webpage* or app*1 or social network* or social media* or facebook* or twitter or blog* or webinar* or webcast* or podcast* or youtube or webcam*).tw.
103	or/94-102
104	61 or 93 or 103
105	33 and 104
106	limit 105 to english language
107	limit 106 to yr="1990 -Current"
108	Letter/ use ppez
109	letter.pt. or letter/ use emez
110	note.pt.
111	editorial.pt.

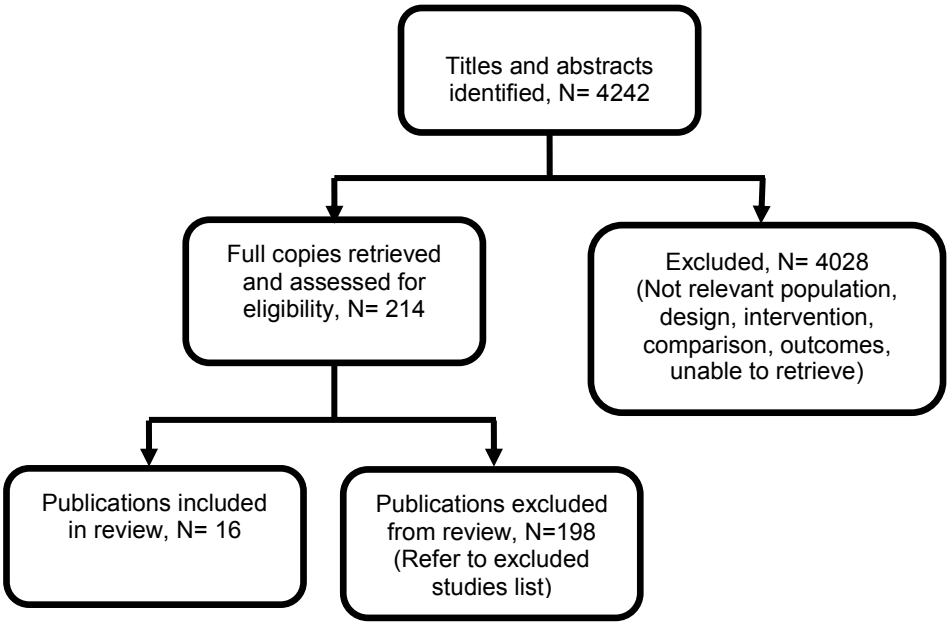
#	Searches
112	Editorial/ use ppez
113	News/ use ppez
114	exp Historical Article/ use ppez
115	Anecdotes as Topic/ use ppez
116	Comment/ use ppez
117	Case Report/ use ppez
118	case report/ or case study/ use emez
119	(letter or comment*).ti.
120	or/108-119
121	randomized controlled trial/ use ppez
122	randomized controlled trial/ use emez
123	random*.ti,ab.
124	or/121-123
125	120 not 124
126	animals/ not humans/ use ppez
127	animal/ not human/ use emez
128	nonhuman/ use emez
129	exp Animals, Laboratory/ use ppez
130	exp Animal Experimentation/ use ppez
131	exp Animal Experiment/ use emez
132	exp Experimental Animal/ use emez
133	exp Models, Animal/ use ppez
134	animal model/ use emez
135	exp Rodentia/ use ppez
136	exp Rodent/ use emez
137	(rat or rats or mouse or mice).ti.
138	or/125-137
139	107 not 138
140	Economics/
141	Value of life/
142	exp "Costs and Cost Analysis"/
143	exp Economics, Hospital/
144	exp Economics, Medical/
145	Economics, Nursing/
146	Economics, Pharmaceutical/
147	exp "Fees and Charges"/
148	exp Budgets/
149	or/140-148 use ppez
150	health economics/
151	exp economic evaluation/
152	exp health care cost/
153	exp fee/
154	budget/
155	funding/
156	or/150-155 use emez
157	budget*.ti,ab.
158	cost*.ti.
159	(economic* or pharmaco?economic*).ti.
160	(price* or pricing*).ti,ab.
161	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
162	(financ* or fee or fees).ti,ab.
163	(value adj2 (money or monetary)).ti,ab.

#	Searches
164	or/157-162
165	149 or 156 or 164
166	139 and 165
167	remove duplicates from 166

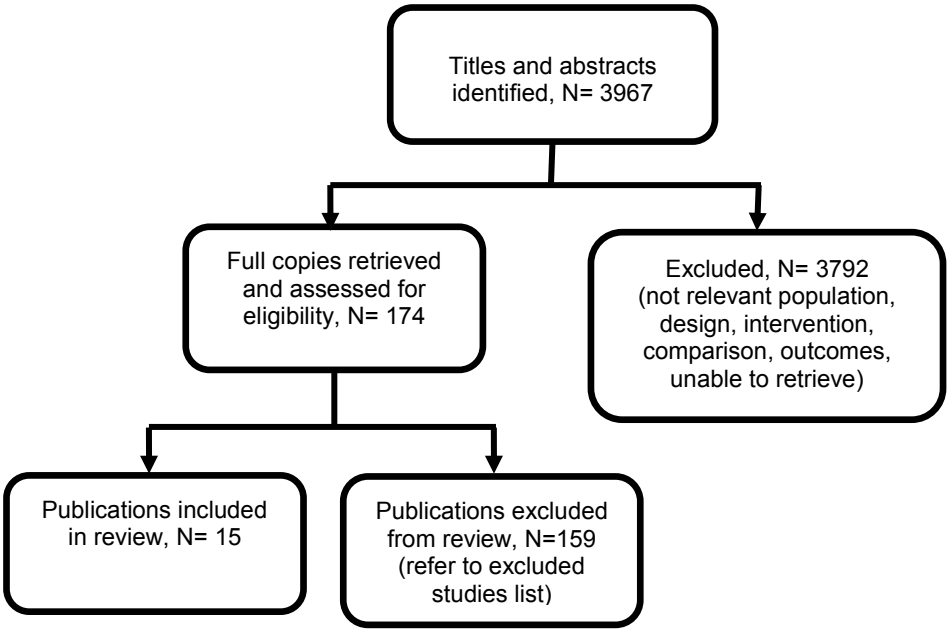
1
2

Appendix C – Clinical evidence study selection

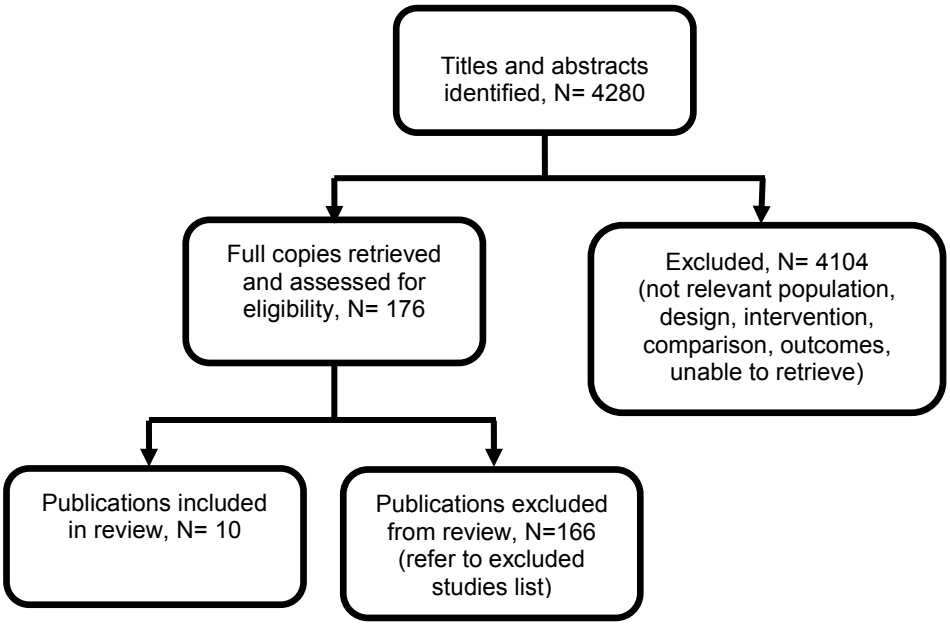
Clinical evidence study selection for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?



Clinical evidence study selection for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?



Clinical evidence study selection for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?



Appendix D – Clinical evidence tables

Clinical evidence tables for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation Als, H, Duffy, Fh, McAnulty, Gb, Rivkin, Mj, Vajapeyam, S, Mulkern, Rv, Warfield, Sk, Huppi, Ps, Butler, Sc, Conneman, N, Fischer, C, Eichenwald, Ec, Early experience alters brain function and structure, Pediatrics, 113, 846-57, 2004 **Ref Id** 697615 **Country/ies where the study was carried out** USA **Study type** RCT	**Sample size** N=30 NIDCAP® = 16 Control (standard care) = 14 **Characteristics** Groups similar for birthweight, gestational age at birth, head circumference, Apgar score, fraction of inspired oxygen, mechanical ventilator use, maternal age, obstetric complications scales scores, PDA, prenatal corticosteroids, parents marital status, first born, gender, race, vaginal delivery and social class **Inclusion criteria** • residence in the greater Boston area • mothers >14 y • absence of major maternal medical or psychiatric illness,	**Interventions** **NIDCAP® group** See Als 1994 **Control group** Standard care that included primary care nursing, parent inclusion, and developmental care (uniform shielding of incubators with white hospital blankets, early use of dressing in T-shirts, side and foot rolls; liberal provision of pacifiers; encouragement of skin-to-skin holding/kangaroo care and breastfeeding)	**Details** Outcomes were assessed at 2wks and 9 months corrected age	**Results** **No. of days in hospital at 2 weeks corrected age** NIDCAP® n=16 = 40.0 (18.50) Control n=14 = 32.21 (16.6) **Bronchopulmonary dysplasia at 2 weeks corrected age** NIDCAP® = 3/16 Control = 1/14	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Unclear risk (No details provided) Allocation concealment: Low risk (Opaque, pre-numbered, sealed envelope opened by parent) Blinding of participants and personnel: High risk (Staff and parents not blinded to treatment allocation) Blinding of outcome assessment: Low risk (The authors state “Outcome assessment staff was purposefully kept ‘blind’ to the infant’s group assignment.”) Incomplete outcome data: Low risk (all available participant outcomes reported) Selective reporting: Low risk (The study protocol is not available but it is clear that the published reports include all

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Aim of the study 'To investigate the effects of early experience with NIDCAP on brain function and structure.' **Study dates** May 1, 2000 to August 30, 2002 **Source of funding** Supported by National Institutes of Health, US Department of Education and the Whitaker Foundation	chronic maternal medication treatment (e.g., insulin, steroids, thyroid replacement, antidepressants, and anticonvulsants), or any history of maternal substance abuse (including alcohol or tobacco) • accessibility by telephone • some English language • PMA at birth of 28 wk 4 d to 33 wk 3 d • 5-min Apgar score >=7 • weight and head circumference at birth 5th to 95th percentile • normal initial cranial ultrasound(s), MRI, and/or EEG • =<72 h of respiratory support (ventilation or CPAP) and vasopressor medication **Exclusion criteria** • congenital or chromosomal abnormality				expected outcomes, including those that were pre-specified) Other bias: None reported **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
	• congenital or acquired infection • absence of prenatal care • known prenatal brain lesions (e.g., cysts or infarctions), and neonatal seizures				
Full citation Als, H, Gilkerson, L, Duffy, Fh, McAnulty, Gb, Buehler, Dm, Vandenberg, K, Sweet, N, Sell, E, Parad, Rb, Ringer, Sa, Butler, Sc, Blickman, Jg, Jones, Kj, A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: medical, neurodevelopmental, parenting, and caregiving effects, Journal of Developmental and Behavioral Pediatrics, 24, 399-408, 2003	**Sample size** N=234 infants eligible for enrolment to study (BWH n= 107: CHO n= 89: CHB n= 41) 124 did not enrol (37 family refusal, 23 too ill (attending physician decision) 14 enrolled in other studies and for 50 study staff were unavailable because of holiday) N=110 infants successfully enrolled, 18 died N=92 study infants (BWH, 19 control, 18 experimental; CHO 20 control, 16 experimental; CHB 8 control, 11 experimental) **Characteristics** BWH - NIDCAP®: n=18, Standard care: n=19 CHO - NIDCAP® n=16, Standard care: n=20	**Interventions** **Intervention group** NIDCAP® **Controls** Routine care	**Details** NIDCAP® 2 HCPs/NICU were trained in the NIDCAP® model and worked with colleagues and families to jointly plan and implement individualised care and to structure individualised environments supportive of each infant. They conducted regular formal observations (recorded every 2 minutes for approximately 1 hour during an activity) of each infant's behaviour that formed the basis for a weekly report describing the infant's current behavioural functioning and	**Results** Initiation of intervention was up to 5 days after birth. Outcomes were assessed at 2 weeks after the expected date of confinement (EDC) **No. of days in hospital to discharge (Mean, SD)** *BWH* NIDCAP® = 85.9, 18.7 Standard care = 101.3, 20.5 *CHO* NIDCAP® = 105.4, 29.6 Standard care = 148.3 99.5 *CHB* NIDCAP® = 99.7, 21.0 Standard care = 101.3, 15.7	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Unclear risk (Randomisation was performed by each participating centre no further details are provided) Allocation concealment: Unclear risk (No details are provided) Blinding of participants and personnel: High risk (Parents and caregiving staff were not blinded to the intervention) Blinding of outcome assessment: Low risk (All outcome assessments were conducted by trained examiners blind to the treatment allocation)

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Ref Id 697616 **Country/ies where the study was carried out** USA **Study type** RCT **Aim of the study** To investigate early experience on brain function and structure comparing the effects of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP®) with standard care. **Study dates** The study took place over a 26-month period at 3 hospitals:	CHB - NIDCAP®: n=11, Standard care: n=8 **Gestational age at birth, wk (Mean, SD)** BWH NIDCAP® = 26, 1.3 Standard care = 26, 1.3 CHO NIDCAP® = 26, 1.78 Standard care = 26.5, 1.3 CHB NIDCAP® = 26, 1.0 Standard care = 26.2, 1.1 **Birth weight, g (Mean, SD)** BWH NIDCAP® = 797, 151 Standard care = 810, 130 CHO NIDCAP® = 806, 150 Standard care = 877, 207 CHB NIDCAP® = 823, 144 Standard care = 915, 162 **FIO2, first 10 d (Mean, SD)** BWH NIDCAP® = 0.32,0.1 Standard care = 0.36, 0.1 CHO NIDCAP® = 0.38, 0.1 Standard care = 0.36, 0.1 CHB NIDCAP® = 0.33, 0.1 Standard care = 0.31, 0.1 There were no significant differences between the control and experimental groups' infant or parent medical or		suggested ways to promote the infant's stability and competence. Routine care Routine care practiced at the respective nurseries which included: • some incubator shielding • sound containment • breast milk use • PT and OT referral and to community early intervention. BWH used kangaroo care	**Bronchopulmonary dysplasia (assessed by double-blind chest radiographs)** *BWH* NIDCAP® = 15/18 Standard care = 13/19 *CHO* NIDCAP® = 15/18 Standard care = 18/20 *CHB* NIDCAP® =10/11 Standard care = 7/8	Incomplete outcome data: Low risk (, all participant outcomes reported) Selective reporting: Low risk (All outcomes listed a priori are reported in the RCT) Other bias: None reported **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Brigham and Women's Hospital, Children's Hospital Oakland and Children's Hospital Boston (BWH: April 1990–June 1992; CHO: June 1990–September 1992; CHB : April 1990–June 1992). **Source of funding** Supported by grants from National Institutes of Health and US Department of Education.	demographic background characteristics **Inclusion criteria** (1) Birth weight < 1250g (2) GA at birth < 28 weeks (3) mechanical ventilation starting within the first 3 hours after birth (4) mechanical ventilation lasting longer than 24 hours in the first 48 hours (5) alive at 48 hours (6) no chromosomal or other major genetic anomalies and congenital infections (7) single birth (8) at least one family member with some English language **Exclusion criteria** None stated				
Full citation Als, H., Lawhon, G., Duffy, F. H., McAnulty, G. B., Gibes-Grossman, R., Blickman, J. G., Individualized	**Sample size** N=38 **Characteristics** Gestational age at birth, wk (Mean, SD)	**Interventions** **NIDCAP® group** Primary care teams were assigned to the care of infants in the experimental group within 3	**Details** On admission to the NICU, infants were screened for meeting selection criteria. Group status was determined by means of a sealed-envelope	**Results** **No of days in hospital (Mean SD)** NIDCAP® group n=20: 87, 26 Control group n=18:151, 120	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Unclear risk (No details are provided)

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
developmental care for the very low-birth-weight preterm infant: Medical and neurofunctional effects, Journal of the American Medical Association, 272, 853-858, 1994 **Ref Id** 413587 **Country/ies where the study was carried out** USA **Study type** RCT **Aim of the study** To test the impact of individualised development care compared to standard care with treatment initiation at the time of admission **Study dates** No details provided	NIDCAP® group n=20: 27.1, 1.6 Control group n=18: 26.5, 1.4 Birthweight,g (Mean, SD) NIDCAP® group n=20: 872, 173 Control group n=18: 862, 145 Groups similar for birthweight, gestational age at birth, Apgar score, fraction of inspired oxygen, maternal age, obstetric complications scales scores, PDA, prenatal corticosteroids, parents marital status, first born, gender, race, vaginal delivery and social class **Inclusion criteria** All of the following criteria • inborn • birthweight l< 1250 g • < 30 weeks and > 24 weeks of estimated gestational age at birth • mechanical ventilation starting within the first 3 hours after birth and lasting longer than 24 hours in the first 48 hours • alive at 48 hours • no chromosomal or other major genetic anomalies, congenital infections, and known	hours. NIDCAP® trained nurses provided care by using special accessories and performing frequent formal systematic observations of each infant's unique repertoire of behaviours ; observation and documentation of infants' behaviour by a developmental specialist by using the APIB tool within 12 h of admission and then every 10th day (until discharge) that (together with nurses recorded observations of behaviours formed the basis for individualised developmental care recommendations and ongoing clinical support for nurses and parents.	random assignment procedure. Medical and developmental outcomes were assessed at 2 weeks and 9 months after the expected date of confinement (EDC).	**BPD (assessed by double blind review of chest roentgenograms)** NIDCAP® group = 18/20(13 mild, 5 mod) Control group = 15/18 (7 mild, 2 mod, 6 severe) =	Allocation concealment: Unclear risk (Sealed envelopes: opaque or sequentially numbered not detailed) Blinding of participants and personnel: Unclear risk (Author states that control group status was unknown to staff and infants' care was not affected, but this is unlikely) Blinding of outcome assessment: Low risk (Not all outcome assessments were blinded, but BPD was and unlikely to affect hositalisation data) Incomplete outcome data: Low risk (all available participant outcomes reported) Selective reporting: Low risk (The study protocol is not available but it is clear that the published reports include all expected outcomes, including those that were pre-specified) Other bias: None reported **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Source of funding Supported by the National Institute on Disability and Rehabilitation Research, the Early Education Programs for Children With Disabilities, Office ofSpecial Education Programs, US Department of Education; the Merck FamilyFund; and the National Institutes of Health	fetal exposure to drugs of addiction • singleton • at least one family member with some English language • telephone access • living within the greater Boston area **Exclusion criteria** None stated	**Control group** Control group infants received standard NICU care which included a standard developmental protocol, involving • uniform shielding of incubators with blanket covers • use of clothing • a 24-hour visiting policy for the parents Author states 'Control group status was not revealed to staff, nor was staffing for infants in the control group influenced in any way' but this might be			

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
		an unrealistic assessment.			
Full citation Maguire, C. M., Walther, F. J., Sprij, A. J., Le Cessie, S., Wit, J. M., Veen, S., Leiden Developmental Care, Project, Effects of individualized developmental care in a randomized trial of preterm infants <32 weeks, Pediatrics, 124, 1021-30, 2009 **Ref Id** 667219 **Country/ies where the study was carried out** The Netherlands **Study type** RCT (referred to as Maguire 2009a) **Aim of the study**	**Sample size** 164/168 recruited infants met the inclusion criteria NIDCAP® Group n=81 Control group n= 83 **Characteristics** **GA, wk (Mean, SD, Range)** NIDCAP® group n=81; 29.3, 1.8, 24.7–31.9 Control group n= 83: 29.2, 1.6, 25.6–31.6 **Birth weight, g (Mean, SD, Range)** NIDCAP® group n=81; 1215, 328, 577–1939 Control group n= 83: 1226, 343, 625–2060 Infants similar at baseline for gestational age, birth weight, length, head circumference, gender, SGA percentile, twin birth, inborn, Apgar scores at 5 min, CRIB score, RDS, surfactant and hyperbilirubinemia **Inclusion criteria**	**Interventions** NIDCAP® The NIDCAP® intervention consisted of weekly formal behavioural observations of the infants performed by a NIDCAP® trained developmental specialist that informed caregiving recommendations and support for staff members and parents. Accessories were available for infants such as incubator covers and positioning aids. Control Basic developmental care (incubator covers and positioning aids)	**Details** Infants were randomly assigned within 48 hours of birth to treatment group and the first NIDCAP® observation occurred within this time frame. NIDCAP® parents were supported in • in understanding their infant's behaviour • in how to approach and to support their infant during caregiving interactions • in provision of photographic booklets explaining pre-term infant behaviour • daily No formal observations in which the control	**Results** **Length of stay, d(Mean, SD) : Median (range) (defined as length of stay until discharge to home)** NIDCAP® group n=70; 61.9, 24.5 : 58.5(30–285) Control group n= 74:67.6, 34.2 : 57.5(32–159) **In-hospital death, n/N (%)** NIDCAP® group = 8/81(9.9) Control group = 3/83(3.6) **BPD (defined as oxygen dependence after 36 wk of postconceptual age), n/N (%)** NIDCAP® group = 12/80 (15.0) Control group = 16/81 (19.8) **Sepsis, n/N (%)** NIDCAP® group = 38/81(46.9) Control group = 45/83(54.2)	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Low risk (Randomisation was computer-generated) Allocation concealment: Unclear risk (Treatment assignment was performed using sealed envelopes - opacity and sequential numbering not addressed) Blinding of participants and personnel: High risk (Author states that staff and parents were not blinded to treatment allocation) Blinding of outcome assessment: Low risk (Not all outcome assessments were blinded, but this is unlikely to affect the outcomes included here) Incomplete outcome data: Low risk (proportion missing not enough to have a clinically relevant effect)

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
'to investigate the effect of basic elements of developmental care (incubator covers and positioning aids) on days of respiratory support and intensive care, growth, and neuromotor development at term age in infants who were born at 32 weeks' gestation' **Study dates** April 2000 to May 2002 **Source of funding** Supported by the Netherlands Organisation for Health Research and Development and the Health Care Efficiency Research Fund of the Leiden University Medical Centre	One inclusion criterion: GA of <32 weeks **Exclusion criteria** Any of: • major congenital anomalies • a need for major surgery • having a drug-addicted mother Infants in both groups who were admitted for <5 days were excluded from follow-up		infants' behaviour was described were made Discharge from intensive care was based on the infant requiring no mechanical ventilation and/or CPAP therapy for 24 hours and weighing >1000 g. Infants were seen at term age by neonatologists who were experienced in developmental assessments and were blinded to the infants' group assignment.		Selective reporting: Low risk (The study protocol is not available but it is clear that the published reports include all expected outcomes, including those that were pre-specified) Other bias: None reported **Other information** Sample size of 140 infants was needed to show a significant difference (P<0.05) 80% power on the basis of a difference of 0.5 SD in the Bayley II scores at 1 and 2 years of age, which was believed to be sufficient power for the short term primary neonatal outcomes

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation McAnulty, Gb, Duffy, Fh, Butler, Sc, Bernstein, Jh, Zurakowski, D, Als, H, Effects of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) at age 8 years: preliminary data, Clinical Pediatrics, 49, 258-270, 2010 **Ref Id** 699172 **Country/ies where the study was carried out** USA **Study type** Follow up of Als 1994 RCT **Aim of the study** 'To explore the continuity of NIDCAP effectiveness into school age, and to	**Sample size** N=22 NIDCAP® =11 Control = 11 **Characteristics** See Als 1994 **Inclusion criteria** See Als 1994 **Exclusion criteria** See Als 1994	**Interventions** See Als 1994	**Details** See Als 1994	**Results** **Cerebral palsy at 8 years CA** NIDCAP® = 0/11 Control = 1/11 **Hearing loss at 8 years CA** NIDCAP® = 1/11 Control = 1/11	**Limitations** See Als 1994 **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
test the predictability of newborn period brain function measures to school age neuropsychological results.' **Study dates** See Als 1994 **Source of funding** Supported by U.S. Department of Education (NIHR, NIDRR, and NCRI-ECI), a National Institutes of Health and the I. B. Harris Foundation					
Full citation McAnulty, G, Duffy, Fh, Butler, S, Parad, R, Ringer, S, Zurakowski, D, Als, H, Individualized developmental care for a large sample of very preterm infants:	**Sample size** Experimental n=56 Control n=51 **Characteristics** **Inclusion criteria**	**Interventions** see Als 1994 and 2003	**Details** see Als 1994 and 2003	**Results** **Days of hospitalization (mean, SD) at 2 weeks corrected age** NIDCAP® group: n =56 83.59 ± 21.21 Control group: n = 51 127.78± 109.12	**Limitations** **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
health, neurobehaviour and neurophysiology, Acta PaediatricaActa Paediatr, 98, 1920-1926, 2009 **Ref Id** 699173 **Country/ies where the study was carried out** USA **Study type** Synthesis of the results of three RCTs **Aim of the study** To report the results of three RCTs performed at one hospital (Brigham Women's Hospital) **Study dates** Over 8 years in 3 funding phases: phase 1: October 1984–June 1986	see AIs 1994 and 2003 **Exclusion criteria** see AIs 1994 and 2003			**Bronchopulmonary Dysplasia at 2 weeks Corrected Age** NIDCAP® group = 47/56 (Stage I:17, II:24, III:5, IV:1) Control group = 43/51(Stage I:11, II:12, III:17, IV:3) **Bayley Scales of Infant Development at 9m** Mental Developmental Index Severe or moderate neurodevelopmental delay (MDI <84) NIDCAP® group = 9/51 Control group = 22/42 Psychomotor Developmental Index Severe or moderate psychomotor delay (PDI <84) NIDCAP® group = 29/51 Control group = 33⁄42	

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(reported in Als 1994) phase 2:December 1986–March 1988 (previously unreported) phase 3: April 1990–May 1992 (reported in Als 2003 BWH data) **Source of funding**					
Full citation Cruz, M., Ye, X. Y., Mirea, L., Tarnow-Mordi, W., Lee, S. K., O'Brien, K., Lee, S., Bracht, M., Caouette, G., Ng, E., McMillan, D., Ly, L., Dow, K., Taylor, R., Monterrosa, L., Canning, R., Sankaran, K., Bingham, W., Soraisham, A., el Helos, S., Alvaro, R.,	**Sample size** **N = 26 tertiary NICUs from Canada, Australia and New Zealand** FIC n=14 (One site discontinued due to poor site enrolment) Standard care n=12 **N= 1786 babies** FIC n=895 babies at 13 tertiary NICUs Standard care n= 891 babies at 12 tertiary NICUs	**Interventions** **FiC** Each FIC site implementation team attended a 2-day training workshop, which focused on the implementation of FIC principles: - 'a parent education programme with small group	**Details** Sites were stratified by country and size before they were randomly assigned to address possible confounding factors in neonatal practice. **FIC** A written protocol and printed educational and training materials were	**Results** **Mortality** FIC groups:11/895 (1%) Standard care groups: 4/891 (<1%) Adjusted OR* = 2·21 (0·64–7·68); p=0·21 **BPD** FIC groups:167/889 (19%) Standard care groups: 149/887 (19%) Adjusted OR* = 0·80 (0·44 to 1·46); p=0·37	**Limitations** **Quality of study:** **Risk of bias assessed using Cochrane risk of bias tool** Random sequence generation: Low risk (Randomisation was by computer-generated random allocation sequence) Allocation concealment: Low risk (Random assignation of sites to treatment by researcher using computer-generated

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Narvey, M., da Silva, O., Osiovich, H., Emberley, J., Catelin, C., St. Aubin, L., Warkentin, T., Kalapesi, Z., Bodani, J., Lui, K., Kho, G., Kecskes, Z., Stack, J., Schmidt, P., Paradisis, M., Broadbent, R., Raiman, C., Wong, C., Cabot, M., L'Herault, M., Gignac, M. A., Marquis, M. H., Leblanc, M., Travell, C., Furlong, M., Van Bergen, A., Ottenhof, M., Keron, H., Bowley, C., Cross, S., Kozinka, G., Cobham-Richards, V., Northrup, K., Gilbert-Rogers, C., Pidgeon, P., McDuff, K., Leger, N., Thiel, C., Willard, S., Ma, E., Kostecky, L., Pogorzelski, D., Jacob, S., Kwiatkowski, K., Cook, V., Granke, N., Geoghegan-Morphet, N., Bowell, H., Claydon, J., Tucker, N., Lemaitre, T.,	**Characteristics** **Sites:** **FIC:** 10 Canada, 4 Australia and New Zealand **Standard care:** 9 Canada, 3 Australia and New Zealand **Babies:** **Birthweight (g), mean (SD)** FIC group = 1219 (413) Standard care Group = 1264 (419**)** **Gestational age** ***22-28 weeks*** FIC group = 445/895 (50%) Standard care Group = 377/891 (42%) ***29-33 weeks*** FIC group = 450/895 (50%) Standard care Group = 514/891 (58%) **Median age at enrolment (days), mean (SD)** FIC group = 15 (8-28) Standard care Group = 12 (6-23) **Surfactant use** FIC group = 465/895 (52%) Standard care Group = 408/889 (46%)	education sessions, parent coaching at the bedside, and parent involvement in medical rounds - a staff training programme with education about the importance of family involvement in infant care and tools for staff to mentor, coach, and support parents - policies, procedures and environmental resources to operationalise parent involvement in caregiving and support prolonged parental presence in the NICU - a programme of psychosocial support that included peer-to-peer and professional	provided to all FICare sites. A trial coordinator at each site enrolled and supported parents to complete questionnaires. At FIC sites, the trial coordinator also introduced the parents to FIC, supporting and providing the parent education sessions. Parents were taught the infant care skills (such as bathing, feeding, providing skin-to-skin care, dressing, nappy changing, administering oral medications and taking temperature) and how to interact with and support their infant's development. Parents were encouraged to actively join in on ward rounds, chart their infant's growth and progress and take part in clinical care decisions with the medical team.	**Mean duration of hospital stay (days)** FIC groups:50 (1·9) Standard care groups:48 (2·3) Adjusted OR* = 1·12 (0·81–1·54); p=0·51 *Adjusted for gestational age, infant age at enrolment, small for gestational age, singleton status, surfactant use and caesarean delivery	sequence.) Blinding of participants and personnel: Unclear risk (Author states that no masking was performed, although randomisation was as site level minimising the effects of contamination between treatment groups) Blinding of outcome assessment: Low risk (Information is not provided, but this is unlikely to affect 2 of the outcomes included here) Incomplete outcome data: Unclear risk (155/895 discontinued in FIC sites and 259/891 discontinued in standard care sites largely due to transfer, discharge or non-compliance. Unclear risk as ITT analysis includes data for all participants, but although details of how outcomes were collected are not presented, the outcomes included here are unlikely to be affected) Selective reporting: Low risk (The study protocol is available) Other bias: Analyses were performed to account for clustering. Author states 'Many infants included in the intention-to-treat analysis were transferred before receiving 3

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Doyon, M., Ryan, C., Sheils, J., Sibbons, E., Feary, A. M., Callander, I., Richard, R., Orbeso, J., Broom, M., Fox, A., Seuseu, J., Hourigan, J., Schaeffer, C., Mantha, G., Lataigne, M., Robson, K., Whitehead, L., Skinner, N., Visconti, R., Crosland, D., Griffin, K., Griffin, B., Collins, L., Meyer, K., Silver, I., Burnham, B., Freeman, R., Muralt, K., Ramsay, C., McGrath, P., Munroe, M., Hales, D., Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial, The Lancet Child and Adolescent Health, 2, 245-254, 2018 **Ref Id**	**CPAP at enrolment (for research sites that recorded this information)** FIC group = 398/797 (50%) All sites N = 895 Standard care Group = 433/859 (50%) All sites N = 891 **Median duration of oxygen support (days)** FIC group = 4 days (0-36) Standard care Group = 3 days (1-33**)** **Inclusion criteria** For inclusion, NICU units needed to take care of preterm infants of 33 weeks' gestation or less from birth and agree to provide specific resources if assigned to receive the FIC intervention - a rest space and sleep room for the exclusive use of parents **-** comfortable bedside reclining chairs - free parking or transport vouchers - nurses with training on FICare Infants born at 33 weeks GA or less, who had no or low-level respiratory support (defined as 'oxygen by cannula or mask or non-invasive ventilation such as CPAP, biphasic CPAP and	support for families while in the NICU' **Standard Care** No details provided	Parents were also informed about tasks in which they could not actively participate eg, adjustment of the infant's CPAP or oxygen levels. Parents were provided with emotional support, coping strategies, stress-reducing activities, and other assistance through informal peer-to-peer support and veteran parent and social work involvement in the education sessions. Site were visited to ensure adherence to FIC requirements, eg the provision of nurse education to more than 90% of active nursing staff, a satisfactory parent education and support programme. **Standard Care** No details provided		weeks of the FICare intervention' **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
811061 **Country/ies where the study was carried out** Canada, Australia and New Zealand **Study type** Cluster randomised controlled trial of 26 tertiary NICUs **Aim of the study** 'to analyse the effect of FICare on infant and parent outcomes, safety, and resource use' **Study dates** Oct 2012 - Aug 2015 **Source of funding** Canadian Institutes of Health Research Partnerships for Health System Improvement, Canadian Institutes of Health Research Team and	NIPAP ventilation') were included. Parents of babies receiving FIC had to commit to being present for at least 6 hours/day for 5 days/week for 3 weeks for participation in ward rounds and education sessions. **Exclusion criteria** i) receipt of palliative care; ii) major life-threatening congenital anomaly; iii) critical illness and unlikely to survive; iv) on a high level of respiratory support (mechanical ventilation, high-frequency oscillatory or jet ventilation, extra-corporeal membrane oxygenation); v) scheduled for early transfer to another hospital; or vi) parents with an inability to participate due to health, social, or language issues that might inhibit their ability to integrate with the health-care team.				

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Ontario Ministry of Health and Long-Term Care. The authors state that "The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report."					
Full citation Peters, K. L., Rosychuk, R. J., Hendson, L., Cote, J. J., McPherson, C., Tyebkhan, J. M., Improvement of short- and long-term outcomes for very low birth weight infants: Edmonton NIDCAP trial, Pediatrics, 124, 1009-20, 2009 **Ref Id** 398285 **Country/ies where the study was carried out** Canada	**Sample size** N=120 VLBW infants NIDCAP® n=56 (4 deaths) Control n=55 (4 deaths and 1 withdrawal). **Characteristics** Gestational age, wk Mean, SD NIDCAP® n=55 :27.5, 1.4 Control n=55 : 27.0, 2.3 No evidence of a statistically significant difference between groups was found for any maternal or infant demographic characteristic (Maternal age, gravidity, parity, Blishen score, prenatal steroid use, inborn, gestational age, age at randomization, caesarean section, birth weight, gender, Apgar scores, SNAPPE-II score, ventilator support at	**Interventions** NIDCAP® group Infant care by NIDCAP®-educated nurses for half of the time, plus behavioural observations and care plans performed by NIDCAP®-certified staff members approximately every fortnight. Control group Standard NICU care Both groups of infants were cared for in the same nursery, sometimes side by side. Incubator	**Details** Attending neonatologists directed routine care for all infants in both groups, assisted by neonatal nurses and fellows. Infants were transferred to intermediate-care nurseries when they no longer required nasal CPAP therapy and parenteral nutrition, if the study site nursery was full, or if it was more convenient for the family. After transfer, NIDCAP® group infants no longer received the intervention.	**Results** **LOS, d (defined as the number of calendar days spent in the hospital)** **Mean (SD)** NIDCAP® = 75.5 (22.65*) Control = 90.2 (34.18*) **Median (range)** NIDCAP® = 71.5 (40–126) Control = 84.0 (32–169) **Sepsis (defined through positive blood culture results) n/N (%)** NIDCAP® = 20/56 (36) Control = 23/55 (42) **MDI score of <70 (n/N %)** NIDCAP® group = 5/51 (10) Control group = 15/50 (30)	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Low risk (Computer-generated random numbers) Allocation concealment: Low risk (Sequentially sealed, opaque envelopes kept in a locked office) Blinding of participants and personnel: High risk The study could not be blinded Blinding of outcome assessment: Low risk The study could not be blinded but unlikely to affect the outcomes here Incomplete outcome data: Low risk All randomly assigned infants accounted for

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Study type RCT **Aim of the study** To determine the impact of NIDCAP-based care on length of stay of VLBW infants **Study dates** September 1999 to September 2004 **Source of funding** Supported by the Alberta Heritage Foundation of Medical Research; Canadian Lung Association; Canadian Nurses Respiratory Society; Alberta Lung Association; Perinatal Clinical Research Centre, University of Alberta; and Neonatal Research Trust Fund.	randomization, and time ventilated at randomization) **Inclusion criteria** • birth weight 500 to 1250 g • gestational age of <32 weeks • birth weight between the 3rd and 97th percentiles for gestational age • age of 2 to 7 days at the time of study entry **Exclusion criteria** • chromosomal or major congenital anomalies • known maternal alcohol or drug abuse • known congenital infection • decision to withdraw life support before 48 hours of life	covers, positioning devices, and kangaroo care were available for all infants but at nurses' discretion for control infants		**CLD, n/N (%)(defined as the need for supplemental oxygen to maintain oxygen saturation levels of 92% to 96%, at 36 weeks GA)** NIDCAP® group = 16/56 (29) Control group = 27/55 (49) **CP** NIDCAP® group = 0/51 (0) Control group = 3/50 (6) **Mortality prior to discharge** NIDCAP® group = 4/60 (IVH, Meningitis, CLD, aspiration pneumonia) Control group = 4/60 (IVH, Meningitis, CLD, NEC) *SDs identified from Ohlsson 2016 systematic review	Selective reporting: Unclear risk (Potential differences in the original protocol submitted post-recruitment (2004) and the registered protocol (submitted 2007)) Other bias: None reported **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation Roberts, K. L., Paynter, C., McEwan, B., A comparison of kangaroo mother care and conventional cuddling care, Neonatal network : NN, 19, 31-35, 2000 **Ref Id** 699608 **Country/ies where the study was carried out** Australia **Study type** RCT **Aim of the study** to examine 6 hypotheses regarding kangaroo care and maternal and infant outcomes	**Sample size** N=30 **Characteristics** Infant age and weight at trial entry: Mean age at recruitment was 31.5 ± 2.7 days and mean weight was 1690 ± 333 g, respectively **Inclusion criteria** Premature or small for gestational age infants born at 30 or more weeks' gestation or corrected age, with 5-minute Apgar of ≥ 5, medically stable, without congenital abnormalities or central nervous system impairment. Infants could have received nasal continuous positive airway pressure in place or a nasal cannula **Exclusion criteria** Phototherapy within previous 24 hours, resuscitated infants, mothers with a history of drug use	**Interventions** KMC group: Infants were dressed in only a diaper, with a bonnet added for smaller infants. They were placed on the mother's skin and covered with a light blanket. Mean duration of KMC was 1.6 ± 0.9 hours per day, 5 days a week (n = 16) Control group: Infants were swaddled in infant clothing and a light blanket. They had contact with the mother only through normal clothing (n = 14)	**Details** Breastfeeding was permitted as desired in both groups Level of care: neonatal intensive care nurseries of 2 hospitals Human resources: doctors and nurses Criteria for infant discharge from the hospital: unreported Scheme for follow-up of infants after discharge: at 6 weeks after discharge or at 3 months of age, whichever was later, and at 6 months of age	**Results** **Length of stay in hospital d (Mean, SD)** KC = 48, 28 Control = 46, 19	**Limitations** Random sequence generation Low risk Shuffling envelopes Allocation concealment Unclear risk Numbered envelopes Blinding of participants and personnel High risk Blinding of participants: no/unfeasible; blinding of clinical staff: no/unfeasible Blinding of outcome assessment All outcomes Unclear risk Unreported Incomplete outcome data All outcomes Low risk No infants lost to follow-up Selective reporting Low risk All outcomes stated in Methods section adequately reported or explained in Results Other bias Low risk Other biases not identified **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Study dates Not stated **Source of funding** Not stated					
Full citation Rojas, Ma, Kaplan, M, Quevedo, M, Sherwonit, E, Foster, L, Ehrenkranz, Ra, Mayes, L, Somatic growth of preterm infants during skin-to-skin care versus traditional holding: a randomized, controlled trial, Journal of Developmental and Behavioral Pediatrics, 24, 163-168, 2003 **Ref Id** 699620 **Country/ies where the study was carried out** USA	**Sample size** N= 60 infants enrolled in the study. Traditional holding group (TH) n=27 Skin-to-skin care (SSC) n=33 **Characteristics** Groups were similar in terms of birth weight, birth length, birth head circumference, GA at birth, Weight at entry, corrected age at entry, gender split, Apgar =<3 at 5 min of age and % ventilated >3 days **GA at birth, wk (Mean, SD)** TH group = 27.2, 2.3 SSC group = 26.6, 2.3 **% ventilated >3 days** TH group = 18/27 65% SSC group = 24/33 73% **Inclusion criteria**	**Interventions** **Traditional Holding Group** Parents removed their infants from the incubator and held them in their arms in supine position with eye-to-eye contact. The infants wore nappies and T-shirts and were wrapped in a blanket. **Skin-to-Skin Care Group** Parents were shown a videotape demonstrating the SSC technique. Infants were held in a prone semi-upright position at approximately 45	**Details** Parents sat in reclining chairs and could hold their infants for a total of 8 hours per day in periods of up to 4 hrs, twice daily, although parents were not obliged to hold their infants for prescribed amounts of time. Infants in the TH group were not offered SSC. Although not encouraged, parents in the SSC group could offer TH in place of SSC because it was considered a standard of care in our unit. Data were collected until infants reached 2000 g or until hospital discharge, whichever came first. Adverse events were followed prospectively	**Results** **Mortality** TH group = 1/27 (NEC and sepsis) SSC group = 2/33 (both severe respiratory failure) **Sepsis (defined as the presence of both clinical deterioration and isolation of a pathogen from peripheral blood or cerebrospinal fluid)** TH group = 8/27 30% SSC group = 5/33 15%	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Low risk (Randomisation was performed using a table of random numbers) Allocation concealment: Low risk (Allocation concealment was performed using previously prepared numbered and sealed opaque envelopes) Blinding of participants and personnel: High risk (No blinding performed) Blinding of outcome assessment: High risk (No blinding performed) Incomplete outcome data: Low risk (ITT analysis, no drop outs) Selective reporting: Low risk (The study protocol is not

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Study type RCT **Aim of the study** 'to determine whether infants receiving skin-to-skin care (SSC) grew more rapidly and had a shorter duration of hospital stay compared with infants held by their parents in a traditional way' **Study dates** August 31, 1995, to April 19, 1998 **Source of funding** Partial support from the Ronald McDonald Children's Charities of Connecticut and Western Massachusetts	All of the following required to be eligible for inclusion: • 32 weeks or less of gestation • 1500 g or less • minimal ventilatory support (peak airway pressure < 8 cm H20 and FiO2 < 40%) or extubated on nasal continuous positive airway pressure or nasal cannula • haemodynamic stability **Exclusion criteria** Any of the following to be excluded: • Mother aged <18y • antenatal history of illicit drug use • clinical evidence of perinatal asphyxia • potential transfer within the first month after birth • presence of a major congenital anomaly • planned adoption • IVH Grade III or IV	degrees, in direct skin-to-skin contact with the parent's chest. The infants wore only a nappy, and their backs were covered with a blanket.	by bedside nurse and parents and by retrospective systematic examination of nursing charts and attending notes. The two groups were similar in data collection periods (TH: 61 ± 33; SSC: 61 ± 28). Interventions started at a median of 1 day post-randomisation for both groups (TH range 0 to 15 days SSC range 0 to 28 days. Parents held their infant at least once per day on average more in the TH group (Mean SD: 22 ± 15 days) compared with those in the SSC group (15 ± 16 days) (p = 0.03). Infants in the TH group were held on average 4.8 ± 3.5 times per week for 76 ± 39 minutes per day, and infants in the SSC group were held 4.0 ± 2.8 times per week for 79 ± 40 minutes per day.		available but it is clear that the published reports include all expected outcomes, including those that were pre-specified) Other bias: None reported **Other information** Sample size of 45 infants/group would provide 86% power to detect a 20% difference in the major outcome scale of mother-infant interaction at an alpha level of 0.05.

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
	• foetal growth restriction (birth weight <10th percentile for age) • suspected sepsis				
Full citation Westrup, B, Böhm, B, Lagercrantz, H, Stjernqvist, K, Preschool outcome in children born very prematurely and cared for according to the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), Acta PaediatricaActa Paediatr, 93, 498-507, 2004 **Ref Id** 700094 **Country/ies where the study was carried out** Sweden **Study type**	**Sample size** In this report, there was follow up to include all 7 children who were intended to be treated in the original study but who were excluded in the previous reports. All surviving infants were included (11 in the NIDCAP® group and 15 in the control group) **Characteristics** See Westrup 2000 **Inclusion criteria** See Westrup 2000 **Exclusion criteria** See Westrup 2000	**Interventions** See Westrup 2000	**Details** See Westrup 2000	**Results** **CP (defined in terms of movement disorder) at 5 years** NIDCAP® group = 1/11 (mild hemiplegia) Control group = 2/15 (mild diplegia, severe diplegia requires walking aids) **Severe hearing impairment at 5 years** NIDCAP® group = 1/11 (80dB loss) Control group = 0/15 **Severe visual impairment at 5 years** NIDCAP® group = 1/11 Control group =0/15	**Limitations** **Quality of study:** Random sequence generation: Unclear risk (Randomisation method is not described) Allocation concealment: Unclear risk (Treatment assignment was performed using sealed envelopes - opaque or sequentially numbered not stated) Blinding of participants and personnel: Low risk (Parents, nurses and attending neonatologists were not blind to intervention but this would not affect the outcomes assessed here.) Blinding of outcome assessment: Low risk (Assessors were blinded to treatment groups) Incomplete outcome data: Low risk (ITT analysis, all available data from participants is presented)

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Follow up study of Westrup 2000 RCT at 5 years **Aim of the study** 'to determine the effect of [NIDCAP] on the development at preschool age of children born with a gestational age of less than 32 wk.' **Study dates** See Westrup 2000 **Source of funding** Supported by The Vardal Foundation, the Centre of Clinical Science-Dalarna, the Smedby Foundation, Salskapet Barnavard, the First of Mayflower Annual Campaign, the Jerring Foundation and the Groschinsky Foundation					Selective reporting: Low risk (The study protocol is not available but it is clear that all expected outcome are presented, including those that were pre-specified) Other bias: None reported **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Full citation Westrup, B., Kleberg, A., von Eichwald, K., Stjernqvist, K., Lagercrantz, H., A randomized, controlled trial to evaluate the effects of the newborn individualized developmental care and assessment program in a Swedish setting, Pediatrics, 105, 66-72, 2000 **Ref Id** 414424 **Country/ies where the study was carried out** Sweden **Study type** RCT **Aim of the study** To investigate the effect of NIDCAP® on	**Sample size** N=25 NIDCAP® group = 12 Control (conventional care) = 13 31 infants were eligible for inclusion at 24 h after birth. 12 were randomised to NIDCAP® and 19 to conventional care. 6 parents from the control group subsequently withdrew. **Characteristics** **Gestational age (wk) Median (Range)** NIDCAP® Group = 27.6 (24.0–28.7) Control Group = 26.1 (23.9–30.3) **Birth weight (g) Median (Range)** NIDCAP® Group = 1083 (630–1411) Control Group = 840 (636–1939) Groups similar at baseline for mother's age, maternal education, prenatal steroids, infant gender, birth weight, head circumference, gestational age, severity of illness (CRIB)	**Interventions** **Intervention** A trained team of nurses performed weekly formal NIDCAP® observations that started <3 days after birth and continued until 36 weeks of postconceptual age **Control** Conventional care For both groups, CPAP treatment was administered to all infants with spontaneous respiration at birth. Surfactant installation and mechanical ventilation were started when respiratory efforts were inadequate, when there were frequent apnoeas, and/or when CPAP at 5 to 6 cm H2O and Fio2 >0.4-0.6 produced a Po2	**Details** Infants were randomized immediately after birth using sealed envelopes in blocks of 4.This assured the NIDCAP® intervention onset at birth. Infants assigned to NIDCAP® were admitted to a special room directly after delivery. This procedure resulted in the randomization of infants who did not fulfil all the criteria for selection 24 hours after birth, who were subsequently excluded from the study. NIDCAP® involves weekly, formalised, naturalistic observations of the infant before, during, and after a care-giving procedure, e.g., feeding, nappy changes, collection of a blood sample, repositioning, etc. Behavioural and physiologic changes are monitored by 2-minute periods.	**Results** **BPD (assessed by chest radiograph at 36 weeks of postconceptual age according to modified Toce recommendations)** NIDCAP® group = 6/11 (all mild) Control group = 8/10 (2 mild, 4 moderate, 2 severe) p= 0.024 **Sepsis (defined as present when a blood culture result was positive and/or antibiotic treatment was administrated for >6 days in response to clinical symptoms and elevated C-reactive protein)** NIDCAP® group = 10/11 (7 >= 2 episodes) Control group = 10/10 (8 >= 2 episodes) **Mortality prior to discharge** NIDCAP® group = 1/12 Control group = 3/13	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Unclear risk (Randomisation method is not described) Allocation concealment: Unclear risk (Treatment assignment was performed using sealed envelopes (opaque or sequentially numbered not stated) Blinding of participants and personnel: High risk (Parents, nurses and attending neonatologists were not blind to intervention) Blinding of outcome assessment: High risk (Masking of patient data from all participants in the research [parents, nurses, and physicians] is unlikely as described) Incomplete outcome data: Unclear risk (6/19 infants' parents withdrew consent [all from control group]. No data are presented regarding these participants) Selective reporting: Low risk (The study protocol is not

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
need of ventilatory assistance, growth, and hospitalization in a Swedish setting. **Study dates** September 1994 and April 1997 **Source of funding** Supported by the Vardal Foundation, Dalarna Research Institute, Federation of County Councils, Smedby Foundation, Sallskapet Barnavard, Sunnerdahls Foundation, First of Mayflower Annual Campaign, and Solstickan Foundation	**Inclusion criteria** All of: • inborn • singleton • postconceptual age of <32 weeks • absence of severe malformation • need of ventilatory support 24 hours after birth, at least in the form of continuous positive airway pressure (CPAP) • family residence in the hospital district to ensure full hospital stays at the study hospital • Swedish language **Exclusion criteria** None stated	<6kPa, Pco2 >8.5 kPa, and/or pH <7.25. CPAP treatment was terminated at pressures of 2 cm H2O and Fio2 <0.3. Transcutaneous oxygen saturation was maintained at 90% to 94%.	Subsequently, the observer writes a report describing in detail the behaviour of the infant during the entire observation. This report is then used to explain the behaviour of the infant in guidance of the parents and caregivers by illustrating complex interactions among the infant's different subsystems. For a trained observer, this entire procedure requires 3 to 4 hours. Based on this procedure, recommendations with respect to care-giving designed to support the individual infant's development are formulated.		available but it is clear that all expected outcome are presented, including those that were pre-specified) Other bias: None reported **Other information** This study was terminated early because recruitment proceeded much more slowly than expected and because there was strong opinion among the nursing staff that NIDCAP® should be implemented throughout the unit, increasing the risk for a spill over effect to the control group. For a power of 80%, a significance level of .05, an increased daily weight gain of 3 g, a decreased need of supplementary oxygen of 25 days, and a 2 weeks earlier discharge would require a sample size of 40, 56, and 48 infants, respectively
Full citation Buehler, D. M., Als, H., Duffy, F. H., McAnulty, G. B.,	**Sample size** N=24 infants NIDCAP® group = 12 Control group = 12	**Interventions** **Intervention group** 12 infants received individu	**Details** Formal systematic observations of each infant's behaviour were conducted, starting	**Results** **Initial admission LOS Mean (SD)** NIDCAP® group = 27 (10.65)	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Liederman, J., Effectiveness of individualized developmental care for low-risk preterm infants: behavioral and electrophysiologic evidence, Pediatrics, 96, 923-32, 1995 **Ref Id** 412378 **Country/ies where the study was carried out** USA **Study type** RCT **Aim of the study** To assess the effectiveness of individualised developmental care i n the special care nursery for low-risk preterm infants **Study dates**	A third group of full term neonates was also recruited - results for this group are not considered here. **Characteristics** Gestational age at birth Mean (SD) NIDCAP® group = 32.19 (0.86) Control group = 32.14 (1.12) Groups similar for gender, birth weight, Apgar score, Mean Daily Pulmonary Index, Obstetric Complications Scale Score, mother's age, parity, Social Readjustment Rating Scale, social class, marital status and ethnicity **Inclusion criteria** • birth weight of 2500 g or less • gestational age at birth between 30 and 34 weeks inclusive • absence of mechanical ventilation and alive at 48 hours • inborn at the study hospital • singleton	alised developmental care. **Control group** 12 infants received the standard special care nursery care.	during the infant's stabilisation and continuing every 7 days until hospital discharge. For each observation, the infant's responses were recorded systematically for approximately 20 minutes before a necessary medical or nursing care giving activity, throughout the duration of the care giving, and for approximately 20 minutes after the care giving activity. The observations were used to formulate descriptive neurobehavioral reports, which included suggestions for the infant's care and incorporating the infants' parents in nurturing and caring for their infants from admission on. Several specifically designed accessories were available to support the experimental-group infants when deemed appropriate, eg a terry	Control group = 29 (10.64)	Random sequence generation: Unclear risk No information provided Allocation concealment: Unclear risk (Sealed envelopes: opaque or sequentially numbered not detailed) Blinding of participants and personnel: Low risk (Staff and parents not blinded to treatment allocation but unlikely to affect outcome here) Blinding of outcome assessment: Low risk (The authors state: "After discharge, the infants' medical records, after removal of the neurobehavioral reports, were reviewed by trained research staff blinded to the group status of the infants and the goals of the study.") Incomplete outcome data: Low risk Outcomes reported for all 24 preterm infants enrolled. Selective reporting: Low risk (The study protocol is not available but it is clear that the published reports include all expected outcomes, including those that were pre-specified) Other bias: None reported

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
August 1990 to June 1992 **Source of funding** Supported by NICHD, EEPCD U.S. Department of Education and Merck Family Fund, Mental Retardation and the Haskins Laboratory, Yale University	• absence of chromosomal or other genetic anomalies (e.g., trisomy 21) • absence of congenital infections (e.g., rubella, toxoplasmosis, cytomegalic inclusion disease, herpes, human immunodeficiency virus) • absence of maternal substance dependency (alcohol, drugs) and major social hardships (homelessness, abuse, legal incarceration of one parent) • absence of major maternal illness (e.g., uncontrolled diabetes, mental retardation, mental illness) • at least one family member with some English • telephone accessibility **Exclusion criteria** Not stated		cloth bunting, a hammock, and a soft nipple sewn into a long terry cloth band. The behavioural reports were used by the parents and primary care teams, with support by the psychologist and nurse specialist, to formulate specific individualized developmental care plans for the NIDCAP® group infants. Standard special nursery care that included primary care nursing and a standard developmental protocol, involving uniform shielding of incubators with blankets, use of clothing, and 24-h visiting for parents. Both groups had outcomes assessed at 2 weeks after the expected date of confinement (EDC).		**Other information**
Full citation	**Sample size**	**Interventions**	**Details**	**Results**	**Limitations**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Fleisher, B. E., VandenBerg, K., Constantinou, J., Heller, C., Benitz, W. E., Johnson, A., Rosenthal, A., Stevenson, D. K., Individualized developmental care for very-low-birth-weight premature infants, Clinical Pediatrics, 34, 523-9, 1995 **Ref Id** 439101 **Country/ies where the study was carried out** **Study type** RCT **Aim of the study** 'To demonstrate that NIDCAP improves medical and neurobehavioral outcomes in VLBW infants at 2 wk CA.'	N=40 **Characteristics** **Gestational age, wk Mean (Range)** NIDCAP® group = 26.5 (24.0-29.4) Control group = 26.1 (23.9-28.7) Groups were similar at baseline for maternal age, schooling and socioeconomic class and for infant birth weight and gestational age. **Inclusion criteria** • BW <1250g • Gestational age <30 wk **Exclusion criteria** • multiple gestation • ventilation not begun in the first 3 h or continued for >24 of the first 48 h of life • chromosomal abnormalities,	**Intervention group n=17** Infants received NIDCAP® care **Control group n=18** Infants received routine care as practiced in the nursery	NIDCAP® care evaluations started within 24 hours of admission and were performed weekly thereafter. Observations were conducted for 20 minutes before and after routing caregiving and during the handling with the infants reponses being recorded every 2 minutes. These observations formed the basis for the individualised care plans prepared by the developmental specialists with the primary nurses and parents. Support was available for parents on a daily basis. Primary nursing, incubator shielding, position, attention to handling and feeding practices were also components of care. Control group care included primary nursing, incubator shielding, position, attention to handling	**Days in hospital Mean (Range)** NIDCAP® group = 91.5 (47-158) Control group = 115.2(55-210) **Sepsis (no definition given)** NIDCAP® group = 8/17 Control group = 8/16	**Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Unclear risk No information provided Allocation concealment: Unclear risk (Sealed envelopes used: opaque or sequentially numbered not detailed) Blinding of participants and personnel: High risk (Staff and parents not blinded to treatment allocation) Blinding of outcome assessment: Low risk (for the outcome reported here) Incomplete outcome data: Unclear risk Outcomes reported for 5/40 infants who died. Selective reporting: Low risk (The study protocol is not available but it is clear that the published reports include all expected outcomes, including those that were pre-specified) Other bias: None reported **Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Study dates July 1992 to March 1994 **Source of funding** Not stated	congenital anomalies, or infection • parents lived beyond a predesignated catchments area • non–English-speaking parents • enrolment in other research studies with conflicting goals		and feeding practices and referral to occupational or physical therapy after stabilisation.		
Full citation Harding, C., Frank, L., Van Someren, V., Hilari, K., Botting, N., How does non-nutritive sucking support infant feeding?, Infant Behavior and Development, 37, 457-464, 2014 **Ref Id** 434980 **Country/ies where the study was carried out** UK **Study type** RCT	**Sample size** N=59 NNS pre tube feed group n=19 NNS on tube feed onset group n=20 Control (received the usual Developmental Care approach) group n=20 **Characteristics** **Gender male** Group 1 NNS pre-NGT feeds = 12/19 Group 2 NNS on onset NGT = 10/20 Group 3 Control = 12/20 **Gestational age mean** Group 1 NNS pre-NGT feeds = 32.53 SD=2.67 Group 2 NNS on onset NGT = 31.60 SD=2.01	**Interventions** NNS pre-NGT feeds n=19 NNS on onset NGT feeds n=20 Normal developmental care n=20	**Details** A computer generated randomization assigned infants to one of three groups. Infants received the intervention once they started to show signs of oral readiness. The target was to engage infants in the programme for a minimum of three times a day until they were taking all of their feeds orally. Parents were encouraged to implement the programme but nursing and therapy staff	**Results** **Number of days in hospital [mean/median/mode/SD /range]** Group 1 NNS pre-NGT feeds n=19 = Mean=36.84 Median=22 Mode=20 SD=29.96 9–104 Group 2 NNS on onset NGT feeds n=20 = Mean=37.90 Median=32 Mode=32 SD=13.94 23–64 Group 3 Control n=20 = Mean=54.40 Median=60.50 Mode=11 SD=28.62 11–110	**Limitations** **Quality of study:** Risk of bias assessed using Cochrane risk of bias tool Random sequence generation: Low risk (Randomisation was performed computer generated randomisation) Allocation concealment: Unclear risk (No details are provided) Blinding of participants and personnel: High risk (Parents and caregiving staff were not blinded to the intervention) Blinding of outcome assessment: Low risk Outcomes were assessed by the first author, a sample of ratings were blind assessed with an independent clinician (agreement 100%) Incomplete outcome data: Low

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Aim of the study To investigate the effectiveness of non-nutritive sucking (NNS) in development of full oral feeding or early language skills and in supporting parents' confidence in infant management **Study dates** No details provided **Source of funding** No statement regarding funding is made	Group 3 Control= 30.95 SD=3.14 **Birthweight mean** Group 1 NNS pre-NGT feeds = 1651.11 SD=403.12 Group 2 NNS on onset NGT feeds = 1757.90 SD=304.82 Group 3 Control = 167.65 SD=648.68 **Inclusion criteria** Both of • 26-35 weeks GA • recruited from level 1 inner city neonatal unit **Exclusion criteria** Any of: • congenital disorder • IVH grade 3 or 4 • severe respiratory problems • NEC		completed the intervention if the parents were unable to be present for one of the feeds. Training and on-line verbal coaching from a speech and language therapist in the identification of key infant behavioural states and responses to these states before the intervention began and on onset of the study was provided. For both NNS pre-NGT feeds and NNS on onset NGT feeds groups, parents were taught how to use NNS to encourage a state (quiet alert) optimal for successful feeding, were encouraged to elicit 3 sequential sucks and to encourage sequential sucking for a minimum of 5 minutes using a dummy		risk (1 participant elected not to continue) Selective reporting: Low risk (The study protocol is not available but it is clear that the published reports include all expected outcomes, including those that were pre-specified) Other bias: None reported **Other information** Sample size of 64 infants was required to detect a decrease in the transition time to achieve full oral feeding of up to 7 days with a type 1 error of 0.05, a power of 80.
Full citation	**Sample size** 153/164 surviving infants (NIDCAP®: 73; control group:	**Interventions** See Maguire 2009a	**Details**	**Results**	**Limitations** See Maguire 2009a

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Maguire, C. M., Walther, F. J., van Zwieten, P. H., Le Cessie, S., Wit, J. M., Veen, S., Follow-up outcomes at 1 and 2 years of infants born less than 32 weeks after Newborn Individualized Developmental Care and Assessment Program, Pediatrics, 123, 1081-7, 2009 **Ref Id** 398274 **Country/ies where the study was carried out** The Netherlands **Study type** Follow up of Maguire 2009a RCT at 1 and 2 years corrected age **Aim of the study** 'to investigate the effect of Newborn Individualized	80) were available for follow up (11 deaths during hospitalization) At 1 year of age 148/153 infants (NIDCAP®: 70 of 73 [95.9%]; control group: 78 of 80 [97.5%]) were seen at follow up (No results for 1 child in NIDCAP® group because they were uncooperative) At 2 years of age 146/148 children (NIDCAP®: 68 of 73 [93.2%]; control group:78 of 80 [97.5%]) were seen at follow-up (No results for 5 children in the NIDCAP® group and 2 children in the control group because they were uncooperative) **Characteristics** See Maguire 2009a **Inclusion criteria** See Maguire 2009a **Exclusion criteria** See Maguire 2009a			**Bayley Scales of Infant Development at 2y corrected age** Mental Developmental Index *Severe or moderate neurodevelopmental delay (MDI <84)* NIDCAP® group = 9/63 Control group = 16/76 Psychomotor Developmental Index *Severe or moderate psychomotor delay (PDI <84)* NIDCAP® group = 23/63 Control group = 24/76	**Other information**

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Developmental Care and Assessment Program on growth, cognitive, psychomotor, and neuromotor development at 1 and 2 years in infants born at <32 weeks' gestational age.' **Study dates** The study inclusion period was July 2002 to August 2004, and this follow-up was from September 2003 to November 2006. **Source of funding** Supported by ZonMW (The Netherlands Organization for Health Research and Development) and the Health Care					

Study details	Participants	Interventions	Methods	Outcomes and Results	Comments
Efficiency Research Fund LUMC.					

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Clinical evidence tables for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

Study details	Participants	Methods	Findings/results	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 **Aim of the study**	**Characteristics** **Study parents** n=8 Mothers, n=8 Age, median (IQR) years: 30 (27-39) Major diagnoses: incompetent cervix, premature rupture of membranes, umbilical cord prolapse, pre-eclamptic toxemia, chorioamnionitis and hypertensions, proteinuria **Study infants** n=9 (7 singletons, 1 set twin boys) Birth weight (mean)= 981.11g	**Setting** NICU in a downtown university teaching hospital in a large, highly diverse central Canadian city **Data Collection** This study used an exploratory, qualitative design based on grounded theory. Mothers were interviewed using a semistructured interview guide with open-ended questions. Interview recordings were transcribed and translated by trained bilingual research assistants who were linguistically matched with	**Themes and categories** Family and friend support • Burdens Parent-to-Parent support • Shared experiences	**Limitations** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined

Study details	Participants	Methods	Findings/results	Comments
The aim of the study was to assess the experiences of non-English-speaking mothers of preterm, very low birth weight infants, as well as to explore mothers' perceptions of a peer support program matching them with parent-buddies who had similar linguistic and cultural backgrounds **Study type** Semi-structured interviews **Study dates** Not reported	Gestation period (mean)=26.8 weeks Length of stay, median (IQR) days=91 (26-140) Major diagnoses: RDS, AOP, ROP, chronic lung disease, anemia, sepsis, feeding intolerance, IVH, PDA Requiring support for breathing, n (%)= 9 (100) **Inclusion criteria** Babies with a birth weight of < 1500 g, born at < 30 weeks gestation and had a mother did not speak English **Exclusion criteria** Not reported	the mothers. As each interview was transcribed, the first author read it and identified common themes. Thematic saturation was assessed through repetition in the current sample and by comparison with themes from previous qualitative research in the study setting and similar themes related to cultural issues emerged in all linguistic and cultural groups represented. Thus, the investigators judged that data saturation was acceptable despite the small sample size. **Data Analysis** After all the interviews were completed, one member of the research team and a research assistant who was not involved in the data collection reviewed each of the transcripts. The authors coded the mothers' responses into themes. For reliability, another member of the team reviewed the transcripts independently and met with the team to compare coding in each of		their own role in the research) 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of

Study details	Participants	Methods	Findings/results	Comments
Source of funding Not reported		the narratives. Over several meetings, a consensus coding framework was developed and finally similar themes were clustered into conceptual categories.		thick description about both the context **Dependability** Use of a convenience sampling was clearly reported. The analytical process was described as well as how themes were identified. **Confirmability** The relationship between the researcher and the participants was clearly reported. Steps were taken to ensure reliability and consensus between themes. The researchers' roles and potential influences in the analytical process were not critically reviewed **Relevance** High confidence **Applicability of findings**

Study details	Participants	Methods	Findings/results	Comments
				Findings are applicable to the context of the review question and review inclusion criteria **Coherence** High confidence **Findings/results** Results were presented clearly with distinction between the authors' interpretations and the participants' quotes **Adequacy of data** High confidence **Data collection** Data was collected through open-ended questions; authors stated that theoretical saturation was met and methods for determining this **Other information**

Study details	Participants	Methods	Findings/results	Comments
Full citation Cescutti-Butler, L., Galvin, K., Parents' perceptions of staff competency in a neonatal intensive care unit, J Clin NursJournal of clinical nursing, 12, 752-761, 2003 **Ref Id** 683204 **Country/ies where the study was carried out** UK **Aim of the study** The goal of this study was to assess and describe parents' perceptions of staff competency in a NICU **Study type**	**Characteristics** N parents = 8 **Inclusion criteria** • Resident in NICU for more than 1 week • Gestation at birth 28 weeks or above • Baby ventilated for at least 3 days • Discharged home within the last 6 months. **Exclusion criteria** Not reported	**Setting** An acute hospital in the south-west of England in an NICU with 14 cots **Data Collection** Participants were interviewed using unstructured tape recorded interviews. Data collection was approached without a rigid set of ideas, but was informed by literature relating to patient satisfaction, user views of health services, definitions of competency and the published research in neonatal care. Data was collected until no new concepts emerged or could be found in the data and thematic saturation was achieved. **Data Analysis** Interpretations and findings were compared with the literature as the data	**Themes and categories** Staff support • Facilitating parents in participating in care • Facilitating transition into parenting rol e • Interpersonal relationships	**Limitations** High confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The study did not provide background demographic information in regards to participants. The authors did discuss the context and setting of the research. **Dependability** "Theoretical sampling was not feasible in its pure form in the present study mainly because of time and other constraints... a purposive sampling strategy was used: participants were chosen because of their knowledge and experience of having been a parent with a child in an NICU." A specific data analysis technique,

Study details	Participants	Methods	Findings/results	Comments
Focused conversational interviews **Study dates** Not reported **Source of funding** Not reported		collection and analysis progressed.		such as thematic content analysis, was not reported. H **Confirmability** The relationship between the researcher and the participants was clearly reported. Researchers critically reviewed their own roles in the process. **Relevance** High confidence **Applicability of findings** Evidence pertained to the supports from staff that parents found beneficial **Coherence** High confidence **Findings/results** Results were presented clearly (e.g. citation/data and the

Study details	Participants	Methods	Findings/results	Comments
				researchers' own input distinguished) **Adequacy of data** High confidence **Data collection** Theoretical saturation was reached; data was collected through focused conversational interviews **Other information**
Full citation Falck, A. J., Moorthy, S., Hussey-Gardner, B., Perceptions of Palliative Care in the NICU, Adv Neonatal CareAdvances in neonatal care : official journal of the National Association of	**Characteristics** Characteristics of mothers n= 6 Age, mean (SD): 28.7 (6.8) Caucasian, n= 3 African, n= 1 African American, n = 2	**Setting** Level IV NICU in an urban setting. The NICU was divided into 5 open rooms, there was no physical barrier between patient bed spaces **Data Collection** Participants were interviewed using an	**Themes and categories** Staff support • Communication to reduce stress • Continuity of care Hospital design	**Limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability**

Study details	Participants	Methods	Findings/results	Comments
Neonatal Nurses, 16, 191-200, 2016 **Ref Id** 683567 **Country/ies where the study was carried out** US **Aim of the study** The aim of the study was to assess the provision of palliative care as experienced by mothers and health care professionals of infants in the NICU with life-threatening illnesses **Study type** Semi-structured interviews **Study dates**	Infant characteristics n= 6 Gestational age, weeks, mean (SD): 29.8 (3.13) Birth weight, g, median (IQR): 770 (460-1830) n on ventilator= 6 Days on ventilator, median (IQR): 33 (6-187) **Inclusion criteria** Inclusion criteria: • Infants experiencing life-threatening illnesses, but be deemed clinically stable by the attending physician at the time of interview **Exclusion criteria** Not reported	interview guide and probes were utilised to obtain details and specific descriptions of participant's experiences. Researchers explored experiences that were meaningful to the participants, when the conversation allowed. A copy of the interview guide was included in the study. **Data Analysis** Researchers coded interview transcripts and data extrapolated from medical record review concurrently with recruitment and resolved discrepancies through repeated discussions. Emerging categories were used to refine interview questions and themes were generated. When no new themes emerged, theoretical saturation was achieved and subject recruitment ceased. Member checks were conducted with mothers and HCPs after themes were generated to	• Need for privacy • Feelings of security or insecurity Social support	The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** "Purposive sampling was utilized to identify a heterogeneous study population of mothers of preterm infants with potentially life-threatening conditions. Specifically, mothers were recruited to ensure variability in maternal age, ethnicity, gestational age and birth weight within the study population." The analytical process was described and how themes were identified. **Confirmability** The relationship between the researchers and the respondents was not clearly reported "Member

Study details	Participants	Methods	Findings/results	Comments
January 2010 to June 2012 **Source of funding** Internal funding, no financial relationships to report		verify and refine researcher interpretation of the data.		checks were conducted with mothers...after themes were generated to verify and refine researcher interpretation of the data." Researchers did not critically reflect on their own roles in the process. **Relevance** High confidence **Applicability of findings** Research method was adequate for answering the research question **Coherence** High confidence **Findings/results** Results were presented clearly with distinction between data and quotes from the participants and the researchers' own interpretations. **Adequacy of data**

Study details	Participants	Methods	Findings/results	Comments
				High confidence **Data collection** "The length of interviews varied slightly; with the average interview lasting approximately 45 minutes. Theoretical saturation was achieved after 12 interviews and 6 infant medical record reviews." **Other information**
Full citation Feeley, N., Waitzer, E., Sherrard, K., Boisvert, L., Zelkowitz, P., Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit, J Clin NursJournal of clinical nursing, 22, 521-530, 2013	**Characteristics** Fathers' characteristics n= 18 Education Junior college or less, n (%)= 10 (55.6) University, n (%)= 8 (44.4) Infant characteristics	**Setting** Two open-space design (one large open room) NICUs in Montreal, Canada **Data Collection** Semi-structured interviews were conducted by a female interviewer in a private room adjacent to the NICU with no other persons present. Interviews were audio recorded and lasted between 45–90 minutes.	**Themes and categories** Family and friend support • Practical support Staff support • Facilitating transition into parenting role	**Limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were completed **Transferability** The authors provided details of the study participants to enable readers to evaluate for which

Study details	Participants	Methods	Findings/results	Comments
Ref Id 683579 **Country/ies where the study was carried out** Canada **Aim of the study** The aim of this study was to assess what fathers perceived were facilitators and barriers to their involvement with their infants in the NICU. **Study type** Semi-structured interviews **Study dates** Not reported	n= 21 Premature birth, n (%)= 21 (100) Medical treatments, n (%) Mechanical ventilation/high-frequency ventilation= 15 (71.4) CPAP/HFNC= 18 (85.7) Intravenous or central line= 21 (100) Isolation= 0 (0) Chest tube= 1 (4.8) Gavage/TPN= 18 (85.7) **Inclusion criteria** Fathers had to be the infant's biological father and had to be living with the infant's mother; the infant had been hospitalised >/= 7 days; the infant's medical condition was stable; and the father could communicate in French or English **Exclusion criteria**	Participants completed a demographic questionnaire, and data pertaining to the infant's condition were gathered from the medical record. **Data Analysis** The interview data were analysed using inductive content analysis. Analysis and interviews occurred concurrently. First, transcripts of the interviews were verified for accuracy, and notes recorded following the interview were inserted into the transcripts. Second, codes were applied and condensed into categories. The research team met on several occasions during data collection to review transcripts discuss coding and the development of categories. After 18 interviews, data saturation was achieved as no new categories of barriers and facilitators of involvement were identified. Descriptive statistics were used to	Parent-to-Parent support • Observational learning Hospital design • Friendly, homelike environment • Feelings of security or insecurity Social support Spousal support Financial support	target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** Sampling method not clearly reported: "Fathers were recruited from 2 open-space design NICUs in a major Canadian urban centre..." The analysis process and process for identifying themes was clearly reported: "The interview data were subjected to inductive content analysis. Analysis and interviews occurred concurrently." **Confirmability** The relationship between the researcher and the participants was not clearly reported. Researchers did not critically reflect on their own roles in the process, though "three aspects of rigour relevant to a qualitative inquiry were addressed."

Study details	Participants	Methods	Findings/results	Comments
Source of funding Not reported	Fathers were excluded if they had a previous child hospitalised in the NICU (previous experience may affect involvement); the infant had a Grade III/IV IVH or a major congenital anomaly	describe the characteristics of the participants and their infants.		**Relevance** High confidence **Applicability of findings** Evidence applicable to review context **Coherence** High confidence **Findings/results** Results were presented clearly (i.e. citation/data ad the researchers' own input distinguished) **Adequacy of data** High confidence **Data collection** Data collected from fathers relied on semi-structured interviews. Thematic saturation was reached and data collection ceased when

Study details	Participants	Methods	Findings/results	Comments
				no new categories of themes were identified. **Other information**
Full citation Flacking, R., Thomson, G., Axelin, A., Pathways to emotional closeness in neonatal units - a cross-national qualitative study, BMC Pregnancy and Childbirth, 16 (1) (no pagination), 2016 **Ref Id** 493769 **Country/ies where the study was carried out** Sweden, England, Finland **Aim of the study**	**Characteristics** Parents information Swedish parents, n= 8 English parents, n= 6 Finnish parents, n= 9 **Inclusion criteria** Not reported **Exclusion criteria** Not reported	**Setting** Level II Swedish NICU with 14 cots; level III NICU with 27 cots; level III Finnish NICU with 18 cots **Data Collection** Parents answered an emotional closeness form. **Data Analysis** Data from completed forms was typed into word documents. Authors independently inductively analysed the data using thematic network analysis. Text segments were organised into themes. Finally, an over-arching	**Themes and categories** Social support • Partners Staff support • Communication to reduce stress Hospital environment • Need for privacy • Participating in care	**Limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context

Study details	Participants	Methods	Findings/results	Comments
The aim of this study was to determine how, when and why parents experience emotional closeness to their infants in the NICU. **Study type** Qualitative interviews **Study dates** Not reported **Source of funding** There was no funding		global theme was determined.		**Dependability** The sampling method was clearly reported. The analytical process was described as well as how themes were identified. **Confirmability** The relationship between the researcher and the participants was not clearly reported. The researchers' roles and potential influences in the analytical process were not critically reviewed. **Relevance** High confidence **Applicability of findings** Findings are applicable to the context of the review question and review inclusion criteria **Coherence** High confidence

Study details	Participants	Methods	Findings/results	Comments
				Findings/results Results were presented clearly with distinction between the authors' interpretations and the participants' quotes **Adequacy of data** Moderate confidence **Data collection** Data was collected through a qualitative questionnaire method. The authors did not discuss whether theoretical saturation was achieved. **Other information**
Full citation Gibbs, D. P., Boshoff, K., Stenley, M. J., The acquisition of parenting occupations in neonatal intensive	**Characteristics** Parents' characteristics n=6 Male, n (%)= 3 (50)	**Setting** Single Level 3 NICU in a large urban centre in the UK **Data Collection**	**Themes and categories** Staff support • Facilitating parents in participating in care	**Limitations** High confidence **Credibility** Member checks, peer debriefing, independent analysis of data by

<table>
<tr><th>Study details</th><th>Participants</th><th>Methods</th><th>Findings/results</th><th>Comments</th></tr>
<tr>
<td>care: a preliminary perspective, Canadian journal of occupational therapy, 83, 91-102, 2016

Ref Id

683729

Country/ies where the study was carried out

UK

Aim of the study

The aim of this study was to assess the experiences that enable parents to participate in roles associated with parenting in the NICU

Study type

Paradigmatic narrative analysis</td>
<td>Infant characteristics

n=3

<table>
<tr><th>Child</th><th>Gestation (weeks)</th><th>Birth weight (g)</th><th>Respiratory support</th><th>Length of stay (days)</th></tr>
<tr><td>Male 1</td><td>24 + 1</td><td>620</td><td>29 days ventilation

76 days CPAP

19 days oxygen

Discharged on home oxygen</td><td>117</td></tr>
<tr><td>Male 2</td><td>28 + 6</td><td>1450</td><td>3 days ventilation

8 days CPAP</td><td>76</td></tr>
<tr><td>Male 3</td><td>29 + 4</td><td>1070</td><td>1 day ventilation

7 days CPAP</td><td>62</td></tr>
</table>
</td>
<td>The participants engaged in a semi-structured in-depth interview. Open-ended questions were used. All participants elected to be interviewed as couples in their home. The interviews, lasting between 60 and 90 min, were digitally recorded and transcribed verbatim by the first author.

Data Analysis

Participants were sent a copy of the transcript to ensure accurate reflection of their experience and were asked to return comments to the first author with any required changes. Transcripts were first read to gather a sense of the meaning, then they were openly coded by the first author, codes were then refined and grouped into larger categories. The summary categories developed from each interview were then compared across transcripts to identify common or recurrent</td>
<td>• Facilitating transition into parenting role
• Communication to reduce stress
• Interpersonal relationships
• Continuity of care

Parent-to-parent support

• Shared experiences

Hospital environment

• Participating in care</td>
<td>more than one researcher, and verbatim quotes were conducted

Transferability

The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context

Dependability

The sampling method was specified: "To enable the recruitment of participants who could provide rich and detailed accounts of their parenting experiences in the NICU, a purposive intensity sampling approach was utilized." The analytical process and how themes were identified was clearly described.

Confirmability</td>
</tr>
</table>

Study details	Participants	Methods	Findings/results	Comments
Study dates Not reported **Source of funding** Not reported	**Inclusion criteria** • Being a parent of a premature infant (< 32 weeks gestation, < 1500 g birth weight, requiring invasive and non-invasive ventilation for a minimum of 7 days) • Having been discharged from the NICU 3 to 6 months prior • Speak English **Exclusion criteria** Not reported	experiences. Decisions regarding applications of codes were documented in the field journal and reviewed by the second and third authors. The journal entries and documentation of the debriefing sessions provided an audit trail regarding methodological decisions.		The relationship between the researchers and the participants was clearly reported. Researchers critically reflected on their own roles in the process. **Relevance** High confidence **Applicability of findings** The study's research question and population reflect the context of the review **Coherence** High confidence **Findings/results** Results were presented clearly (i.e. citation/data and the researchers' own interpretation were distinguished). **Adequacy of data** High confidence

Study details	Participants	Methods	Findings/results	Comments
				Data collection Data collected from parents relied on semi-structured interviews; thematic saturation was achieved **Other information**
Full citation Guillaume, Sonia, Michelin, Natacha, Amrani, Elodie, Bernier, Brigett, Durrmeyer, Xacier, Lescure, Sandra, Bony, Charlotte, Danan, Claude, Baud, Oliver, Jarreau, Pierre-Henri, Zana-Glaieb, Elodie, Caeymaex, Laurence, Parents expectation of staff in the early bonding process with their premature babies in the intensive care setting: a qualitative multicenter study with 60 parents, Neonatal Intensive	**Characteristics** Parents' characteristics n= 60 Fathers, n (%)= 30 (50) Age mother, years, mean (SD): 30.7 (6.6) Age father, years, mean (SD): 33.5 (6.8) History of preterm delivery, n (%)= 6 (10) Infant characteristics n= 49 Female, n (%)= 29 (59)	**Setting** Three tertiary care centers in Paris, France **Data Collection** Semi-directive interviews lasting 60 to 90 minutes were conducted by a social psychologist trained in research and not involved in a NICU. Audio recordings of the interviews were made, with the parents' oral consent. Fathers and mothers were interviewed separately. The interview guide was developed from a review of the literature and from 10 preliminary interviews discussed within	**Themes and categories** Staff support • Facilitating parents in participating in care • Facilitating transition into parenting role • Communication to reduce stress • Continuity of care Hospital design	**Limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of

Study details	Participants	Methods	Findings/results	Comments
Care, 26, 40-46, 2013 **Ref Id** 683815 **Country/ies where the study was carried out** France **Aim of the study** The aim of this study was to assess parents' perceptions of how an early bond with their premature infant is established and to identify their expectations of caregivers, and the tangible things that helped and hindered them. **Study type** Prospective qualitative discourse analysis	Gestational age, weeks, mean (SD)= 27 (2) Birth weight, g, mean (SD)= 965 (206) Ventilation type at time of interview, n (%) Spontaneous ventilation, 8 (16) Nasal ventilation, 30 (61) Endotracheal ventilation, 11 (22) **Inclusion criteria** Inclusion criteria: • Spoke French • Infant was born at < 32 weeks gestation • Infant was 15-30 days old at inclusion • Infant had no recent severe clinical aggravation, according to the attending physician **Exclusion criteria** Not reported	focus groups of caregivers, conducted by the researchers. **Data Analysis** The interviews were analysed using discourse analysis. The analysis was performed separately by the research psychologist and research assistant with the manual coding of themes. Convergences and divergences of the same theme were identified across interviews. Attention was paid to the emergence of new themes and contradictory results as the interviews and analysis progressed and data saturation occurred.	• Feelings of security or insecurity	thick description about both the context **Dependability** Sample selection was not clearly reported; the analytical process and process of identifying themes was clearly reported. **Confirmability** The relationship between the researcher and the participants was reported: "semi-directive interviews lasting 60-90 minutes were conducted by a social psychologist trained in research and not involved in the NICU." The researchers did not critically reflect on their own roles in the analysis process **Relevance** High confidence **Applicability of findings** The study's population and research question were

Study details	Participants	Methods	Findings/results	Comments
Study dates November 2009 to March 2010 **Source of funding** Not reported				applicable to the context of this review **Coherence** High confidence **Findings/results** Data collected from participants relied on a semi-structured interview approach. Data saturation was achieved. **Adequacy of data** High confidence **Data collection** Results were presented clearly (i.e. citation/data and the researchers' own input were identified) **Other information**
Full citation	**Characteristics**	**Setting**	**Themes and categories**	**Limitations** High confidence

Study details	Participants	Methods	Findings/results	Comments
Heinemann, A. B., Hellstrom-Westas, L., Nyqvist, K. H., Factors affecting parents' presence with their extremely preterm infants in a neonatal intensive care room, Acta PaediatricaActa Paediatr, 102, 695-702, 2013 **Ref Id** 683932 **Country/ies where the study was carried out** Sweden **Aim of the study** The aim of this study was to describe the experiences of parents with factors that influenced their stay with their extremely premature infants in a NICU.	Parents characteristics Mothers, n= 7 Fathers, n= 6 Infants characteristics n=7 n requiring ventilator support= 7 Gestational age at birth, weeks, median (IQR)= 25 + 4 (23 + 5 to 27 + 6) Range of birth weights, g= 492 - 1044 **Inclusion criteria** • Ability to speak and understand Swedish • Child is extremely preterm **Exclusion criteria** • Substance abuse	3 level III NICUs at a Swedish, regional/university level III hospital. **Data Collection** Data was collected through interviews with parents that took place at least 1 week after the infant's transfer from a NICU room to another room in the hospital. Interviews were conducted by the first author using a conversation guide. **Data Analysis** Analysis of the data took place continuously throughout the interview period. The authors read the text and used qualitative content analysis - first they identified meaning units, secondly they condensed these units into codes and further subcategories.	Social support • Partners Staff support • Facilitating parents in participating in care • Communication to reduce stress • Interpersonal relationships Hospital environment • Need for privacy • Friendly, homelike environment	**Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** The analytical process was described as well as how themes were identified. The sample collection process was clearly reported **Confirmability**

Study details	Participants	Methods	Findings/results	Comments
Study type Qualitative descriptive design **Study dates** Not reported **Source of funding** Gillbergska Foundation				The relationship between the researchers and the participants was clearly described. The researchers' roles and potential influences in the analytical process were critically reviewed. **Relevance** High confidence **Applicability of findings** Findings are applicable to the context of the review question and review inclusion criteria **Coherence** High confidence **Findings/results** Results were presented clearly with distinction between the authors' interpretations and the participants' quotes **Adequacy of data**

Study details	Participants	Methods	Findings/results	Comments
				Moderate confidence **Data collection** Data was collected through semi-structured interviews; the authors did not discuss if data saturation had been achieved **Other information**
Full citation Holditch-Davis, D., Miles, M. S., Mothers' stories about their experiences in the neonatal intensive care unit, Neonatal Network: the Journal of Neonatal Nursing, 19, 13-21, 2000 **Ref Id** 683985 **Country/ies where the study was carried out**	**Characteristics** Parents' characteristics Mothers, n = 31 Age, mean (SD)= 29.1 (5.4) Infant characteristics Female, n= 18 Male, n= 28 Gestation at birth, weeks, mean (SD)= 30.4 (2.7)	**Setting** Tertiary, university-based NICU **Data Collection** A member of the research team visited the mother when the infant was 6 months old corrected for prematurity. Data was collected through semi-structured interviews in which the mother was given the chance to fully share her experiences and feelings about her infant and the NICU. Interviews	**Themes and categories** Staff support • Communication to reduce stress • Interpersonal relationships Hospital design • Feelings of security or insecurity	**Limitations** Moderate **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual

Study details	Participants	Methods	Findings/results	Comments
US **Aim of the study** The aim of this study was to enable mothers to tell their stories of their NICU experiences. **Study type** Qualitative thematic content analysis **Study dates** Not reported **Source of funding** National Institute for Nursing Research, National Institutes of Health	Birth weight, g, mean (SD)= 1437 (543) Mechanical ventilation, n= 27 Supplemental oxygen when off the ventilator, n= 22 Length of ventilation, days, mean (SD)= 6.7 (7.8) Length of supplemental oxygen, days, mean (SD)= 10.6 (12.7) Medical conditions, n Patent ductus arteriosis= 12 Apnea of prematurity= 20 Grade I IVH= 6 Grade II IVH= 2 **Inclusion criteria** Inclusion criteria: • Birth weight < 1500 g or mechanically ventilated or both	lasted approximately an hour, were audiotaped, and were transcribed verbatim. **Data Analysis** Each interview was read and coded based on an a priori conceptual framework. The quotes were edited to remove identifying information and to improve clarity.		background information, demographics, the provision of thick description about both the context **Dependability** Sample selection was not clearly reported. The analytical process and process of identifying themes was described. **Confirmability** The relationship between the researcher and the participants was not clearly reported. Researchers did not critically review their own roles in the process. **Relevance** High confidence **Applicability of findings** The population and focus of the study was applicable to the context of this review

Study details	Participants	Methods	Findings/results	Comments
	Exclusion criteria Not reported			**Coherence** High confidence **Findings/results** Results were presented clearly i.e. citation/data and the researchers' own input distinguished. **Adequacy of data** Moderate confidence **Data collection** Data collected from participants relied on a semi-structured interview approach. Achievement of data saturation was not discussed. **Other information**
Full citation Jackson, K., Ternestedt, B. M., Schollin, J., From	**Characteristics** Parents characteristics	**Setting** A large university hospital with a level III NICU in a	**Themes and categories**	**Limitations** Moderate confidence **Credibility**

Study details	Participants	Methods	Findings/results	Comments
alienation to familiarity: experiences of mothers and fathers of preterm infants, Journal of Advanced Nursing, 43, 120-9, 2003 **Ref Id** 445669 **Country/ies where the study was carried out** Sweden **Aim of the study** The aim of this study was to examine how mothers and fathers of preterm infants describe their experiences of being a parent during the infant's first 18 months of life. **Study type**	n= 7 Mother's age, years, median (IQR)= 32.5 (28-37) Father's age, years, median (IQR)= 32.5 (31-39) Infants characteristics n=8 Male= 5 Female= 3 Birth weight, g, median (range)= 1467.5 (660 to 2385) Length of gestation, weeks, median (range)= 30 (25-34) Major diagnoses, n Hyperbilirubinaemia= 7 Sepsis= 3 Respiratory distress syndrome= 2 Transient tachypnoea= 4 Medical technology, n	county in the middle of Sweden. **Data Collection** Parents were interviewed as dyadic mother-father units (with the exception of 2 pairs who were interviewed separately). Each new interview was based on the findings from the previous interview. 30 interviews were conducted in total by one author, each one lasted between 45-90 minutes and were audiotaped and transcribed verbatim. **Data Analysis** Analysis was conducted in systematic steps, which included: reading the interview transcripts to understand the content as a whole; dividing the text into meaning units; transforming the meaning units into a nursing perspective; condensing the units into four syntheses; integrating	Staff support • Interpersonal relationships Hospital environment • Need for privacy Financial support	Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted. **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context. **Dependability** The method for sample selection was not clearly reported. The analytical process was described as well as how themes were identified. **Confirmability**

Study details	Participants	Methods	Findings/results	Comments
Phenomenological descriptive study **Study dates** 1999 **Source of funding** Not reported	CPAP= 4 Ventilator support= 2 **Inclusion criteria** • Infants born at </= 34 weeks gestation • Without any known congenital or chromosomal defect • Swedish-speaking parents who resided in the county • Infants were judged by a neonatologist at 1 week of age to have a good chance of survival **Exclusion criteria** Not reported	the four themes into the structure of the phenomenon of parenthood; validating the structure by the second author		The relationship between the researchers and the participants was not described. The researchers' roles and potential influences in the analytical process were not critically reviewed. **Relevance** Moderate confidence **Applicability of findings** Some of the findings were not applicable to the review context as some of the interviews took place with parents after the infant had been discharged from the NICU **Coherence** High confidence **Findings/results** Results were presented clearly with distinction between the authors' interpretations and the participants' quotes

Study details	Participants	Methods	Findings/results	Comments
				Adequacy of data Moderate confidence **Data collection** Data was collected through open-ended questions; the authors did not discuss if data saturation had been achieved **Other information**
Full citation Neu, M., Parents' perception of skin-to-skin care with their preterm infants requiring assisted ventilation, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 28, 157-164, 1999 **Ref Id** 684777	**Characteristics** Parents' characteristics n= 9 Mothers, n= 8 Age, mean= 25.9 Singleton birth, n= 9 First time parents, n = 4	**Setting** Tertiary neonatal care setting and homes of parents **Data Collection** A naturalistic inquiry was used to assess the experiences of parents who had participated in skin-to-skin care. The design incorporated two interviews, one conducted immediately after two skin-to-skin care	**Themes and categories** Staff support • Facilitating transition into parenting role Hospital design • Need for privacy	**Limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out US **Aim of the study** The aim of this study was to assess parents' perceptions of skin-to-skin care with their preterm infant who was on assisted ventilation, and to determine factors influencing the decision to continue or discontinue skin-to-skin care. **Study type** Naturalistic inquiry **Study dates** Not reported	Infant characteristics n= 9 n on assisted ventilation= 9 Female, n= 6 Birth weight, g, mean (SD)= 1064 (423) Gestational age, weeks, mean (SD)= 27.2 (2.0) **Inclusion criteria** Not reported **Exclusion criteria** Not reported	session and a follow-up interview conducted several months later. Video scenes lasting 8 -10 minutes were filmed by the investigator or a research assistant. **Data Analysis** The investigator transcribed the open-ended telephone interviews verbatim. The investigator coded the transcriptions. Codes were grouped into subthemes and main themes. Content of the videotaped segments were compiled and pooled with parent/infant behavioural data from the field notes and the parent narrative to provide a more complete description of the parent's experience. The investigator's involvement in the nursery enhanced the credibility and confirmability. The investigator also presented preliminary findings of this study to several colleagues and incorporated their input. Verbatim transcriptions, videotaped segments, detailed field notes, and a		target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** The sample was selected from the sample in a previous study, but the sampling process was not explained in detail. The analytical process and the process for identifying themes was identified. **Confirmability** The relationship between the researcher and the participants was clearly reported. Researchers did not critically reflect on their own roles in the process. **Relevance** High confidence **Applicability of findings**

Study details	Participants	Methods	Findings/results	Comments
Source of funding National Association of Neonatal Nurses		record of analytic decisions provided an audit trail that contributed to credibility and confirmability in addition to providing a rich description.		The sample population was directly applicable to the review context. Findings apply to activities undertaken in the NICU. **Coherence** High confidence **Findings/results** Findings were presented clearly i.e. citation/data and the researchers' own input distinguished. **Adequacy of data** Moderate confidence **Data collection** Data collected from participants relied on open-ended interviews and videos. There was no discussion of data saturation. **Other information**

Study details	Participants	Methods	Findings/results	Comments
Full citation Pohlman, S., Fathering premature infants and the technological imperative of the neonatal intensive care unit: An interpretive inquiry, Advances in Nursing Science, 32, E1-E17, 2009 **Ref Id** 414210 **Country/ies where the study was carried out** US **Aim of the study** The aims of this study were to reveal the stressful episodes and coping practices of fathers; assess fathers' resources and barriers as they develop a relationship with	**Characteristics** Parent characteristics Fathers, n= 9 Age, years, median (IQR)= 36 (22-39) Infant characteristics n= 9 Gestational age, weeks, median (IQR)= 28 (25-32) Birth weight, g, median (IQR)= 933 (515-2196) **Inclusion criteria** • English speaking white fathers • Singleton infant born at less than 33 weeks' gestation • No congenital abnormalities • Fathers were over the age of 22, share a home with the infant's mother, be enrolled within 1 month after their infant's birth **Exclusion criteria**	**Setting** 3 Midwestern hospitals **Data Collection** Interviews were conducted every 2-3 weeks and lasted 60-90 minutes. Interviews were audio-recorded and transcribed verbatim. Interview guides were used to initiate conversation and encourage dialogue. **Data Analysis** Data was analysed using an interpretive approach, which involved a systematic and circular process including reading of the narrative text; coding; and creating interpretive files	**Themes and categories** Social support • Partners Staff support • Communication to reduce stress • Continuity of care	**Limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** The sampling method was not reported clearly. The analytical process as well as how themes were identified were described.

Study details	Participants	Methods	Findings/results	Comments
their infants; describe how fathers learn practical caregiving skills; and explore how fathers own personal meanings of self, family, fatherhood, and work shape his caregiving practices. **Study type** Interpretive phenomenological design **Study dates** Not reported **Source of funding** National Institutes of Nursing Research; Foundation for	Not reported			**Confirmability** The relationship between the researchers and participants was not clearly reported. The researchers' roles and potential influences in the analytical process were not critically reviewed. **Relevance** High confidence **Applicability of findings** Findings are applicable to the context of the review question and review inclusion criteria **Coherence** High confidence **Findings/results** Results were presented clearly with distinction between the authors' interpretations and the participants' quotes

Study details	Participants	Methods	Findings/results	Comments
Neonatal Research and Education				**Adequacy of data** Moderate confidence **Data collection** Data was collected through semi-structured interviews; authors did not identify if data saturation had been achieved **Other information**
Full citation Smith, V. C., Steelfisher, G. K., Salhi, C., Shen, L. Y., Coping with the neonatal intensive care unit experience: Parents' strategies and views of staff support, Journal of Perinatal and Neonatal Nursing, 26, 343-352, 2012 **Ref Id** 685388	**Characteristics** Parents' characteristics n=29 Parent, n (%) Mother= 20 (69) Father= 9 (31) Parental age at delivery, n (%) 18-24 y= 3 (10) 24-34 y= 10 (34)	**Setting** NICU in a 600-bed, major urban teaching hospital. NICU has 40 intensive and intermediate care beds **Data Collection** A researcher trained in interview techniques conducted all interviews either in person or by telephone, using the interview script. Interviews were conducted at all hours of the day/night and days of	**Themes and categories** Family and friend support • Practical support • Burdens Staff support • Facilitating transition into parenting role • Interpersonal relationships	**Limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out US **Aim of the study** The aim of the study was to examine parental reports of their NICU experiences, oping strategies, and views of the ways NICU staff supported them. **Study type** Qualitative analysis **Study dates** June to July 2007 **Source of funding**	>/= 35 y= 2 (7) Missing/declined= 2 (7) Infant characteristics n= 40 Infant gestational age at delivery, n (%) </= 28 wk= 15 (37) 29-33 wk= 19 (48) >/= 11 (28) Singleton, n (%)= 11 (28) Twin= 20 (50) Triplet= 9 (22) Complications, n (%) RDS treated with surfactant= 29 (72) PDA treated either medically or surgically= 14 (35) Retinopathy of prematurity= 5 (13)	the week including weekends. The in-person interviews were conducted either in the infant's room in the NICU, in one of the NICU parent rooms, or in a researcher's office, depending on family's preference. The interviews spanned from 21 to 80 minutes, with the average being 45 minutes and were digitally recorded and transcribed with a secondary check for accuracy. **Data Analysis** Through the application of the grounded theory approach, themes were identified and organised. Three authors developed a codebook from a sample of 9 interviews and then refined the codebook until they had reached thematic saturation. The analytic approach followed high standards for validity and reliability in qualitative research. The full research team reviewed the codebook at each stage to	Parent-to-parent support • Shared experiences Spousal support	valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** The sample selection was clearly reported. The analytical process and process for identifying themes was described. **Confirmability** The relationship between the researcher and the participants was not clearly reported. Researchers did not critically review their own roles in the process. **Relevance** High confidence **Applicability of findings**

Study details	Participants	Methods	Findings/results	Comments
Department of Neonatology at BIDMC	**Inclusion criteria** Inclusion criteria: • Parents were > 18 years old • Surviving infant • Able to speak or read English • Retaining custody of the infant(s) • Families in the NICU or involved with the postdischarge family group **Exclusion criteria** Not reported	ensure validity and comprehensiveness. Decisions about coding practices were carefully documented to help ensure comparative coding. Researchers also reviewed each other's practices; discrepancies in coding were discussed and finalized after consensus.		Evidence was applicable to the context of the review **Coherence** High confidence **Findings/results** Results were presented clearly (i.e. citation/data and the researchers' own input distinguished). **Adequacy of data** High confidence **Data collection** Data collected from participants relied on a semi-structured interview approach. Thematic saturation was achieved. **Other information**

Study details	Participants	Methods	Findings/results	Comments
Full citation Wigert, H., Dellenmark Blom, M., Bry, K., Parents' experiences of communication with neonatal intensive-care unit staff: An interview study, BMC PediatrBMC pediatrics, 14 (1) (no pagination), 2014 **Ref Id** 685782 **Country/ies where the study was carried out** Sweden **Aim of the study** The objective of this study was to describe parents' experiences with NICU staff. **Study type**	**Characteristics** Parents' characteristics n= 27 Fathers, n= 11 Mothers, n=16 First-time parents, n= 5 Non-Scandinavian descent, n= 3 Mother's age, mean= 33 Fathers age, mean= 34 Infant characteristics n= 22 Number of days in the NICU, median (IQR)= 33 (11 to 120) Infants born prematurely, n= 17 Infants born at full term, n= 5 Mechanical ventilation, n= 13	**Setting** Level III NICU at a university hospital in Sweden **Data Collection** Open-ended, 23-70 minute long interviews were conducted and recorded digitally in the parent's home. All parents were encouraged to speak openly about their experiences, and follow-up questions were used to confirm the researchers' understanding of the narratives provided. Since the last interviews revealed essentially no new data, no additional families were contacted. **Data Analysis** The interviews were transcribed verbatim. No predetermined hypotheses or theories were employed. The meanings in	**Themes and categories** Staff support • Facilitating parents in participating in care • Facilitating transition into parenting role • Communication to reduce stress • Interpersonal relationships • Continuity of care	**Limitations** High confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** Sample selection was clearly reported. The analytical process and process of identifying themes was described. **Dependability** The relationship between the researcher and the participants was not clearly reported. Researchers critically reflected on the necessity of reading "all the text...without preconceived ideas and critically several times to understand parents' experiences of communication with the NICU staff, including underlying

Study details	Participants	Methods	Findings/results	Comments
Hermeneutic lifeworld interview study **Study dates** Not reported **Source of funding** Not reported	Nasal CPAP, n= 13 RDS, n= 18 Cerebral haemorrhage or neonatal stroke, n= 8 Congenital anomaly, n= 3 **Inclusion criteria** • Neonatal care was initially given in a level III NICU • Less than 12 months had passed since discharge from the NICU • Parents spoke and understand Swedish **Exclusion criteria** Not reported	the text were condensed, compared and grouped in clusters, which were compared and contrasted. The analytic phase was open and flexible with a distancing, reflective and critical approach. The interpretations of the parts of each transcript were constantly compared with the interpretation of the whole transcript, in order to decide whether there was a discrepancy between the understanding of the parts and the understanding of the whole.		meanings and explanations that were not immediately obvious." **Confirmability** **Relevance** Moderate confidence **Applicability of findings** 5 infants were born at full-term, therefore, study population is indirect for the systematic review. **Coherence** High confidence **Findings/results** Results were presented clearly (i.e. citation/data and the researchers' own input distinguished) **Adequacy of data** Moderate confidence

Study details	Participants	Methods	Findings/results	Comments
				Data collection Data collected from participants relied on open-ended interviews. There was no indication of data saturation. **Other information**
Full citation MacDonald, Margaret, Mothers of pre-term infants in neonate intensive care, Early Child Development and Care, 177, 821-838, 2007 **Ref Id** 702986 **Country/ies where the study was carried out** Canada **Aim of the study**	**Characteristics** Study parents Mothers, n= 8 Average age= 33 Study infants n=14 Singletons, n= 3 Twins, n=4 Triplets, n= 1 Gestational age, weeks, median (IQR)= 25 + 5 (23 + 4 to 29 +6)	**Setting** A Canadian NICU **Data Collection** Interviews took place in person with open-ended questions. Responses were audio-recorded. Follow-up weekly visits were used to observe, photograph and document the mothers' interactions with their infant(s). Mothers were then asked to questions about the images. **Data Analysis**	**Themes and categories** Social support • Partners Staff support • Continuity of care Hospital environment • Participating in care	**Limitations** Moderate confidence **Credibility** The sample selection process was clearly reported; the relationship between the researchers and the participants was not described **Transferability** The process of identifying themes was clearly reported; the researchers did not reflect on the role they played in the analysis process

Study details	Participants	Methods	Findings/results	Comments
The aim of this study was to explore the experiences of mothering infants in the NICU. **Study type** Observational case studies **Study dates** February to December 2006 **Source of funding** Social Sciences and Humanities Research Council	Birth weight, g, median (IQR)= 718.5 (480 to 1577) **Inclusion criteria** • Likelihood the infant(s) would be staying in the NICU for up to 6 additional weeks • Relative stability of the infant sand mothers **Exclusion criteria** • Experiencing severe depression • Extenuating health or emotional issues	Data was analysed using the constant comparative method developed in grounded theory. The researchers developed a provisional hypothesis and then verified it by reviewing the data and clarifying with the participants to validate the researchers' interpretations. Data were then organised into recurring common themes.		**Dependability** **Confirmability** **Relevance** High confidence **Applicability of findings** The findings were relevant to the review's inclusion criteria and context **Coherence** High confidence **Findings/results** The results were presented clearly with distinction between data and participants' quotes and the researchers' interpretations **Adequacy of data** Moderate confidence **Data collection**

Study details	Participants	Methods	Findings/results	Comments
				Data relied on semi-structured interviews and videotaped observations; the researchers did not comment on whether data saturation had been achieved **Other information**

1

2 **Clinical evidence tables for question 6.3 What information, and in what format, is valued by parents and carers of preterm**
3 **babies who are receiving respiratory support on the neonatal unit?**

Study details	Participants	Methods	Findings/results	Comments
Full citation Calam, R. M., Lambrenos, K., Cox, A. D., Weindling, A. M., Maternal appraisal of information given around the time of preterm delivery, Journal of Reproductive and Infant Psychology, 17, 267-280, 1999 **Ref Id**	**Characteristics** Study parents Mothers, n= 76 Median age, median (IQR)= 25 (17 to 40) Study infants n= 76 Male, n= 44	**Setting** NICUs in Merseyside, UK **Data Collection** Mothers were interviewed using a semi-structured interview format 12-24 weeks after birth. Mothers also completed a Malaise	**Themes and categories** Prenatal and postnatal information -Difficulty absorbing prenatal information -Postnatal care	**Methodological limitations** Moderate confidence **Credibility** Member checks, verbatim quotes, peer debriefing, and independnent analysis of data by more than one researcher were performed **Transferability**

Study details	Participants	Methods	Findings/results	Comments
336202 **Country/ies where the study was carried out** UK **Aim of the study** The aim of the study was to assess the extent to which mothers recall and understand information given to them at the time of preterm delivery. **Study type** Semi-structured interviews **Study dates** Not reported **Source of funding**	Gestational age, weeks, median (IQR)= 28 (23-34) Birth weight, g, median (IQR)= 1185 (661-2230) Days on NICU, median (IQR)= 61 (8-251) Intracranial haemorrhage, n =34 **Inclusion criteria** • Infants had been judged to be at high risk • Admitted to NICU • Had been ventilated **Exclusion criteria** Not reported	Inventory to assess current emotional well-being. **Data Analysis** Data generated from interviews were categorised and coded. Researchers applied numerical codes according to the degree of recall, understanding or satisfaction to the prediction for the future and assessment of maternal mental health.		Authors provided details of the study participants to enable readers to evaluation for which target groups the study provides valuable information, there were thick descriptions about the study context and setting **Dependability** The sampling method was not clearly reported; the analytical process was described as well as how themes were identified **Confirmability** The relationship between the researcher and the participants was not clearly reported; the researchers' roles and potential influences in the analytical process were not critically reviewed **Relevance** High confidence **Applicability of findings**

Study details	Participants	Methods	Findings/results	Comments
Mersey Regional Health Authority				Findings are applicable to the context of the review question and review inclusion criteria **Coherence** High confidence **Findings/results** Results were presented clearly with distinction between the authors' interpretations and the participants' quotes **Adequacy of data** Moderate confidence **Data collection** Data was collected through semi-structured; authors did not state whether theoretical saturation was achieved **Other information**

Study details	Participants	Methods	Findings/results	Comments
Full citation Feeley, N., Waitzer, E., Sherrard, K., Boisvert, L., Zelkowitz, P., Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit, J Clin NursJournal of clinical nursing, 22, 521-530, 2013 **Ref Id** 683579 **Country/ies where the study was carried out** Canada **Aim of the study** The aim of this study was to assess what fathers perceived were facilitators and barriers to their involvement with	**Characteristics** Fathers' characteristics n= 18 Education Junior college or less, n (%)= 10 (55.6) University, n (%)= 8 (44.4) Infant characteristics n= 21 Premature birth, n (%)= 21 (100) Medical treatments, n (%) Mechanical ventilation/high-frequency ventilation= 15 (71.4) CPAP/HFNC= 18 (85.7) Intravenous or central line= 21 (100) Isolation= 0 (0) Chest tube= 1 (4.8)	**Setting** Two open-space design (one large open room) NICUs in Montreal, Canada **Data Collection** Semi-structured interviews were conducted by a female interviewer in a private room adjacent to the NICU with no other persons present. Interviews were audio recorded and lasted between 45–90 minutes. Participants completed a demographic questionnaire, and data pertaining to the infant's condition were gathered from the medical record. **Data Analysis** The interview data were analysed using inductive content analysis. Analysis and interviews occurred concurrently. First, transcripts of the interviews were verified for accuracy, and notes recorded following the	**Themes and categories** Infant's health status -Understanding the infant's medical condition Caring for the infant -Parenting activities For the Future -Decision making	**Methodological limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were completed **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** Sampling method not clearly reported: "Fathers were recruited from 2 open-space design NICUs in a major Canadian urban centre..." The analysis process and process for identifying themes was clearly reported: "The

Study details	Participants	Methods	Findings/results	Comments
their infants in the NICU. **Study type** Semi-structured interviews **Study dates** Not reported **Source of funding** Not reported	Gavage/TPN= 18 (85.7) **Inclusion criteria** Fathers had to be the infant's biological father and had to be living with the infant's mother; the infant had been hospitalised >/= 7 days; the infant's medical condition was stable; and the father could communicate in French or English **Exclusion criteria** Fathers were excluded if they had a previous child hospitalised in the NICU (previous experience may affect involvement); the infant had a Grade III/IV IVH or a major congenital anomaly	interview were inserted into the transcripts. Second, codes were applied and condensed into categories. The research team met on several occasions during data collection to review transcripts discuss coding and the development of categories. After 18 interviews, data saturation was achieved as no new categories of barriers and facilitators of involvement were identified. Descriptive statistics were used to describe the characteristics of the participants and their infants.		interview data were subjected to inductive content analysis. Analysis and interviews occurred concurrently." **Confirmability** The relationship between the researcher and the participants was not clearly reported. Researchers did not critically reflect on their own roles in the process, though "three aspects of rigour relevant to a qualitative inquiry were addressed." **Relevance** High confidence **Applicability of findings** Evidence applicable to review context **Coherence** High confidence

Study details	Participants	Methods	Findings/results	Comments
				Findings/results Results were presented clearly (i.e. citation/data ad the researchers' own input distinguished) **Adequacy of data** High confidence **Data collection** Data collected from fathers relied on semi-structured interviews. Thematic saturation was reached and data collection ceased when no new categories of themes were identified. **Other information**
Full citation Guillaume, S., Michelin, N., Amrani, E., Benier, B., Durrmeyer, X., Lescure, S., Bony, C., Danan, C., Baud,	**Characteristics** Parents' characteristics n= 60	**Setting** Three tertiary care centers in Paris, France **Data Collection**	**Themes and categories** Infant's health status	**Methodological limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by

Study details	Participants	Methods	Findings/results	Comments
O., Jarreau, P. H., Zana-Taieb, E., Caeymaex, L., Parents' expectations of staff in the early bonding process with their premature babies in the intensive care setting: A qualitative multicenter study with 60 parents, BMC Pediatrics, 13 (1) (no pagination), 2013 **Ref Id** 493858 **Country/ies where the study was carried out** France **Aim of the study** The aim of this study was to assess parents' perceptions of how an early bond with their premature infant is established and to identify their expectations of caregivers, and the tangible things that	Fathers, n (%)= 30 (50) Age mother, years, mean (SD): 30.7 (6.6) Age father, years, mean (SD): 33.5 (6.8) History of preterm delivery, n (%)= 6 (10) Infant characteristics n= 49 Female, n (%)= 29 (59) Gestational age, weeks, mean (SD)= 27 (2) Birth weight, g, mean (SD)= 965 (206) Ventilation type at time of interview, n (%) Spontaneous ventilation, 8 (16) Nasal ventilation, 30 (61) Endotracheal ventilation, 11 (22) **Inclusion criteria** • Spoke French	Semi-directive interviews lasting 60 to 90 minutes were conducted by a social psychologist trained in research and not involved in a NICU. Audio recordings of the interviews were made, with the parents' oral consent. Fathers and mothers were interviewed separately. The interview guide was developed from a review of the literature and from 10 preliminary interviews discussed within focus groups of caregivers, conducted by the researchers. **Data Analysis** The interviews were analysed using discourse analysis. The analysis was performed separately by the research psychologist and research assistant with the manual coding of themes. Convergences and divergences of the same theme were identified across interviews. Attention was paid to the emergence of new themes and contradictory results as the interviews and	-Receiving updates -Recall of information Caring for the infant -Changes in care -Behavioural cues Understanding the NICU environment Formats -Telephone	more than one researcher, verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** Sample selection was not clearly reported; the analytical process and process of identifying themes was clearly reported. **Confirmability** The relationship between the researcher and the participants was reported: "semi-directive interviews lasting 60-90 minutes were conducted by a social

Study details	Participants	Methods	Findings/results	Comments
helped and hindered them. **Study type** Prospective qualitative discourse analysis **Study dates** November 2009 to March 2010 **Source of funding** Not reported	• Infant was born at < 32 weeks gestation • Infant was 15-30 days old at inclusion • Infant had no recent severe clinical aggravation, according to the attending physician **Exclusion criteria** Not reported	analysis progressed and data saturation occurred.		psychologist trained in research and not involved in the NICU." The researchers did not critically reflect on their own roles in the analysis process **Relevance** High confidence **Applicability of findings** The study's population and research question were applicable to the context of this review **Coherence** High confidence **Findings/results** Data collected from participants relied on a semi-structured interview approach. Data saturation was achieved. **Adequacy of data** High confidence **Data collection**

Study details	Participants	Methods	Findings/results	Comments
				Results were presented clearly (i.e. citation/data and the researchers' own input were identified) **Other information**
Full citation Heinemann, A. B., Hellstrom-Westas, L., Hedberg Nyqvist, K., Factors affecting parents' presence with their extremely preterm infants in a neonatal intensive care room, Acta Paediatr, 102, 695-702, 2013 **Ref Id** 418096 **Country/ies where the study was carried out** Sweden **Aim of the study**	**Characteristics** Parents characteristics Mothers, n= 7 Fathers, n= 6 Infants characteristics n=7 n requiring ventilator support= 7 Gestational age at birth, weeks, median (IQR)= 25 + 4 (23 + 5 to 27 + 6) Range of birth weights, g= 492 - 1044 **Inclusion criteria**	**Setting** 3 level III NICUs at a Swedish, regional/university level III hospital. **Data Collection** Data was collected through interviews with parents that took place at least 1 week after the infant's transfer from a NICU room to another room in the hospital. Interviews were conducted by the first author using a conversation guide. **Data Analysis**	**Themes and categories** Infant's health status -Recall of information Caring for the infant -Parenting activities	**Methodological limitations** High confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of

Study details	Participants	Methods	Findings/results	Comments
The aim of this study was to explore parents' experiences of factors that influenced their stay with their preterm infants in a NICU **Study type** Qualitative descriptive design **Study dates** Not reported **Source of funding** Gillbergska Foundation	• Ability to speak and understand Swedish • Child is extremely preterm **Exclusion criteria** • Substance abuse	Analysis of the data took place continuously throughout the interview period. The authors read the text and used qualitative content analysis - first they identified meaning units, secondly they condensed these units into codes and further subcategories.		thick description about both the context **Dependability** The analytical process was described as well as how themes were identified. The sample collection process was clearly reported **Confirmability** The relationship between the researchers and the participants was clearly described. The researchers' roles and potential influences in the analytical process were critically reviewed. **Relevance** High confidence **Applicability of findings** Findings are applicable to the context of the review question and review inclusion criteria

Study details	Participants	Methods	Findings/results	Comments
				Coherence High confidence **Findings/results** Results were presented clearly with distinction between the authors' interpretations and the participants' quotes **Adequacy of data** Moderate confidence **Data collection** Data was collected through semi-structured interviews; the authors did not discuss if data saturation had been achieved **Other information**
Full citation Kavanaugh, K., Savage, T., Kilpatrick, S., et al.,, Life support decisions for	**Characteristics** Study parents Mothers, n= 6	**Setting** Private hospital room	**Themes and categories** Prenatal and postnatal	**Methodological limitations** Moderate confidence **Credibility**

Study details	Participants	Methods	Findings/results	Comments
extremely premature infants: report of a pilot study, Journal of Pediatric Nursing, 20, 347-359, 2005 **Ref Id** 695111 **Country/ies where the study was carried out** US **Aim of the study** The aim of this study was to describe the decision making process and the decision support needs of parents, physicians, and nurses in regards to life support decisions made for preterm infants. **Study type** Collective case study	Fathers, n=2 Mother's age, years, mean (SD)= 28 (5.09) Father's age, years= 21 and 31 Years of education, mean (SD)= 12.87 (1.64) Study infants Birth weight, g, range= 597-723 Receiving ventilatory support at the end of data collection period, n= 2 **Inclusion criteria** • Mothers hospitalised for threatened premature delivery • Potential birth of their infant between 22 + 0 and 25 + 6 weeks' gestation **Exclusion criteria** Not reported	**Data Collection** Prenatal interviews were performed in person and audio-recorded and maternal and infant hospital records were reviewed. The co-investigator conducted interviews with the physicians and nurses. Parents were contacted weekly until the 25th week of gestation of the infant to ascertain life support decisions. Postnatal interviews were conducted. An end-of-life interview was conducted with the mother of the infant who died **Data Analysis** Interviews were transcribed verbatim and data from interviews were combined with medical records and demographic forms to acquire an overall picture of the participants' experiences. The Ottawa Framework was used as the organising framework for data management. Data were coded as per the framework and were	-Inability to absorb information prenatally -Prenatal maternal and infant health Postnatal Caring for the infant -Breastfeeding For the future -Plans for future pregnancies -Decision making Formats -Nurses -Physician or neonatologist -Timing and consistency	Member checks, peer debriefing, independent analysis of data by more than one researcher, verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** Use of a convenience sampling was clearly reported. The analytical process was described as well as how themes were identified. **Confirmability**

Study details	Participants	Methods	Findings/results	Comments
Study dates Not reported **Source of funding** University of Illinois Campus Research Board		compared within and across each case.		The relationship between the researcher and the participants was clearly reported. The researchers' roles and potential influences in the analytical process were not critically reviewed **Relevance** Moderate confidence **Applicability of findings** Not all findings are applicable to the context of the review question, as some participants were practitioners and nurses **Coherence** High confidenc e **Findings/results** Results were presented clearly with distinction between the authors' interpretations and the participants' quotes **Adequacy of data**

Study details	Participants	Methods	Findings/results	Comments
				Moderate confidence **Data collection** Data was collected through semi-structured interviews and observations; authors did not state whether data saturation was achieved **Other information**
Full citation Neu, M., Parents' perception of skin-to-skin care with their preterm infants requiring assisted ventilation, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 28, 157-164, 1999 **Ref Id** 684777 **Country/ies where the study was carried out**	**Characteristics** Parents' characteristics n= 9 Mothers, n= 8 Age, mean= 25.9 Singleton birth, n= 9 First time parents, n = 4 Infant characteristics	**Setting** Tertiary neonatal care setting and homes of parents **Data Collection** A naturalistic inquiry was used to assess the experiences of parents who had participated in skin-to-skin care. The design incorporated two interviews, one conducted immediately after two skin-to-skin care session and a follow-up interview conducted several months later. Video scenes lasting 8 -10 minutes	**Themes and categories** Caregiving information -Skin to skin care	**Methodological limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable

Study details	Participants	Methods	Findings/results	Comments
US **Aim of the study** The aim of this study was to assess parents' perceptions of skin-to-skin care with their preterm infant who was on assisted ventilation, and to determine factors influencing the decision to continue or discontinue skin-to-skin care. **Study type** Naturalistic inquiry **Study dates** Not reported **Source of funding**	n= 9 n on assisted ventilation= 9 Female, n= 6 Birth weight, g, mean (SD)= 1064 (423) Gestational age, weeks, mean (SD)= 27.2 (2.0) **Inclusion criteria** Not reported **Exclusion criteria** Not reported	were filmed by the investigator or a research assistant. **Data Analysis** The investigator transcribed the open-ended telephone interviews verbatim. The investigator coded the transcriptions. Codes were grouped into subthemes and main themes. Content of the videotaped segments were compiled and pooled with parent/infant behavioural data from the field notes and the parent narrative to provide a more complete description of the parent's experience. The investigator's involvement in the nursery enhanced the credibility and confirmability. The investigator also presented preliminary findings of this study to several colleagues and incorporated their input. Verbatim transcriptions, videotaped segments, detailed field notes, and a record of analytic decisions provided an audit trail that contributed to credibility and confirmability in		information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** The sample was selected from the sample in a previous study, but the sampling process was not explained in detail. The analytical process and the process for identifying themes was identified. **Confirmability** The relationship between the researcher and the participants was clearly reported. Researchers did not critically reflect on their own roles in the process. **Relevance** High confidence **Applicability of findings** The sample population was directly applicable to the review

Study details	Participants	Methods	Findings/results	Comments
National Association of Neonatal Nurses		addition to providing a rich description.		context. Findings apply to activities undertaken in the NICU. **Coherence** High confidence **Findings/results** Findings were presented clearly i.e. citation/data and the researchers' own input distinguished. **Adequacy of data** Moderate confidence **Data collection** Data collected from participants relied on open-ended interviews and videos. There was no discussion of data saturation. **Other information**
Full citation	**Characteristics**	**Setting**	**Themes and categories**	**Methodological limitations** Moderate confidence

Study details	Participants	Methods	Findings/results	Comments
Pohlman, S., Fathering premature infants and the technological imperative of the neonatal intensive care unit: An interpretive inquiry, Advances in Nursing Science, 32, E1-E17, 2009 **Ref Id** 414210 **Country/ies where the study was carried out** US **Aim of the study** The aims of this study were to reveal the stressful episodes and coping practices of fathers; assess fathers' resources and barriers as they develop a relationship with their infants; describe how fathers learn practical caregiving	Parent characteristics Fathers, n= 9 Age, years, median (IQR)= 36 (22-39) Infant characteristics n= 9 Gestational age, weeks, median (IQR)= 28 (25-32) Birth weight, g, median (IQR)= 933 (515-2196) **Inclusion criteria** • English speaking white fathers • Singleton infant born at less than 33 weeks' gestation • No congenital abnormalities • Fathers were over the age of 22, share a home with the infant's mother, be enrolled within 1 month after their infant's birth **Exclusion criteria** Not reported	3 Midwestern hospitals **Data Collection** Interviews were conducted every 2-3 weeks and lasted 60-90 minutes. Interviews were audio-recorded and transcribed verbatim. Interview guides were used to initiate conversation and encourage dialogue. **Data Analysis** Data was analysed using an interpretive approach, which involved a systematic and circular process including reading of the narrative text; coding; and creating interpretive files	Caring for the infant -Parenting activities Understanding the NICU environment	**Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** The sampling method was not reported clearly. The analytical process as well as how themes were identified were described. **Confirmability**

Study details	Participants	Methods	Findings/results	Comments
skills; and explore how fathers own personal meanings of self, family, fatherhood, and work shape his caregiving practices. **Study type** Interpretive phenomenological design **Study dates** Not reported **Source of funding** National Institutes of Nursing Research; Foundation for Neonatal Research and Education				The relationship between the researchers and participants was not clearly reported. The researchers' roles and potential influences in the analytical process were not critically reviewed. **Relevance** High confidence **Applicability of findings** Findings are applicable to the context of the review question and review inclusion criteria **Coherence** High confidence **Findings/results** Results were presented clearly with distinction between the authors' interpretations and the participants' quotes **Adequacy of data**

Study details	Participants	Methods	Findings/results	Comments
				High confidence **Data collection** Data was collected through semi-structured interviews; authors did not identify if data saturation had been achieved **Other information**
Full citation Smith, V. C., SteelFisher, G. K., Salhi, C., Shen, L. Y., Coping With the Neonatal Intensive Care Unit Experience Parents' Strategies and Views of Staff Support, Journal of Perinatal & Neonatal NursingJ Perinat Neonatal Nurs, 26, 343-352, 2012 **Ref Id** 695972	**Characteristics** Parents' characteristics n=29 Parent, n (%) Mother= 20 (69) Father= 9 (31) Parental age at delivery, n (%) 18-24 y= 3 (10) 24-34 y= 10 (34)	**Setting** NICU in a 600-bed, major urban teaching hospital. NICU has 40 intensive and intermediate care beds **Data Collection** A researcher trained in interview techniques conducted all interviews either in person or by telephone, using the interview script. Interviews were conducted at all hours of the day/night and days of the week including weekends. The in-person interviews were conducted	**Themes and categories** Prenatal and postnatal information -Inability to absorb information prenatally Caring for infant -Parenting activities Formats	**Methodological limitations** Moderate confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual

Study details	Participants	Methods	Findings/results	Comments
Country/ies where the study was carried out US **Aim of the study** The aim of the study was to examine parental reports of their NICU experiences, oping strategies, and views of the ways NICU staff supported them. **Study type** Qualitative analysis **Study dates** June to July 2007 **Source of funding**	>/= 35 y= 2 (7) Missing/declined= 2 (7) Infant characteristics n= 40 Infant gestational age at delivery, n (%) </= 28 wk= 15 (37) 29-33 wk= 19 (48) >/= 11 (28) Singleton, n (%)= 11 (28) Twin= 20 (50) Triplet= 9 (22) Complications, n (%) RDS treated with surfactant= 29 (72) PDA treated either medically or surgically= 14 (35) Retinopathy of prematurity= 5 (13)	either in the infant's room in the NICU, in one of the NICU parent rooms, or in a researcher's office, depending on family's preference. The interviews spanned from 21 to 80 minutes, with the average being 45 minutes and were digitally recorded and transcribed with a secondary check for accuracy. **Data Analysis** Through the application of the grounded theory approach, themes were identified and organised. Three authors developed a codebook from a sample of 9 interviews and then refined the codebook until they had reached thematic saturation. The analytic approach followed high standards for validity and reliability in qualitative research. The full research team reviewed the codebook at each stage to ensure validity and comprehensiveness. Decisions about coding practices were carefully documented to help ensure comparative coding.	-Telephone -Medical team -Nurses -Physician or neonatologist -Timing and consistency -Other resources	background information, demographics, the provision of thick description about both the context **Dependability** The sample selection was clearly reported. The analytical process and process for identifying themes was described. **Confirmability** The relationship between the researcher and the participants was not clearly reported. Researchers did not critically review their own roles in the process. **Relevance** High confidence **Applicability of findings** Evidence was applicable to the context of the review

Study details	Participants	Methods	Findings/results	Comments
Department of Neonatology at BIDMC	**Inclusion criteria** • Parents were > 18 years old • Surviving infant • Able to speak or read English • Retaining custody of the infant(s) • Families in the NICU or involved with the postdischarge family group **Exclusion criteria** Not reported	Researchers also reviewed each other's practices; discrepancies in coding were discussed and finalized after consensus.		**Coherence** High confidence **Findings/results** Results were presented clearly (i.e. citation/data and the researchers' own input distinguished). **Adequacy of data** High confidence **Data collection** Data collected from participants relied on a semi-structured interview approach. Thematic saturation was achieved. **Other information**
Full citation Wigert, H., Dellenmark Blom, M., Bry, K., Parents' experiences of communication with	**Characteristics** Parents' characteristics n= 27	**Setting** Level III NICU at a university hospital in Sweden	**Themes and categories**	**Methodological limitations** High confidence **Credibility**

Study details	Participants	Methods	Findings/results	Comments
neonatal intensive-care unit staff: An interview study, BMC PediatrBMC pediatrics, 14 (1) (no pagination), 2014 **Ref Id** 685782 **Country/ies where the study was carried out** Sweden **Aim of the study** The objective of this study was to describe parents' experiences with NICU staff. **Study type** Hermeneutic lifeworld interview study **Study dates**	Fathers, n= 11 Mothers, n=16 First-time parents, n= 5 Non-Scandinavian descent, n= 3 Mother's age, mean= 33 Fathers age, mean= 34 Infant characteristics n= 22 Number of days in the NICU, median (IQR)= 33 (11 to 120) Infants born prematurely, n= 17 Infants born at full term, n= 5 Mechanical ventilation, n= 13 Nasal CPAP, n= 13 RDS, n= 18 Cerebral haemorrhage or neonatal stroke, n= 8	**Data Collection** Open-ended, 23-70 minute long interviews were conducted and recorded digitally in the parent's home. All parents were encouraged to speak openly about their experiences, and follow-up questions were used to confirm the researchers' understanding of the narratives provided. Since the last interviews revealed essentially no new data, no additional families were contacted. **Data Analysis** The interviews were transcribed verbatim. No predetermined hypotheses or theories were employed. The meanings in the text were condensed, compared and grouped in clusters, which were compared and contrasted. The analytic phase was open and flexible with a distancing, reflective and critical approach. The interpretations of the parts of each transcript were	Prenatal and postnatal information -Postnatal Understanding the infant's health status -Understanding the medical condition Caring for the infant -Parenting activities	Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context **Dependability** Sample selection was clearly reported. The analytical process and process of identifying themes was described. **Confirmability** The relationship between the researcher and the participants

Study details	Participants	Methods	Findings/results	Comments
Not reported **Source of funding** Not reported	Congenital anomaly, n= 3 **Inclusion criteria** • Neonatal care was initially given in a level III NICU • Less than 12 months had passed since discharge from the NICU • Parents spoke and understand Swedish **Exclusion criteria** Not reported	constantly compared with the interpretation of the whole transcript, in order to decide whether there was a discrepancy between the understanding of the parts and the understanding of the whole.		was not clearly reported. Researchers critically reflected on the necessity of reading "all the text...without preconceived ideas and critically several times to understand parents' experiences of communication with the NICU staff, including underlying meanings and explanations that were not immediately obvious." **Relevance** Moderate confidence **Applicability of findings** 5 infants were born at full-term, therefore, study population is indirect for the systematic review. **Coherence** High confidence **Findings/results** Results were presented clearly (i.e. citation/data and the researchers' own input distinguished)

Study details	Participants	Methods	Findings/results	Comments
				Adequacy of data Moderate confidence **Data collection** Data collected from participants relied on open-ended interviews. There was no indication of data saturation. **Other information**
Full citation Gibbs, D. P., Boshoff, K., Stanley, M. J., The acquisition of parenting occupations in neonatal intensive care: A preliminary perspective, Canadian Journal of Occupational Therapy, 83, 91-102, 2016 **Ref Id** 702987	**Characteristics** Parents' characteristics n=6 Male, n (%)= 3 (50) Infant characteristics n=3	**Setting** Single Level 3 NICU in a large urban centre in the UK **Data Collection** The participants engaged in a semi-structured in-depth interview. Open-ended questions were used. All participants elected to be interviewed as couples in their home. The interviews, lasting between 60 and 90 min, were digitally recorded and	**Themes and categories** Infant's health status -Understanding the medical condition Caring for the infant -Parenting activities	**Methodological limitations** High confidence **Credibility** Member checks, peer debriefing, independent analysis of data by more than one researcher, and verbatim quotes were conducted **Transferability** The authors provided details of the study participants to enable readers to evaluate for which

Study details	Participants	Methods	Findings/results	Comments

Country/ies where the study was carried out

UK

Aim of the study

The aim of this study was to assess the experiences that enable parents to participate in roles associated with parenting in the NICU

Study type

Paradigmatic narrative analysis

Study dates

Not reported

Source of funding

Not reported

Child	Gestation (weeks)	Birth weight (g)	Respiratory support	Length of stay (days)
Male 1	24 + 1	620	29 days ventilation 76 days CPAP 19 days oxygen Discharged on home oxygen	117
Male 2	28 + 6	1450	3 days ventilation 8 days CPAP	76
Male 3	29 + 4	1070	1 day ventilation 7 days CPAP	62

Inclusion criteria

- Being a parent of a premature infant (< 32 weeks gestation, < 1500 g birth weight, requiring invasive and non-

transcribed verbatim by the first author.

Data Analysis

Participants were sent a copy of the transcript to ensure accurate reflection of their experience and were asked to return comments to the first author with any required changes. Transcripts were first read to gather a sense of the meaning, then they were openly coded by the first author, codes were then refined and grouped into larger categories. The summary categories developed from each interview were then compared across transcripts to identify common or recurrent experiences. Decisions regarding applications of codes were documented in the field journal and reviewed by the second and third authors. The journal entries and documentation of the debriefing sessions provided an audit trail regarding methodological decisions.

target groups the study provides valuable information, provided contextual background information, demographics, the provision of thick description about both the context

Dependability

The sampling method was specified: "To enable the recruitment of participants who could provide rich and detailed accounts of their parenting experiences in the NICU, a purposive intensity sampling approach was utilized." The analytical process and how themes were identified was clearly described.

Confirmability

The relationship between the researchers and the participants was clearly reported. Researchers critically reflected on their own roles in the process.

Relevance

Study details	Participants	Methods	Findings/results	Comments
	invasive ventilation for a minimum of 7 days) • Having been discharged from the NICU 3 to 6 months prior • Speak English **Exclusion criteria** Not reported			High confidence **Applicability of findings** The study's research question and population reflect the context of the review **Coherence** High confidence **Findings/results** Results were presented clearly (i.e. citation/data and the researchers' own interpretation were distinguished). **Adequacy of data** High confidence **Data collection** Data collected from parents relied on semi-structured interviews; thematic saturation was achieved **Other information**

Study details	Participants	Methods	Findings/results	Comments

1

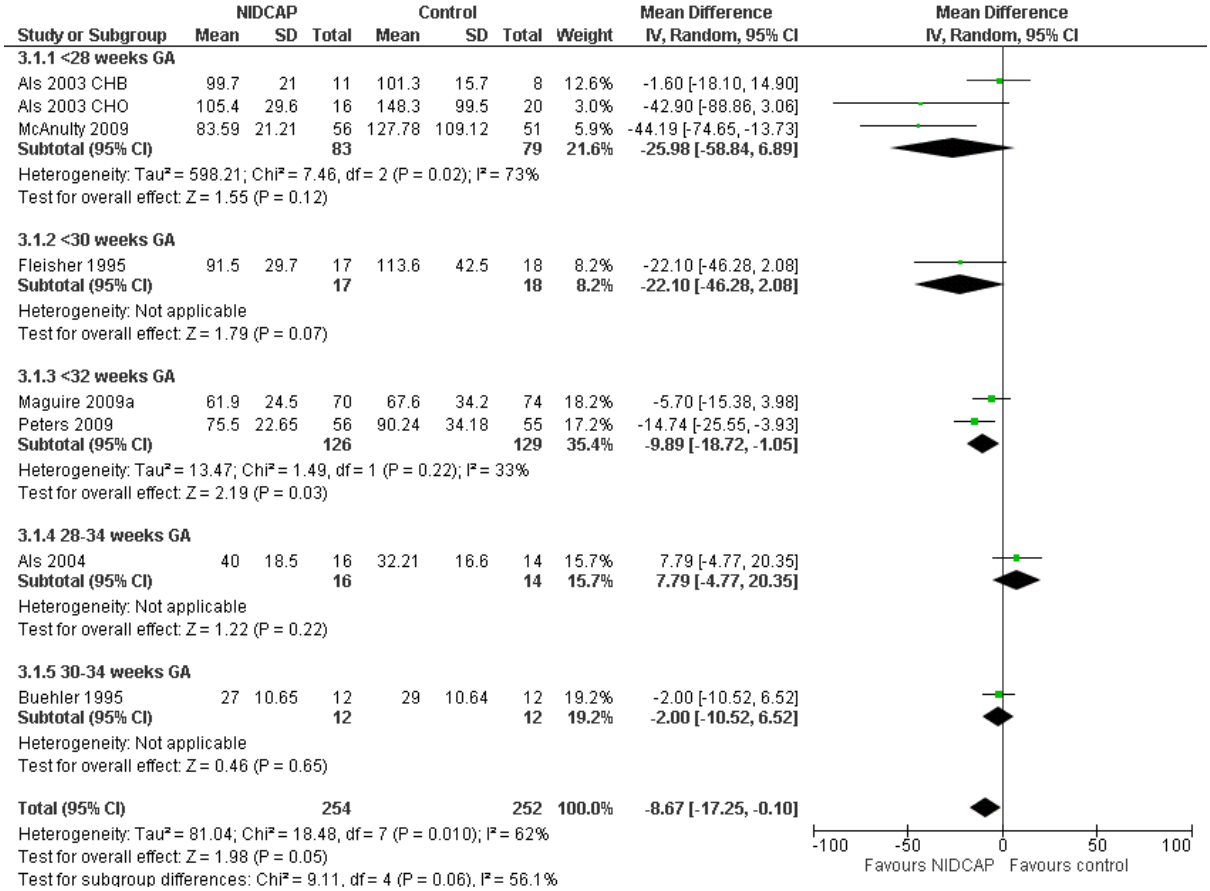
2

Appendix E – Forest plots

Forest plots for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

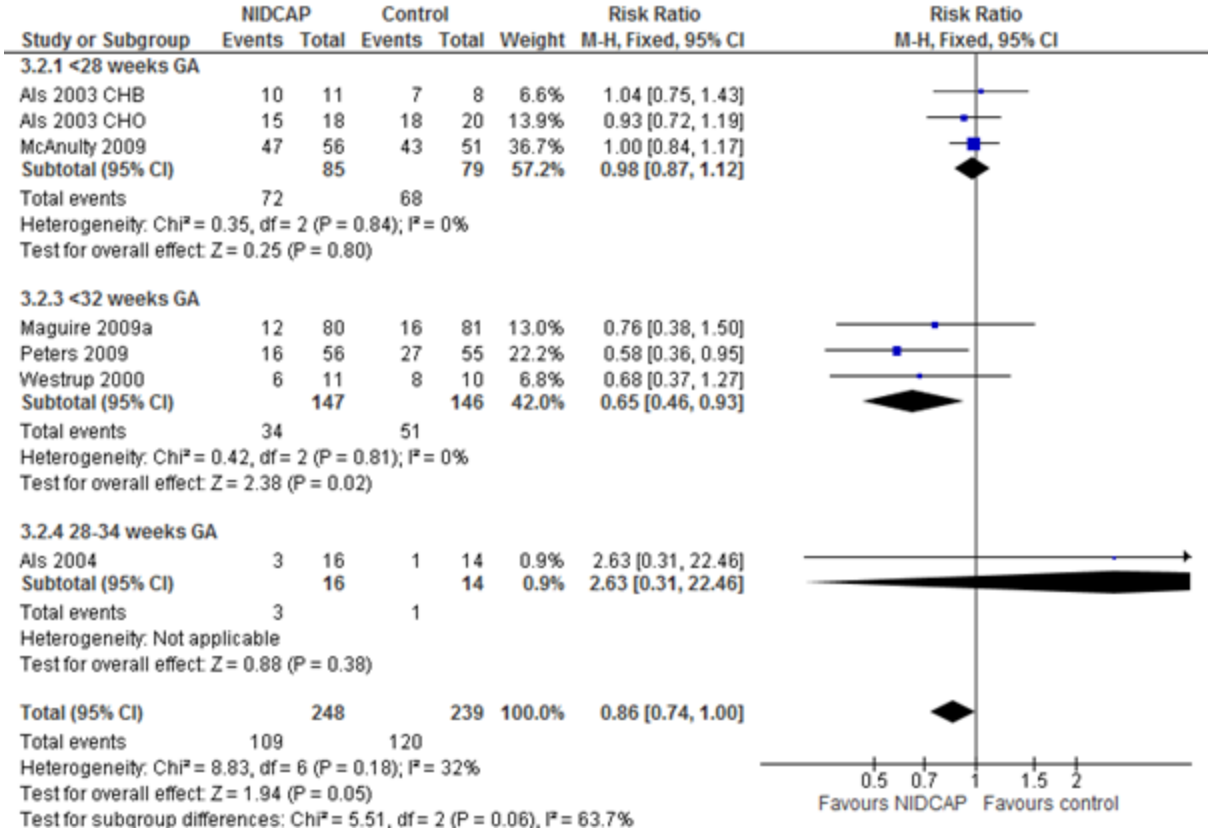
Comparison 4: NIDCAP® versus standard care

Figure 3: Initial admission length of stay



CI: confidence interval; GA: gestational age; IV: inverse variance; NIDCAP®; Newborn Individualised Developmental Care and Assessment Programme

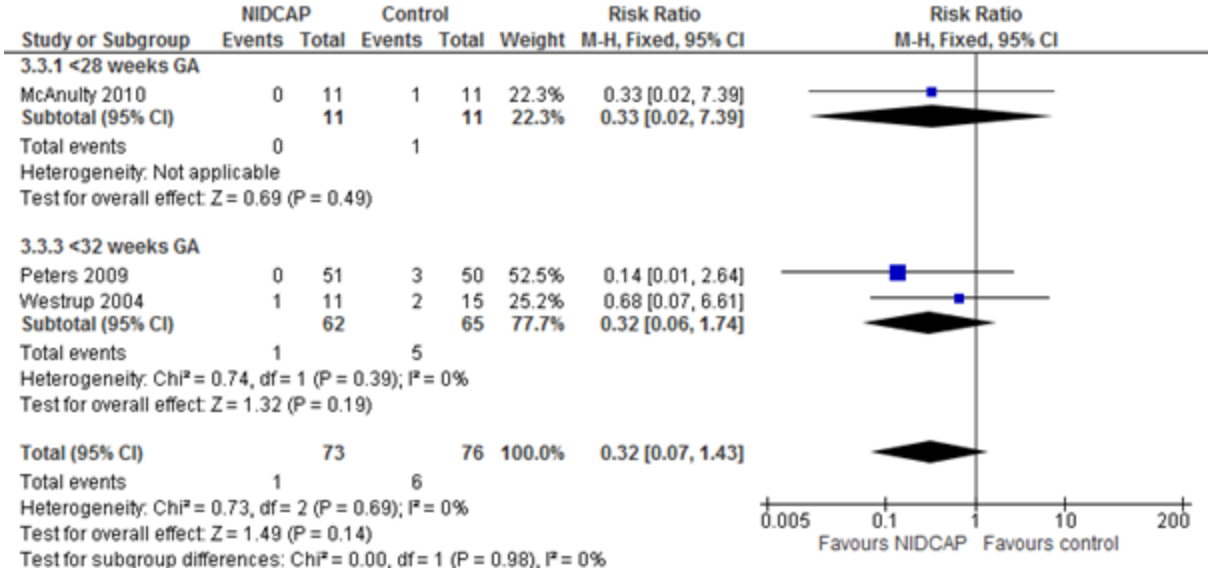
Figure 4: Bronchopulmonary dysplasia



CI: confidence interval; GA: gestational age; M-H: Mantel Haenszel; NIDCAP®; Newborn Individualised Developmental Care and Assessment Programme

1

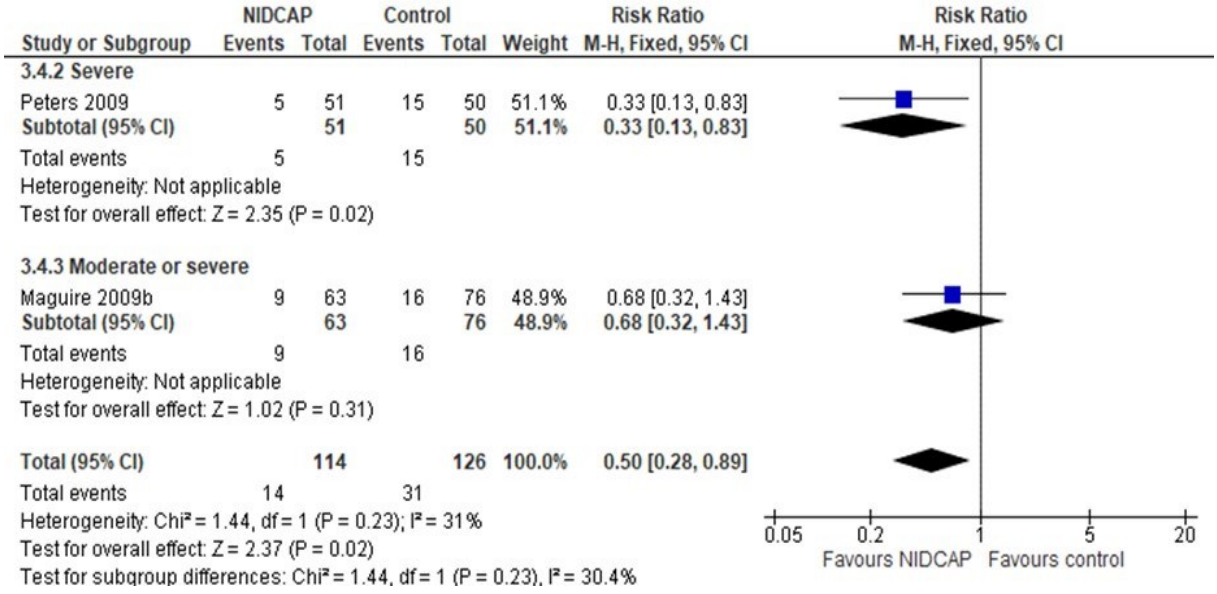
Figure 5: Cerebral palsy



CI: confidence interval; GA: gestational age; M-H: Mantel Haenszel; NIDCAP®; Newborn Individualised Developmental Care and Assessment Programme

2

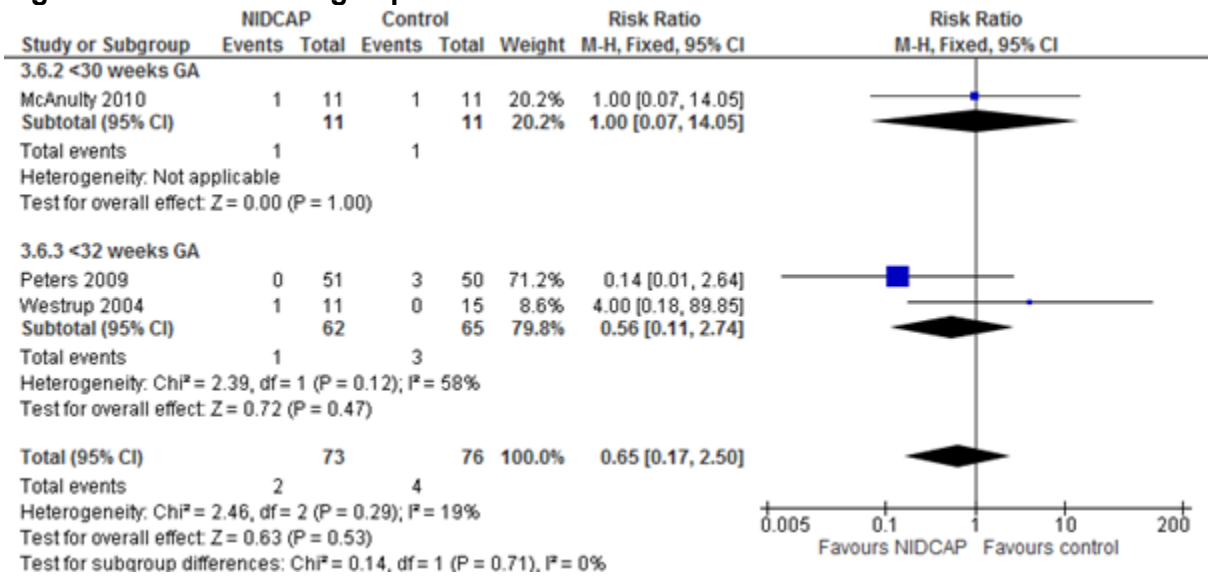
Figure 6: Neurodevelopmental mental delay



CI: confidence interval; M-H: Mantel Haenszel; NIDCAP®; Newborn Individualised Developmental Care and Assessment Programme

1

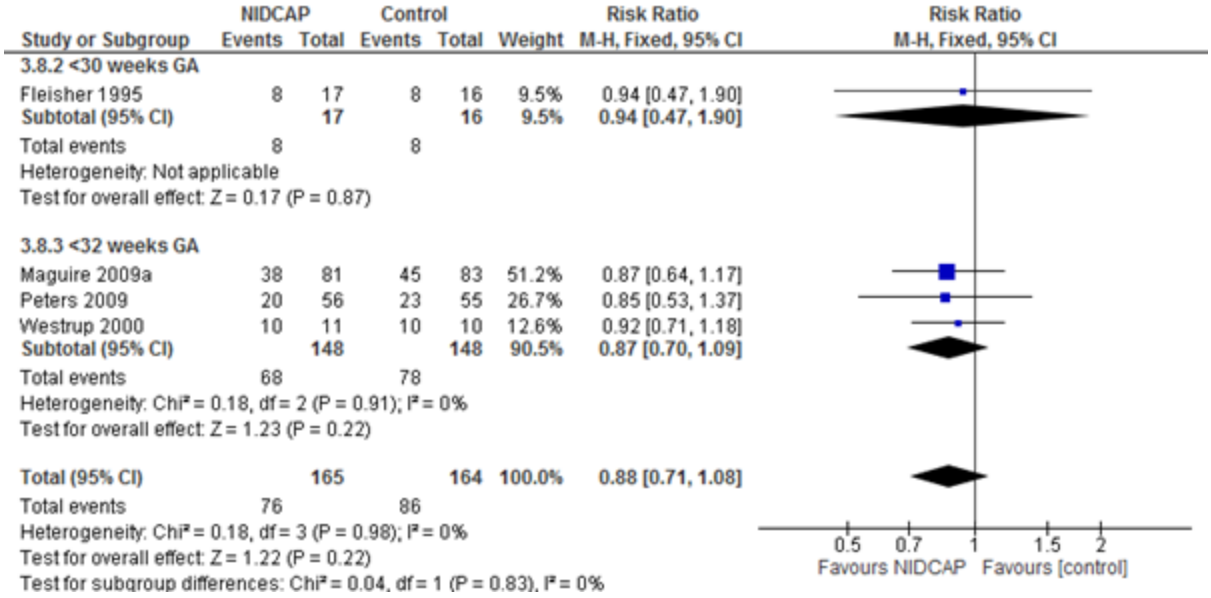
Figure 7: Severe hearing impairment



CI: confidence interval; GA: gestational age; M-H: Mantel Haenszel; NIDCAP®; Newborn Individualised Developmental Care and Assessment Programme

2

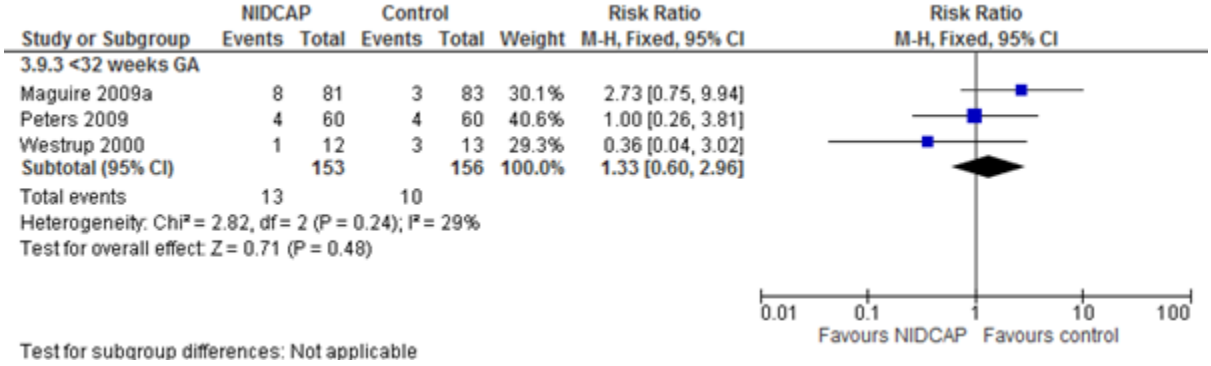
Figure 8: Sepsis before discharge



CI: confidence interval; GA: gestational age; M-H: Mantel Haenszel;; NIDCAP®; Newborn Individualised Developmental Care and Assessment Programme

1

Figure 9: Mortality before discharge



CI: confidence interval; GA: gestational age; M-H: Mantel Haenszel; NIDCAP®; Newborn Individualised Developmental Care and Assessment Programme

2 **Forest plots for question 6.2 What support is valued by parents and carers of**
3 **preterm babies requiring respiratory support?**

4 Not applicable for this review.

5 **Forest plots for question 6.3 What information, and in what format, is valued by**
6 **parents and carers of preterm babies who are receiving respiratory support on**
7 **the neonatal unit?**

8 Not applicable for this review.

9

Appendix F – GRADE and GRADE CERQual tables

GRADE tables for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

Table 7: Clinical evidence profile: Comparison 1. Kangaroo care or skin to skin care versus conventional care

Quality assessment							Number of participants		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	KC or STS	Control	Relative (95% CI)	Absolute		
Initial admission LOS (Days; better indicated by lower values)[a]												
1	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	very serious[1]	none	16	14	-	MD 2 higher (14.95 lower to 18.95 higher)	LOW	CRITICAL
Sepsis[b]												
1	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	very serious[1]	none	5/33 (15.2%)	8/27 (29.6%)	RR 0.51 (0.19 to 1.38)	145 fewer per 1000 (from 240 fewer to 112 more)	LOW	IMPORTANT
Mortality prior to discharge[b]												
1	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	very serious[1]	none	2/33 (6.1%)	1/27 (3.7%)	RR 1.64 (0.16 to 17.09)	24 more per 1000 (from 31 fewer to 595 more)	LOW	IMPORTANT

CI: confidence interval; KC: kangaroo care; LOS: length of stay; MD: mean difference; MID: minimal important difference; STS: skin-to-skin care
a Intervention described as Kangaroo care
b Intervention described as Skin to skin care
1 Downgraded by 2 because 95% CI crosses 2 default MIDs

Table 8: Clinical evidence profile: Comparison 2. Non-nutritive sucking (NNS) versus no NNS

Quality assessment	Number of participants	Effect	Quality	Importance

No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	Non-nutritive sucking	Control	Relative (95% CI)	Absolute		
Initial admission LOS – NNS Pre-NGT feeds (Better indicated by lower values)												
1	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[1]	none	19	20	-	MD 17.56 lower (35.97 lower to 0.85 higher)	MODERATE	CRITICAL
Initial admission LOS – NNS Onset NGT feeds (Better indicated by lower values)												
1	randomised trials	no serious risk of bias	no serious inconsistency	no serious indirectness	serious[1]	none	20	20	-	MD 16.5 lower (30.45 to 2.55 lower)	MODERATE	CRITICAL

CI: confidence interval; LOS: length of stay; MD: mean difference; MID: minimal important difference; NGT: nasogastric tube; NNS: non-nutritive sucking
1 Downgraded by 1 because 95% CI crosses 1 default MID

Table 9: Clinical evidence profile: Comparison 3. Family Integrated Care (FIC) versus standard care

Quality assessment							Number of participants		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	FIC	Control	Relative (95% CI)	Absolute		
Initial admission LOS (Days; Better indicated by lower values)												
1	randomised trials	serious[1]	no serious inconsistency	no serious inconsistency	no serious imprecision	none	895	891	-	MD 2 higher (1.8 to 2.2 higher)	MODERATE	CRITICAL
BPD												
1	randomised trials	serious[1]	no serious inconsistency	no serious inconsistency	serious imprecision[2]	none	167/889 (19%)	149/887 (17%)	AdjOR 0·80 (0·44 to 1·46)	26 fewer per 1000 (from 79 fewer to 55 more)	LOW	CRITICAL
Mortality prior to discharge												

1	randomised trials	serious[1]	no serious inconsistency	no serious inconsistency	serious imprecision[2]	none	11/895 (1.2%)	4/891 (0.45%)	AdjOR 2.21 (0.64 to 7.68)	5 more per 1000 (from 2 fewer to 29 more)	LOW	IMPORTANT

AdjOR: adjusted odds ratio; CI: confidence interval; BPD: bronchopulmonary dysplasia; FIC: Family Integrated Care; LOS: length of stay; MD: mean difference
1 A greater proportion of infants in the FICare group were born at a younger gestational age (22–28 weeks) than those in the standard care group (50% versus 42%)
2 Downgraded by 1 level because the 95% CI of the univariate risk ratio includes 1 MID

Table 10: Clinical evidence profile: Comparison 4. NIDCAP® versus standard care

Quality assessment							Number of participants		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	NIDCAP®	Control	Relative (95% CI)	Absolute		
Initial admission LOS – all gestational ages (Days; Better indicated by lower values)												
8	randomised trials	serious[1]	serious[2]	no serious indirectness	no serious imprecision	none	254	252	-	MD 8.67 lower (17.25 to 0.10 lower)	LOW	CRITICAL
Initial admission LOS - <28 weeks GA (Days; Better indicated by lower values)												
3	randomised trials	serious[1]	serious[2]	no serious indirectness	serious[4]	none	83	79	-	MD 25.98 lower (58.84 lower to 6.89 higher)	VERY LOW	CRITICAL
Initial admission LOS - <30 weeks GA (Days; Better indicated by lower values)												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[4]	none	17	18	-	MD 22.1 lower (46.28 lower to 2.08 higher)	LOW	CRITICAL
Initial admission LOS - <32 weeks GA (Days; Better indicated by lower values)												
2	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	no serious imprecision	none	126	129	-	MD 9.72 lower (16.93 to 2.51 lower)	MODERATE	CRITICAL
Initial admission LOS - 28-34 weeks GA (Days; Better indicated by lower values)												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[4]	none	16	14	-	MD 7.79 higher (4.6 lower to 20.18 higher)	LOW	CRITICAL
Initial admission LOS - 30-34 weeks GA (Days; Better indicated by lower values)												

1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	12	12	-	MD 2 lower (10.52 lower to 6.52 higher)	VERY LOW	CRITICAL
BPD – all gestational ages												
7	randomised trials	serious[1]	no serious inconsistency	serious[6]	serious[4]	none	109/248 (44%)	120/239 (50.2%)	RR 0.86 (0.74 to 1)	70 fewer per 1000 (from 131 fewer to 0 more)	VERY LOW	CRITICAL
BPD - <28 weeks GA												
3	randomised trials	serious[1]	no serious inconsistency	serious[6]	no serious imprecision	none	72/85 (84.7%)	68/79 (86.1%)	RR 0.98 (0.87 to 1.12)	17 fewer per 1000 (from 112 fewer to 103 more)	LOW	CRITICAL
BPD - <32 weeks GA												
3	randomised trials	serious	no serious inconsistency	serious[6]	serious[4]	none	34/147 (23.1%)	51/146 (34.9%)	RR 0.65 (0.46 to 0.93)	122 fewer per 1000 (from 24 fewer to 189 fewer)	VERY LOW	CRITICAL
BPD - 28-34 weeks GA												
1	randomised trials	serious[1]	no serious inconsistency	serious[6]	very serious[5]	none	3/16 (18.8%)	1/14 (7.1%)	RR 2.62 (0.31 to 22.46)	115 more per 1000 (from 49 fewer to 1000 more)	VERY LOW	CRITICAL
Cerebral Palsy – all gestational ages												
3	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	1/73 (1.4%)	6/76 (7.9%)	RR 0.32 (0.07 to 1.43)	54 fewer per 1000 (from 73 fewer to 34 more)	VERY LOW	CRITICAL
Cerebral Palsy - <28 weeks GA												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	0/11 (0%)	1/11 (9.1%)	RR 0.33 (0.02 to 7.39)	61 fewer per 1000 (from 89 fewer to 581 more)	VERY LOW	CRITICAL
Cerebral Palsy - <32 weeks GA												
2	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	1/62 (1.6%)	5/65 (7.7%)	RR 0.32 (0.06 to 1.74)	52 fewer per 1000 (from 72 fewer to 57 more)	VERY LOW	CRITICAL
Moderate or severe neurodevelopmental mental delay												
2	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[4]	none	14/114 (12.3%)	31/126 (24.6%)	RR 0.5 (0.28 to 0.89)	123 fewer per 1000 (from 27 fewer to 177 fewer)	LOW	CRITICAL

Neurodevelopmental mental delay - Severe												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[4]	none	5/51 (9.8%)	15/50 (30%)	RR 0.33 (0.13 to 0.83)	201 fewer per 1000 (from 51 fewer to 261fewer)	LOW	CRITICAL
Neurodevelopmental mental delay - Moderate or severe												
1	randomised trials	serious[1]	serious[7]	no serious indirectness	very serious[5]	none	9/63 (154.3%)	16/76 (21.1%)	RR 0.68 (0.32 to 1.43)	67 fewer per 1000 (from 143 fewer to 91 more)	VERY LOW	CRITICAL
Psychomotor delay - Moderate or severe												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	23/63 (36.5%)	24/76 (31.6%)	RR 1.16 (0.73 to 1.84)	51 more per 1000 (from 85 fewer to 265 more)	VERY LOW	CRITICAL
Severe hearing impairment – all gestational ages												
3	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	2/73 (2.7%)	4/76 (5.3%)	RR 0.65 (0.17 to 2.5)	18 fewer per 1000 (from 44 fewer to 79 more)	VERY LOW	CRITICAL
Severe hearing impairment - <30 weeks GA												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	1/11 (9.1%)	1/11 (9.1%)	RR 1 (0.07 to 14.05)	0 fewer per 1000 (from 85 fewer to 1000 more)	VERY LOW	CRITICAL
Severe hearing impairment - <32 weeks GA												
2	randomised trials	serious[1]	serious[8]	no serious indirectness	very serious[5]	none	1/62 (1.6%)	3/65 (4.6%)	RR 0.56 (0.11 to 2.74)	20 fewer per 1000 (from 41 fewer to 80 more)	VERY LOW	CRITICAL
Severe visual impairment - <32 weeks GA												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	1/11 (9.1%)	0/15 (0%)	RR 4 (0.18 to 89.85)	-	VERY LOW	CRITICAL
Sepsis – all gestational ages												
4	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[4]	none	76/165 (46.1%)	86/164 (52.4%)	RR 0.88 (0.71 to 1.08)	63 fewer per 1000 (from 152 fewer to 42 more)	LOW	IMPORTANT
Sepsis - <30 weeks GA												
1	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	8/17 (47.1%)	8/16 (50%)	RR 0.94 (0.47 to 1.9)	30 fewer per 1000 (from 265 fewer to 450 more)	VERY LOW	IMPORTANT

Sepsis - <32 weeks GA												
3	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	serious[4]	none	68/148 (45.9%)	78/148 (52.7%)	RR 0.87 (0.7 to 1.09)	69 fewer per 1000 (from 158 fewer to 47 more)	LOW	IMPORTANT
Mortality prior to discharge <32 weeks GA												
3	randomised trials	serious[1]	no serious inconsistency	no serious indirectness	very serious[5]	none	13/153 (8.5%)	10/156 (6.7%)	RR 1.33 (0.6 to 2.96)	22 more per 1000 (from 27 fewer to 131 more)	VERY LOW	IMPORTANT

CI: confidence interval; BPD: bronchopulmonary dysplasia; GA: gestational age; LOS: length of stay; MD: mean difference; NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme; RR: risk ratio

1 Although some authors maintain that blinding of parents and NICU staff to treatment allocation was achieved, other authors report that this is not feasible and there is a high risk of contamination across treatment groups

2 Downgraded by 1 as there may be serious heterogeneity (I2 = 62%); subgroup analysis done according to gestational age and random effects model used

3 Downgraded by 1 as there may be serious heterogeneity (I2 = 75%); subgroup analysis done according to gestational age and random effects model used

4 Downgraded by 1 because 95%CI crosses 1 default MID

5 Downgraded by 2 because 95% CI crosses 2 default MIDs

6 Some studies defined BPD on the basis of a chest X-ray rather than the preferred definition on the basis of oxygen dependency at 36 wks PCA

7 Downgraded by 1 as there may be moderate heterogeneity (I2 =48%)

8 Downgraded by 1 as there may be moderate heterogeneity (I2 = 58%)

GRADE CERQual tables for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

Table 11: Qualitative evidence profile: Theme 1. Social and psychological support

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: Friends and family					
3 (Ardal 2011; Feeley 2013; Smith 2012)	3 semi-structured interviews	3 studies conducted in different countries (Canada, USA) among fathers and parents of preterm infants requiring respiratory support in the NICU reported that practical support, including meal preparation, assistance with household tasks, and child care, from friends and family assisted the parents in involving themselves with their preterm infant in the NICU. Parents also found that family and friends who were familiar with the NICU and demonstrated empathy and understanding of the parents' anxieties reduced the stress over the burden of educating and	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
		reassuring those in the social support network who were not familiar with the situation.			
Sub theme 2: Counselling					
2 (Falck 2016; Feeley 2013)	2 semi-structured interviews	2 studies conducted in different countries (USA, Canada) among parents and fathers of preterm infants requiring respiratory support in the NICU reported that an interdisciplinary NICU team with professionals who are able to provide psychological and spiritual support was valuable and some fathers utilised online chat rooms with similar parents in order to guide their involvement in their child's care.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	
Sub theme 3: Partners					
6 (Feeley 2013; Flacking 2016; Heinemann 2013; MacDonald 2007; Pohlman 2009; Smith 2012)	1 structured questionnaire; 5 semi-structured interviews	6 studies conducted in different countries (USA, Canada, Sweden, England, Finland) among parents, mothers, fathers of preterm infants requiring respiratory support in the NICU reported that being able to talk about the NICU experience with their partner and developing a routine around caregiving activities supported parents in coping with having their infant in the NICU.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

1 *NICU: neonatal intensive care unit*
2 *[1]The confidence in the methodological quality was downgraded by 1 due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Falck 2016;*
3 *Feeley 2013; Flacking 2016; MacDonald 2007; Pohlman 2009; Smith 2012)*
4 *[2]The confidence in the adequacy of the evidence was downgraded by 2 due to the evidence not being sufficiently rich or too small a number in the context of the review finding*

5 **Table 12: Qualitative evidence profile: Theme 2. Staff support**

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Facilitating parents in participating in care					
5 (Cescutti-Butler 2003; Gibbs 2016; Guillaume 2013; Heinemann 2013; Wigert 2014)	1 focused conversational interview; 3 semi-structured interviews; 1 open-ended interview	5 studies conducted in different countries (UK, France, Sweden) among parents of preterm infants requiring respiratory support in the NICU reported that staff acted as gatekeepers to their participation in their infant's care. Participating in ward rounds, hearing information about their child, and caring behaviour facilitate and support parents in becoming involved with their infant's care.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Facilitating the transition into parenting role					

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
7 (Cescutti-Butler 2003; Feeley 2013; Gibbs 2016; Guillaume 2013; Neu 1999; Smith 2012; Wigert 2014)	1 focused conversational interview; 4 semi-structured interviews; 2 unstructured interviews	7 studies conducted in different countries (UK, Canada, France, USA, Sweden) among parents and fathers of preterm infants requiring respiratory support in the NICU found that parents felt more confident transitioning into the parenting role when staff provided encouragement and the parents felt they had the freedom to care for their child with the staff present to help if needed. Staff who provided informal and formal training on providing care and who acted as role models that the parents could observe were also welcome supports.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 3: Communication to reduce stress					
8 (Falck 2016; Flacking 2016; Gibbs 2016; Guillaume 2013; Heinemann 2013; Holditch-Davis 2000; Pohlman 2009; Wigert 2014)	1 structured questionnaire; 6 semi-structured interviews; 1 open-ended interview	8 studies conducted in different countries (USA, UK, France, Sweden, Finland) among parents and mothers of preterm infants requiring respiratory support in the NICU reported that communication with staff was crucial for developing a trusting relationship with staff and minimising parental anxiety. Elements such as using transparent communication methods to provide personalised information, family meetings to facilitate shared decision making, and regular phone updates when the parents are not in the NICU, assisted the parents and mothers to reduce stress. Parents need to feel that their beliefs and concerns are respected and that the information they receive is shared at the appropriate time and is not too medical.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub-theme 4: Interpersonal relationships					
7 (Cescutti-Butler 2003; Gibbs 2016; Heinemann 2013; Holditch-Davis 2000; Jackson 2003; Smith 2012; Wigert 2014)	1 focused conversational interview; 5 semi-structured interviews; 1 open-ended interview	7 studies conducted in different countries (UK, USA, Sweden) among parents and mothers of preterm infants requiring respiratory support in the NICU reported that feeling a sense of rapport with staff gave the parents both self-confidence in their parenting role and that their infant was being cared for well in the NICU. Parents found it beneficial when staff facilitated friendships with other parents and NICU graduate parents, through activities such as coffee hours or scrapbooking sessions, as enjoyed interacting with people whose child was or had been receiving the same care.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub-theme 5: Continuity of care					

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
6 (Falck 2016; Gibbs 2016; Guillaume 2013; MacDonald 2003; Pohlman 2009; Wigert 2014)	5 semi-structured interviews; 1 open-ended interview	6 studies conducted in different countries (Canada, USA, UK, France, Sweden) among parents of preterm infants requiring respiratory support in the NICU reported that having continuity in the staff caring for their infant facilitated a sense of trust and confidence in the care the nurses were providing. Parents felt that lack of consistency in care meant that staff did not always know the infant and would have different opinions on the type of care that was needed. Parents felt supported by having a contact or designated nurse or doctor.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

NICU: neonatal intensive care unit
[1]The confidence in the methodological quality was downgraded by 1 due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Falck 2016; Feeley 2013; Flacking 2016; Guillaume 2013; Holditch-Davis 2000; Jackson 2003; MacDonald 2007; Neu 1999; Pohlman 2009; Smith 2012)

Table 13: Qualitative evidence profile: Theme 3. Parent-to-parent support

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: Shared experiences					
3 (Ardal 2011; Gibbs 2016; Smith 2012)	3 semi-structured interviews	3 studies conducted in different countries (Canada, UK, USA) among parents of preterm infants requiring respiratory support in the NICU reported that having a parent-buddy who spoke the same language, was from the same ethno-cultural background, and had the same experience with an infant in the NICU enabled them to communicate their feelings and concerns and understand the preterm birth experience. Engaging with other NICU parents helped parents to cope because it provided them with information and perspective.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Observational learning					
1 (Feeley 2013)	1 semi-structured interview	1 study conducted in Canada among fathers of preterm infants requiring respiratory support in the NICU reported that being able to watch other parents in open-spaced NICUs as they cared for their own infants helped them to become more involved with their infant.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	

NICU: neonatal intensive care unit
[1]The confidence in the methodological quality was downgraded by 1 due to a study not clearly reporting the sampling method or relationship between the researcher and participants (Feeley 2013)

[2]*The confidence in the adequacy of the evidence was downgraded by 2 due to the evidence not being sufficiently rich or too small a number in the context of the review finding*

Table 14: Qualitative evidence profile: Theme 4. Hospital environment

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Need for privacy					
5 (Falck 2016; Flacking 2016; Heinemann 2013; Jackson 2003; Neu 1999)	1 structured questionnaire; 3 semi-structured interviews; 1 open-ended interview	5 studies conducted in different countries (USA, UK, Sweden, Finland) among parents of preterm infants requiring respiratory support in the NICU reported that the lack of privacy, noise, and business in the NICU prevented parents from engaging in skin-to-skin care and feeling comfortable expressing emotions.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Friendly, homelike environments					
2 (Feeley 2013; Heinemann 2013)	2 semi-structured interviews	2 studies conducted in different countries (Canada, Sweden) among parents and fathers of preterm infants requiring respiratory support in the NICU reported that allowing 24 hour visiting access and an NICU environment with décor and furniture that resembled a home environment facilitated involvement in their infant's care.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	
Sub theme 3: Feelings of security or insecurity					
4 (Falck 2016; Feeley 2013; Holditch-Davis 2000; Guillaume 2013)	4 semi-structured interviews	4 studies conducted in different countries (USA, Canada, France) among parents, fathers, and mothers of preterm infants requiring respiratory support in the NICU reported that in order to feel secure in the NICU environment they had to understand the different medical equipment and monitors. An open-room design made some mothers feel safer and secure as they were in close proximity to medical staff.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub-theme 4: Participating in care					
3 (Flacking 2016; Gibbs 2016; MacDonald 2007)	3 semi-structured interviews	3 studies conducted in different countries (Canada, UK, Sweden, Finland) among parents of preterm infants requiring respiratory support in the NICU reported that the presence of respiratory equipment and lines in the NICU environment highlighted the severity of their infant's health condition and limited their involvement in nurturing their infant. The cultural environment of the NICU, including policies, restricted visiting hours, and prevention from joining in ward rounds, hindered parents from being able to engage with their infant.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	

NICU: neonatal intensive care unit

[1]The confidence in the methodological quality was downgraded by 1 due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Falck 2016; Feeley 2013; Flacking 2016; Guillaume 2013; Holditch-Davis 2000; Jackson 2003; MacDonald 2007; Neu 1999)

[2]The confidence in the adequacy of the evidence was downgraded by 2 due to the evidence not being sufficiently rich or too small a number in the context of the review finding

Table 15: Qualitative evidence profile: Theme 5. Employment support

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Assessment of Concerns	Overall Confidence
2 (Feeley 2013; Jackson 2003)	1 structured questionnaire; 1 semi-structured interview	2 studies conducted in different countries (Canada, Sweden) among parents and fathers of preterm infants requiring respiratory support in the NICU reported that having employers who provided paternity leaves enabled them to participate more in their infant's care and visit the NICU more frequently.	Methodological limitations	Minor concerns[1]	Low
			Relevance of findings	Minor concerns[2]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[3]	

NICU: neonatal intensive care unit

[1]The confidence in the methodological quality was downgraded by due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Feeley 2013; Jackson 2003)

[2]The confidence in the relevance of the findings was downgraded by 1 due to indirectness in the study population (Jackson 2003)

[3]The confidence in the adequacy of the evidence was downgraded by 2 due to the evidence not being sufficiently rich or too small a number in the context of the review finding

GRADE CERQual tables for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

Table 16: Qualitative evidence profile: Theme 1. Prenatal and postnatal information

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: Prenatal maternal and infant health					
1 (Kavanaugh 2005)	1 semi-structured interview	1 study conducted in the US among parents of preterm infants requiring respiratory support in the NICU reported that parents were given information, including morbidity and mortality for preterm infants born at different gestational ages. However, parents wanted more specific information on the treatments their infants would likely need after delivery.	Methodological limitations	Minor concerns[1]	Low
			Relevance of findings	Minor concerns[2]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[3]	
Sub theme 2: Postnatal information					
3 (Calam 1999; Kavanaugh 2005; Wigert 2014)	1 open-ended interview; 2 semi-	3 studies conducted in different countries (US, Canada, Sweden) among parents of preterm	Methodological limitations	Minor concerns[1]	Low
			Relevance of findings	Minor concerns[2]	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
	structured interviews	infants requiring respiratory support in the NICU reported that staff provided the most information at the beginning of the infant's hospitalisation, but parents would have liked a delayed postnatal review of what happened prenatally and during the birth, as many mothers were still recovering from the birth when they received the majority of the information.	Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[3]	

[1]The confidence in the methodological quality was downgraded by 1 due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Calam 1999; Kavanaugh 2005)
[2]The confidence in the relevance of the findings was downgraded by 1 due to indirectness in the study populations (Kavanaugh 2005; Wigert 2014)
[3]The confidence in the adequacy of the evidence was downgraded by 1 due to the evidence not being sufficiently rich or too small a number in the context of the review finding

Table 17: Qualitative evidence profile: Theme 2. Infant's health status information

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: Understanding the infant's medical condition (qualitative)					
3 (Feeley 2013; Gibbs 2016; Wigert 2014)	3 semi-structured interviews	3 studies conducted in different countries (Canada, UK, Sweden) among fathers and parents of preterm infants requiring respiratory support in the NICU reported that understanding their infant's medical condition and care was crucial. However, parents found that staff did not always fully explain complex medical issues or would leave parents waiting for information about their infant's illness, which caused them anxiety.	Methodological limitations	No concerns	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Receiving updates of the infant's health status					
1 (Guillaume 2013)	1 semi-structured interview	1 study conducted in France among parents of preterm infants requiring respiratory support in the NICU reported that parents appreciated receiving clear information about their infant's health status immediately after exam results or tests. Mothers did not like when they had to receive information from their husbands and would have preferred to receive updates from a physician.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

[1]The confidence in the methodological quality was downgraded by 1 due to a study not clearly reporting the sampling method or relationship between the researcher and participants (Guillaume 2013)

Table 18: Qualitative evidence profile: Theme 3. Caring for the infant information

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: Parenting activities					
6 (Feeley 2013; Gibbs 2016; Heinemann 2013; Pohlman 2009; Smith 2012; Wigert 2014)	1 open-ended interview; 5 semi-structured interview	6 studies conducted in different countries (Canada, US, UK, Sweden) among parents and fathers of preterm infants requiring respiratory support in the NICU reported that nurses were crucial in providing information in regards to caregiving practices, such as feeding and diapering. Informal and formal training provided by patient staff assisted parents in developing the confidence to participate in their child's care.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Changes in care					
1 (Guillaume 2013)	1 semi-structured interview	1 study conducted in France among parents of preterm infants requiring respiratory support in the NICU reported that parents insisted on receiving information in regards to changes in the infant's medical treatment, such as changes in intubation, catheter, location in the hospital. Parents preferred to receive this information from the neonatologist as opposed to the nurse.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	
Sub-theme 3: Understanding behavioural cues					
1 (Guillaume 2013)	1 semi-structured interview	1 study conducted in France among parents of preterm infants requiring respiratory support in the NICU reported that mothers, more often than fathers, wanted explanations of the infant's reactions and behaviours.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	
Sub-theme 4: Breast feeding					
1 (Kavanaugh 2005)	1 semi-structured interview	1 study conducted in the US among parents of preterm infants requiring respiratory support in the NICU reported that mothers found information provided in breast-feeding programs useful as it helped them make decisions in regards to feeding their infant.	Methodological limitations	Minor concerns[1]	Low
			Relevance of findings	Minor concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	
Sub-theme 5: Skin-to-skin care					
1 (Neu 1999)	1 semi-structured interview	1 study conducted in the US among parents of preterm infants requiring respiratory support in the NICU reported that parents were reluctant and lacked confidence to engage in skin to skin care when nurses did not provide them with information on how to hold and transfer the infant without dislodging tubes and ventilator equipment.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	

[1]*The confidence in the methodological quality was downgraded by 1 due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Feeley 2013; Guillaume 2013; Kavanaugh 2005; Neu 1999; Pohlman 2009; Smith 2012)*
[2]*The confidence in the adequacy of the evidence was downgraded by 1 due to the evidence not being sufficiently rich or too small a number in the context of the review finding*
[3]*The confidence in the relevance of the findings was downgraded by 1 due to indirectness in the study population (Kavanaugh 2005)*

Table 19: Qualitative evidence profile: Theme 4: Future information

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Plans to have children in the future					
1 (Kavanaugh 2005)	1 semi-structured interview	1 study conducted in the US among parents of preterm infants requiring respiratory support in the NICU reported that one mother whose infant had died wanted more information on the cause of death and advice for pregnancies in the future. Mothers who knew someone who had an extremely premature infant who survived found that this information gave them hope for their child.	Methodological limitations	Minor concerns[1]	Low
			Relevance of findings	Minor concerns[2]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[3]	
Sub theme 2: Decision making					
2 (Feeley 2013; Kavanaugh 2005)	2 semi-structured interviews	2 studies conducted in different countries (Canada, US) among fathers and parents of preterm infants requiring respiratory support in the NICU reported that staff sharing information and providing opportunities to ask questions facilitated parents becoming involved in decision-making about the infant's care. Adequate and clear information enabled parents to feel confident when physicians asked them to make a decision about their infant's care.	Methodological limitations	Minor concerns[1]	Low
			Relevance of findings	Minor concerns[2]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[3]	

[1]*The confidence in the methodological quality was downgraded by 1 due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Feeley 2013; Kavanaugh 2005)*
[2]*The confidence in the relevance of the findings was downgraded by 1 due to indirectness in the study population (Kavanaugh 2005)*
[3]*The confidence in the adequacy of the evidence was downgraded by 1 due to the evidence not being sufficiently rich or too small a number in the context of the review finding*

Table 20: Qualitative evidence profile: Theme 5: Neonatal unit environment information

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
2 (Guillaume 2013; Pohlman 2009)	2 semi-structured interviews	2 studies conducted in different countries (France, US) among parents and fathers of preterm infants requiring respiratory support in the NICU reported that having regular explanations of the medical equipment, upper and lower limits of monitors,	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
		and the meaning of different alarms and buzzers would prevent frightening experiences and feelings of helplessness.			

[1]*The confidence in the methodological quality was downgraded by due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Guillaume 2013; Pohlman 2009)*

[2]*The confidence in the adequacy of the evidence was downgraded by 1 due to the evidence not being sufficiently rich or too small a number in the context of the review finding*

Table 21: Qualitative evidence profile: Theme 6: Information formats

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: Telephone					
2 (Guillaume 2013; Smith 2012)	2 semi-structured interviews	2 studies conducted in different countries (US, France) among parents of preterm infants requiring respiratory support in the NICU found that regular and ritualised phone calls were appreciated. Parents reported feeling reassured and linked to their child by receiving regular phone calls when they were at home and the infant was still in the NICU. In contrast, receiving routine information at home through an unexpected phone call caused alarm, as it was assumed that an unplanned call was linked to bad news.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	
Sub theme 2: Medical team (member not specified)					
2 (Heinemann 2013; Smith 2012)	2 semi-structured interviews	2 studies conducted in different countries (US, Sweden) among parents of preterm infants requiring respiratory support in the NICU found that information should be shared by staff members who are adequately trained to provide tailored medical information that is tailored to their emotional needs and technical knowledge and who provide parents with the opportunity to ask questions and recommend additional resources.	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	
Sub-theme 3: Nurses					
2 (Kavanaugh 2005; Smith 2012)	2 semi-structured interviews	2 studies conducted in the US among parents of preterm infants requiring respiratory support in the NICU reported that nurses assisted parents in understanding complex medical concepts and reduced feelings of anxiety. Due to nurses' regular interactions with the infant, parents felt that primary nurses were most adept at providing day-	Methodological limitations	Minor concerns[1]	Low
			Relevance of findings	Minor concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	

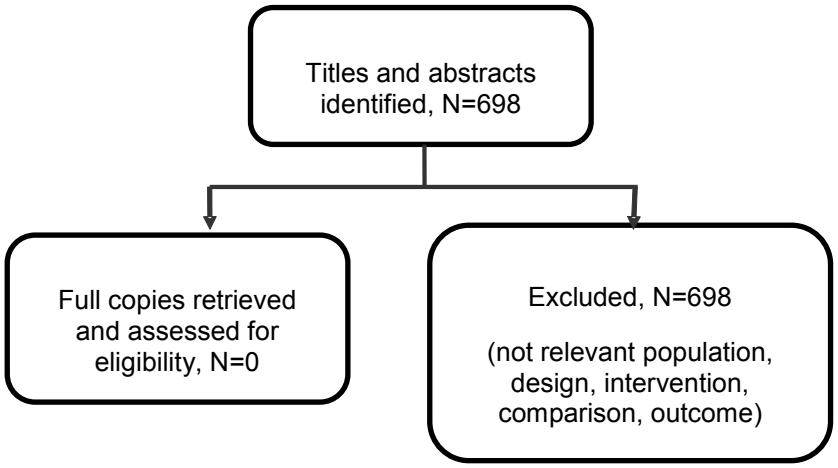
Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
		to-day information and was the best source of information about changes in their baby's medical condition.			
Sub-theme 4: Physicians or neonatologists					
2 (Kavanaugh 2004; Smith 2012)	2 semi-structured interviews	2 studies conducted in the US among parents of preterm infants requiring respiratory support in the NICU reported that the neonatologist was the preferred source of information for technical or complex information, even if parents required additional explanations from nurses afterwards. Physicians should provide as much information as is required to convey the complexities of the situation and allow the parents to ask as many questions as needed.	Methodological limitations	Minor concerns[1]	Low
			Relevance of findings	Minor concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	
Sub-theme 5: Timing and consistency					
4 (Calam 1999; Guillaume 2013; Kavanaugh 2005; Smith 2012)	4 semi-structured interviews	4 studies conducted in different countries (France, UK, US) among parents of preterm infants requiring respiratory support in the NICU that parents, especially mothers, struggled to absorb and understand information that was shared with them during prenatal consultations when they learned their infant would be premature. Many parents were overwhelmed by the amount of information they received during this emotional experience, which later prevented them from being able to recall information. Parents stated that their preferred time to receive information would be during clinical rounds as opposed to during the prenatal consultation, immediately after delivery, or before discharge. Parents would be interested in receiving information at a time separate from rounds. Additionally, it is crucial for parents to receive honest information that is shared consistently by all the members of the care team to avoid having parents receive confusing and varying messages.	Methodological limitations	Minor concerns[1]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub-theme 6: Other resources (including books, internet resources, friends and family)					
1 (Smith 2012)	1 semi-structured interview	1 study conducted in the US among parents of preterm infants requiring respiratory support in the NICU reported that the majority of parents received information from staff and the medical care team, although sources such as printed	Methodological limitations	Minor concerns[1]	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[2]	

Study information			CERQual assessment of the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Assessment of Concerns	Overall Confidence
		materials, friends and family, or the internet were also consulted.			

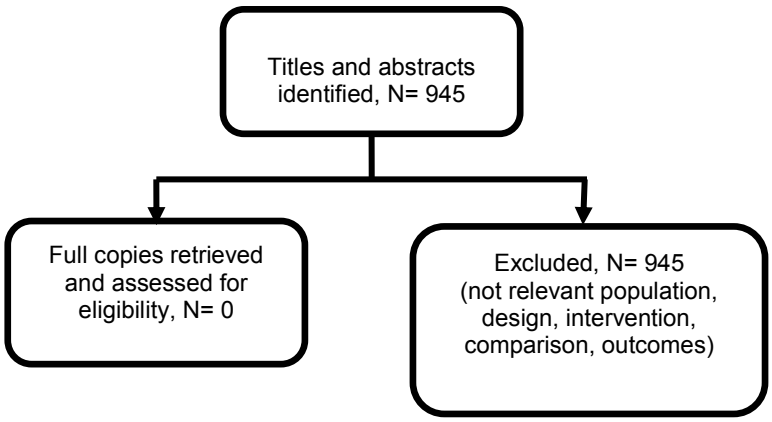
[1]*The confidence in the methodological quality was downgraded by 1 due to studies not clearly reporting the sampling method or relationship between the researcher and participants (Calam 1999; Guillaume 2013; Kavanaugh 2005; Smith 2012)*
[2]*The confidence in the adequacy of the evidence was downgraded by 1 due to the evidence not being sufficiently rich or too small a number in the context of the review finding*
[3]*The confidence in the relevance of the findings was downgraded by 1 due to indirectness in the study population (Kavanaugh 2005)*

Appendix G – Economic evidence study selection

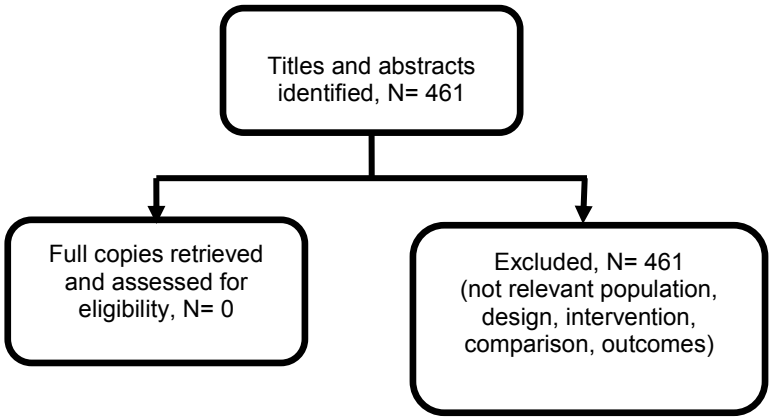
Economic evidence study selection for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?



Economic evidence study selection for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?



Economic evidence study selection for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?



Appendix H – Economic evidence tables

Economic evidence tables for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

No economic evidence was identified for this review.

Economic evidence tables for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

No economic evidence was identified for this review.

Economic evidence tables for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

No economic evidence was identified for this review.

Appendix I – Health economic evidence profiles

Health economic evidence profiles for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

NIDCAP® (in addition to standard care) versus standard care only

Study and country	Limitations	Applicability	Other comments	Incremental costs	Incremental effects (QALYs)	ICER (cost/QALY)	Uncertainty
Guideline economic analysis	Minor limitations[1]	Directly applicable[2]	Type of economic analysis: cost-utility analysis Time horizon: 18 years Outcome: QALYs	<27 weeks gestational age: £1,802	<27 weeks gestational age: 0.24	£7,400	The probability of NIDCAP® being cost-effective at the threshold of £20,000 per QALY was 0.889. When using the upper confidence interval value for the risk ratio of neurodevelopmental problems (0.890) for NIDCAP® versus standard care the ICER of NIDCAP® versus standard care increased to £46,236 per QALY. The results were robust to changes in all other model inputs. From a wider public sector perspective NIDCAP® is dominant treatment option. NIDCAP® is unlikely to be cost-effective in babies >27 weeks GA from the NHS perspective. However, it may potentially be cost-effective in babies 27-31 weeks GA from a wider public sector perspective.

1. The baseline risk of neurodevelopmental problems from USA study, some model inputs based on the committee expert opinion
2. UK study, QALYs

Health economic evidence profiles for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

No economic evidence was identified for this review.

Health economic evidence profiles for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

No economic evidence was identified for this review.

Appendix J – Health economic analysis

Health economic analysis for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

Introduction – objective of economic modelling

The cost-effectiveness of interventions supporting parent and carer involvement in the care of preterm babies requiring respiratory care was considered by the committee as an area with likely significant resource implications. In particular, the committee highlighted Newborn Individualised Developmental Care and Assessment Programme (NIDCAP®) since it has high intervention costs.

There was no existing economic evidence on the cost effectiveness of interventions that support parent and carer involvement in the care of preterm babies requiring respiratory support. Therefore, an economic analysis was undertaken to assess the cost-effectiveness of effective interventions that support parent and carer involvement in the care of preterm babies requiring respiratory care.

Economic modelling methods

Interventions assessed

The choice of treatments assessed in the economic analysis was determined by the availability of respective clinical data included in the guideline systematic literature review. The economic analysis considered effective treatments, as demonstrated by the systematic review of clinical evidence. The committee explained that interventions such as kangaroo care and skin to skin contact, and non-nutritive sucking have negligible intervention costs, and also clinical data was very limited for these interventions. According to the committee expert opinion, NIDCAP® is the only intervention that is associated with high intervention costs and therefore should be pursued in the economic evaluation. NIDCAP® model postulates that an understanding of the neurodevelopmental expectations of the preterm as expressed in the infant's behavior will provide a reliable basis for the examination, and adaptation of traditionally delivered newborn intensive care, including a realignment of the parent and carer involvement (Als 2011). The model considered standard care treatment as a comparator.

Model structure

A simple Markov model was constructed using Microsoft Office Excel 2013. The structure of the model was determined by the availability of clinical data. According to the model structure, hypothetical cohorts of 100 babies born preterm (<27 weeks' gestation) requiring respiratory care were initiated on either NIDCAP® (in addition to standard care) or standard care only. Across the report NIDCAP® will refer to NIDCAP® in addition to standard care.

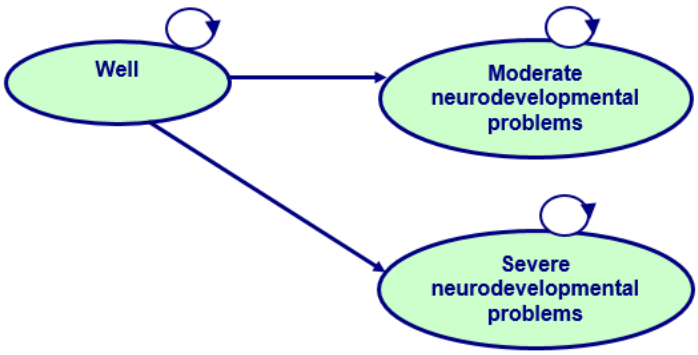
Babies initiated on NIDCAP® were assumed to have continuous involvement from their NIDCAP® professional for the duration of the initial hospital stay. The model included the following health states: 'well', 'moderate neurodevelopmental problems', and 'severe neurodevelopmental problems'. The model included yearly cycles. At the end of each cycle a baby could remain in the 'well' state, move to 'moderate neurodevelopmental problems' state, or the 'severe neurodevelopmental problems' state. According to the committee expert opinion once a baby is in either the moderate or severe neurodevelopmental problems state they will remain in that health state for the duration of the model (that is, there are no

transitions between moderate and severe states). In the model neurodevelopmental problems were defined as neurodevelopmental mental delay.

The half-cycle correction was applied in the Markov model to compensate for the fact that transitions between states, in reality, occur in the middle of each cycle on average.

Given the lack of long term clinical and cost data the time horizon of the analysis was 18 years. A schematic diagram of the model is presented in Figure 10.

Figure 10: Schematic diagram of the Markov model constructed for the assessment of the relative cost-effectiveness of NIDCAP® for preterm babies requiring respiratory support



Costs and outcomes considered in the analysis

The economic analysis adopted the perspective of the National Health Service (NHS) and personal social services (PSS), as recommended by (NICE, 2014). Costs consisted of intervention costs, including initial observation and follow-up support to the family and team with integration of recommendations and adapting these to suit the baby's changing developmental needs by the NIDCAP® professional and other health care costs incurred by children with moderate or severe neurodevelopmental problems.

The committee explained that costs accruing to the education sector are important in this population. As a result, a secondary analysis was undertaken where public sector costs (inclusive of education costs) were considered.

The measure of outcome was the quality adjusted life year (QALY). A discount rate of 3.5% was used for all future cost and outcomes (NICE, 2014).

Clinical input parameters and overview of methods employed for evidence synthesis

Clinical input parameters consisted of the risk ratio of developing moderate or severe neurodevelopmental problems with NIDCAP® versus standard care. The guideline meta-analysis identified 2 RCTs assessing NIDCAP® versus standard care that provided efficacy data (that is, moderate or severe neurodevelopmental problems). Both Peters 2009 (n =101) and Maguire 2009b (n=139) reported data at approximately 2 year follow-up**.** In both studies neurodevelopmental problems were assessed using Bayley Scales of Infant Development (BSID) II Mental Developmental Index (MDI).

Other clinical input parameters included the absolute risk of moderate or severe neurodevelopmental problems associated with standard care. The committee identified 1 UK-based prospective cohort study (Moore 2012) that provided the number of babies developing moderate or severe neurodevelopmental problems when using standard care treatment. In this study a community-based cohort of surviving babies (n=1,031) born in 2006 before 27 completed weeks of gestation was studied prospectively over a 3 year period. The

study reported neurodevelopment disability on different domains including motor, hearing, vision, cognition, and communication. Neurodevelopmental outcomes were assessed in 576 preterm babies, with 501 of babies assessed using the BSID III, 39 using the Wechsler preschool and primary scales of intelligence, and 10 using only the cognitive scale of BSID III. The effectiveness review identified statistically significant effect of NIDCAP® only on the MDI subdomain of the BSID II scale. The committee explained that BSID II MDI subdomain evaluates sensory-perception, knowledge, memory, problem solving, and early language. Thus, BSID II MDI measures a combination of early cognitive and language development. Based on the above the committee concluded that BSID II MDI equates most closely with the cognitive function subdomain reported in Moore 2012. For the purposes of modelling a 3-year cumulative probabilities reported in Moore 2012 were used to estimate annual probabilities of developing moderate or severe neurodevelopmental problems (on a cognitive function subdomain), assuming exponential function, which were subsequently attached to the standard care treatment.

Given the lack of longer term data the efficacy data was applied only over 2 years. The absolute risk of neurodevelopmental problems (mental delay) associated with NIDCAP® was estimated by multiplying the respective relative risk by the baseline risks of moderate or severe neurodevelopmental problems (cognitive function subdomain) as calculated for standard care.

In the model the final membership in each health state in year 2 was carried over to the subsequent years for the duration of the model to estimate associated costs and outcomes.

The mortality was not considered in this analysis since, as indicated by the clinical review, there is no clinically significant difference in mortality with NIDCAP® compared to standard care for preterm babies requiring respiratory care.

2.5 Utility data and estimation of QALYs

In order to express outcomes in the form of QALYs, the health states of the economic model needed to be linked to appropriate utility scores. Utility scores represent the health-related quality of life (HRQoL) associated with specific health states on a scale from 0 (death) to 1 (perfect health); they are estimated using preference-based measures that capture people's preferences on the HRQoL experienced in the health states under consideration.

NICE recommends the EuroQol five dimensions questionnaire (EQ-5D) (Brooks, 1996) as the preferred measure of HRQoL in adults for use in cost-utility analysis. The standard version of the EQ-5D has not been designed for use in children. As a result an alternative standardised and validated preference-based measures of health-related quality of life that have been designed specifically for use in children can be considered (NICE, 2013).

Petrou (2013) estimated utility scores associated with neurodevelopment impairment using parents' ratings of their children's HRQoL around the child's eleventh birthday on both the HUI2 and HUI3. The HUI is a family of preference-based multi-attribute utility measures (Torrance 1995). The HUI2 consists of 6 domains: sensation, mobility, emotion, cognition, self-care, and pain. A seventh domain of fertility can be added if relevant. The HUI3 health state classification has many similarities to the HUI2, but with the sensation domain expanded into 3 separate attributes of vision, hearing and speech, and additional response levels added to some domains.

Responses to HUI3 can be converted into utility scores using a published algorithm that was developed based on the principles of multi-attribute utility theory, following a valuation survey of members of the general population in Canada; respondents' preferences were elicited using visual analogue scale and standard gamble (Feeny 2002).

In the analysis, HUI2 scores were used since unlike HUI3 it has an underpinning multi-attribute utility scoring algorithm that has been estimated on the basis of the preferences of members of the UK general population with respondents' preferences elicited using standard gamble (McCabe 2005; Petrou & Kupek, 2009), which is a method recommended by NICE.

Cost data

Intervention cost for NIDCAP® was calculated by combining resource use estimates with respective national unit costs. Intervention cost consisted of NIDCAP® professionals' time. The cost of a NIDCAP® professional's time was estimated by combining the mean total NIDCAP® professional's time per child treated, as advised by the committee expert opinion, with the national unit cost of a Band 7 hospital nurse (Curtis & Burns, 2017). According to the committee's expert opinion, all babies receiving NIDCAP® would have an initial observation that combined with the report preparation would take approximately 1 day. It was further explained that the NIDCAP® professional would spend additional 3 hours per week for the duration of the initial hospital stay to assist with the implementation of the recommendations in the report which is prepared by the NIDCAP® professional. This follow-up involvement supports the family and team with the integration of recommendations and adapting these to suit the baby's changing developmental needs.

The duration of initial hospital stay was obtained from a recent study by Seaton (2018). In the study the authors predicted the length of stay in neonatal care for all admissions of singleton babies born at 24–31 weeks' gestation from 2011 to 2014. Data were extracted from the National Neonatal Research Database in the UK. A total of 20,571 preterm babies were included. In the study the median length of stay was reported for each gestational age. Using the reported data a weighted average length of stay was calculated to estimate the duration of length of stay for the average preterm baby born 22-26 weeks' gestation. The estimated duration of length of stay was used to approximate the duration of NIDCAP® professional involvement beyond the initial observation.

The unit cost of a hospital nurse per hour of client contact was estimated based on the mean full time equivalent basic salary for Agenda for Change Band 7of the July 2016-June 2017 NHS Staff Earnings estimates, including salary, salary oncosts and overheads. The apportioned qualification costs per hour of contact were negligible and were not considered.

The intervention cost of standard care was zero given that it was administered in both arms.

The health and social care costs incurred by children with neurodevelopment problems were obtained from Petrou (2013). Like for health related quality of life, economic costs were extracted from detailed postal questionnaires completed by the main parent around the child's 11th birthday asking about resource use over the previous year. The economic costs were estimated from an NHS and PSS perspective and included hospital inpatient care, hospital outpatient and day care, community health and social care, drugs and medications. The resource use estimates were combined with appropriate unit costs taken from national sources in order to estimate an overall annual health and social care cost incurred by children with moderate or severe neurodevelopment problems. Petrou (2013) also reported cost data for children in the control group (that is, school classmates who were born at full term and matched for age, sex and ethnic group). The above costs were used to estimate incremental NHS and PSS costs in children who are in the 'moderate' or 'severe' neurodevelopmental problems health state, respectively.

Petrou (2013) also estimated incremental public sector costs (inclusive of education costs), during the 11th year of life for children but only for children with severe neurodevelopmental problems. The cost categories included in the public sector costs besides education costs were not reported. Given the lack of public sector costs in children with moderate neurodevelopmental problems, a ratio of incremental public sector costs to health and social care costs was estimated using cost data for children with severe neurodevelopmental

problems. The resulting ratio was applied to health and social care costs for children with moderate neurodevelopmental problems to approximate costs from public sector costs in this population. The committee explained that the costs associated with neurodevelopmental problems are likely to be higher once the child starts school. As a result, in the secondary analysis, NHS and PSS costs were included up to the age of 5 years and wider public sector costs (inclusive of education costs) were applied at 5 years onwards for the duration of the model.

The analysis considered only costs associated with neurodevelopmental problems and did not include costs associated with children who are in the 'well' health state.

All costs were uplifted to 2016/17 prices using the hospital and community health services inflation index (Curtis & Burns, 2017).

Table 22 reports the mean (deterministic) values of all input parameters used in the economic model and provides information on the distributions assigned to specific parameters in probabilistic sensitivity analysis.

Table 22: Input parameters used in the economic model of NIDCAP® for preterm babies requiring respiratory support

Input parameter	Deterministic value	Probabilistic distribution	Source of data - comments
Absolute risk of ND problems Moderate Severe	 0.10 0.06	**Beta distribution** α = 57; β = 519 α = 37; β = 539	Moore (2012), three year rates from EPICure cohort born in England during 2006, 22-25 weeks' gestation, cognition subdomain. In the economic model the rates were annualised.
Risk ratio of moderate or severe ND problems NIDCAP® versus standard care	 0.50	**Log-normal distribution: 95% CIs** 0.28 to 0.89	Guideline systematic review (Peters 2009 and Maguire 2009); risk ratio at 2 years.
Utilities No ND problems Moderate ND problems Severe ND problems	 0.955 0.801 0.638	**Beta distribution** α = 240; β = 11 α = 45; β = 11 α = 14; β = 8	Utility data from Petrou 2013. Utility scores based on HUI2 preference-based multi-attribute utility measure with UK general population norms.
Intervention cost NIDCAP®	 £2,887	**Gamma distribution** SE: 20% of mean value (assumption)	According to the committee expert opinion, the initial observation and report write up takes approximately 1 working day. It was further assumed that NIDCAP® professional will be involved 3 hours per week for the duration of the initial hospital stay to support the family and team with integration of recommendations and adapting these to suit the baby's changing developmental needs. The duration of the initial hospital was estimated to be 105 days (Seaton 2018). NIDCAP® is delivered by a Band 7 nurse specialist (£54 per hour) (Curtis & Burns, 2017).
Costs (incremental) - NHS & PSS perspective Moderate ND problems Severe ND problems	 £576 £1,313	**Gamma distribution** SE: 20% of mean value (assumption)	Costs data from Petrou 2013 uplifted to 2016/17 prices using the hospital & community health services inflation index (Curtis & Burns, 2017).
Costs (incremental) – public sector Moderate ND problems	 £4,670	NA	Costs data from Petrou 2013 uplifted to 2016/17 prices using the hospital & community health services inflation index (Curtis & Burns, 2017).

Input parameter	Deterministic value	Probabilistic distribution	Source of data - comments
Severe ND problems	£10,646		For babies with moderate neurodevelopmental problems a ratio of health and social care costs to NHS & PSS plus education costs was estimated in babies with severe neurodevelopmental problems. The resulting ratio was applied to NHS & PSS costs in moderate neurodevelopmental problems to approximate public sector costs in these babies.
Discount rate		NA	NICE.2014.
Costs	3.5%		
Outcomes	3.5%		

Note: CI: Confidence interval; ND: Neurodevelopment; NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme; PSS: Personal Social Services; SE: Standard error

Data analysis and presentation of the results

Two methods were employed to analyse the input parameter data and present the results of the economic analysis.

First, a deterministic analysis was undertaken, where data are analysed as point estimates; results are presented as mean total costs and QALYs associated with each treatment option are assessed. Relative cost-effectiveness between alternative treatments was estimated using incremental analysis: all options were ranked from most to least cost-effective. Options that were dominated by absolute dominance (that is, they were less effective and more costly than one or more other options) or by extended dominance (that is, they were less effective and more costly than a linear combination of two alternative options) were excluded from further analysis. Subsequently, incremental cost-effectiveness ratios (ICERs) were calculated for all pairs of consecutive options remaining in the analysis.

ICERs expressed the additional cost per additional unit of benefit associated with one treatment option relative to its comparator. Estimation of such a ratio allowed consideration of whether the additional benefits were worth the additional cost when choosing one treatment option over another.

The treatment option with the highest ICER below the cost-effectiveness threshold was deemed to be the most cost-effective option.

One-way sensitivity analyses explored impact of varying:

- the risk ratio estimate (using upper and lower CI);
- the baseline risk estimates (±20% around the base-case value);
- the utility values (±20% around the base-case value);
- the intervention cost (±50% around the base-case value);
- the costs of neurodevelopment problems (±50% around the base-case value).

In addition to deterministic analysis, a probabilistic analysis was also conducted.

In this case, all model input parameters were assigned probability distributions (rather than being expressed as point estimates), to reflect the uncertainty characterising the available clinical and cost data. Subsequently, 10,000 iterations were performed, each drawing random values out of the distributions fitted onto the model input parameters. This exercise provided more accurate estimates of mean costs and benefits for each intervention assessed (averaging results from the 10,000 iterations), by capturing the non-linearity characterising the economic model structure (Briggs 2006).

The relative risk estimates were given a log-normal distribution. The baseline risk estimates of neurodevelopment problems and utility values were assigned a beta distribution. Costs were assigned a gamma distribution. Where standard error estimate was not available the assumption was made that costs had a standard error of 20% of their mean value.

Results of probabilistic analysis were presented in the form of cost-effectiveness acceptability curves (CEACs), which demonstrated the probability of each treatment option being the most cost effective among the strategies assessed at various cost-effectiveness thresholds.

Sub-group analyses

A recent cohort study in France by Pierrat (2017) looked at neurodevelopment outcomes at 2 years for preterm children born between 22 to 34 weeks' gestation. The study found that among live births survival at 2 years corrected age without severe or moderate neuromotor and sensory disabilities was 48.5%, 90.0%, and 97.5% at 22-26, 27-31, and 32-34 weeks'

gestation, respectively. Consequently, an exploratory sub-group analysis was undertaken where the base-case probabilities of neurodevelopment problems were reduced by 90.0% and 97.5% to estimate the potential cost-effectiveness of NIDCAP® in preterm babies who are 27-31 and 32-34 weeks' gestation, respectively.

In this analysis the duration of initial hospital admission was recalculated based on Seaton (2018) and was estimated to be 50 days for a preterm baby >26 weeks' gestation. This, in effect, reduced NIDCAP® professional involvement from 105 days to 50 days and resulted in the NIDCAP® intervention cost of £1,618 per baby.

Only the deterministic results were calculated for the alternative base-case rates generated using different gestational ages.

The cost-effectiveness of NIDCAP® in different sub-groups was estimated from both an NHS and PSS perspective and also from a wider public sector perspective that included education costs.

Economic modelling results

Results of the deterministic analysis – NHS and PSS perspective, <27 weeks' gestation, over 18 years

According to deterministic analysis, from an NHS and PSS perspective NIDCAP® was a cost-effective option in preterm children (<27 weeks' gestation) with a cost per QALY of £14,380 versus standard care treatment that is well below the threshold of £20,000 per QALY.

Table 23 provides mean NHS and PSS costs and QALYs for NIDCAP® and standard care.

Table 23: Mean NHS and PSS costs and QALYs for NIDCAP® and standard care alone for preterm children <27 weeks' gestation over 18 years - results for a cohort of 100 preterm babies

Treatment option	Mean total costs (NHS & PSS)	Mean total QALYs	Cost effectiveness (cost/QALY)
Standard care	£122,116	1,277	£14,380 (versus standard care)
NIDCAP®	£340,709	1,292	

Note: NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme; PSS: Personal Social Services; QALY: Quality-adjusted life year

From NHS and PSS perspective the ICER of NIDCAP® versus standard care was sensitive to the estimate of risk ratio of neurodevelopmental problems. When using the upper confidence interval value for the risk ratio of neurodevelopmental problems (0.890) for NIDCAP® versus standard care the ICER of NIDCAP® versus standard care increased to £80,486 which is above the threshold of £30,000 per QALY. Similarly, the results were sensitive to the utility value associated with moderate neurodevelopmental problems. For example, using the upper estimate of the utility value (0.961, base case 0.801) NIDCAP® resulted in the ICER of £26,071 which was above the lower threshold of £20,000 per QALY but below the upper threshold of £30,000 per QALY. The results were robust to changes in all other model inputs (Table 24).

Table 24: Summary of deterministic sensitivity analyses, NHS and PSS perspective, <27 weeks' gestation

Parameter	Values tested (upper and lower) & base case	ICER of NIDCAP® versus standard care with low and high value	Threshold value
Risk ratio of ND problems for NIDCAP® versus standard care	0.28; 0.89 Base-case: 0.499	£8719, £80486	0.62
Utility weight moderate ND problems	0.64; 0.96	£9928, £26071	0.90
NIDCAP® cost	£2310; £3464	£10710, £18050	£3771
Utility severe ND problems	0.51; 0.77	£11701, £18651	0.80
Baseline annual risk of severe ND problems	0.04; 0.06 Base-case: 0.04	£16692, £12541	NA
Incremental annual NHS & PSS cost for severe ND problems	£657; £1970 Base-case: £1313	£15989, £13027	NA
Baseline annual risk of moderate ND problems	0.03; 0.05 Base-case: 0.04	£15558, £13202	NA
Incremental annual NHS & PSS cost for moderate ND problems	£288; £864 Base-case: £576	£15186, £13574	NA

Note: ICER: incremental cost effectiveness ratio; ND: Neurodevelopmental; NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme; PSS: Personal Social Services; QALY: Quality-adjusted life year

Results of the probabilistic analysis – NHS and PSS perspective, <27 weeks' gestation, over 18 years

Conclusions of probabilistic analysis were very similar to those of deterministic analysis. NIDCAP® remained the cost-effective option when mean costs and QALYs derived from 10,000 iterations were estimated. The ICER of NIDCAP® versus standard care was £15,210 in preterm babies <27 weeks' gestation, over 18 years. At the threshold of £20,000 per QALY (NICE., 2008b) the probability of NIDCAP® being cost-effective was 0.673 and it increased to 0.843 at the threshold of £30,000 per QALY. Table 25 provides the results of the probabilistic analysis.

Table 25: Mean NHS and PSS costs and QALYs for NIDCAP® and standard care alone for preterm children <27 weeks' gestation over 18 years – results for a cohort of 100 preterm babies

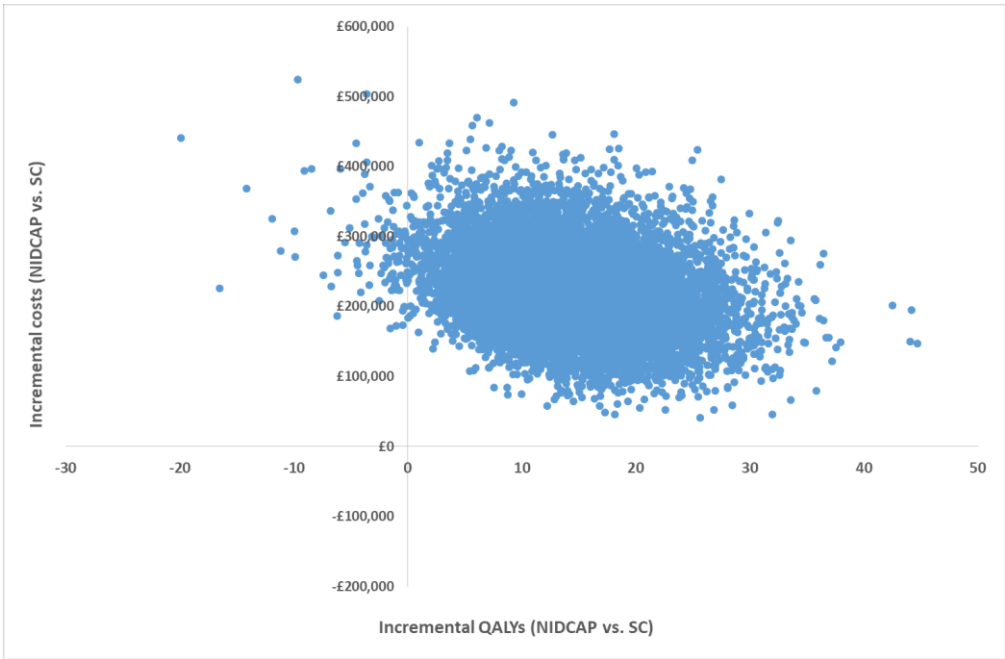
Treatment option	Mean total costs (NHS & PSS)	Mean total QALYs	Cost effectiveness (cost/QALY)
Standard care	£121,841	1,277	£15,210 (vs. standard care)
NIDCAP®	£342,796	1,291	

Note: NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme; PSS: Personal Social Services; QALY: Quality-adjusted life year

Figure 11 provides the cost-effectiveness plane showing the incremental costs and QALYs of NIDCAP® versus standard care. It can be seen that most of the incremental costs and

QALYs are either in the north-east quadrant indicating that NIDCAP® versus standard care resulted in higher costs and QALYs.

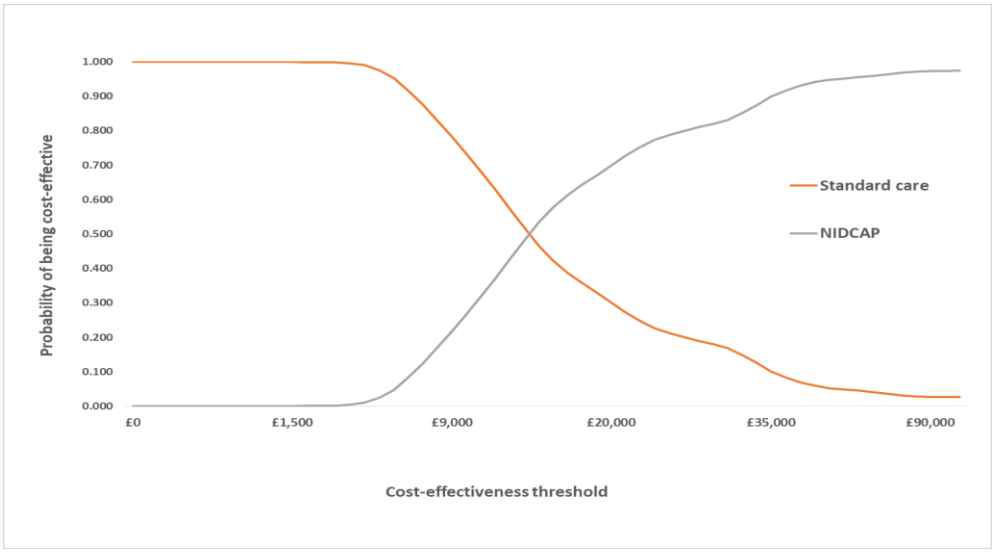
Figure 11: Cost-effectiveness plane of NIDCAP® assessed in the economic analysis plotted against standard care treatment – incremental NHS and PSS costs and QALYs, for a chort of 100 of children <27 weeks' gestation (10,000 iterations)



Note: NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme; PSS: Personal Social Services; QALY: Quality-adjusted life year; SC: Standard care

Figure 12 shows the CEACs generated for each treatment option assessed in the economic model and indicates that at any willingness-to-pay value of greater than £15,000 per QALY, NIDCAP® has the highest probability of being cost effective.

Figure 12: CEACs of NIDCAP® and standard care treatment only for children with respiratory problems assessed in the economic analysis (NHS and PSS perspective)



Note: NIDCAP®: Newborn Individualised Developmental Care and Assessment Programme; PSS: Personal Social Services

Sub-group analysis

According to the sub-group analysis, where the impact of varying the baseline rate of neurodevelopment problems in babies of different gestational ages was explored, the ICER of NIDCAP® versus standard care from an NHS and PSS perspective always remained well above the threshold of £30,000 per QALY. For children 27-31 weeks' gestation the ICER of NIDCAP® versus standard care was £264,221 per QALY and for children 32-34 weeks' gestation the ICER of NIDCAP® versus standard care was as high as £4.3 mil., per QALY.

Secondary analysis

According to the secondary analysis, where the impact of including wider public sector costs was explored, NIDCAP® versus standard care was dominant in children of 22-26 weeks' gestation (that is, it resulted in lower costs and better outcomes). From a public sector perspective, in preterm children of 27-31 weeks' gestation the ICER of NIDCAP® versus standard care of £132,664 per QALY was still above the threshold of £30,000 per QALY. Similarly, from a public sector perspective, in preterm children of 32-34 weeks' gestation the ICER of NIDCAP® versus standard care of £4.2 mil., per QALY was well above the threshold of £30,000 per QALY. The cost-ineffectiveness of NIDCAP® in these babies was attributed to a small number of babies developing neurodevelopmental problems and relatively low public sector costs in babies with neurodevelopmental problems.

The committee noted that the annual public sector costs reported by Petrou (2013) are likely to be underestimated since many preterm children with neurodevelopmental problems would attend private specialist schools due to the lack of state-funded places. The committee further explained that local authorities are required to fund places at private specialist schools and that there are virtually no state specialist schools. As a result, the majority of local authorities have to send children with neurodevelopmental problems to private specialist schools. Given the lack of studies reporting accurate and up to date public sector costs in preterm babies with neurodevelopmental problems a threshold analysis was undertaken to explore what the incremental public sector costs would need to be for NIDCAP® to be cost-effective in preterm babies 27-31 and 32-34 weeks' gestation, respectively.

According to the threshold analysis, in preterm babies 27-31 weeks' gestation the incremental public sector costs would need to be approximately £80,000 per annum for a case with neurodevelopmental problems for a cost per QALY of NIDCAP® to be just below the threshold of £20,000 per QALY. However, in children between 31-34 weeks' gestation the incremental public sector cost would need to be approximately £1.3 mil., per annum for a case with neurodevelopmental problems for a cost per QALY to be just below the threshold of £20,000 per QALY.

Discussion – limitations of the analysis

The results of the economic analysis suggested that NIDCAP® for parent and carer involvement was likely to be a cost-effective treatment for preterm children <27 weeks' gestation who are receiving respiratory support. NIDCAP® resulted in an ICER that was below the threshold of £20,000 per QALY. The probability of NIDCAP® being cost-effective was 0.673 at a threshold of £20,000 per QALY. The cost effectiveness of NIDCAP® in preterm children <27 weeks' gestation was attributed to a number of factors: relatively high baseline risk of neurodevelopment problems in this population, high costs and health related quality of life decrements associated with neurodevelopment problems.

The clinical review searched for evidence on a wider set of neurodevelopmental outcomes, in the economic analysis the clinical data for the effectiveness of NIDCAP® was based on only 2 studies (n=240) focusing on neurodevelopmental mental delay since this was the only statistically significant finding which was judged by the committee to be noteworthy. The sensitivity analyses indicated that when using the upper confidence interval value for the effectiveness of NIDCAP® in babies <27 weeks' gestation from an NHS and PSS perspective, NIDCAP® resulted in an ICER that was above the threshold of £30,000 per QALY. However, NIDCAP® remained dominant when considering a wider public sector perspective and the upper confidence interval value for the effectiveness of NIDCAP®.

Overall, the findings were robust in various scenarios explored in the sensitivity analysis. The estimated cost of NIDCAP® of £2,887 is substantially higher than that referred to by Westrup (2007). However, even at this much higher estimated intervention cost, NIDCAP® is a cost-effective intervention in preterm babies of <27 weeks' gestation requiring respiratory support.

The length of stay in preterm babies of 22-26 weeks' gestation was approximated using the length of stay reported in Seaton (2018) in preterm babies of 24-26 weeks' gestation. This could have potentially underestimated the length of stay in preterm babies of 22-26 weeks' gestation. Although, the median length of stay was simillar for preterm babies of 24, 25, and 26 weeks' gestation. Also, the deterministic sensitivity analysis indicated that when varying the cost of NIDCAP® (which, in effect, is equivalent to changing the length of stay) the results for preterm babies of <27 weeks' gestation were robust to this model input. Moreover, the proportion of babies born at 22-23 weeks' gestation is small and the impact of this assumption on the cost-effectiveness is likely to be negligible.

The sub-group analysis indicated that the potential for NIDCAP® is reduced in preterm babies of 27-34 weeks' gestation, given the relatively low rate of neurodevelopment problems in these babies to start with. The threshold analysis indicated that NIDCAP® is unlikely to be cost-effective in children born at >27 weeks' gestation even when considering wider public sector costs. The estimated incremental public sector cost for a child with neurodevelopmental problems would need to be at least £80,000 per annum for NIDCAP® versus standard care to be cost-effective, which is above what the committee would expect such costs to be. A recent independent review by Schools Week (2018) found that councils spent an average £52,000 per pupil on independent special school places for 2015-16. However, this cost estimate of £52,000 is well below to the estimates obtained from the threshold analysis.

Also, in the sub-group analysis due to the lack of appropriate data, the number of preterm babies developing neurodevelopmental problems (cognitive domain) at various gestational ages were approximated using the percentage of preterm babies with no neuromotor or sensory disabilities at various gestational ages reported in Pierrat 2017. The committee acknowledged that this is not perfect. However, given the lack of more suitable data these estimates provide a reasonable approximation and the resulting rates of neurodevelopmental problems on the cognitive subdomain stratified by the gestational age are in line with the rates observed in their clinical practice.

The cost-effectiveness of NIDCAP® is likely to have been underestimated since neurodevelopmental problems have significant life-long costs and quality of life consequences. However, due to the lack of suitable data the time horizon of this analysis was limited to 18 years. The committee also noted that NIDCAP® results in greater parent and carer satisfaction and if NIDCAP® is made available at such crucial early stages of care the philosophy tends to spread around the nursery. However, to capture such benefits was beyond the scope of this analysis.

Another limitation of the economic analysis was that the costs and utilities were based on postal questionnaires completed by the main parent around the child's 11th birthday (over

the previous year) and may not be fully representative of children in earlier years of life. Nevertheless, the extensive sensitivity analyses indicated that the conclusions were robust to cost and utility estimates and large changes in the base-case values would be required for the conclusions to change.

The committee also discussed implementation challenges, in particular high costs associated with training to set up for NIDCAP®.

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NICE 2014

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Health economic analysis for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

No health economic analysis was undertaken for this review.

Health economic analysis for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

No health economic analysis was undertaken for this review.

Appendix K – Excluded studies

Excluded studies for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

Clinical studies

Study	Reason for Exclusion
Family Nurture Intervention in the Neonatal Intensive Care Unit improves social-relatedness, attention, and neurodevelopment of preterm infants at 18 months in a randomized controlled trial, Journal of child psychology and psychiatry, and allied disciplines. 56 (11) (pp 1202-1211), 2015. Date of Publication: 01 Nov 2015., 2015	Duplicate reference
The effect of kangaroo ward care in comparison with "intermediate intensive care" on the growth velocity in preterm infant with birth weight <1100 g: randomized control trial, European journal of pediatrics. (pp 1-8), 2016. Date of publication: 26 aug 2016., 2016	Duplicate reference
Abdallah, B., Badr, L. K., Hawwari, M., The efficacy of massage on short and long term outcomes in preterm infants, Infant Behavior & Development, 36, 662-9, 2013	Population not relevant to protocol - preterm infants on any kind of respiratory assisted devices were excluded
Adamson-macedo, Elvidina N., Roiste, Aine de, Wilson, Ann, de Carvalho, Francisco A., Dattani, Lesh, Brief report: TAC-TIC therapy with high-risk, distressed, ventilated preterms, Journal of Reproductive and Infant Psychology, 12, 249-252, 1994	Case series of preterm infants receiving modified TAC-TIC
Als, H, Duffy, Fh, McAnulty, G, Butler, Sc, Lightbody, L, Kosta, S, Weisenfeld, Ni, Robertson, R, Parad, Rb, Ringer, Sa, Blickman, Jg, Zurakowski, D, Warfield, Sk, NIDCAP improves brain function and structure in preterm infants with severe intrauterine growth restriction, Journal of perinatology : official journal of the California Perinatal Association, 32, 797-803, 2012	Population is not relevant to the protocol - preterm infants with severe intrauterine growth restriction (IUGR)
Als, H, Duffy, Fh, McAnulty, Gb, Fischer, Cb, Kosta, S, Butler, Sc, Parad, Rb, Blickman, Jg, Zurakowski, D, Ringer, Sa, Is the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) effective for preterm infants with intrauterine growth restriction?, Journal of Perinatology, 31, 130-136, 2011	Population is not relevant to the protocol - preterm infants with severe intrauterine growth restriction (IUGR)
Als, H, Lawhon, G, Brown, E, Gibes, R, Duffy, Fh, McAnulty, G, Blickman, Jg, Individualized behavioral and environmental care for the very low birth weight preterm infant at high risk for bronchopulmonary dysplasia: neonatal intensive care unit and developmental outcome, Pediatrics, 78, 1123-1132, 1986	Small study (n=16)published in 1985
Als, H., Duffy, F. H., McAnulty, G. B., Effectiveness of individualized neurodevelopmental care in the newborn intensive care unit (NICU), Acta Paediatrica Supplement, 416, 21-30, 1996	Narrative review
Anderson, Gc, Chiu, S H, Dombrowski, M A, Swinth, J Y, Albert, J M, Wada, N, Mother-newborn contact in a randomised trial of kangaroo (skin-to- skin) care, Journal of Obstetric,Gynecologic, & Neonatal Nursing, 32, 604-11, 2003	Reported outcome is not relevant to protocol - type and percent time of kangaroo care skin contact 0-48 hours postbirth

Study	Reason for Exclusion
Ariagno, R. L., Thoman, E. B., Boeddiker, M. A., Kugener, B., Constantinou, J. C., Mirmiran, M., Baldwin, R. B., Developmental care does not alter sleep and development of premature infants, Pediatrics, 100, E9, 1997	Reported outcomes are not relevant to the protocol
Axelin,A., Lehtonen,L., Pelander,T., Salantera,S., Mothers' different styles of involvement in preterm infant pain care, JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing, 39, 415-424, 2010	Study design -descriptive and exploratory study
Badr, L. K., Abdallah, B., Kahale, L., A Meta-Analysis of Preterm Infant Massage: An Ancient Practice With Contemporary Applications, Mcn, The American journal of maternal child nursing. 40, 344-358, 2015	Systematic review - included studies checked for relevance to protocol
Benzies, Km, Shah, V, Aziz, K, Isaranuwatchai, W, Palacio-Derflingher, L, Scotland, J, Larocque, J, Mrklas, K, Suter, E, Naugler, C, Stelfox, Ht, Chari, R, Lodha, A, Zanoni, P, Fowler, A, Scringer, M, Kurilova, J, Brockway, M, Delhenty, S, Akierman, A, Amin, H, Hoch, J, Phillipos, E, Soraicham, A, Staub, K, Walker-Kendall, S, Family Integrated Care (FICare) in Level II Neonatal Intensive Care Units: study protocol for a cluster randomized controlled trial, Trials, 18, 2017	Protocol for a FIC study
Bernardo, G, Svelto, M, Giordano, M, Sordino, D, Riccitelli, M, Supporting parents in taking care of their infants admitted to a neonatal intensive care unit: a prospective cohort pilot study, Italian Journal of Pediatrics, 43, 2017	Pilot study that is a prospective cohort study with small number of participants
Bieleninik, L., Ghetti, C., Gold, C., Music therapy for preterm infants and their parents: A meta-analysis, PediatricsPediatrics, 138 (3) (no pagination), 2016	Systematic review - included studies checked for relevance to protocol
Blomqvist, Yt, Ewald, U, Gradin, M, Nyqvist, Kh, Rubertsson, C, Initiation and extent of skin-to-skin care at two Swedish neonatal intensive care units, Acta PaediatricaActa Paediatr, 102, 22-8, 2013	Descriptive and explorative study
Boo,N.Y., Jamli,F.M., Short duration of skin-to-skin contact: effects on growth and breastfeeding, Journal of Paediatrics and Child Health, 43, 831-836, 2007	Study location: Malaysia
Boundy, E. O., Dastjerdi, R., Spiegelman, D., Fawzi, W. W., Missmer, S. A., Lieberman, E., Kajeepeta, S., Wall, S., Chan, G. J., Kangaroo Mother Care and Neonatal Outcomes: A Meta-analysis, Pediatrics, 137, 2016	Systematic review: included studies checked for relevance to protocol
Brown, Ld, Heermann, Ja, The effect of developmental care on preterm infant outcome, Applied Nursing ResearchAppl Nurs Res, 10, 190-197, 1997	Study design: Retrospective comparative study n=25
Byers,J.F., Lowman,L.B., Francis,J., Kaigle,L., Lutz,N.H., Waddell,T., Diaz,A.L., A quasi-experimental trial on individualized, developmentally supportive family-centered care, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 35, 105-115, 2006	Study design: Quasi randomised study.
Cevasco, A. M., The effects of mothers' singing on full-term and preterm infants and maternal emotional responses, Journal of Music Therapy, 45, 273-306, 2008	Population not relevant to protocol - healthy full-term infants were included
Chi Luong, K., Long Nguyen, T., Huynh Thi, D. H., Carrara, H. P. O., Bergman, N. J., Newly born low birthweight infants stabilise better in skin-to-skin contact than when separated from their mothers: A randomised	Study location: South Africa

Study	Reason for Exclusion
controlled trial, Acta Paediatrica, International Journal of Paediatrics, 105, 381-390, 2016	
Choi, Mh, Kang, Is, Kim, Yh, Effects of Hearing Recorded Mother's Voice on Physiological Reactions and Behavioral State of Sleep, Weight of Very Low Birth Weight Infants, Child health nurs res, 20, 185-195, 2014	Unavailable from the British Library
Chorna, O, Wang, L, Maitre, N, A Randomized Clinical Trial of Mother's Voice with a Pacifier-Activated Music Player To Decrease Hospitalization and Improve Feeding in Preterm Infants, Pediatric Academic Societies Annual Meeting, 2013	Population is not relevant to protocol - infants receiving assisted ventilation, continuous positive airway pressure, or high-flow nasal cannula .2 L/min were excluded
Chorna, O. D., Slaughter, J. C., Wang, L., Stark, A. R., Maitre, N. L., In Reply, Pediatrics, 134, e617-e618, 2014	No data presented - authors' response to letter
Chorna, Od, Slaughter, Jc, Wang, L, Stark, Ar, Maitre, Nl, A pacifier-activated music player with mother's voice improves oral feeding in preterm infants, Pediatrics, 133, 462-8, 2014	Population not relevant to protocol - infants receiving assisted ventilation, continuous positive airway pressure or high-flow nasal cannula >2 L/min were excluded
Chwo, Mj, Anderson, Gc, Good, M, Dowling, Da, Shiau, Sh, Chu, Dm, A randomized controlled trial of early kangaroo care for preterm infants: effects on temperature, weight, behavior, and acuity, Journal of Nursing ResearchJ Nurs Res, 10, 129-142, 2002	Study location: Taiwan
Clarke-Pounder, J. P., Boss, R. D., Roter, D. L., Hutton, N., Larson, S., Donohue, P. K., Communication intervention in the neonatal intensive care unit: Can It backfire?, Journal of Palliative Medicine, 18, 157-161, 2015	Reported outcomes are not relevant to the protocol
Conde-Agudelo, Agustin, Díaz-Rossello, José L, Kangaroo mother care to reduce morbidity and mortality in low birthweight infants, Cochrane Database of Systematic ReviewsCochrane Database Syst Rev, 2016	Systematic review - included studies checked for relevance to protocol
Cooper,L.G., Gooding,J.S., Gallagher,J., Sternesky,L., Ledsky,R., Berns,S.D., Impact of a family-centered care initiative on NICU care, staff and families, Journal of Perinatology, 27, S32-S37, 2007	Reported outcomes are not relevant to protocol and are derived from a survey
Cusson, R. M., Lee, A. L., Parental interventions and the development of the preterm infant, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 23, 60-68, 1994	Narrative review
Darcy Mahoney, A., Zauche, L. H., Hallowell, S., Weldon, A., Stapel-Wax, J., Leveraging the Skills of Nurses and the Power of Language Nutrition to Ensure a Better Future for Children, Advances in neonatal care : official journal of the National Association of Neonatal Nurses, 17, 45-52, 2017	Narrative review
de Roiste, A; Bushnell, L. , Cardiorespiratory and transcutaneous oxygen monitoring of high-risk preterms receiving systematic stroking, Int J Prenatal Perinatal Psychol Med, 12, 89-95, 2000	Reported outcomes are not relevant to protocol
Diego, M. A., Field, T., Hernandez-Reif, M., Vagal activity, gastric motility, and weight gain in massaged preterm neonates, J Pediatr, 147, 50-5, 2005	Intervention is not relevant to protocol - massage performed by professional therapists
Doyle, L. W., Kangaroo mother care, Lancet, 350, 1721-1722, 1997	Commentary

Study	Reason for Exclusion
Evereklian, M., Posmontier, B., The Impact of Kangaroo Care on Premature Infant Weight Gain, J Pediatr NursJournal of pediatric nursing, 34, e10-e16, 2017	Systematic review - included studies checked for relevance to protocol
Ferber,S.G., Kuint,J., Weller,A., Feldman,R., Dollberg,S., Arbel,E., Kohelet,D., Massage therapy by mothers and trained professionals enhances weight gain in preterm infants, Early Human Development, 67, 37-45, 2002	Population not relevant to protocol - weaned from ventilatory assistance was an inclusion criterion
Filippa, M., Panza, C., Ferrari, F., Frassoldati, R., Kuhn, P., Balduzzi, S., D'Amico, R., Systematic review of maternal voice interventions demonstrates increased stability in preterm infants, Acta Paediatrica, International Journal of Paediatrics, 106, 1220-1229, 2017	Systematic review - included studies checked for relevance to protocol
Foster, J., Bidewell, J., Buckmaster, A., Lees, S., Henderson-Smart, D., Parental stress and satisfaction in the non-tertiary special care nursery, Journal of advanced nursing, 61, 522-530, 2008	Intervention not relevant to protocol - comparison of oxygen administration techniques
Franck, L. S., Oulton, K., Nderitu, S., Lim, M., Fang, S., Kaiser, A., Parent involvement in pain management for NICU infants: A randomized controlled trial, PediatricsPediatrics, 128, 510-518, 2011	Reported outcomes are not relevant to protocol
Fucile, S., Gisel, E. G., Sensorimotor interventions improve growth and motor function in preterm infants, Neonatal NetwNeonatal network : NN, 29, 359-66, 2010	Comparison not relevant to protocol - head to head comparison of an oral, a tactile/kinaesthetic and a combined intervention
Fucile, S., Gisel, E. G., Lau, C., Effect of an oral stimulation program on sucking skill maturation of preterm infants, Dev Med Child NeurolDevelopmental medicine and child neurology, 47, 158-62, 2005	Reported outcomes are not relevant to protocol
Fucile, S., Gisel, E., Lau, C., Oral stimulation accelerates the transition from tube to oral feeding in preterm infants, J Pediatr, 141, 230-6, 2002	Intervention not relevant to protocol - oral stimulation
Furman, L., Kennell, J., Breastmilk and skin-to-skin kangaroo care for premature infants. Avoiding bonding failure, Acta Paediatrica, International Journal of Paediatrics, 89, 1280-1283, 2000	Narrative review
Gabis, L. V., Hacham-Pilosof, K., Yosef, O. B., Rabinovitz, G., Leshem, G., Shilon-Hadass, A., Biran, Y., Reichman, B., Kuint, J., Bart, O., The influence of a multisensory intervention for preterm infants provided by parents, on developmental abilities and on parental stress levels, Journal of Child Neurology, 30, 896-903, 2015	Reported outcomes are not relevant to the protocol
Gaebler, Christine P., Hanzlik, Jodie Redditi, The Effects of a Prefeeding Stimulation Program on Preterm Infants, American Journal of Occupational Therapy, 50, 184-192, 1996	Intervention is not relevant to the protocol - prefeeding oral stimulation
Gathwala,G., Singh,B., Balhara,B., KMC facilitates mother baby attachment in low birth weight infants, Indian Journal of Pediatrics, 75, 43-47, 2008	Study location: India
Gathwala,G., Singh,B., Singh,J., Effect of Kangaroo Mother Care on physical growth, breastfeeding and its acceptability, Tropical Doctor, 40, 199-202, 2010	Study location: India
Ghavane, S., Murki, S., Subramanian, S., Gaddam, P., Kandraju, H., Thumalla, S., Kangaroo Mother Care in Kangaroo ward for improving the growth and	Population not relevant to protocol - babies not on oxygen or respiratory

Study	Reason for Exclusion
breastfeeding outcomes when reaching term gestational age in very low birth weight infants, Acta Paediatrica, International Journal of Paediatrics, 101, e545-e549, 2012	support were included in the study. Study location: India
Gianní, Ml, Picciolini, O, Ravasi, M, Gardon, L, Vegni, C, Fumagalli, M, Mosca, F, The effects of an early developmental mother-child intervention program on neurodevelopment outcome in very low birth weight infants: a pilot study, Early Human Development, 82, 691-695, 2006	Reported outcomes are not relevant to protocol
Glazebrook,C., Marlow,N., Israel,C., Croudace,T., Johnson,S., White,I.R., Whitelaw,A., Randomised trial of a parenting intervention during neonatal intensive care, Archives of Disease in Childhood Fetal and Neonatal Edition, 92, F438-F443, 2007	Reported outcomes are not relevant to protocol
Gonya,J., Martin,E., McClead,R., Nelin,L., Shepherd,E., Empowerment programme for parents of extremely premature infants significantly reduced length of stay and readmission rates, Acta Paediatrica, 103, 727-731, 2014	Study design uses historical controls
Gonzalez, Ap, Vasquez-Mendoza, G, García-Vela, A, Guzmán-Ramirez, A, Salazar-Torres, M, Romero-Gutierrez, G, Weight gain in preterm infants following parent-administered Vimala massage: a randomized controlled trial, American Journal of Perinatology, 26, 247-252, 2009	Population not relevant to protocol - infants requiring no supplemental oxygen or any additional intervention were included in the study
Greene, Zelda, O'Donnell, Colm Pf, Walshe, Margaret, Oral stimulation for promoting oral feeding in preterm infants, The Cochrane database of systematic reviews, 9, CD009720, 2016	Systematic review - included studies checked for relevance to protocol
Griffin, T. L., Meier, P. P., Bradford, L. P., Bigger, H. R., Engstrom, J. L., Mothers' performing creamatocrit measures in the NICU: accuracy, reactions, and cost, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 29, 249-257, 2000	Reported intervention and outcomes are not relevant to protocol
Gund,A., Sjoqvist,B.A., Wigert,H., Hentz,E., Lindecrantz,K., Bry,K., A randomized controlled study about the use of eHealth in the home health care of premature infants, BMC Medical Informatics and Decision Making, 13, 22-, 2013	Intervention not relevant to protocol - web application to support discharge from hospital
Gustafson, K. W., LaBrecque, M. A., Graham, D. A., Tella, N. M., Curley, M. A., Effect of Parent Presence During Multidisciplinary Rounds on NICU-Related Parental Stress, JOGNN - Journal of Obstetric, Gynecologic, & Neonatal NursingJ Obstet Gynecol Neonatal Nurs, 45, 661-70, 2016	Reported outcomes are not relevant to protocol
Hake-Brooks,S.J., Anderson,G.C., Kangaroo care and breastfeeding of mother-preterm infant dyads 0-18 months: a randomized, controlled trial, Neonatal Network - Journal of Neonatal Nursing, 27, 151-159, 2008	Reported outcomes are not relevant to protocol - breastfeeding exclusivity and duration
Hamer, Eg, Hielkema, T, Bos, Af, Dirks, T, Hooijsma, Sj, Reinders-Messelink, Ha, Toonen, Rf, Hadders-Algra, M, Effect of early intervention on functional outcome at school age: follow-up and process evaluation of a randomised controlled trial in infants at risk, Early Human Development, 106-107, 67-74, 2017	Population not relevant to protocol - infants were included on the basis of definitely abnormal general movements

Study	Reason for Exclusion
Hane, A. A., Myers, M. M., Hofer, M. A., Ludwig, R. J., Halperin, M. S., Austin, J., Glickstein, S. B., Welch, M. G., Family nurture intervention improves the quality of maternal caregiving in the neonatal intensive care unit: evidence from a randomized controlled trial, Journal of developmental and behavioral pediatrics : JDBP, 36, 188-196, 2015	Reported outcomes are not relevant to protocol
Harding, C, Frank, L, Someren, V, Hilari, K, Botting, N, How does non-nutritive sucking support infant feeding?, Infant Behavior & DevelopmentInfant behav, 37, 457-64, 2014	Reported outcomes are not relevant to protocol
Harding, CM; Law, J; Pring, T., The use of non-nutritive sucking to promote functional sucking skills in premature infants: an exploratory trial, Infant, 2, 238-43, 2006	Unavailable from the British Library
Harrison, L. L., Williams, A. K., Berbaum, M. L., Stem, J. T., Leeper, J., Physiologic and behavioral effects of gentle human touch on preterm infants, Research in nursing & health, 23, 435-446, 2000	Reported outcomes are not relevant to protocol
Harrison, L., Olivet, L., Cunningham, K., Bodin, M. B., Hicks, C., Effects of gentle human touch on preterm infants: pilot study results, Neonatal network : NN, 15, 35-42, 1996	Reported outcomes are not relevant to protocol
Harrison, L; Williams, AK; Berbaum, ML; Stem, JT; Leeper, J. , Effects of developmental, health status, behavioral, and environmental variables on preterm infantsâ□™ responses to a gentle human touch intervention, Int J Prenatal Perinatal Psychol Med, 12, 109-122, 2000	Reported outcomes are not relevant to protocol
Hielkema,T., Blauw-Hospers,C.H., Dirks,T., Drijver-Messelink,M., Bos,A.F., Hadders-Algra,M., Does physiotherapeutic intervention affect motor outcome in high-risk infants? An approach combining a randomized controlled trial and process evaluation, Developmental Medicine and Child Neurology, 53, e8-15, 2011	Population not relevant to protocol - babies were included on the basis of definitely abnormal general movements
Holditch-Davis, D., White-Traut, R. C., Levy, J. A., O'Shea, T. M., Geraldo, V., David, R. J., Maternally administered interventions for preterm infants in the NICU: effects on maternal psychological distress and mother-infant relationship, Infant Behavior & Development, 37, 695-710, 2014	Reported outcomes are not relevant to the protocol
Holditch-Davis, D., White-Traut, R., Levy, J., Williams, K. L., Ryan, D., Vonderheid, S., Maternal satisfaction with administering infant interventions in the neonatal intensive care unit, JOGNN - Journal of Obstetric, Gynecologic, & Neonatal Nursing, 42, 641-54, 2013	Reported outcome is not relevant to the protocol - unvalidated parental satisfaction questionnaire
Im, Hs, Yakson vs. GHT therapy effects on growth and physical response of preterm infants and on maternal attachment, Taehan Kanho Hakhoe chi, 36, 255-264, 2006	Article is in Korean
Jacobs, S. E., Sokol, J., Ohlsson, A., The Newborn Individualized Developmental Care and Assessment Program is not supported by meta-analyses of the data, Journal of pediatrics, 140, 699-706, 2002	Systematic review - included studies checked for relevance to protocol

Study	Reason for Exclusion
Jacobs, Se, Ohlsson, A, Nidcap-a systematic review and meta-analyses of randomized controlled trials, Journal of Paediatrics and Child Health, 49, 11, 2013	Conference abstract: insufficient detail of study is presented
Jarjour, I. T., Neurodevelopmental outcome after extreme prematurity: A review of the literature, Pediatric Neurology, 52, 143-152, 2015	Systematic review: no comparisons relevant to the protocol were examined
Jayaraman, D., Mukhopadhyay, K., Bhalla, A. K., Dhaliwal, L. K., Randomized Controlled Trial on Effect of Intermittent Early Versus Late Kangaroo Mother Care on Human Milk Feeding in Low-Birth-Weight Neonates, Journal of Human LactationJ Hum Lact, 890334416685072, 2017	Comparison is not relevant to protocol - infants who received late care were completely stabilized (defined as off respiratory support and intravenous fluids)
Johnson, S., Whitelaw, A., Glazebrook, C., Israel, C., Turner, R., White, I. R., Croudace, T., Davenport, F., Marlow, N., Randomized trial of a parenting intervention for very preterm infants: outcome at 2 years, Journal of Pediatrics, 155, 488-94, 2009	Intervention is not relevant to protocol
Kaaresen, Pi, Rønning, Ja, Tunby, J, Nordhov, Sm, Ulvund, Se, Dahl, Lb, A randomized controlled trial of an early intervention program in low birth weight children: outcome at 2 years, Early Human Development, 84, 201-209, 2008	Intervention not relevant to protocol
Kadivar, M., Seyedfatemi, N., Akbari, N., Haghani, H., The effect of narrative writing on maternal stress in neonatal intensive care settings, Journal of Maternal-Fetal & Neonatal MedicineJ Matern Fetal Neonatal Med, 28, 938-943, 2015	Study location: Iran
Kadivar, M., Seyedfatemi, N., Akbari, N., Haghani, H., The effect of narrative writing of mothers on their satisfaction with care in the neonatal intensive care unit, Journal of Maternal-Fetal & Neonatal MedicineJ Matern Fetal Neonatal Med, 30, 352-356, 2017	Study location: Iran
Karda, Özdemir F, Güdücü, Tüfekci F, The effect of individualised developmental care practices on the growth and hospitalisation duration of premature infants: the effect of mother's scent and flexion position, Journal of clinical nursing, 23, 3036-3044, 2014	Intervention is not relevant to the protocol
Kaya, V, Aytekin, A, Effects of pacifier use on transition to full breastfeeding and sucking skills in preterm infants: a randomised controlled trial, Journal of Clinical NursingJ Clin Nurs, 26, 2055-2063, 2017	No outcomes relevant to the protocol
Kaya, V., Aytekin, A., Effects of pacifier use on transition to full breastfeeding and sucking skills in preterm infants: a randomised controlled trial, Journal of clinical nursing, 26, 2055-2063, 2017	Population is not relevant to protocol - preterm infants with respiratory distress are not included
Keshavars,M., Kiani,A., Nasani,L., Hoseini,A.F., Effect of touch therapy by mothers on weight gaining of preterm newborns, Koomesh, 13, 240-246, 2012	Unavailable from the British Library
Kiechl-Kohlendorfer, U, Merkle, U, Deufert, D, Neubauer, V, Peglow, Up, Griesmaier, E, Effect of developmental care for very premature infants on neurodevelopmental outcome at 2 years of age, Infant Behavior & DevelopmentInfant behav, 39, 166-72, 2015	Study design - prospective phase- lag cohort study
Kleberg, A, Westrup, B, Stjernqvist, K, Developmental outcome, child behaviour and mother-child interaction at 3	Study design: cohort study with historical control group

Study	Reason for Exclusion
years of age following Newborn Individualized Developmental Care and Intervention Program (NIDCAP) intervention, Early Human Development, 60, 123-35, 2000	
Kleberg, A., Warren, I., Norman, E., Morelius, E., Berg, A. C., Mat-Ali, E., Holm, K., Fielder, A., Nelson, N., Hellstrom-Westas, L., Lower stress responses after Newborn Individualized Developmental Care and Assessment Program care during eye screening examinations for retinopathy of prematurity: a randomized study, Pediatrics, 121, e1267-78, 2008	Reported outcomes are not relevant to protocol
Kleberg, A., Westrup, B., Stjernqvist, K., Lagercrantz, H., Indications of improved cognitive development at one year of age among infants born very prematurely who received care based on the Newborn Individualized Developmental Care and Assessment Program (NIDCAP), Early Hum DevEarly human development, 68, 83-91, 2002	Reported outcomes are not relevant to population - neurodevelopmental delay reported at 1 year
Kyno, N. M., Ravn, I. H., Lindemann, R., Fagerland, M. W., Smeby, N. A., Torgersen, A. M., Effect of an early intervention programme on development of moderate and late preterm infants at 36 months: a randomized controlled study, Infant Behavior & Development, 35, 916-26, 2012	Population is not relevant to protocol - under 66% received respiratory support (approx. 39%)
Lawn, J. E., Mwansa-Kambafwile, J., Horta, B. L., Barros, F. C., Cousens, S., Kangaroo mother care' to prevent neonatal deaths due to preterm birth complications, International Journal of Epidemiology, 39, i144-i154, 2010	Systematic review: included studies checked for relevance to protocol
Legault, M., Goulet, C., Comparison of kangaroo and traditional methods of removing preterm infants from incubators, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 24, 501-506, 1995	Insufficient detail reported for patient satisfaction outcome
Legendre, V., Burtner, P. A., Martinez, K. L., Crowe, T. K., The evolving practice of developmental care in the neonatal unit: a systematic review, Physical & Occupational Therapy in Pediatrics, 31, 315-38, 2011	Systematic review: included studies checked for relevance to protocol
Lessen, B. S., Effect of the premature infant oral motor intervention on feeding progression and length of stay in preterm infants, Advances in Neonatal Care, 11, 129-39, 2011	Population is not relevant to protocol - exclusion criteria included infants who were receiving assistive ventilation
Macho, P., Individualized Developmental Care in the NICU: A Concept Analysis, Advances in Neonatal Care, 17, 162-174, 2017	Systematic review: no comparative data reported
Maguire, C. M., Veen, S., Sprij, A. J., Le Cessie, S., Wit, J. M., Walther, F. J., Effects of basic developmental care on neonatal morbidity, neuromotor development, and growth at term age of infants who were born at <32 weeks, PediatricsPediatrics, 121, e239-e245, 2008	Intervention is not relevant to protocol - basic developmental care with no parental involvement
Maguire, Cm, Veen, S, Wit, Jm, Sprij, A, Houwelingen, Ac, Walther, Fj, The Leiden developmental care study: the effect of developmental care on growth of preterm infants <32 weeks gestational age, Pediatric Research, 54, 578, 2003	Conference abstract - insufficient details of data are reported
Mellis, C., Kangaroo Mother Care and neonatal outcomes: A meta-analysis, Journal of Paediatrics & Child HealthJ Paediatr Child Health, 52, 579, 2016	Commentary on Boundy 2016 systematic review
Melnyk, B. M., Alpert-Gillis, L., Feinstein, N. F., Fairbanks, E., Schultz-Czarniak, J., Hust, D., Sherman, L., LeMoine,	Intervention not relevant to protocol - COPE parental education intervention

Study	Reason for Exclusion
C., Moldenhauer, Z., Small, L., Bender, N., Sinkin, R. A., Improving cognitive development of low-birth-weight premature infants with the COPE program: a pilot study of the benefit of early NICU intervention with mothers, Research in Nursing & Health, 24, 373-389, 2001	
Melnyk, B. M., Feinstein, N. F., Alpert-Gillis, L., Fairbanks, E., Crean, H. F., Sinkin, R. A., Stone, P. W., Small, L., Tu, X., Gross, S. J., Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial, Pediatrics, 118, e1414-27, 2006	Intervention not relevant to protocol - COPE parental education intervention
Mendes, Ew, Procianoy, Rs, Massage therapy reduces hospital stay and occurrence of late-onset sepsis in very preterm neonates, Journal of Perinatology, 28, 815-820, 2008	Study location: Brazil
Miles, R, Modi, N, Cowan, F, Glover, V, Stephenson, J, A controlled trial of daily mother-infant skin-to-skin contact after extremely preterm birth, Pediatric Research, 54, 569, 2003	Conference abstract: insufficient detail of data reported
Miles,R., Cowan,F., Glover,V., Stevenson,J., Modi,N., A controlled trial of skin-to-skin contact in extremely preterm infants, Early Human Development, 82, 447-455, 2006	Population not relevant to protocol - infants receiving ventilation were not included
Milgrom, J., Newnham, C., Martin, P. R., Anderson, P. J., Doyle, L. W., Hunt, R. W., Achenbach, T. M., Ferretti, C., Holt, C. J., Inder, T. E., Gemmill, A. W., Early communication in preterm infants following intervention in the NICU, Early Human Development, 89, 755-62, 2013	Intervention and reported outcomes are not relevant to protocol
Mirghafourvand, M., Ouladsahebmadarek, E., Hosseini, M. B., Heidarabadi, S., Asghari-Jafarabadi, M., Hasanpour, S., The effect of creating opportunities for parent empowerment program on parent's mental health: A systematic review, Iran J PediatrIranian journal of pediatrics, 27 (2) (no pagination), 2017	Systematic review:Reported outcomes are not relevant to protocol. Included studies were checked for relevance to protocol
Moody, C., Callahan, T. J., Aldrich, H., Gance-Cleveland, B., Sables-Baus, S., Early Initiation of Newborn Individualized Developmental Care and Assessment Program (NIDCAP) Reduces Length of Stay: A Quality Improvement Project, Journal of Pediatric Nursing, 32, 59-63, 2017	Study design: Retrospective study
Narayanan, I., Kumar, H., Singhal, P. K., Dutta, A. K., Maternal participation in the care of the high risk infant: follow-up evaluation, Indian Pediatrics, 28, 161-167, 1991	Study location: India
Nearing, G. B., Salas, A. A., Granado-Villar, D., Chandler, B. D., Soliz, A., Psychosocial parental support programs and short-term clinical outcomes in extremely low-birth-weight infants, Journal of Maternal-Fetal and Neonatal Medicine, 25, 89-93, 2012	Study design: Retrospective study
Nelson,M.N., White-Traut,R.C., Vasan,U., Silvestri,J., Comiskey,E., Meleedy-Rey,P., Littau,S., Gu,G., Patel,M., One-year outcome of auditory-tactile-visual-vestibular intervention in the neonatal intensive care unit: effects of severe prematurity and central nervous system injury, Journal of Child Neurology, 16, 493-498, 2001	Intervention not relevant to protocol

Study	Reason for Exclusion
Northrup, T. F., Evans, P. W., Lillie, M. L., Tyson, J. E., A free parking trial to increase visitation and improve extremely low birth weight infant outcomes, Journal of Perinatology, 36, 1112-1115, 2016	Intervention not relevant to protocol
O'Brien, K., Bracht, M., Robson, K., Xiang, Y., Lucia, M., Cruz, M., Soraisham, A., DaSilva, O., Ng, E., Monterossa, L., Alvaro, R., Narvey, M., Lui, K., Tarnow-Mordi, W., Lee, S. K., Evaluation of family integrated care(Ficare);a cluster randomized controlled trial(RCT) in Canada, Australia and New Zealand, European Journal of Pediatrics, 175 (11), 1507-1508, 2016	Conference abstract. Insufficient detail of data reported
Ohlsson, A., Jacobs, S. E., NIDCAP: a systematic review and meta-analyses of randomized controlled trials, Pediatrics, 131, e881-93, 2013	Systematic review - included studies checked for relevance to protocol
Ortenstrand, A., Westrup, B., Brostrom, E. B., Sarman, I., Akerstrom, S., Brune, T., Lindberg, L., Waldenstrom, U., The Stockholm Neonatal Family Centered Care Study: effects on length of stay and infant morbidity, Pediatrics, 125, e278-85, 2010	Population not relevant to protocol - under 66% received respiratory support
O'Toole, A., Francis, K., Pugsley, L., Does Music Positively Impact Preterm Infant Outcomes?, Advances in Neonatal Care, 17, 192-202, 2017	Systematic review: included studies checked for relevance to protocol
Parashar, P., Samuel, A. J., Bansal, A., Aranka, V. P., Yakson touch as a part of early intervention in the Neonatal Intensive Care Unit: A systematic narrative review, Indian Journal of Critical Care Medicine, 20, 349-352, 2016	Study location: India
Parker, S. J., Zahr, L. K., Cole, J. G., Brecht, M. L., Outcome after developmental intervention in the neonatal intensive care unit for mothers of preterm infants with low socioeconomic status, Journal of Pediatrics, 120, 780-785, 1992	Population not relevant to protocol - under 66% had respiratory complications
Picciolini, O., Porro, M., Meazza, A., Gianni, M. L., Rivoli, C., Lucco, G., Barretta, F., Bonzini, M., Mosca, F., Early exposure to maternal voice: Effects on preterm infants development, Early Human Development, 90, 287-292, 2014	Study design: case control
Pineda, R., Guth, R., Herring, A., Reynolds, L., Oberle, S., Smith, J., Enhancing sensory experiences for very preterm infants in the NICU: An integrative review, Journal of Perinatology, 37, 323-332, 2017	Systematic review: included studies checked for relevance to protocol
Polkki, T., Korhonen, A., The effectiveness of music on pain among preterm infants in the neonatal intensive care unit: a systematic review, JBI Library of Systematic ReviewisJBI Libr Syst Rev, 10, 4600-4609, 2012	Unavailable from the British Library
Pridham, K, Brown, R, Clark, R, Limbo, Rk, Schroeder, M, Henriques, J, Bohne, E, Effect of guided participation on feeding competencies of mothers and their premature infants, Research in nursing & health, 28, 252-267, 2005	Reported outcomes are not relevant to the protocol
Procianoy,, Effect of Maternal Touch Care on Very Low Birth Weight Infants, Pediatric academic society, http://www.abstracts2view.com/pas/, 2007	Unavailable from the British Library
Procianoy,R.S., Mendes,E.W., Silveira,R.C., Massage therapy improves neurodevelopment outcome at two	Study location: Brazil

Study	Reason for Exclusion
years corrected age for very low birth weight infants, Early Human Development, 86, 7-11, 2010	
Provenzi, L., Broso, S., Montirosso, R., Do mothers sound good? A systematic review of the effects of maternal voice exposure on preterm infants' development, Neuroscience and Biobehavioral Reviews, 88, 42-50, 2018	Systematic review of exposure to maternal voice - included studies checked for relevance to protocol
Ramanathan, K., Paul, V. K., Deorari, A. K., Taneja, U., George, G., Kangaroo Mother Care in very low birth weight infants, Indian Journal of Pediatrics, 68, 1019-1023, 2001	Study location: India
Ramey, Ct, Bryant, Dm, Wasik, Bh, Sparling, Jj, Fendt, Kh, LaVange, Lm, Infant Health and Development Program for low birth weight, premature infants: program elements, family participation, and child intelligence, Pediatrics, 89, 454-465, 1992	Reported outcomes are not relevant to protocol
Renfrew, M. J., Craig, D., Dyson, L., McCormick, F., Rice, S., King, S. E., Misso, K., Stenhouse, E., Williams, A. F., Breastfeeding promotion for infants in neonatal units: A systematic review and economic analysis, Health Technology Assessment, 13, ix-170, 2009	Systematic review: included studies checked for relevance to protocol
Roue, J. M., Kuhn, P., Lopez Maestro, M., Maastrup, R. A., Mitanchez, D., Westrup, B., Sizun, J., Eight principles for patient-centred and family-centred care for newborns in the neonatal intensive care unit, Archives of Disease in Childhood: Fetal and Neonatal Edition, 102, F364-F368, 2017	Overview: no data presented
Rushforth, K, A randomised controlled trial of weaning from mechanical ventilation in paediatric intensive care (PIC). Methodological and practical issues, Intensive & critical care nursing, 21, 76-86, 2005	Comparison not relevant to protocol: Nurse-led versus medical-led weaning of infants from mechanical ventilation
Sajaniemi, N, Mäkelä, J, Salokorpi, T, Wendt, L, Hämäläinen, T, Hakamies-Blomqvist, L, Cognitive performance and attachment patterns at four years of age in extremely low birth weight infants after early intervention, European child & adolescent psychiatry, 10, 122-129, 2001	Population not relevant to protocol - infants were recruited 3 months after birth and intervention started 6 months after birth in the home. No details are given regarding respiratory support received.
Sannino, P., Gianni, M. L., De Bon, G., Fontana, C., Picciolini, O., Plevani, L., Fumagalli, M., Consonni, D., Mosca, F., Support to mothers of premature babies using NIDCAP method: A non-randomized controlled trial, Early Human Development, 95, 15-20, 2016	Non-randomised comparative study
Santoro Jr, W., Martinez, F. E., Effect of intervention on the rates of breastfeeding of very low birth weight newborns. [Portuguese, English], Jornal de Pediatria, 83, 541-546, 2007	Study location: Brazil
Schanler, R. J., Outcomes of Human Milk-Fed Premature Infants, Seminars in Perinatology, 35, 29-33, 2011	Narrative review
Schappin, R., Wijnroks, L., Uniken Venema, M., Wijnberg-Williams, B., Veenstra, R., Koopman-Esseboom, C., Mulder-De Tollenaer, S., van der Tweel, I., Jongmans, M., Primary Care Triple P for parents of NICU graduates with behavioral problems: a randomized, clinical trial using observations of parent-child interaction, BMC Pediatrics, 14, 305, 2014	Population, intervention and outcomes not relevant to protocol: cohort of preterm and term babies with no confirmation of receipt of respiratory support, intervention at age 2, no relevant reported outcomes

Study	Reason for Exclusion
Schraeder, B. D., Czajka, C., Kalman, D. D., McGeady, S. J., Respiratory health, lung function, and airway responsiveness in school-age survivors of very-low-birth-weight, Clinical Pediatrics, 37, 237-45, 1998	No outcomes relevant to protocol reported
Schroeder,M., Pridham,K., Development of relationship competencies through guided participation for mothers of preterm infants, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 35, 358-368, 2006	Reported outcomes are not relevant to protocol
Segre, L. S., Chuffo-Siewert, R., Brock, R. L., O'Hara M, W., Emotional distress in mothers of preterm hospitalized infants: A feasibility trial of nurse-delivered treatment, Journal of Perinatology, 33, 924-928, 2013	Intervention is not relevant to protocol: nurse delivered listening visit with mother
Seigel, J. K., Smith, P. B., Ashley, P. L., Cotten, C. M., Herbert, C. C., King, B. A., Maynor, A. R., Neill, S., Wynn, J., Bidegain, M., Early administration of oropharyngeal colostrum to extremely low birth weight infants, Breastfeeding Medicine: The Official Journal of the Academy of Breastfeeding MedicineBreastfeed Med, 8, 491-5, 2013	Intervention not relevant to protocol
Servel, A. C., Rideau Batista Novais, A., Single-family rooms for neonatal intensive care units impacts on preterm newborns, families, and health-care staff. A systematic literature review, Archives de Pediatrie, 23, 921-926, 2016	Article is in French
Shahheidari, M., Homer, C., Impact of the design of neonatal intensive care units on neonates, staff, and families: A systematic literature review, Journal of Perinatal and Neonatal Nursing, 26, 260-266, 2012	Systematic review: Population and comparison is not relevant to the protocol
Sharifah, H., Lee, K. S., Ho, J. J., Separate care for new mother and infant versus rooming-in for increasing the duration of breastfeeding, Cochrane Database of Systematic Reviews, (3) (no pagination), 2007	Systematic review: included study was checked for relevance to protocol
Sharma, D., Farahbakhsh, N., Sharma, S., Sharma, P., Sharma, A., Role of kangaroo mother care in growth and breast feeding rates in very low birth weight (VLBW) neonates: a systematic review, Journal of Maternal-Fetal & Neonatal MedicineJ Matern Fetal Neonatal Med, 1-14, 2017	Systematic review: included studies checked for relevance to protocol
Sharma, D., Murki, S., Pratap, O. T., The effect of kangaroo ward care in comparison with "intermediate intensive care" on the growth velocity in preterm infant with birth weight <1100 g: randomized control trial, European Journal of Pediatrics, 175, 1317-24, 2016	Study location: India
Shukri, Nhm, Wells, J, Mukhtar, F, Fewtrell, M, A randomised trial to test the effectiveness of maternal relaxation therapy during breastfeeding: effects on infant behaviour, 62, 662, 2016	Unavailable from the British Library
Simmer, K., Metcalf, R., Daniels, L., The use of breastmilk in a neonatal unit and its relationship to protein and energy intake and growth, Journal of Paediatrics & Child Health, 33, 55-60, 1997	Audit data
Singer, L. T., Salvator, A., Guo, S., Collin, M., Lilien, L., Baley, J., Maternal psychological distress and parenting stress after the birth of a very low-birth-weight infant, JAMA, 281, 799-805, 1999	Intervention and outcomes not relevant to protocol

Study	Reason for Exclusion
Smith, J. R., Comforting touch in the very preterm hospitalized infant: An integrative review, Advances in Neonatal Care, 12, 349-365, 2012	Systematic review: included studies checked for relevance to protocol
Smith, K, Layne, M, Garell, D, The impact of care coordination on children with special health care needs, Children's Health Care, 23, 251-266, 1994	Population is not relevant to protocol - children with special care needs
Snyder, R., Herdt, A., Mejias-Cepeda, N., Ladino, J., Crowley, K., Levy, P., Early provision of oropharyngeal colostrum leads to sustained breast milk feedings in preterm infants, Pediatrics & NeonatologyPediatr neonatol, 10, 10, 2017	Population and intervention are not relevant to protocol
Spencer-Smith, M. M., Spittle, A. J., Doyle, L. W., Lee, K. J., Lorefice, L., Suetin, A., Pascoe, L., Anderson, P. J., Long-term benefits of home-based preventive care for preterm infants: a randomized trial, Pediatrics, 130, 1094-101, 2012	Population is not relevant to protocol - <66% of babies were receiving respiratory support at the time of intervention
Spittle, A., Doyle, L., Treyvaud, K., Anderson, P., A randomised controlled trial of an early preventative care program for infants born very preterm: The role of social risk on cognitive outcomes throughout early childhood, Developmental Medicine and Child Neurology, 59, 44, 2017	No data presented - Protocol for a randomised controlled trial
Spittle, Aj, Ferretti, C, Anderson, Pj, Orton, J, Eeles, A, Bates, L, Boyd, Rn, Inder, Te, Doyle, Lw, Improving the outcome of infants born at <30 weeks' gestation--a randomized controlled trial of preventative care at home, BMC Pediatrics, 9, 73, 2009	Conference abstract: insufficient detail of data presented
Swarnkar, K., Vagha, J., Effect of kangaroo mother care on growth and morbidity pattern in low birth weight infants, Journal of Krishna Institute of Medical Sciences University, 5, 91-99, 2016	Study location: India
Syfrett, Eb, Anderson, Gc, Very early kangaroo care beginning at birth for healthy preterm infants and mothers who choose to breastfeed: effect on outcome, A workshop on the kangaroo-mother method for low birthweight infants. World health organisation; 1996 october; trieste, italy, 1996	Unavailable from the British Library
Symington, A., Pinelli, J., Developmental care for promoting development and preventing morbidity in preterm infants, Cochrane Database of Systematic Reviews, CD001814, 2006	Systematic review: included studies checked for relevance to protocol
Tan, K., Lai, N. M., Telemedicine for the support of parents of high risk newborn infants, Cochrane Database of Systematic Reviews, (4) (no pagination), 2007	Systematic review: Intervention is not relevant to protocol
Tessier, R, Cristo, M, Velez, S, Giron, M, Calume, Zf, Ruiz-Palaez, Jg, Charpak, Y, Charpak, N, Kangaroo mother care and the bonding hypothesis, Pediatrics, 102, e17, 1998	Study location: Colombia
Tessier,R., Charpak,N., Giron,M., Cristo,M., de Calume,Z.F., Ruiz-Pelaez,J.G., Kangaroo Mother Care, home environment and father involvement in the first year of life: a randomized controlled study, Acta Paediatrica, 98, 1444-1450, 2009	Study location: Colombia
Teti, D. M., Hess, C. R., O'Connell, M., Parental perceptions of infant vulnerability in a preterm sample:	Longitudinal observational study

Study	Reason for Exclusion
prediction from maternal adaptation to parenthood during the neonatal period, Journal of Developmental & Behavioral Pediatrics, 26, 283-92, 2005	
Thukral, A., Sankar, M. J., Agarwal, R., Gupta, N., Deorari, A. K., Paul, V. K., Early skin-to-skin contact and breast-feeding behavior in term neonates: A randomized controlled trial, Neonatology, 102, 114-119, 2012	Study location: India
Tully, K. P., Holditch-Davis, D., White-Traut, R. C., David, R., O'Shea, T. M., Geraldo, V., A Test of Kangaroo Care on Preterm Infant Breastfeeding, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN, 45, 45-61, 2016	Reported outcomes are not relevant to the protocol
Unanue, Ra, The effect of parent education on the motor performance of premature infants and parent caregiving abilities, 2002	Conference abstract: insufficient detail of data presented
Vaidya, K, Sharma, A, Dhungel, S, Effect of early mother-baby close contact over the duration of exclusive breastfeeding, Nepal Medical College journal : NMCJ, 7, 138-140, 2005	Study location: Nepal
van Der Pal, S. M., Maguire, C. M., Bruil, J., Le Cessie, S., Wit, J. M., Walther, F. J., Veen, S., Health-related quality of life of very preterm infants at 1 year of age after two developmental care-based interventions, Child: care, health and development, 34, 619-625, 2008	Reported outcomes are not relevant to the protocol
van der Pal, S. M., Maguire, C. M., le Cessie, S., Wit, J. M., Walther, F. J., Bruil, J., Parental experiences during the first period at the neonatal unit after two developmental care interventions, Acta Paediatrica, 96, 1611-6, 2007	Narrative summary of two previous RCTs, reported outcomes are not relevant to protocol
Vandoesum, K, Kowalenko, Nm, A national comprehensive program of COPMI interventions in the Netherlands, Neuropsychiatrie de l'enfance et de l'adolescence, 60, S131, 2012	Conference abstract: no data presented
Verma, A., Maria, A., Pandey, R. M., Hans, C., Verma, A., Sherwani, F., Family-Centered Care to Complement Care of Sick Newborns: A Randomized Controlled Trial, Indian Pediatrics, 54, 455-459, 2017	Study location: India
Vickers, Andrew, Ohlsson, Arne, Lacy, Janet, Horsley, Angela, Massage for promoting growth and development of preterm and/or low birth-weight infants, Cochrane Database of Systematic Reviews, 2004	Systematic review: included studies checked for relevance to protocol
Vohr, B. R., Poindexter, B. B., Dusick, A. M., McKinley, L. T., Wright, L. L., Langer, J. C., Poole, W. K., Nichd Neonatal Research Network, Beneficial effects of breast milk in the neonatal intensive care unit on the developmental outcome of extremely low birth weight infants at 18 months of age, Pediatrics, 118, e115-23, 2006	Prospective cohort study
Wallin, L., Eriksson, M., Newborn Individual Development Care and Assessment Program (NIDCAP): a systematic review of the literature, Worldviews on Evidence-Based Nursing, 6, 54-69, 2009	Systematic review - included studies checked for relevance to protocol
Wang, Y., Shi, J. P., Li, Y. H., Yang, W. H., Tian, Y. J., Gao, J., Li, S. J., AIMS baby movement scale application in high-risk infants early intervention analysis, European	Study location: China

Study	Reason for Exclusion
review for medical and pharmacological sciences, 20, 3447-3451, 2016	
Wasik, Bh, Ramey, Ct, Bryant, Dm, Sparling, Jj, A longitudinal study of two early intervention strategies: project CARE, Child development, 61, 1682-1696, 1990	Population is not relevant to protocol - not infants requiring respiratory support
Watson, Julie, McGuire, William, Responsive versus scheduled feeding for preterm infants, Cochrane Database of Systematic Reviews, 2016	Systematic review: Intervention is not relevant to protocol. Included studies checked for relevance to protocol
Welch, M, Stark, R, Hofer, M, Andrews, H, Austin, J, Myers, M, Family Nurture Intervention: Safety and Feasibility of a Randomized Controlled Trial in the NICU, Pediatric Academic Societies Annual Meeting, 2013	Unavailable from the British Library
Welch, M. G., Firestein, M. R., Austin, J., Hane, A. A., Stark, R. I., Hofer, M. A., Garland, M., Glickstein, S. B., Brunelli, S. A., Ludwig, R. J., Myers, M. M., Family Nurture Intervention in the Neonatal Intensive Care Unit improves social-relatedness, attention, and neurodevelopment of preterm infants at 18 months in a randomized controlled trial, Journal of Child Psychology & Psychiatry & Allied Disciplines, 56, 1202-11, 2015	Intervention and outcomes are not relevant to protocol
Welch, M. G., Hofer, M. A., Stark, R. I., Andrews, H. F., Austin, J., Glickstein, S. B., Ludwig, R. J., Myers, M. M., F. N. I. Trial Group, Randomized controlled trial of Family Nurture Intervention in the NICU: assessments of length of stay, feasibility and safety, BMC Pediatrics, 13, 148, 2013	Intervention is not relevant to protocol
Welch, Mg Grieve Pg Stark Ri Fiedor Es Koukaz Ya Hofer Ma Johnson Jg Lorenz Jm Myers Mm, Efficacy of Family Nurture Intervention in the NICU (FNI-NICU): A Mid-Study Report of Neurobehavioral Effects on Pre-Term Infants and Mothers, Pediatric Academic Societies Annual Meeting, 2011	Unavailable from the British Library
Welch, Mg, Firestein, Mr, Austin, J, Hane, Aa, Stark, Ri, Hofer, Ma, Family Nurture Intervention in the Neonatal Intensive Care Unit improves social-relatedness, attention, and neurodevelopment of preterm infants at 18 months in a randomized controlled trial, Journal of child psychology and psychiatry, and allied disciplines, 2015	Duplicate reference
Welch, Mg, Hofer, Ma, Stark, Ri, Andrews, Hf, Austin, J, Glickstein, Sb, Ludwig, Rj, Myers, Mm, Afifi, L, Bechar, A, Beebe, B, Brunelli, Sa, Carnazza, Ke, Chang, Cy, Farrell, Pa, Fiedor, Es, Karim, Q, Kofman, S, Koukaz, Ya, McKiernan, Mt, Fifer, Wp, Sopterian, S, Bateman, Dv, Grieve, Pg, Lorenz, Jm, Polin, Ra, Sahni, R, Merle, Dp, Hane, Aa, Randomized controlled trial of Family Nurture Intervention in the NICU: Assessments of length of stay, feasibility and safety, BMC Pediatrics, 13, 2013	Duplicate reference
Welch, Mg, Stark, Ri, Brunelli, Sa, Austin, Jf, Fiedor, Es, Polin, Ra, Lorenz, Jm, Hofer, Ma, Myers, Mm, Family nurture intervention (FNI) in the NICU: Can we prevent transgenerational effects of adverse rearing in prematurely born infants?, Comprehensive Psychiatry, 54, E13, 2013	Conference abstract: no data are presented
Wen, Lm, Baur, La, Simpson, Jm, Rissel, C, Flood, Vm, Effectiveness of an early intervention on infant feeding practices and "tummy time": a randomized controlled trial,	Population is not relevant to protocol - maternal participation

Study	Reason for Exclusion
Archives of Pediatrics & Adolescent MedicineArch Pediatr Adolesc Med, 165, 701-707, 2011	
Wendland-Carro, J, Piccinini, Ca, Millar, Ws, The role of an early intervention on enhancing the quality of mother-infant interaction, Child development, 70, 713-721, 1999	Reported outcomes are not relevant to protocol
Westrup, B, Bohm, B, Lagercrantz, H, Stjernqvist, K, Preschool outcome in children born very prematurely and cared for according to NIDCAP, Pediatric Research, 54, 557, 2003	Conference abstract: insufficient detail of data presented
Westrup, B., Hellstrom-Westas, L., Stjernqvist, K., Lagercrantz, H., No indications of increased quiet sleep in infants receiving care based on the newborn individualized developmental care and assessment program (NIDCAP), Acta Paediatrica, 91, 318-22; discussion 262-3, 2002	Reported outcomes are not relevant to protocol
Whipple, J., The effect of parent training in music and multimodal stimulation on parent-neonate interactions in the neonatal intensive care unit, Journal of Music Therapy, 37, 250-268, 2000	Quasi RCT n=20
Whitelaw, A., Kangaroo baby care: just a nice experience or an important advance for preterm infants?, Pediatrics, 85, 604-5, 1990	Commentary, narrative review
White-Traut, R, Norr, Kf, Fabiyi, C, Rankin, Km, Li, Z, Liu, L, Mother-infant interaction improves with a developmental intervention for mother-preterm infant dyads, Infant Behavior & DevelopmentInfant behav, 36, 694-706, 2013	Population not relevant to protocol - Infants had to be clinically stable for enrolment (not receiving ventilator support or oxygen therapy via nasal cannula)
White-Traut, R, Rankin, Km, Pham, T, Li, Z, Liu, L, Preterm infants' orally directed behaviors and behavioral state responses to the integrated H-HOPE intervention, Infant Behavior & DevelopmentInfant behav, 37, 583-596, 2014	Population not relevant to protocol - Infants had to be clinically stable for enrolment (not receiving ventilator support or oxygen therapy via nasal cannula)
White-Traut, R. C., Nelson, M. N., Silvestri, J. M., Cunningham, N., Patel, M., Responses of preterm infants to unimodal and multimodal sensory intervention, Pediatr NursPediatric nursing, 23, 169-75, 193, 1997	Reported outcomes are not relevant to protocol
White-Traut, R. C., Nelson, M. N., Silvestri, J. M., Patel, M. K., Kilgallon, D., Patterns of physiologic and behavioral response of intermediate care preterm infants to intervention, Pediatric Nursing, 19, 625-9, 1993	Reported outcomes are not relevant to protocol
White-Traut, R. C., Nelson, M. N., Silvestri, J. M., Vasan, U., Littau, S., Meleedy-Rey, P., Gu, G., Patel, M., Effect of auditory, tactile, visual, and vestibular intervention on length of stay, alertness, and feeding progression in preterm infants, Dev Med Child NeurolDevelopmental medicine and child neurology, 44, 91-7, 2002	Population is not relevant to the protocol - over 66% had a CNS injury
White-Traut, Rc, Rankin, Km, Yoder, Jc, Liu, L, Vasa, R, Geraldo, V, Norr, Kf, Influence of H-HOPE intervention for premature infants on growth, feeding progression and length of stay during initial hospitalization, Journal of perinatology : official journal of the California Perinatal Association, 35, 636-41, 2015	Population not relevant to protocol - Infants had to be clinically stable for enrolment (not receiving ventilator support or oxygen therapy via nasal cannula)
Wielenga,J.M., Smit,B.J., Unk,L.K., How satisfied are parents supported by nurses with the NIDCAP model of care for their preterm infant?, Journal of Nursing Care Quality, 21, 41-48, 2006	Study design: Prospective cohort study with group recruitment during different time periods

Study	Reason for Exclusion
Wirth, L, Dorn, F, Wege, M, Zemlin, M, Lemmer, B, Gorbey, S, Timmesfeld, N, Maier, Rf, Effects of standardized acoustic stimulation in premature infants: a randomized controlled trial, Journal of Perinatology, 36, 486-492, 2016	Reported outcomes are not relevant to protocol
Wu, Y. C., Hsieh, W. S., Hsu, C. H., Chang, J. H., Chou, H. C., Hsu, H. C., Chiu, N. C., Lee, W. T., Chen, W. J., Ho, Y. W., Jeng, S. F., Intervention effects on emotion regulation in preterm infants with very low birth weight: A randomize controlled trial, Research in Developmental Disabilities, 48, 1-12, 2016	Study location: Taiwan
Yigit,S., Kerem,M., Livanelioglu,A., Oran,O., Erdem,G., Mutlu,A., Turanli,G., Tekinalp,G., Yurdakok,M., Early physiotherapy intervention in premature infants, Turkish Journal of Pediatrics, 44, 224-229, 2002	Partially randomised study, elements of intervention are not described
Yu, Yt, Hsieh, Ws, Hsu, Ch, Lin, Yj, Hsieh, S, Lu, L, Fan, Pc, Chen, Wj, Jeng, Sf, Short-term effect of a family-centered intervention program on the cortical auditory processing function in very low birth weight preterm infants, Physiotherapy (United Kingdom), 101, eS1708-eS1709, 2015	Study location: Taiwan
Zahr, L. K., Parker, S., Cole, J., Comparing the effects of neonatal intensive care unit intervention on premature infants at different weights, Journal of developmental and behavioral pediatrics : JDBP, 13, 165-172, 1992	Population not relevant to protocol - for inclusion infants needed to be medically stable defined as not requiring respiratory support or 1:1 care
Zelkowitz,P., Feeley,N., Shrier,I., Stremler,R., Westreich,R., Dunkley,D., Steele,R., Rosberger,Z., Lefebvre,F., Papageorgiou,A., The Cues and Care Trial: a randomized controlled trial of an intervention to reduce maternal anxiety and improve developmental outcomes in very low birthweight infants, BMC Pediatrics, 8, 38-, 2008	No data presented - Protocol for a randomised controlled trial
Zhang, X., Kurtz, M., Lee, S. Y., Liu, H., Early Intervention for Preterm Infants and Their Mothers: A Systematic Review, Journal of Perinatal & Neonatal Nursing, 18, 18, 2014	Systematic review - included studies checked for relevance to protocol
Zimmerman, E, Lahav, A, Effects of Maternal Voice and Heartbeat Sounds on Weight Gain Velocity and Head Circumference in Preterm Infants: A Randomized Controlled Trial, Pediatric Academic Societies Annual Meeting, 2013	Unavailable from the British Library
Zimmerman, E, Ringer, S, Norton, M, McMahon, E, Arnold, B, Insoft, R, Audio Technology for Delivering Maternal Voice and Biological Sounds to Very Low Birth Weight Infants While in the Incubator: Effects of Respiratory and Growth Outcomes, Pediatric Academic Societies Annual Meeting, 2012	Unavailable from the British Library
Zukowsky, K., Breast-fed low-birth-weight premature neonates: developmental assessment and nutritional intake in the first 6 months of life, Journal of Perinatal & Neonatal Nursing, 21, 242-9, 2007	No outcomes relevant to the protocol are presented

Economic studies

2 All economic studies were excluded at the initial title and abstract screening stage.

Excluded studies for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

Clinical studies

Study	Reason for Exclusion
Al Maghaireh, D. F., Abdullah, K. L., Chan, C. M., Piaw, C. Y., Al Kawafha, M. M., Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit, J Clin NursJournal of clinical nursing, 25, 2745-56, 2016	Population not relevant - infants did not require respiratory support
Alves Correa Neiva, Camila, de Oliveira GuimarÃ£es, Kaama, Nogueira do Vale, IanÃª, Valentim Carmona, Elenice, Opinion of mothers of hospitalized babies about nursing interventions: a descriptive study, Online Brazilian Journal of Nursing, 12, 844-853, 2013	Population not relevant - infants did not require respiratory support
Alves, E., Rodrigues, C., Fraga, S., Barros, H., Silva, S., Parents' views on factors that help or hinder breast milk supply in neonatal care units: systematic review, Archives of Disease in Childhood Fetal & Neonatal Edition, 98, F511-7, 2013	Population not relevant - infants did not require respiratory support
Arnold, L., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., Ayers, S., Parents' first moments with their very preterm babies: A qualitative study, BMJ OpenBMJ open, 3 (4) (no pagination), 2013	Population not relevant - infants did not require respiratory support
Arockiasamy,V., Holsti,L., Albersheim,S., Fathers' experiences in the neonatal intensive care unit: a search for control, Pediatrics, 121, e215-e222, 2008	Not specified if infants required respiratory support
Baia, I., Alves, E., Amorim, M., Fraga, S., Silva, S., Parental needs and stress in neonatal intensive care units: Effect of data collection period, Arquivos de Medicina, 29, 160-162, 2015	Study was not qualitative
Balbino, F., Yamanaka, C., Pettengill, M., The shared experience in a support group at a neonatal unit for hospitalized Newborn's parents, Pediatric Critical Care Medicine, 1), A58, 2011	Conference abstract
Ballantyne, M., Orava, T., Bernardo, S., McPherson, A. C., Church, P., Fehlings, D., Parents' early healthcare transition experiences with preterm and acutely ill infants: a scoping review, 30, 30, 2017	Population not relevant - infants did not require respiratory support
Bass, L. S., What do parents need when their infant is a patient in the NICU?, Neonatal NetwNeonatal network : NN, 10, 25-33, 1991	Full text unavailable
Baylis, Rebecca, Ewald, Uwe, Gradin, Maria, Nyqvist, Kerstin Hedberg, Rubertsson, Christine, Blomqvist, Ylva Thernstrom, First-time events between parents and preterm infants are affected by the designs and routines of neonatal intensive care units, Acta PaediatricaActa Paediatr, 103, 1045-1052, 2014	Not specified if infants required respiratory support
Beal, J. A., Quinn, M., The nurse practitioner role in the NICU as perceived by parents, MCN - American Journal of Maternal Child Nursing, 27, 183-188, 2002	Population not relevant - infants did not require respiratory support
Beck, S. A., Weis, J., Greisen, G., et al.,, Room for family-centered care - a qualitative evaluation of a neonatal intensive care unit remodeling project, Journal of Neonatal Nursing, 15, 88-89, 2009	Number of infants on respiratory support was not specified
Bennett,R., Sheridan,C., Mothers' perceptions of 'rooming-in' on a neonatal intensive care unit, Infant, 1, 171-174, 2005	Population not relevant - infants did not require respiratory support
Blackburn, A. C., Stories, ethics and the interpretation of meaning: bearing witness to mothers' stories of their neonatal intensive care unit experience, Ph.D., 305 p-305 p, 2009	Less than 2/3 of infants were on respiratory support

Study	Reason for Exclusion
Blomqvist, Y. T., Rubertsson, C., Kylberg, E., Joreskog, K., Nyqvist, K. H., Kangaroo mother care helps fathers of preterm infants gain confidence in the paternal role, Journal of Advanced Nursing, 68, 1988-1996, 2012	Population not relevant - infants did not require respiratory support
Blomqvist, Ylva Thernstrom, Frolund, Lovisa, Rubertsson, Christine, Nyqvist, Kerstin Hedberg, Provision of Kangaroo Mother Care: Supportive factors and barriers perceived by parents, Scandinavian journal of caring sciences, 27, 345-353, 2013	Population not relevant - infants did not require respiratory support
Blomqvist,Y.T., Nyqvist,K.H., Swedish mothers' experience of continuous Kangaroo Mother Care, Journal of Clinical Nursing, 20, 1472-1480, 2011	< 2/3 of study infants were on respiratory support
Bonet, M., Blondel, B., Forcella, E., Cuttini, M., Agostino, R., Draper, E., Zeitlin, J., Barriers and facilitators for breastfeeding very preterm infants: Management of mother's milk in neonatal units in England, France and Italy, Archives of Disease in Childhood: Fetal and Neonatal Edition, 96, Fa11, 2011	Conference abstract
Bonner, O., Beardsall, K., Crilly, N., Lasenby, J., 'There were more wires than him': The potential for wireless patient monitoring in neonatal intensive care, BMJ Innovations, 3, 12-18, 2017	Not specified if infants required respiratory support
Boss, R., Geller, G., Donohue, P., Arnold, R., Decision-making consensus in the NICU: What does parent-clinician collaboration actually look like?, Journal of Pain and Symptom Management, 49 (2), 361, 2015	Conference abstract
Boukydis, C. F. Z., Support services and peer support for parents of at-risk infants: an international perspective, Children's Health Care, 29, 129-145, 2000	Population not relevant - infants did not require respiratory support
Boukydis, C. F. Z., International Survey of Support for Parents of Premature and High-Risk Infants, 2000	Full text unavailable
Bower, K., Burnette, T., Lewis, D., et al.,, "I Had One Job and That Was To Make Milk": Mothers' Experiences Expressing Milk for Their Very-Low-Birth-Weight Infants, Journal of Human Lactation, 33, 188-194, 2017	Population not relevant - infants did not require respiratory support
Bracht,M., O'Leary,L., Lee,S.K., O'Brien,K., Implementing family-integrated care in the NICU: a parent education and support program, Advances in Neonatal Care, 13, 115-126, 2013	Population not relevant - infants did not require respiratory support
Brazier, L., Harper, K., Marrington, S., Hospital visiting costs: an exploratory study into travelling expenses incurred by parents with babies in a regional neonatal unit, Journal of Neonatal Nursing, 1, 29-31, 1995	Not specified if infants required respiratory support
Brelsford, Gina M., Doheny, Kim K., Religious and spiritual journeys: Brief reflections from mothers and fathers in a Neonatal Intensive Care Unit (NICU), Pastoral Psychology, 65, 79-87, 2016	Population not relevant - infants did not require respiratory support
Brett,J., Staniszewska,S., Newburn,M., Jones,N., Taylor,L., A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants, BMJ Open, 1, e000023-, 2011	Population not relevant - infants did not require respiratory support
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	Number of infants on respiratory support was not specified
Brinchmann, B. S., Vik, T., Parents' involvement in life- and-death decisions in neonatal intensive care: Norwegian attitudes, Newborn and Infant Nursing Reviews, 5, 77-81, 2005	Duplicate

Study	Reason for Exclusion
Broom, M., Davies, D., Smith, J., Abdel-Latif, M. E., Participating in clinical bedside rounds: The perspective of parents and staff members, Journal of Paediatrics and Child Health, 50, 72, 2014	Conference abstract
Broom, M., Mebberson, K., Zsuzsoka, K., Families' experiences in a two-cot nicu, Journal of Paediatrics and Child Health, 51, 13, 2015	Conference abstract
Bruns, D. A., Klein, S., An evaluation of family-centered care in a Level III NICU, Infants & Young Children: An Interdisciplinary Journal of Early Childhood Intervention, 18, 222-233, 2005	Population not relevant - infants did not require respiratory support
Buarque, V., Lima Mde, C., Scott, R. P., Vasconcelos, M. G., The influence of support groups on the family of risk newborns and on neonatal unit workers, Jornal de Pediatria, 82, 295-301, 2006	Study not in English
Caeymaex, L., Speranza, M., Vasilescu, C., Danan, C., Bourrat, M. M., Garel, M., Jousselme, C., Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their newborn in the NICU, PLoS ONE [Electronic Resource], 6, e28633, 2011	Population not relevant - infants did not require respiratory support
Caldeira, S., Hall, J., Spiritual leadership and spiritual care in neonatology, Journal of Nursing Management, 20, 1069-1075, 2012	Population not relevant - infants did not require respiratory support
Casper, C., Caeymaex, L., Dicky, O., Akrich, M., Reynaud, A., Bouvard, C., Evrard, A., Kuhn, P., Allen, A., Brandicourt, A., Duboz, M. A., Fichtner, C., Girard, L., Gonnaud, F., Haumont, D., Huppi, P., Isaia, S., Knezovic, N., Legouais, S., Mons, F., Pelofy, V., Picaud, J. C., Pierrat, V., Renesme, L., Sizun, J., Souet, G., Thiriez, G., Truffert, P., Zaoui, C., Zores, C., Parental perception of their involvement in the care of their children in French neonatal units, Archives de Pediatrie, 23, 974-982, 2016	Full text unavailable
Catlin, E. A., Guillemin, J. H., Thiel, M. M., Hammond, S., Wang, M. L., O'Donnell, J., Spiritual and religious components of patient care in the neonatal intensive care unit: Sacred themes in a secular setting, Journal of Perinatology, 21, 426-430, 2001	Population not relevant - participants were NICU staff
Chen, Y. C., Chang, M. Y., Chang, L. Y., Mu, P. F., Experiences of parents providing kangaroo care to a premature infant: A systematic review of the qualitative evidence protocol, JBI Database of Systematic Reviews and Implementation Reports, 13, 112-119, 2015	Population not relevant - infants did not require respiratory support
Cleveland, L. M., Parenting in the neonatal intensive care unit, JOGNN: Journal of Obstetric, Gynecologic and Neonatal Nursing, 37, 666-691, 2008	Systematic review; included studies reported individually
Coffman, S., Levitt, M. J., Deets, C., Personal and professional support for mothers of NICU and healthy newborns, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 20, 406-415, 1991	Quantitative survey method
Cooper,L.G., Gooding,J.S., Gallagher,J., Sternesky,L., Ledsky,R., Berns,S.D., Impact of a family-centered care initiative on NICU care, staff and families, Journal of Perinatology, 27, S32-S37, 2007	Quantitative survey method
Coppola,G., Cassibba,R., Bosco,A., Papagna,S., In search of social support in the NICU: Features, benefits and antecedents of parents' tendency to share with others the premature birth of their baby, Journal of Maternal-Fetal and Neonatal Medicine, 26, 1737-1741, 2013	Quantitative survey method
Cortezzo, D. E., Sanders, M. R., Brownell, E. A., Moss, K., End-of-Life Care in the Neonatal Intensive Care Unit: Experiences of Staff and Parents, American Journal of Perinatology, 32, 713-723, 2014	Not specified if infants required respiratory support
Couto, C. S., Tupinamba, M. C., Rangel, A. U., Frota, M. A., Martins, E. M., Nobre, C. S., Landim, A. L., Spectra of mothers of premature	Not specified if infants required respiratory support

Study	Reason for Exclusion
children about the educative circle of culture, Revista Da Escola de Enfermagem Da Usp. 48 Spec NoRev Esc Enferm USP, 2, 3-8, 2014	
Cox, C. L., Bialoskurski, M., Neonatal intensive care: communication and attachment, British Journal of Nursing, 10, 668-676, 2001	Not specified if infants required respiratory support
Craig, Jenene Woods, The Neonatal Intensive Care Unit (NICU): Self-efficacy of caregiving and the lived experience of parents post-NICU discharge, Dissertation Abstracts International: Section B: The Sciences and Engineering, 76, No Pagination Specified, 2016	Study assessed supports parents wanted in the home
Currie, E. R., Christian, B. J., Hinds, P. S., Perna, S. J., Robinson, C., Day, S., Meneses, K., Parent Perspectives of Neonatal Intensive Care at the End-of-Life, J Pediatr NursJournal of pediatric nursing, 31, 478-489, 2016	Not specified if infants required respiratory support
D'Agata, Amy L., McGrath, Jacqueline M., A Framework of Complex Adaptive Systems: Parents as partners in the neonatal intensive care unit, Advances in Nursing Science, 39, 244-256, 2016	Quantitative survey method
de Araujo, B. B. M., Rodrigues, Bmrd, Mothers' experiences and perspectives regarding their premature infant's stay at the Neonatal Intensive Care Unit, Revista Da Escola de Enfermagem Da UspRev Esc Enferm USP, 44, 865-872, 2010	Not specified if infants required respiratory support
de Oliveira Dornasbach, Jéssica, Barbosa de Freitas, Hilda Maria, Santini Costenaro, Regina Gema, Rangel, Rosiane Filipin, Zamberlan, Claudia, Ilha, Silomar, NEONATAL INTENSIVE CARE: FEELING OF PARENTS AFTER DISCHARGE OF THE CHILD, Journal of Nursing UFPE / Revista de Enfermagem UFPE, 8, 2660-2666, 2014	Not specified if infants required respiratory support
Dewlett, S., Polychronakis, T., Ng, G. Y. T., Look who's talking: How well are we communicating with parents in the neonatal unit? A patient survey, Intensive Care Medicine, 37, S419-S420, 2011	Conference abstract
Diaz, Z., Caires, S., Experiences of parents of infants admitted in unit neonatology: A perspective of parents and health professionals, Atencion Primaria, 45, 178, 2013	Conference abstract
Domanico, R., Davis, D. K., Coleman, F., Davis Jr, B. O., Documenting the NICU design dilemma: Parent and staff perceptions of open ward versus single family room units, Journal of Perinatology, 30, 343-351, 2010	Quantitative survey design
Duarte, E. D., de Sena, R. R., Dittz, E. D., Tavares, T. S., Lopes, A. F. C., Silva, P. M., THE ROLE OF THE FAMILY IN CARE DELIVERY TO HOSPITALIZED NEWBORNS: POSSIBILITIES AND CHALLENGES TOWARDS COMPREHENSIVE CARE, Texto & Contexto Enfermagem, 21, 870-878, 2012	Not specified if infants required respiratory support
Edell-Gustafsson, Ulla, Angelhoff, Charlotte, Johnsson, Ewa, Karlsson, Jenny, Morelius, Evalotte, Hindering and buffering factors for parental sleep in neonatal care. A phenomenographic study, J Clin NursJournal of clinical nursing, 24, 717-727, 2015	Less than 2/3 of infants were on respiratory support
Epstein,E.G., End-of-life experiences of parents, nurses and physicians in the newborn intensive care unit, -297, 2007	Full text unavailable
Fegran, L., Fagermoen, M. S., Helseth, S., Development of parent-nurse relationships in neonatal intensive care units--from closeness to detachment, Journal of Advanced Nursing, 64, 363-71, 2008	Not specified if infants required respiratory support
Fegran, L., Helseth, S., The parent-nurse relationship in the neonatal intensive care unit context - Closeness and emotional involvement, Scandinavian Journal of Caring Sciences, 23, 667-673, 2009	Less than 2/3 of the infants required respiratory support

Study	Reason for Exclusion
Fenwick, J., Barclay, L., Schmied, V., Interactions in neonatal nurseries: women's perceptions of nurses and nursing, Journal of Neonatal Nursing, 6, 197-203, 2000	Not specified if infants required respiratory support
Findlay, M. P., Parenting a hospitalized preterm infant: a phenomenological study, PH.D., 171 p-171 p, 1997	Full text unavailable
Flacking, R., Dykes, F., Creating a positive place and space in NICUs, The practising midwife, 17, 18-20, 2014	Full text unavailable
Foster, Christine, Monterosso, Leanne, The ventilator-dependent infant requiring palliative care in the neonatal intensive care unit: a literature review, Neonatal, Paediatric & Child Health Nursing, 15, 8-20, 2012	Full text unavailable
Foster, Mandie Jane, Whitehead, Lisa, Maybee, Patricia, Cullens, Victoria, The Parentsâ□™, Hospitalized Childâ□™s, and Health Care Providersâ□™ Perceptions and Experiences of Family Centered Care Within a Pediatric Critical Care Setting: A Metasynthesis of Qualitative Research, Journal of family nursing, 19, 431-468, 2013	Not specified if infants required respiratory support
Foster, V., Young, A., Reflecting on participatory methodologies: research with parents of babies requiring neonatal care, International Journal of Social Research Methodology, 18, 91-104, 2015	Literature review
Franck, L. S., McNulty, A., Alderdice, F., The Perinatal-Neonatal Care Journey for Parents of Preterm Infants: What Is Working and What Can Be Improved, Journal of Perinatal & Neonatal Nursing, 31, 244-255, 2017	Not specified if infants required respiratory support
Frank, D. I., Paredes, S. D., Curtin, J., Perceptions of parent and nurse relationships and attitudes of parental participation in caring for infants in the NICU, The Florida nurse, 45, 9-10, 1997	Full text unavailable
French, K. B., Care of Extremely Small Premature Infants in the Neonatal Intensive Care Unit: A Parent's Perspective, Clin PerinatolClinics in perinatology, 44, 275-282, 2017	Full text unavailable
Gardner, G., Barrett, T., Coonan, K., Cox, H., Roberson, B., Parent support programmes in neonatal intensive care: researching the issues, Neonatal, Paediatric & Child Health Nursing, 5, 20-25, 2002	Not specified if infants required respiratory support
Garne, K., Brodsgaard, A., Zachariassen, G., Clemensen, J., Telemedicine in Neonatal Home Care: Identifying Parental Needs Through Participatory Design, JMIR Res ProtocJMIR research protocols, 5, e100, 2016	Not specified if infants required respiratory support
Garten, L., Nazary, L., Metze, B., et al.,, Pilot study of experiences and needs of 111 fathers of very low birth weight infants in a neonatal intensive care unit, Journal of Perinatology, 33, 65-69, 2013	Not specified if infants required respiratory support
Gavey, J., Parental perceptions of neonatal care, Journal of Neonatal Nursing, 13, 199-206, 2007	Not specified if infants required respiratory support
Gibbs, D., Parenting occupations in the neonatal intensive care unit, Archives of Disease in Childhood: Fetal and Neonatal Edition, 96, Fa8, 2011	Conference abstract
Gibbs, D., Boshoff, K., Stanley, M., Becoming the parent of a preterm infant: a meta-ethnographic synthesis, British Journal of Occupational Therapy, 78, 475-487, 2015	Not specified if infants required respiratory support
Granrud, M. D., Ludvigsen, E., Andershed, B., Parents' experiences of their premature infants' transportation from a university hospital NICU to the NICU at two local hospitals, J Pediatr NursJournal of pediatric nursing, 29, e11-e18, 2014	Not specified if infants required respiratory support

Study	Reason for Exclusion
Hadian, Z. S., Sharif, F., Rakhshan, M., Pishva, N., Jahanpour, F., Lived experience of caregivers of family-centered care in the neonatal intensive care unit: "Evocation of being at home", Iran J PediatrIranian journal of pediatrics, 26 (5) (no pagination), 2016	Not specified if infants required respiratory support
Hall, E. O. C., Brinchmann, B. S., Mothers of preterm infants: experiences of space, tone and transfer in the neonatal care unit, Journal of Neonatal Nursing, 15, 129-136, 2009	Not specified if infants required respiratory support
Hall, S. L., Ryan, D. J., Beatty, J., et al.,, Recommendations for peer-to-peer support for NICU parents, Journal of Perinatology, 2015	Not specified if infants required respiratory support
Hasanpour, M., Sadeghi, N., Heidarzadeh, M., Parental needs in infant's end-of-life and bereavement in NICU: A qualitative study, Journal of Education & Health PromotionJ, 5, 19, 2016	Not specified if infants required respiratory support
Hawkes, G. A., Livingstone, V., Ryan, C. A., Dempsey, E. M., Perceptions of webcams in the neonatal intensive care unit: Here's looking at you kid!, American Journal of Perinatology, 30, 131-136, 2015	Not specified if infants required respiratory support
Herbst, A., Maree, C., Empowerment of parents in the neonatal intensive care unit by neonatal nurses, Health SA Gesondheid, 11, 3-13, 2006	Not specified if infants required respiratory support
Heydarpour, S., Keshavarz, Z., Bakhtiari, M., Factors affecting adaptation to the role of motherhood in mothers of preterm infants admitted to the neonatal intensive care unit: a qualitative study, Journal of advanced nursing, 73, 138-148, 2017	Not specified if infants required respiratory support
Hingley, S. R., Das Nair, R., Glazebrook, C., Fathers' experiences of interacting with their preterm infants, Developmental Medicine and Child Neurology, 54, 25-26, 2012	Conference abstract
Howes, C., Caring until the end: a systematic literature review exploring Paediatric Intensive Care Unit end-of-life care, Nursing in Critical Care, 20, 41-51, 2015	Proportion on respiratory support not specified
Huber, D. T., Parents' lived-experience with the admission of their newborn into a newborn intensive care unit: a phenomenological study, Ph.D., 196 p-196 p, 1998	Full text unavailable
Hurst, I., One size does not fit all: Parents' evaluations of a support program in a newborn intensive care nursery, Journal of Perinatal and Neonatal Nursing, 20, 252-261, 2006	Not specified if infants required respiratory support
Hurst, I., Mothers' experiences of having a hospitalized premature baby, PH.D., 330 p-330 p, 1996	Full text unavailable
Hurst, I., Carvajal, S., Boelter, M., Primary topics of discussion in a support group for parents of infants hospitalized in a neonatal intensive care nursery, Neonatal Network, 14, 72-72, 1995	Not specified if infants required respiratory support
Hynan, M. T., Hall, S. L., Psychosocial program standards for NICU parents, Journal of Perinatology, 35, S1-S4, 2015	Not specified if infants required respiratory support
Johnson, M. A. T., Parent education in the intensive care nursery, Ed.D., 129 p-129 p, 2000	Full text unavailable
Jones, L., Peters, K., Rowe, J., Sheeran, N., The Influence of Neonatal Nursery Design on Mothers' Interactions in the Nursery, J Pediatr NursJournal of pediatric nursing, 31, e301-e312, 2016	Not specified if infants required respiratory support
Jones, L., Taylor, T., Watson, B., Fenwick, J., Dordic, T., Negotiating Care in the Special Care Nursery: Parents' and Nurses' Perceptions of Nurse-Parent Communication, Journal of Pediatric Nursing, 30, e71-80, 2015	Not specified if infants required respiratory support

Study	Reason for Exclusion
Jones, L., Woodhouse, D., Rowe, J., Effective nurse parent communication: A study of parents' perceptions in the NICU environment, Patient Education and Counseling, 69, 206-212, 2007	Not specified if infants required respiratory support
Kearvell, H., Grant, J., Getting connected: how nurses can support mother/infant attachment in the neonatal intensive care unit, Australian Journal of Advanced Nursing, 27, 75-82, 2010	Full text unavailable
Kistareddy, V. R., Hauptfleisch, C., McGowan, J., Parental perception of neonatal care, Archives of Disease in Childhood, 100, A263-A264, 2015	Conference abstract
Kumaran, K., Reichert, A., Davies, D., Ellinger, M., Conway, L., Mayan, M., Alvadj-Korenic, T., Delivering palliative care in a neonatal intensive care unit, Paediatrics and Child Health (Canada), 19 (6), e56, 2014	Conference abstract
Lantz, B., Ottosson, C., Parental interaction with infants treated with medical technology, Scandinavian journal of caring sciences, 27, 597-607, 2013	Quantitative survey method
Lawhon, G., Facilitation of parenting the premature infant within the newborn intensive care unit, J Perinat Neonatal NursThe Journal of perinatal & neonatal nursing, 16, 71-82, 2002	Not specified if infants required respiratory support
Lee, S. K., O'Brien, K., Parents as primary caregivers in the neonatal intensive care unit, CmajCMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne, 186, 845-7, 2014	Literature review
Logan, R., Dormire, S., The Lived Experience of Fathering a Premature Infant in a Neonatal Intensive Care Unit, Advances in Neonatal Care, 17, E16-E16, 2017	Conference abstract
Logan, Rebecca Michelle, Providing Support for Fathers of Premature Infants in the NICU, JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing, 46, S44-S44, 2017	Full text unavailable
Lucas, R., Paquette, R., Briere, C. E., et al.,, Furthering our understanding of the needs of mothers who are pumping breast milk for infants in the NICU: an integrative review, Advances in Neonatal Care, 14, 241-252, 2014	Not specified if infants required respiratory support
Martine, L. G., Fonseca, L. M. M., Scochi, C. G. S., The participation of parents in the care of premature children in a neonatal unit: Meanings attributed by the health team, Revista latino-americana de enfermagem, 15, 239-246, 2007	Population not relevant - did not involve parents or carers
McCormick, M. C., Bernbaum, J. C., Eisenberg, J. M., et al.,, Costs incurred by parents of very low birth weight infants after the initial neonatal hospitalization, PediatricsPediatrics, 88, 533-541, 1991	Not specified if infants required respiratory support
McHaffie, H. E., Neonatal intensive care support systems, Nursing times, 87, 54-55, 1991	Full text unavailable
McHaffie, H. E., Social support in the neonatal intensive care unit, Journal of Advanced Nursing, 17, 279-287, 1992	Not specified if infants required respiratory support
McIntosh,J., Shute,J., The process of health visiting and its contribution to parental support in the Starting Well demonstration project, Health and Social Care in the Community, 15, 77-85, 2007	Quantitative survey method
McLoughlin, A., Hillier, V. F., Robinson, M. J., Parental costs of neonatal visiting, Archives of Disease in Childhood (Fetal and Neonatal Edition), 68, 597-599, 1993	Quantitative research design used
Miles,M.S., Carlson,J., Funk,S.G., Sources of support reported by mothers and fathers of infants hospitalized in a neonatal intensive care unit, Neonatal Network - Journal of Neonatal Nursing, 15, 45-52, 1996	Not all of the infants were preterm

Study	Reason for Exclusion
Miyagishima, S., Himuro, N., Kozuka, N., Mori, M., Tsutsumi, H., Family-centered care for preterm infants: Parent and physical therapist perceptions, Pediatrics International, 59, 698-703, 2017	Not specified if infants required respiratory support
Morris,H., Premature birth and online social support: the parents' perspective, -196, 2008	Study not available
Morris,Heidi, Bertram,Dale, Therapist utilization of online social support for parents of premature infants, Contemporary Family Therapy: An International Journal, 35, 583-598, 2013	Not specified if infants required respiratory support
Nelson, A. M., Bedford, P. J., Mothering a Preterm Infant Receiving NIDCAP Care in a Level III Newborn Intensive Care Unit, J Pediatr NursJournal of pediatric nursing, 31, e271-e282, 2016	Not specified if infants required respiratory support
Niela-Vilen, H., Axelin, A., Melender, H. L., et al.,, 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	Not specified if infants required respiratory support
Noergaard, B., Ammentorp, J., Fenger-Gron, J., Kofoed, P. E., Johannessen, H., Fathers' Needs and Masculinity Dilemmas in a Neonatal Intensive Care Unit in Denmark, Advances in Neonatal Care, 17, E13-E22, 2017	Not specified if infants required respiratory support
Nottage, S. L., Parents' use of nonmedical support services in the neonatal intensive care unit, Issues in Comprehensive Pediatric Nursing, 28, 2005	Not specified if infants required respiratory support
Nyqvist, K. H., Sjoden, P. O., Ewald, U., Mothers' advice about facilitating breastfeeding in a neonatal intensive care unit, Journal of human lactation : official journal of International Lactation Consultant Association, 10, 237-243, 1994	Less than 2/3 of the infants required respiratory support
Padden, T., Glenn, S., Maternal experiences of preterm birth and neonatal intensive care, Journal of Reproductive and Infant Psychology, 15, 121-139, 1997	Not specified if infants required respiratory support
Paredes, S. D., Frank, D. I., Nurse/parent role perceptions in care of neonatal intensive care unit infants: implications for the advanced practice nurse, Clinical excellence for nurse practitioners : the international journal of NPACE, 4, 294-301, 2000	Quantitative survey method
Parker, L., Mothers' experience of receiving counselling/psychotherapy on a neonatal intensive care unit (NICU), Journal of Neonatal Nursing, 17, 182-189, 2011	Not specified if infants required respiratory support
Peeler, A., Fulbrook, P., Kildea, S., The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: A phenomenological study, Journal of Child Health CareJ Child Health Care, 19, 216-228, 2015	Infants were not preterm
Pepper, D., Rempel, G., Austin, W., et al.,, More than information: a qualitative study of parents' perspectives on neonatal intensive care at the extremes of prematurity, Advances in Neonatal Care, 12, 303-309, 2012	Number of infants on respiratory support was not specified
Provenzi, L., Santoro, E., The lived experience of fathers of preterm infants in the Neonatal Intensive Care Unit: a systematic review of qualitative studies, J Clin NursJournal of clinical nursing, 24, 1784-1794, 2015	Not specified if infants required respiratory support
Prudhoe,C.M., Peters,D.L., Social support of parents and grandparents in the neonatal intensive care unit, Pediatric Nursing, 21, 140-146, 1995	Less than 2/3 of infants required respiratory support
Reid,S., Support for parents anticipating premature birth, Neonatal, Paediatric and Child Health Nursing, 1, 18-22, 1998	Quantitative survey method

Study	Reason for Exclusion
Reis, M. D., Rempel, G. R., Scott, S. D., Brady-Fryer, B. A., Van Aerde, J., Developing nurse/parent relationships in the NICU through negotiated partnership, JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing, 39, 675-683, 2010	Not specified if infants required respiratory support
Rhoads, S. J., Green, A., Gauss, C. H., Mitchell, A., Pate, B., Web Camera Use of Mothers and Fathers When Viewing Their Hospitalized Neonate, Advances in Neonatal Care, 15, 440-446, 2015	Not specified if infants required respiratory support
Roman,L.A., Lindsay,J.K., Boger,R.P., DeWys,M., Beaumont,E.J., Jones,A.S., Haas,B., Parent-to-parent support initiated in the neonatal intensive care unit, Research in Nursing and Health, 18, 385-394, 1995	Not specified if infants required respiratory support
Rosenbaum, J. L., Smith, J. R., Zollfrank, R., Neonatal end-of-life spiritual support care, Journal of Perinatal & Neonatal Nursing, 25, 61-9; quiz 70-1, 2011	Proportion of infants on respiratory support not specified
Rossman, B., Engstrom, J. L., Meier, P. P., Vonderheid, S. C., Norr, K. F., Hill, P. D., â□œtheyâ□™ve walked in my shoesâ□• : mothers of very low birth weight infants and their experiences with breastfeeding peer counselors in the neonatal intensive care unit, Journal of Human Lactation, 27, 14-24 11p, 2011	Not specified if infants required respiratory support
Rossman, B., Greene, M. M., Meier, P. P., The role of peer support in the development of maternal identity for "NICU Moms", Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 44, 3-16, 2015	Not specified if infants required respiratory support
Rowe,J., Jones,L., Facilitating transitions. Nursing support for parents during the transfer of preterm infants between neonatal nurseries, Journal of Clinical Nursing, 17, 782-789, 2008	Not specified if infants required respiratory support
Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., Ayers, S., Very Preterm Birth Qualitative Collaborative, Group, Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study, BMC PediatrBMC pediatrics, 14, 230, 2014	Not specified if infants required respiratory support
Russell, Judith Bornstein, The Building of a Trust Relationship between a Nurse and Parent in a Neonatal Intensive Care Unit, Ph.D., 171 p-171 p, 2011	Not specified if infants required respiratory support
Sadeghi, N., Hasanpour, M., Heidarzadeh, M., Information and communication needs of parents in infant end-of-life: A qualitative study, Iranian Red Crescent Medical Journal, 18 (6) (no pagination), 2016	Not specified if infants required respiratory support
Sawyer, A., Rabe, H., Abbott, J., Ayers, S., Gyte, G., Duley, L., Parents' satisfaction with care during the birth of their very preterm baby: A qualitative study, Archives of Disease in Childhood, 97, A488, 2012	Conference abstract
Servel, A. C., Rideau Batista Novais, A., Single-family rooms for neonatal intensive care units impacts on preterm newborns, families, and health-care staff. A systematic literature review, Archives de Pediatrie, 23, 921-926, 2016	Full text unavailable
Shahheidari, M., Homer, C., Impact of the Design of Neonatal Intensive Care Units on Neonates, Staff, and Families A Systematic Literature Review, Journal of Perinatal & Neonatal Nursing, 26, 260-266, 2012	Not specified if infants required respiratory support
Shelkowitz, E., Vessella, S. L., O'Reilly, P., Tucker, R., Lechner, B. E., Counseling for personal care options at neonatal end of life: a quantitative and qualitative parent survey, BMC Palliative Care, 14, 70, 2015	Not specified if infants required respiratory support
Silva, D., Silva, E., Vieira, N., Parents' experience during the hospitalization of their premature newborn, Journal of Maternal-Fetal and Neonatal Medicine, 27, 396-397, 2014	Conference abstract

Study	Reason for Exclusion
Simpson, C., Support for women feeding their premature babies, MIDIRS Study Day, 1992	Full text unavailable
Sisk, P., Quandt, S., Parson, N., et al.,, Breast milk expression and maintenance in mothers of very low birth weight infants: supports and barriers, Journal of Human Lactation, 26, 368-375, 2010	Not specified if infants required respiratory support
Song, C., Patel, R. M., Hunt, L., Gillaspy, S., Willeitner, A., The virtual nicu: Using social media tools to reduce stress and increase satisfaction in parents of very low birth weight infants, Journal of Investigative Medicine, 61 (2), 432-433, 2013	Conference abstract
Stacey, Sarah, Osborn, Mike, Salkovskis, Paul, Life is a rollercoasterâ□¦What helps parents cope with the Neonatal Intensive Care Unit (NICU)?, Journal of Neonatal Nursing, 21, 136-141, 2015	Not specified if infants required respiratory support
Stevens,E.E., Gazza,E., Pickler,R., Parental experience learning to feed their preterm infants, Advances in Neonatal Care, 14, 354-361, 2014	Infants on mechanical ventilation were excluded
Szlachetka, D. M., Family-focused briefs. Bridging the language barrier, Advances in Neonatal Care (Elsevier Science), 1, 57-57, 2001	Not specified if infants required respiratory support
Treherne, S. C., Feeley, N., Charbonneau, L., Axelin, A., Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU, 46, 737-747, 2017	Not specified in infants required respiratory support
Tsironi, Spyridoula, Bovaretos, Nikolaos, Tsoumakas, Konstantinos, Giannakopoulou, Margarita, Matziou, Vassiliki, Factors affecting parental satisfaction in the neonatal intensive care unit, Journal of Neonatal Nursing, 18, 183-192, 2012	Infants were not preterm neonates
Turner, M., Chur-Hansen, A., Winefield, H., Mothers' experiences of the NICU and a NICU support group programme, Journal of Reproductive and Infant Psychology, 33, 165-179, 2015	Not specified if infants required respiratory support
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	Not specified if infants required respiratory support
Twaddell, Jennifer W., Parent education needs of infants with complex life-threatening illnesses, Ph.D., 262 p-262 p, 2013	Less than 2/3 of infants required respiratory support
Van De Vijver, M., Bertaud, S., Nailor, S., Marais, G., Baby diaries: A tool to improve parental communication in the neonatal unit, Archives of Disease in Childhood, 99, A81-A82, 2014	Conference abstract
van der Pal, S. M., Maguire, C. M., le Cessie, S., et al.,, Parental experiences during the first period at the neonatal unit after two developmental care interventions, Acta PaediatricaActa Paediatr, 96, 1611-1616, 2007	Not specified if infants required respiratory support
Vasquez, V., Cong, X., Dejong, A., Maternal and paternal knowledge and perceptions regarding infant pain in the NICU, Neonatal Network: the Journal of Neonatal Nursing, 34, 337-344, 2015	Quantitative survey design of non-preterm infants
Vazquez, V., Cong, X., Parenting the NICU infant: A meta-ethnographic synthesis, International Journal of Nursing Sciences, 1, 281-290, 2014	Not specified if infants required respiratory support
Verbiest, Sarah, McClain, Erin, Stuebe, Alison, Menard, M., Postpartum health services requested by mothers with newborns receiving intensive care, Maternal and child health journal, 20, S125-S131, 2016	Focus was on supports for the mothers' health
Voos, K. C., Ross, G., Ward, M. J., Yohay, A. L., Osorio, S. N., Perlman, J. M., Effects of implementing family-centered rounds (FCRs)	Not specified if infants required respiratory support

Study	Reason for Exclusion
in a neonatal intensive care unit (NICU), Journal of Maternal-Fetal and Neonatal Medicine, 24, 1-4, 2011	
Ward, F. R., Parents and professionals in the NICU: communication within the context of ethical decision making--an integrative review, Neonatal NetwNeonatal network : NN, 24, 25-33, 2005	Not specified if infants required respiratory support
Ward, K., Perceived needs of parents of critically ill infants in a neonatal intensive care unit (NICU), Pediatric nursing, 27, 281-286, 2001	Quantitative study method
Weimers, L., Kristin Svensson, K., Dumas, L., et al.,, Hands-on approach during breastfeeding support in a neonatal intensive care unit: a qualitative study of Swedish mothers' experiences, International Breastfeeding JournalInt Breastfeed J, 1, 11, 2006	Not specified if infants required respiratory support

Economic studies

All economic studies were excluded at the initial title and abstract screening stage.

Excluded studies for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

Clinical studies

Study	Reason for Exclusion
Aliabadi, F., Kamali, M., Borimnejad, L., Rassafiani, M., Rasti, M., Shafaroodi, N., Rafii, F., Askari Kachoosangi, R., Parental self-support: A study of parents' confront strategy when giving birth to premature infants, Medical Journal of the Islamic Republic of IranMed J Islam Repub Iran, 28, 82, 2014	Infants did not require respiratory support
Alur, P., Cirelli, J., Goodstein, M., Bell, T., Liss, J., Audiovisual Presentations on a Handheld PC are Preferred As an Educational Tool by NICU Parents, Applied Clinical InformaticsAppl Clin Inform, 1, 142-8, 2010	Not specified if infants required respiratory support
Amorim, M., Alves, E., Barros, H., Silva, S., Parental roles and needs in neonatal intensive care: a review of Portuguese guidelines, Ciencia & Saude Coletiva, 21, 2583-2594, 2016	Not English
Arnold, L., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., Ayers, S., Very Preterm Birth Qualitative, Col, Parents' first moments with their very preterm babies: a qualitative study, BMJ OpenBMJ open, 3, 2013	Infants did not require respiratory support
Axelin, A., Lehtonen, L., Pelander, T., et al.,, Mothers' different styles of involvement in preterm infant pain care, JOGNN: Journal of Obstetric, Gynecologic and Neonatal Nursing, 39, 415-424, 2010	Less than 2/3 on respiratory support
Ballantyne, M., Orava, T., Bernardo, S., McPherson, A. C., Church, P., Fehlings, D., Parents' early healthcare transition experiences with preterm and acutely ill infants: a scoping review, 30, 30, 2017	Infants did not require respiratory support

Study	Reason for Exclusion
Bass, L. S., What do parents need when their infant is a patient in the NICU?, Neonatal NetwNeonatal network : NN, 10, 25-33, 1991	Full text unavailable
Bracht,M., O'Leary,L., Lee,S.K., O'Brien,K., Implementing family-integrated care in the NICU: a parent education and support program, Advances in Neonatal Care, 13, 115-126, 2013	Infants did not require respiratory support
Branchett, K., Stretton, J., Neonatal palliative and end of life care: What parents want from professionals, Journal of Neonatal Nursing, 18, 40-44, 2012	Did not specify if infants required respiratory support
Brazy, J. E., Anderson, B. M. H., Becker, P. T., et al.,, How parents of premature infants gather information and obtain support, Neonatal Network: the Journal of Neonatal Nursing, 20, 41-48, 2001	Not specified if infants required respiratory support
Brett,J., Staniszewska,S., Newburn,M., Jones,N., Taylor,L., A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants, BMJ Open, 1, e000023-, 2011	Did not specify if infants required respiratory support
Brodsgaard, A., Helth, T., Andersen, B. L., Petersen, M., Rallying the Troops: How Sharing Knowledge With Grandparents Supports the Family of the Preterm Infant in Neonatal Intensive Care Unit, Advances in Neonatal Care, 17, E1-E10, 2017	Did not specify if infants required respiratory support
Broom, M., Davies, D., Smith, J., Abdel-Latif, M. E., Participating in clinical bedside rounds: The perspective of parents and staff members, Journal of Paediatrics and Child Health, 50, 72, 2014	Conference abstract
Broom, M., Mebberson, K., Zsuzsoka, K., Families' experiences in a two-cot nicu, Journal of Paediatrics and Child Health, 51, 13, 2015	Conference abstract
Casper, C., Caeymaex, L., Dicky, O., Akrich, M., Reynaud, A., Bouvard, C., Evrard, A., Kuhn, P., Allen, A., Brandicourt, A., Duboz, M. A., Fichtner, C., Girard, L., Gonnaud, F., Haumont, D., Huppi, P., Isaia, S., Knezovic, N., Legouais, S., Mons, F., Pelofy, V., Picaud, J. C., Pierrat, V., Renesme, L., Sizun, J., Souet, G., Thiriez, G., Truffert, P., Zaoui, C., Zores, C., Parental perception of their involvement in the care of their children in French neonatal units, Archives de Pediatrie, 23, 974-982, 2016	Full text unavailable
Cescutti-Butler, L., Galvin, K., Parents' perceptions of staff competency in a neonatal intensive care unit, J Clin NursJournal of clinical nursing, 12, 752-761, 2003	Did not pertain to information and formats parents preferred
Chiodi, L. C., Aredes, N. D. A., Scochi, C. G. S., Fonseca, L. M. M., Health education and the family of the premature baby: an integrative	Did not specify if infants required respiratory support

Study	Reason for Exclusion
review, Acta Paulista De Enfermagem, 25, 969-974, 2012	
Chivers, S., Warr, L., Francis, S., Mohinuddin, S., Information needs of parents with babies on neonatal units, Archives of Disease in Childhood, 101, A253, 2016	Conference abstract
Choi, J., Bakken, S., Web-based education for low-literate parents in Neonatal Intensive Care Unit: Development of a website and heuristic evaluation and usability testing, International Journal of Medical Informatics, 79, 565-575, 2010	Did not specify if infants required respiratory support
Choi, J., Starren, J. B., Bakken, S., Web-based educational resources for low literacy families in the NICU, Amia .., Annual Symposium proceedings / AMIA Symposium. AMIA Symposium., 922, 2005	Participating in clinical bedside rounds: The perspective of parents and staff members
Clark, David A., Ensher, Gail L., Born too early, 57-71, 2011	Full text unavailable
Cleveland, L. M., Parenting in the neonatal intensive care unit, JOGNN: Journal of Obstetric, Gynecologic and Neonatal Nursing, 37, 666-691, 2008	Systematic review; individual studies did not pertain to preterm infants requiring respiratory support
Coppola,G., Cassibba,R., Bosco,A., Papagna,S., In search of social support in the NICU: Features, benefits and antecedents of parents' tendency to share with others the premature birth of their baby, Journal of Maternal-Fetal and Neonatal Medicine, 26, 1737-1741, 2013	Quantitative design
Currie, E. R., Christian, B. J., Hinds, P. S., Perna, S. J., Robinson, C., Day, S., Meneses, K., Parent Perspectives of Neonatal Intensive Care at the End-of-Life, J Pediatr NursJournal of pediatric nursing, 31, 478-489, 2016	Did not specify if infants required respiratory support
De Rouck, S., Leys, M., Illness trajectory and Internet as a health information and communication channel used by parents of infants admitted to a neonatal intensive care unit, Journal of Advanced Nursing, 69, 1489-99, 2013	Did not specify if infants required respiratory support
Deeney, K., Lohan, M., Spence, D., Parkes, J., Experiences of fathering a baby admitted to neonatal intensive care: A critical gender analysis, Social Science and Medicine, 75, 1106-1113, 2012	Did not specify if infants required respiratory support
Dhillon, A. S., Albersheim, S. G., Alsaad, S., Pargass, N. S., Zupancic, J. A. F., Internet use and perceptions of information reliability by parents in a neonatal intensive care unit, Journal of Perinatology, 23, 420-424, 2003	Quantitative design
Diaz, Z., Caires, S., Experiences of parents of infants admitted in unit neonatology: A perspective of parents and health professionals, Atencion Primaria, 45, 178, 2013	Conference abstract

Study	Reason for Exclusion
Doron,Mia Wechsler, Trenti-Paroli,Emma, Linden,Dana Wechsler, Supporting parents in the NICU: A new app from the US, 'Mypreemie': A tool to provide parents of premature babies with support, empowerment, education and participation in their infant's care, Journal of Neonatal Nursing, 19, 303-307, 2013	Not specified if infants required respiratory support
Dzubaty, Dolores R., Supporting neonatal intensive care unit parents through social media, J Perinat Neonatal NursThe Journal of perinatal & neonatal nursing, 30, 214-217, 2016	Not specified if infants required respiratory support
Epstein, E. G., Arechiga, J., Dancy, M., et al.,, Integrative Review of Technology to Support Communication With Parents of Infants in the NICU, JOGNN: Journal of Obstetric, Gynecologic and Neonatal Nursing, 46, 357-366, 2017	Did not specify if infants required respiratory support
Epstein, E. G., Miles, A., Rovnyak, V., Baernholdt, M., Parents' Perceptions of Continuity of Care in the Neonatal Intensive Care Unit Pilot Testing an Instrument and Implications for the Nurse-Parent Relationship, Journal of Perinatal & Neonatal NursingJ Perinat Neonatal Nurs, 27, 168-175, 2013	Did not specify if infants required respiratory support
Epstein, Elizabeth Gingell, Sherman, Jessica, Blackman, Amy, Sinkin, Robert A., Testing the feasibility of Skype and FaceTime updates with parents in the neonatal intensive care unit, American Journal of Critical Care, 24, 290-296, 2015	Quantitative design
Eriksson, H., Salzmann-Erikson, M., Supporting a caring fatherhood in cyberspace - an analysis of communication about caring within an online forum for fathers, Scandinavian Journal of Caring Sciences, 27, 63-69, 2013	Did not specify if infants required respiratory support
Feeley, N., Sherrard, K., Waitzer, E., Boisvert, L., The father at the bedside: Patterns of involvement in the NICU, Journal of Perinatal and Neonatal Nursing, 27, 72-80, 2013	Duplicate study
Fegran, L., Fagermoen, M. S., Helseth, S., Development of parent-nurse relationships in neonatal intensive care units--from closeness to detachment, Journal of Advanced Nursing, 64, 363-71, 2008	Did not specify if infants required respiratory support
Fegran, Liv, Helseth, Solvi, The parent nurse relationship in the neonatal intensive care unit context - closeness and emotional involvement, Scandinavian Journal of Caring Sciences, 23, 667-673, 2009	Did not specify if infants required respiratory support
Fenwick, J., Barclay, L., Schmied, V., 'Chatting': an important clinical tool in facilitating mothering in neonatal nurseries, Journal of advanced nursing, 33, 583-593, 2001	Did not specify if infants required respiratory support
Fenwick, J., Barclay, L., Schmied, V., Struggling to mother: a consequence of inhibitive nursing	Did not specify if infants required respiratory support

Study	Reason for Exclusion
interactions in the neonatal nursery, J Perinat Neonatal NursThe Journal of perinatal & neonatal nursing, 15, 49-64, 2001	
Fenwick, J., Barclay, L., Schmied, V., Learning and playing the game: women's experiences of mothering in the level II nursery, Journal of Neonatal Nursing, 8, 58-64, 2002	Did not specify if infants required respiratory support
Ferecini, G. M., Fonseca, L. M. M., Leite, A. M., Dare, M. F., Assis, C. S., Scochi, C. G. S., Perceptions of mothers of premature babies regarding their experience with a health educational program, Acta Paulista De Enfermagem, 22, 250-256, 2009	Not specified if infants required respiratory support
Flacking, R., Thomson, G., Axelin, A., Pathways to emotional closeness in neonatal units - a cross-national qualitative study, BMC Pregnancy and Childbirth, 16 (1) (no pagination), 2016	Did not pertain to the information and format that parents want
Frank, D. I., Paredes, S. D., Curtin, J., Perceptions of parent and nurse relationships and attitudes of parental participation in caring for infants in the NICU, The Florida nurse, 45, 9-10, 1997	Full text unavailable
Frisman, Gunilla H., Eriksson, Carrie, Pernehed, Sara, Morelius, Evalotte, 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	Did not specify if infants required respiratory support
Gabbert,T.I., Metze,B., Buhrer,C., Garten,L., Use of social networking sites by parents of very low birth weight infants: Experiences and the potential of a dedicated site, European Journal of Pediatrics, 172, 1671-1677, 2013	Not specified if infants required respiratory support
Gale, G., Franck, L. S., Kools, S., Lynch, M., Parents' perceptions of their infant's pain experience in the NICU, Int J Nurs Stud, 41, 51-8, 2004	Did not specify if infants required respiratory support
Gale, G., Franck, L., Lund, C., Skin-to-skin (kangaroo) holding of the intubated premature infant, Neonatal Network, 12, 49-57, 1993	Did not pertain to the information and format parents want
Gibbs, Deanna, Boshoff, Kobie, Lane, Alison, Understanding parenting occupations in neonatal intensive care: application of the Person-Environment-Occupation Model, The British Journal of Occupational Therapy, 73, 55-63, 2010	Not a qualitative design
Globus, O., Leibovitch, L., Maayan-Metzger, A., et al.,, The use of short message services (SMS) to provide medical updating to parents in the NICU, Journal of Perinatology, 36, 739-743, 2016	Not specified if infants required respiratory support
Hadian, Z. S., Sharif, F., Rakhshan, M., Pishva, N., Jahanpour, F., Lived experience of caregivers of family-centered care in the neonatal intensive care unit: "Evocation of being	Did not specify if infants required respiratory support

Study	Reason for Exclusion
at home", Iran J PediatrIranian journal of pediatrics, 26 (5) (no pagination), 2016	
Hall, S. L., Ryan, D. J., Beatty, J., Grubbs, L., Recommendations for peer-to-peer support for NICU parents, Journal of Perinatology, 35, S9-S13, 2015	Did not specify if infants required respiratory support
Harvey, M. E., Nongena, P., Gonzalez-Cinca, N., 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	Did not specify if infants required respiratory support
Hawkes, G. A., Livingstone, V., Ryan, C. A., Dempsey, E. M., Perceptions of webcams in the neonatal intensive care unit: Here's looking at you kid!, American Journal of Perinatology, 30, 131-136, 2015	Quantitative design
Hayes, G. R., Cheng, K. G., Hirano, S. H., Tang, K. P., Nagel, M. S., Baker, D. E., Estrellita: A Mobile Capture and Access Tool for the Support of Preterm Infants and Their Caregivers, Acm Transactions on Computer-Human Interaction, 21, 2014	Infants were at home, not in NICU
Heermann, J. A., Wilson, M. E., Wilhelm, P. A., Mothers in the NICU: outsider to partner, Pediatric Nursing, 31, 176-81, 2005	Did not specify how many infants were on respiratory support
Hendriks, M. J., Abraham, A., End-of-Life Decision Making for Parents of Extremely Preterm Infants, 46, 727-736, 2017	Did not specify if infants required respiratory support
Hingley, S. R., Das Nair, R., Glazebrook, C., Fathers' experiences of interacting with their preterm infants, Developmental Medicine and Child Neurology, 54, 25-26, 2012	Conference abstract
Holbrook, S., Howlett, A., Hicks, M., Buddhavarapu, S., Hart, K., Boulton, J., Parent reports of stressful experiences in a shared room versus a single family room nicu, Paediatrics and Child Health (Canada), 20 (5), e59, 2015	Conference abstract
Holman, K., Di Giulio, N., Parent education in the liverpool neonatal intensive care unit: The occupational therapy and physiotherapy perspective, Journal of Paediatrics and Child Health, 48, 83-84, 2012	Conference abstract
Hughes, M., McCollum, J., Sheftel, D., Sanchez, G., How parents cope with the experience of neonatal intensive care, Children's health care : journal of the Association for the Care of Children's Health, 23, 1-14, 1994	Did not specify if infants required respiratory support
Hurst, I., One size does not fit all - Parents' evaluations of a support program in a newborn intensive care nursery, Journal of Perinatal & Neonatal NursingJ Perinat Neonatal Nurs, 20, 252-261, 2006	Did not specify if infants required respiratory support

Study	Reason for Exclusion
Hurst, I., Vigilant watching over: mothers' actions to safeguard their premature babies in the newborn intensive care nursery, The Journal of perinatal & neonatal nursing, 15, 39-57, 2001	Did not specify how many infants required respiratory support
Hurst, I., Carvajal, S., Boelter, M., Primary topics of discussion in a support group for parents of infants hospitalized in a neonatal intensive care nursery, Neonatal Network, 14, 72-72, 1995	Conference abstract
Hwang, Sunah, Rybin, Denis, Heeren, Timothy, Colson, Eve, Corwin, Michael, Trust in Sources of Advice about Infant Care Practices: The SAFE Study, Maternal & Child Health JournalMatern Child Health J, 20, 1956-1964, 2016	Did not specify if infants required respiratory support
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	Did not specify if infants required respiratory support
Ikonen, R., Paavilainen, E., Kaunonen, M., Trying to Live With Pumping: Expressing Milk for Preterm or Small for Gestational Age Infants, Mcn, The American journal of maternal child nursing. 41, 110-115, 2016	Did not specify if infants required respiratory support
Jackson, K., Ternestedt, B. M., Schollin, J., From alienation to familiarity: experiences of mothers and fathers of preterm infants, Journal of Advanced Nursing, 43, 120-9, 2003	Does not pertain to the information and format that parents value
Jones, L., Woodhouse, D., Rowe, J., Effective nurse parent communication: A study of parents' perceptions in the NICU environment, Patient Education and Counseling, 69, 206-212, 2007	Infants requiring mechanical ventilation were excluded
Kadivar, M., Seyedfatemi, N., Mokhlesabadi Farahani, T., Mehran, A., Pridham, K. F., Effectiveness of an internet-based education on maternal satisfaction in NICUs, Patient Education and Counseling, 100, 943-949, 2017	Quantitative design
Kantrowitz-Gordon, I., Altman, M. R., Vandermause, R., Prolonged Distress of Parents After Early Preterm Birth, J Obstet Gynecol Neonatal NursJournal of obstetric, gynecologic, and neonatal nursing : JOGNN, 45, 196-209, 2016	Did not specify how many infants required respiratory support
Kantrowitz-Gordon, Ira, Distress after preterm birth: A discourse analysis of parents' accounts and photographs, Dissertation Abstracts International: Section B: The Sciences and Engineering, 75, No Pagination Specified, 2014	Less than 2/3 of infants required respiratory support
Kerr, S., King, C., Hogg, R., et al.,, Transition to parenthood in the neonatal care unit: a qualitative study and conceptual model designed to illuminate parent and professional views of	Did not specify if infants required respiratory support

Study	Reason for Exclusion
the impact of webcam technology, BMC PediatrBMC pediatrics, 2017	
Kim, H. N., Wyatt, T. H., Li, X., Gaylord, M., Use of Social Media by Fathers of Premature Infants, J Perinat Neonatal NursThe Journal of perinatal & neonatal nursing, 30, 359-366, 2016	Did not specify if infants required respiratory support
King, C., Kerr, S., Hogg, R., McPherson, K. E., Hanley, J., Brierton, M., Ainsworth, S., Evaluation of a new e-health intervention in neonatal care: Perspectives of parents and health professionals, Archives of Disease in Childhood, 101, A95, 2016	Conference abstract
Koh, Tieh Hee Hai Guan, Smartphones improve communication with parents in NICU, The Lancet, 381, 535-536, 2013	Conference abstract
Kowalski,W.J., Leef,K.H., Mackley,A., Spear,M.L., Paul,D.A., Communicating with parents of premature infants: who is the informant?, Journal of Perinatology, 26, 44-48, 2006	Quantitative study design
Lantz, Bjorn, Ottosson, Cornelia, Parental interaction with infants treated with medical technology, Scandinavian Journal of Caring Sciences, 27, 597-607, 2013	Quantitative design
Lasiuk,G.C., Comeau,T., Newburn-Cook,C., Unexpected: an interpretive description of parental traumas' associated with preterm birth, BMC Pregnancy and Childbirth, 13 Suppl 1, S13-, 2013	Did not specify if infants required respiratory support
Lee, J. Y., Du, Y. L. E., Coki, O., Flynn, J. T., Starren, J., Chiang, M. F., Parental perceptions toward digital imaging and telemedicine for retinopathy of prematurity management, Graefes Archive for Clinical and Experimental Ophthalmology, 248, 141-147, 2010	Did not specify if infants required respiratory support
Lee, S. Y., Weiss, S. J., When east meets west: Intensive care unit experiences among first-generation Chinese American parents, Journal of Nursing Scholarship, 41, 268-275, 2009	Did not specify if infants required respiratory support
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	Did not specify if infants required respiratory support
Lerner, Claire, Ciervo, Lynette, Parlakian, Rebecca, Little Kids, Big Questions: Using Technology to Inform and Support Parents and Professionals, Zero to Three, 32, 4-5, 2012	Children were not preterm; quantitative design
Lessen, R., Crivelli-Kovach, A., Prediction of initiation and duration of breast-feeding for neonates admitted to the neonatal intensive care unit, Journal of Perinatal and Neonatal Nursing, 21, 256-266, 2007	Did not specify if infants required respiratory support
Lindberg, B., Access to videoconferencing in providing support to parents of preterm infants:	Did not specify if infants required respiratory support

Study	Reason for Exclusion
Ascertaining parental views, The Journal of Neonatal Nursing, 19, 259-265, 2013	
Lindberg, B., Axelsson, K., Ohrling, K., Adjusting to being a father to an infant born prematurely: Experiences from Swedish fathers, Scandinavian Journal of Caring Sciences, 22, 79-85, 2008	Did not specify if infants required respiratory support
Lindberg, B., Ohrling, K., Experiences of having a prematurely born infant from the perspective of mothers in northern Sweden, International journal of circumpolar health, 67, 461-471, 2008	Did not specify if infants required respiratory support
Lindberg, Birgitta, Axelsson, Karin, Ohrling, Kerstin, The birth of premature infants: Experiences from the fathers' perspective, Journal of Neonatal Nursing, 13, 142-149, 2007	Did not specify if infants required respiratory support
Loo, K. K., Espinosa, M., Tyler, R., Howard, J., Using knowledge to cope with stress in the NICU: how parents integrate learning to read the physiologic and behavioral cues of the infant, Neonatal NetwNeonatal network : NN, 22, 31-37, 2003	Not a qualitative design
Lopes, P., Franca, A., Andrade, L., To touch my child: The experience of mothers in a NICU, Journal of Maternal-Fetal and Neonatal Medicine, 27, 395, 2014	Conference abstract
Lucas, R., Paquette, R., Briere, C. E., et al.,, Furthering our understanding of the needs of mothers who are pumping breast milk for infants in the NICU: an integrative review, Advances in Neonatal Care, 14, 241-252, 2014	Population was not parents of preterm infants
Lyndon, A., Wisner, K., Holschuh, C., Fagan, K. M., Franck, L. S., Parents' Perspectives on Navigating the Work of Speaking Up in the NICU, 46, 716-726, 2017	Less than half the infants were premature
MacDonald,Margaret, Mothers of pre-term infants in neonate intensive care, Early Child Development and Care, 177, 821-838, 2007	Did not pertain to the information and formats parents value
Macdonell, Kristy, Omrin, Danielle, Pytlik, Kasia, Pezzullo, Sam, Bracht, Marianne, Diambomba, Yenge, An effective communication initiative: Using parents' experiences to improve the delivery of difficult news in the NICU, Journal of Neonatal Nursing, 21, 142-149, 2015	Did not interview parents
Macdonell,K., Christie,K., Robson,K., Pytlik,K., Lee,S.K., O'Brien,K., Implementing family-integrated care in the NICU: engaging veteran parents in program design and delivery, Advances in Neonatal Care, 13, 262-269, 2013	Did not specify how many infants required respiratory support
Macnab, A. J., Beckett, L. Y., Park, C. C., et al.,, Journal writing as a social support strategy for parents of premature infants: a pilot study, Patient Education and Counseling, 33, 149-159, 1998	Did not specify how many infants required respiratory support
Mannix,T.G., French,J., Parental support in the NICU: A systematic review of the evidence,	Conference abstract

Study	Reason for Exclusion
Journal of Paediatrics and Child Health, 50, 95-, 2014	
Martel, M. J., Milette, I., Bell, L., Tribble, D. S., Payot, A., Establishment of the Relationship Between Fathers and Premature Infants in Neonatal Units, Advances in Neonatal Care, 16, 390-398, 2016	Did not specify how many infants required respiratory support
Maypole, J., Trozzi, M., Augustyn, M., Prematurity and Parental Expectations: Too Early and Now Too Much, Journal of Developmental and Behavioral Pediatrics, 32, 341-343, 2011	Did not specify how many infants required respiratory support
McHaffie, H. E., Social support in the neonatal intensive care unit, Journal of Advanced Nursing, 17, 279-287, 1992	Quantitative design
Mckinnon,Kathleen Marie, Sources of stress and support among mothers of very low birth weight infants, Dissertation Abstracts International Section A: Humanities and Social Sciences, 58, 2161-, 1997	Quantitative design
Meyer, E. C., Brodsky, D., Hansen, A. R., Lamiani, G., Sellers, D. E., Browning, D. M., An interdisciplinary, family-focused approach to relational learning in neonatal intensive care, Journal of Perinatology, 31, 212-219, 2011	Did not specify how many infants required respiratory support
Miles,M.S., Carlson,J., Funk,S.G., Sources of support reported by mothers and fathers of infants hospitalized in a neonatal intensive care unit, Neonatal Network - Journal of Neonatal Nursing, 15, 45-52, 1996	Did not specify if infants required respiratory support
Miles,M.S., Funk,S.G., Kasper,M.A., The stress response of mothers and fathers of preterm infants, Research in Nursing and Health, 15, 261-269, 1992	Less than 2/3 required respiratory support
Miracle, D. J., Meier, P. P., Bennett, P. A., Mothers' decisions to change from formula to mothers' milk for very-low-birth-weight infants, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 33, 692-703, 2004	Did not specify how many infants required respiratory support
Miyagishima, S., Himuro, N., Kozuka, N., Mori, M., Tsutsumi, H., Family-centered care for preterm infants: Parent and physical therapist perceptions, Pediatrics International, 59, 698-703, 2017	Did not specify how many infants required respiratory support
Mok,E., Leung,S.F., Nurses as providers of support for mothers of premature infants, Journal of Clinical Nursing, 15, 726-734, 2006	Quantitative design
Morey, Jo Ann, Gregory, Katherine, Nurse-led education mitigates maternal stress and enhances knowledge in the NICU, MCN: The American Journal of Maternal/Child Nursing, 37, 182-191, 2012	Quantitative design
Morris, Heidi, Premature birth and online social support: The parents' perspective, Dissertation	Full text unavailable

Study	Reason for Exclusion
Abstracts International Section A: Humanities and Social Sciences, 70, 703, 2009	
Mouradian, Le, DeGrace, Bw, Thompson, Dm, Art-based occupation group reduces parent anxiety in the neonatal intensive care unit: A mixed-methods study, American Journal of Occupational Therapy, 67, 692-700., 2013	Did not specify how many infants required respiratory support
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	Did not specify how many infants required respiratory support
Niela-Vilen, H., Axelin, A., Melender, H. L., et al.,, 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	Did not specify how many infants required respiratory support
Noergaard, B., Ammentorp, J., Fenger-Gron, J., Kofoed, P. E., Johannessen, H., Thibeau, S., Fathers' Needs and Masculinity Dilemmas in a Neonatal Intensive Care Unit in Denmark, Advances in Neonatal Care, 17, E13-E22, 2017	Did not specify how many infants required respiratory support
Nottage, S. L., Parents' use of nonmedical support services in the neonatal intensive care unit, Issues in Comprehensive Pediatric Nursing, 28, 2005	Did not specify how many infants required respiratory support
Nyqvist, K. H., Sjoden, P. O., Ewald, U., Mothers' advice about facilitating breastfeeding in a neonatal intensive care unit, Journal of human lactation : official journal of International Lactation Consultant Association, 10, 237-243, 1994	Infants requiring respiratory support were excluded
Olsson, E., Eriksson, M., Anderzen-Carlsson, A., Skin-to-Skin Contact Facilitates More Equal Parenthood - A Qualitative Study From Fathers' Perspective, J Pediatr NursJournal of pediatric nursing, 34, e2-e9, 2017	Did not specify how many infants required respiratory support
O'Sullivan, B., Douglas, L., Jacobs, S., Davis, P., Eye contact or icontact: How do parents prefer to receive information in neonatal intensive and special care (NISC)?, Journal of Paediatrics and Child Health, 49, 127, 2013	Conference abstract
Padden, T., Glenn, S., Maternal experiences of preterm birth and neonatal intensive care, Journal of Reproductive and Infant Psychology, 15, 121-139, 1997	Did not specify how many infants required respiratory support
Parker, L., Mothers' experience of receiving counselling/psychotherapy on a neonatal intensive care unit (NICU), Journal of Neonatal Nursing, 17, 182-189, 2011	Did not specify how many infants required respiratory support
Pepper,D., Rempel,G., Austin,W., Ceci,C., Hendson,L., More than information: a qualitative study of parents' perspectives on neonatal	Did not specify how many infants required respiratory support

Study	Reason for Exclusion
intensive care at the extremes of prematurity, Advances in Neonatal Care, 12, 303-309, 2012	
Perlman, N. B., Freedman, J. L., Abramovitch, R., Whyte, H., Kirpalani, H., Perlman, M., Informational needs of parents of sick neonates, Pediatrics, 88, 512-8, 1991	Quantitative design
Pichler-Stachl, E., Pichler, G., Baik, N., Urlesberger, B., Alexander, A., Urlesberger, P., Cheung, P. Y., Schmolzer, G. M., Maternal stress after preterm birth: Impact of length of antepartum hospital stay, Women and Birth, 29, E105-E109, 2016	Quantitative design
Pohlman, S., When worlds collide: The meanings of work and fathering among fathers of premature infants, Ph.D., 330 p-330 p, 2003	Did not pertain to the information and format that parents value
Prendergast, Carol C., Perceptions of parenting experiences in the neonatal intensive care unit by parents of very low birth weight premature infants, Dissertation Abstracts International: Section B: The Sciences and Engineering, 61, 3308, 2000	Did not specify if infants required respiratory support
Pridham, K. F., Limbo, R., Schroeder, M., Thoyre, S., Van Riper, M., Guided participation and development of care-giving competencies for families of low birth-weight infants, Journal of advanced nursing, 28, 948-958, 1998	Did not specify if infants required respiratory support
Provenzi, L., Santoro, E., The lived experience of fathers of preterm infants in the Neonatal Intensive Care Unit: a systematic review of qualitative studies, J Clin NursJournal of clinical nursing, 24, 1784-1794, 2015	Did not specify if infants required respiratory support
Prudhoe,C.M., Peters,D.L., Social support of parents and grandparents in the neonatal intensive care unit, Pediatric Nursing, 21, 140-146, 1995	Did not specify if infants required respiratory support
Pusins, J. M., Alduraibi, A. M., Psychological impact of the NICU environment: It's more than meets the eye, Dysphagia, 32 (1), 202, 2017	Conference abstract
Raiskila, S., Lehtonen, L., Tandberg, B. S., Normann, E., Ewald, U., Caballero, S., Varendi, H., Toome, L., Nordhov, M., Hallberg, B., Westrup, B., Montirosso, R., Axelin, A., Scene Res Grp, Parent and nurse perceptions on the quality of family-centred care in 11 European NICUs, Australian Critical CareAust Crit Care, 29, 201-209, 2016	Quantitative design
Rhoads, S. J., Green, A., Gauss, C., et al.,, Web camera use of mothers and fathers when viewing their hospitalized neonate, Advances in Neonatal Care, 15, 440-446, 2015	Not specified if infants required respirator support
Rieves, Priscilla, The lived experiences of transition to parenthood for parents of preterm infants, Dissertation Abstracts International: Section B: The Sciences and Engineering, 76, No Pagination Specified, 2015	Not specified if infants required respirator support

Study	Reason for Exclusion
Rolfe, S. A., Armstrong, K. J., Early childhood professionals as a source of social support: The role of parent-professional communication, Australasian Journal of Early Childhood, 35, 60-67, 2010	Full text unavailable
Roman, Lee Anne, Lindsay, Judith K., Boger, Robert P., DeWys, Mary, Beaumont, Ed J., Jones, Alan S., Haas, Bruce, Parent-to-parent support initiated in the neonatal intensive care unit, Research in nursing & health, 18, 385-394, 1995	Not specified if infants required respirator support
Rosenstock, A., van Manen, M., Adolescent parenting in the neonatal intensive care unit, J Adolesc HealthThe Journal of adolescent health : official publication of the Society for Adolescent Medicine, 55, 723-9, 2014	Not specified if infants required respirator support
Rossman, B., Greene, M. M., Meier, P. P., The role of peer support in the development of maternal identity for "NICU Moms", Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 44, 3-16, 2015	Not specified if infants required respirator support
Rossman, B., Meier, P. P., Janes, J. E., Lawrence, C., Patel, A. L., Human Milk Provision Experiences, Goals, and Outcomes for Teen Mothers with Low-Birth-Weight Infants in the Neonatal Intensive Care Unit, Breastfeeding Medicine, 12, 351-358, 2017	Not specified if infants required respirator support
Rouck, S., Leys, M., Illness trajectory and Internet as a health information and communication channel used by parents of infants admitted to a neonatal intensive care unit, Journal of advanced nursing, 69, 1489-1499, 2013	Number of infants requiring respiratory support not specified
Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., Ayers, S., Very Preterm Birth Qualitative Collaborative, Group, Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study, BMC PediatrBMC pediatrics, 14, 230, 2014	Not specified if infants required respirator support
Sartore, Gina, Lagioia, Vince, Mildon, Robyn, Peer support interventions for parents and carers of children with complex needs, Cochrane Database of Systematic Reviews, 2013	Not specified if infants required respirator support
Schenk, L. K., Kelley, J. H., Mothering an extremely low birth-weight infant: A phenomenological study, Advances in Neonatal Care, 10, 88-97, 2010	Not specified if infants required respirator support
Schuster, M. A., Duan, N., Regalado, M., Klein, D., Anticipatory guidance - What information do parents receive? What information do they want?, Archives of Pediatrics & Adolescent MedicineArch Pediatr Adolesc Med, 154, 1191-1198, 2000	Not specified if infants required respirator support

Study	Reason for Exclusion
Shah, V., O'Brien, K., Bracht, M., Warre, R., Ho, V., Chen, C., Davey, C., Ying, E., Campbell, D., Chisamore, B., Lee, S., "Family integrated care" in level II NICUs: Perspectives of administrators, healthcare personnel, and parents regarding implementation, Paediatrics and Child Health (Canada), 20 (5), e70, 2015	Conference abstract
Shahheidari, M., Homer, C., Impact of the design of neonatal intensive care units on neonates, staff, and families: A systematic literature review, Journal of Perinatal and Neonatal Nursing, 26, 260-266, 2012	Quantitative design
Shaw, C., Stokoe, E., Gallagher, K., Aladangady, N., Marlow, N., Parental involvement in neonatal critical care decision-making, Sociology of Health & IllnessSociol Health Illn, 38, 1217-1242, 2016	Infants were not preterm
Sheeran, N., Jones, L., Rowe, J., Joys and challenges of motherhood for Australian young women of preterm and full-term infants: an Interpretative Phenomenological Analysis, Journal of Reproductive and Infant Psychology, 33, 512-527, 2015	Not specified if infants required respirator support
Silva, D., Silva, E., Vieira, N., Parents' experience during the hospitalization of their premature newborn, Journal of Maternal-Fetal and Neonatal Medicine, 27, 396-397, 2014	Conference abstract
Sisk, P., Quandt, S., Parson, N., et al.,, Breast milk expression and maintenance in mothers of very low birth weight infants: supports and barriers, Journal of Human Lactation, 26, 368-375, 2010	Not specified if infants required respirator support
Sisson, H., Jones, C., Williams, R., Lachanudis, L., Metaethnographic Synthesis of Fathers' Experiences of the Neonatal Intensive Care Unit Environment During Hospitalization of Their Premature Infants, Journal of obstetric, gynecologic, and neonatal nursing : JOGNN / NAACOG, 44, 471-480, 2015	Not specified if babies required respiratory support
Skene,C., Franck,L., Curtis,P., Gerrish,K., Parental Involvement in Neonatal Comfort Care, JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing, 41, 786-797, 2012	Not specified if infants required respirator support
Smith,J.R., Jamerson,P.A., Bernaix,L.W., Schmidt,C.A., Seiter,L., Fathers' perceptions of supportive behaviors for the provision of breast milk to premature infants, Advances in Neonatal Care, 6, 341-348, 2006	Not specified if infants required respirator support
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	Not specified if infants required respirator support
Song, C., Patel, R. M., Hunt, L., Gillaspy, S., Willeitner, A., The virtual nicu: Using social media tools to reduce stress and increase	Conference abstract

Study	Reason for Exclusion
satisfaction in parents of very low birth weight infants, Journal of Investigative Medicine, 61 (2), 432-433, 2013	
Stevens,E.E., Gazza,E., Pickler,R., Parental experience learning to feed their preterm infants, Advances in Neonatal Care, 14, 354-361, 2014	Infants requiring mechanical ventilation were excluded from study inclusion
Swartz,M.K., Parenting preterm infants: a meta-synthesis, MCN, American Journal of Maternal Child Nursing, 30, 115-120, 2005	Not specified if infants required respiratory support
Tracey, Norma, Parents of premature infants: Their emotional world, xvi, 310, 2000	Full text unavailable
Treherne, S. C., Feeley, N., Charbonneau, L., Axelin, A., Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU, 46, 737-747, 2017	Did not specify if infants required respiratory support
Turner, M., Supporting the neonatal intensive care parent - Research into parental supports and perceptions of the intensive care experience in Australia, European Psychiatry. Conference: 18th European Congress of Psychiatry. Munich Germany. Conference Publication:, 25, 2010	Conference abstract
Turner, Melanie, Chur-Hansen, Anna, Winefield, Helen, Mothers' experiences of the NICU and a NICU support group programme, Journal of Reproductive and Infant Psychology, 33, 165-179, 2015	Not specified if infants required respiratory support
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	Not specified if infants required respiratory support
Vazquez, V., Cong, X., Parenting the NICU infant: A meta-ethnographic synthesis, International Journal of Nursing Sciences, 1, 281-290, 2014	Not specified if infants required respiratory support
Voos, K. C., Park, N., Implementing an Open Unit Policy in a Neonatal Intensive Care Unit Nurses' and Parents' Perceptions, Journal of Perinatal & Neonatal Nursing, 28, 313-318, 2014	Not specified if infants required respiratory support
Weems, M. F., Graetz, I., Lan, R., et al.,, Electronic communication preferences among mothers in the neonatal intensive care unit, Journal of Perinatology, 36, 997-1000, 2016	Quantitative design
Weis, J., Zoffmann, V., Egerod, I., Enhancing person-centred communication in NICU: a comparative thematic analysis, Nursing in Critical Care, 20, 287-98, 2015	Not specified if infants required respiratory support
Wernet, M., Ayres, J. R., Viera, C. S., Leite, A. M., de Mello, D. F., Mother recognition in the Neonatal Intensive Care Unit, Revista brasileira de enfermagem, 68, 203-9, 228-34, 2015	Not specified if infants required respiratory support
Whittingham, K., Boyd, R. N., Sanders, M. R., Colditz, P., Parenting and Prematurity: Understanding Parent Experience and	Not specified if infants required respiratory support

Study	Reason for Exclusion
Preferences for Support, Journal of Child and Family Studies, 23, 1050-1061, 2014	
Wiebe, A., Young, B., Parent perspectives from a neonatal intensive care unit: A missing piece of the culturally congruent care puzzle, Journal of Transcultural Nursing, 22, 77-82, 2011	Not specified if infants required respiratory support
Wigert, H., Johansson, R., Berg, M., Hellstrom, A. L., Mothers' experiences of having their newborn child in a neonatal intensive care unit, Scandinavian journal of caring sciences, 20, 35-41, 2006	Not specified if infants required respiratory support

Economic studies

All economic studies were excluded at the initial title and abstract screening stage.

Appendix L – Research recommendations

Research recommendations for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

What is the impact of parental involvement as part of Family integrated care (FIC) or the Newborn individualised developmental care and assessment programme (NIDCAP®) on the incidence of bronchopulmonary dysplasia and length of hospital stay?

Why this is important

Parents are their baby's best advocates and carers, a fact that is recognised by the growing implementation of programmes and philosophies of care such as NIDCAP® and FIC. Parents' involvement in caring for their baby contributes to optimum neurodevelopmental outcomes. However, there is insufficient evidence on their impact on oxygen requirements, which may limit lung damage from mechanical ventilation and prolonged oxygen use, and on length of stay (and implicitly hospital costs) and parental satisfaction. Studies are required to determine this, and to identify which aspects of parental involvement have the greatest impact.

Table 26: Research recommendation rationale

Research question	What is the impact of parental involvement as part of Family integrated care (FIC) or the Newborn individualised developmental care and assessment programme (NIDCAP®) on the incidence of bronchopulmonary dysplasia and length of hospital stay?
Importance to 'patients' or the population	Babies cared for on a neonatal unit who require respiratory support also require attention to their ongoing developmental needs, particularly when the need for support with breathing is over an extended period. Preterm babies who require respiratory support may be cared for on the neonatal unit for an extended period of time. This is costly financially for both the family and the hospital as well as being costly emotionally for the parents. Need for prolonged respiratory support also has a negative impact on the baby's development, including inhibiting progression from tube to oral feeding. For these reasons, reducing bronchopulmonary dysplasia would be beneficial to the baby, family and hospital.
Relevance to NICE guidance	High priority Studies identified as part of the NICE review, indicated that there may be a clinically significant reduction in bronchopulmonary dysplasia and in length of initial hospital admission with NIDCAP®; however, the quality of evidence was very low. Future NICE guidance would greatly benefit from more robust studies informing which particular aspects of parental involvement as part of NIDCAP® and FIC have most impact on reducing bronchopulmonary dysplasia and length of stay.
Relevance to the NHS	There will be a cost saving to the NHS if preterm babies who are receiving respiratory support can be weaned earlier from mechanical ventilation and supplemental oxygen. There is also a possible cost saving longer-term associated with a reduction in hospital readmission. There will be a cost saving to the NHS if preterm babies who are receiving respiratory support can be discharged home earlier from the neonatal unit.

Research question	What is the impact of parental involvement as part of Family integrated care (FIC) or the Newborn individualised developmental care and assessment programme (NIDCAP®) on the incidence of bronchopulmonary dysplasia and length of hospital stay?
National priorities	Better Births National Maternity Review. Points 4.56-4.58 discuss priorities for neonatal care and state 'parents should be actively encouraged to participate in their baby's care on the neonatal unit and in discussions and decision making with the neonatal team.' https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf The Better Births review also recommends that neonatal services be reviewed separately. This is underway and a draft is currently with NHSE but the Government has committed to consulting on this and it is likely family involvement will be an element given that family centred care is discussed throughout the CRG service specification. https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e08-serv-spec-neonatal-critical.pdf The British Association of Perinatal Medicine (BAPM) have recently published Neonatal Service Quality Indicators which define features of a high-quality neonatal service, with family-partnership in care being a key tenant. https://www.bapm.org/sites/default/files/files/NSQI%20FINAL.pdf
Current evidence base	In the NICE evidence review no robust evidence was identified about the impact of parental involvement as part of FIC or NIDCAP® on reduction of bronchopulmonary dysplasia or on length of stay.
Equality	Currently, there is inconsistent practice both in the delivery of family centred, individualised developmental care and with regard to parental involvement of preterm infants who are receiving respiratory support in neonatal units. Babies and their families have an equal right to high quality, evidenced based care practices which will both improve the baby's outcome and neonatal experience for the family.
Feasibility	There is difficulty in carrying out high quality RCTs comparing FIC or NIDCAP® with conventional care because of the risk of contamination between the control group and experimental groups. Limitations to carrying out high quality studies include the difficulty in preventing bias; it is difficult to 'blind' the randomisation and parents within the control group in previous NIDCAP studies have requested to receive the same care practice observed with babies in the experimental group. Therefore, cohort studies, which do not rely on blinding and randomisation may be more practical for research. The ability of families to be present and involved on the neonatal unit may also be a feasibility issue for such studies. For example, FIC may require parental presence for 8 hours per day.
Other comments	It has traditionally been difficult to obtain funding for studies looking at developmental care and parental involvement. This is, in part, due to the complexities of carrying out RCTs (see example, above) and, in part, due to the lack of financial incentive for drug or technology companies as the research is not directly related to either.

1 **Table 27: Research recommendation modified PICO table**

Criterion	Explanation
Population	Preterm infants who are receiving respiratory support.
Intervention	• FIC • NIDCAP® This would be difficult to do within one neonatal unit due to risk of bias.
Comparator	Conventional care
Outcome	• Length of stay

Criterion	Explanation
	• Bronchopulmonary dysplasia • Neurodevelopmental outcomes • Parental confidence (validated scale) • Infant-parent relationship (validated scale) • Transition to oral feeding
Study design	Randomised controlled trial Prospective cohort study
Timeframe	3 years follow-up

Research recommendations for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

No research recommendations were made for this review.

Research recommendations for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

No research recommendations were made for this review.

Appendix M – Economic methodology checklists

Economic methodology checklists for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

NIDCAP® (in addition to standard care) versus standard care only

Study identification **Guideline economic analysis**		
Guidance topic: parent and carer involvement in the care of preterm babies who are receiving respiratory support		**Review question no: 6.1**
Checklist completed by: Eric Slade		
Section 1: Applicability (relevance to specific review questions and the NICE reference case as described in section 7.5)	**Yes/partly/no /unclear/NA**	**Comments**
1.1 Is the study population appropriate for the review question?	Yes	*Preterm babies <27 weeks GA; sub-group analysis up to 34 weeks GA*
1.2 Are the interventions appropriate for the review question?	Yes	*NIDCAP® vs. standard care treatment*
1.3 Is the system in which the study was conducted sufficiently similar to the current UK context?	Yes	*UK study*
1.4 Are the perspectives clearly stated and are they appropriate for the review question?	Yes	*NHS and PSS; public sector*
1.5 Are all direct effects on individuals included, and are all other effects included where they are material?	Yes	*QALYs*
1.6 Are all future costs and outcomes discounted appropriately?	Yes	*3.5% for costs and outcomes*
1.7 Is QALY used as an outcome, and was it derived using NICE's preferred methods? If not, describe rationale and outcomes used in line with analytical perspectives taken (item 1.4 above).	Yes	*QALYs (HUI2, UK general population norms). No EQ-5D utility scores were available.*
1.8 Are costs and outcomes from other sectors fully and appropriately measured and valued?	*Unclear*	*Published public sector costs used in the analysis seem to have underestimated education costs in children with neurodevelopmental problems.*
1.9 Overall judgement: Directly applicable		
Other comments:		
Section 2: Study limitations (the level of methodological quality)	**Yes/partly/no /unclear/NA**	**Comments**
2.1 Does the model structure adequately reflect the nature of the topic under evaluation?	Yes	
2.2 Is the time horizon sufficiently long to reflect all important differences in costs and outcomes?	Yes	*Time horizon: 18 years*
2.3 Are all important and relevant outcomes included?	Yes	QALYs

2.4 Are the estimates of baseline outcomes from the best available source?	Yes	*From a cohort study*
2.5 Are the estimates of relative intervention effects from the best available source?	Yes	*From a review of RCTs (meta-analysis)*
2.6 Are all important and relevant costs included?	Yes	
2.7 Are the estimates of resource use from the best available source?	Yes	*Published studies supplemented with the committee expert opinion*
2.8 Are the unit costs of resources from the best available source?	Yes	*National sources*
2.9 Is an appropriate incremental analysis presented or can it be calculated from the data?	Yes	
2.10 Are all important parameters whose values are uncertain subjected to appropriate sensitivity analysis?	Yes	*Deterministic and probabilistic sensitivity analyses*
2.11 Is there any potential conflict of interest?	No	
2.12 Overall assessment: Minor limitations		
Other comments:		

1

Economic methodology checklists for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

4 No economic evidence was identified for this review.

Economic methodology checklists for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

8 No economic evidence was identified for this review.

Appendix N – Qualitative quotes and excerpts

Qualitative quotes and excerpts for question 6.1 What parent and carer involvement is effective in the care of preterm babies who are receiving respiratory support?

Not applicable to this review.

Qualitative quotes and excerpts for question 6.2 What support is valued by parents and carers of preterm babies requiring respiratory support?

Table 28: Theme 1: Social Support

Study ID	Evidence
Subtheme 1: Friends and Family	
Feeley 2013	"Instrumental support from family and friends, including meal preparation and assistance with household tasks and child care diminished demands, and this in turn provided time for fathers' involvement."
Feeley 2013	"'I have my in-laws… they are always there, whether it be for moral or practical support.'"
Smith 2012	"Parents commonly engaged family and friends for both pragmatic and emotional support… Friends and family members with medical backgrounds and/or NICU experience were particularly emotionally supportive, often serving as key information resources for many parents."
Smith 2012	"'The family support was also there. You know they were always coming and making sure that there was food in the house and helping to clean.'"
Ardal 2011	"Communication issues can arise as family members and friends struggle to provide support… mothers reported that they felt a lack of empathy for and understanding of the depth of their own anxiety, and of the reality of what their baby was going through"
Ardal 2011	"NICU mothers reported the added burden of educating and reassuring those in their support network who had no familiarity with the situation: 'Mothers who have gone through the same experience… are the only persons who understand us… and what we went through.'"
Smith 2012	"Family and friends who had little familiarity with the NICU were frequently perceived as unhelpful or even burdensome. These individuals often had concerns that reawakened parents' own worries."
Smith 2012	"'It was hard to talk to people that weren't in the immediate family, that weren't day-to-day following the babies…They had no experience with preemies and … you have to start from the beginning…That put a lot of stress on me.'"
Subtheme 2: Counselling	
Falck 2016	"Psychological and spiritual support provided by the interdisciplinary NICU was extremely valuable. Some mothers sought mental health services outside the hospital."
Falck 2016	"'I see a counselor because the whole birth process was overwhelming and traumatic. I think I have post-traumatic stress syndrome.'"
Feeley 2013	"Some fathers turned to online chat rooms dedicated to parents experiencing their infant's hospitalisation and used the concrete advice acquired there to guide their involvement."
Subtheme 3: Partners	
Falcking 2016	"Some mothers described feeling proud when watching their partners bond with their infant, as well as when they received encouragement and affirmation from their partners when providing care."

Falcking 2016	"'I cleaned him and changed him more confidently 2nd time… My partner was very impressed with me!!!'"
Feeley 2013	"Some couples developed a routine around caregiving activity, carving out a specific role for the father…Nonetheless, some mothers overtly discouraged fathers' involvement."
Heinemann 2013	"The participants also described supporting each other as partners as extremely important. Some of the fathers described their strategy of pushing aside their own feelings in favour of the mother, who they considered in greater need of emotional support."
MacDonald 2007	"When fathers were later observed in the NICU, they were actively engaged in the care of their infants to the extent that they could, and supported their spouse by assisting in diapering, taking temperatures, weighing and bathing the infants and helping to position the infants for feeding."
MacDonald 2007	"These out-of-town families received extra support by being house at Easter Seal House, a non-profit housing unit located within blocks of the hospital, and in the case of one family being allowed to park their fifth-wheel motor home close to the hospital."
Pohlman 2009	"'I don't need my wife to be upset. I know that after giving birth to a baby that a woman goes through the postpartum blues and it was real hard on her…Being at home every day and not being in the NICU and when she gets in the NICU she don't want to leave, which I don't want to either, but I know I have to. It's real hard.'"
Smith 2012	"'Every night when we left, [my partner and I] talked about it…I think that was good. It was constant communication. And so we weren't afraid to tell each other how we were feeling or what we were feeling. I think that kind of got us through it.'"
Smith 2012	"Being at home, parents were able to reconnect with each other and any older children."
Smith 2012	"Partners also lessened material strains by dividing responsibilities related to work, household activities, and being in the NICU."

Table 29: Theme 2: Staff Support

Study ID	Evidence
Subtheme 1: Facilitating Parents in Participating in Care	
Cescutti-Butler 2003	"Caring involves behaviour from staff that will facilitate parent involvement in their infant's care and work with parents as equal partners by sharing knowledge, values, responsibilities, outcomes and visions."
Cescutti-Butler 2003	"Parents did not always feel they were equal partners in care…For instance, one of the fathers interviewed felt uncomfortable about obtaining information from his baby's charts, and would only look at the charts when the staff were not present."
Gibbs 2016	"Becoming actively engaged in the provision of tube feeds assisted in achieving a sense of occupational engagement rather than being a spectator in their baby's care."
Guillaume 2013	"Parents described their ability to have contact with the baby linked to the nurses' conduct, because it made the contact possible (or not) and pleasant (or not)."
Heinemann 2013	"Increased participation strengthened their self-esteem and parental role, which increased their motivation to be present."
Heinemann 2013	"The staff had shown patience when parents did not feel ready for learning a procedure and had invited the parents to learn step by step and gradually take over most of the infant's care. The participants had felt encouraged by positive feedback on their performance of caregiving activities."
Wigert 2014	"Not being allowed to participate in the ward round involving their child to hear some of the information that emerged was described as being deprived of their parental role."

Study ID	Evidence
Wigert 2014	"'It was weird because it was my child who was lying there, so I wanted to know what they said'."
Wigert 2014	"When nurses provided information, encouragement to become involved and coaching, involvement was fostered."
Subtheme 2: Facilitating Transition into Parenting Role	
Cescutti-Butler 2003	"Providing mothers and fathers with the opportunity to see and touch their infants in the delivery room or prior to transport may reduce stressful feelings. However, when this is not possible, minimizing the delay in time between birth and the first visit may be helpful for mothers."
Cescutti-Butler 2003	"Once they were more familiar with the NICU, parents often felt they had little control of their own lives let alone of their baby, 'The nurses like do more, it's my baby and I wanted to do more - they were doing stuff that I knew I could do and I would have liked to have been asked to do.'"
Cescutti-Butler 2003	"Having an element of control and feeling integrated will help parents acclimatize to the strange environment that having a baby in a NICU presents."
Feeley 2013	"Fathers were involved in decision-making about the infant's care when staff shared information and provided the opportunity to ask questions."
Feeley 2013	"'Yeah, getting involved in the decision process was easier at night. I could talk and ask questions.'"
Feeley 2013	"Fathers also described how nurses acted as role models. They carefully observed nurses providing care to their infant and learned how to do so, thus facilitating their involvement."
Feeley 2013	"Explicit verbal encouragement from nursing staff or their partner helped fathers to begin to partake in caregiving activities."
Feeley 2013	"'If the nurses were passing by and there was any improvement needed, then they would make suggestions.'"
Guillaume 2013	"After the delivery, many mothers reported having had to wait a day or two before being authorized to see their baby, for health reasons. The photograph of the baby and the NICU caregivers' visit to the mother's room were the two factors described as very useful for feeling closer to the child in these cases."
Guillaume 2013	"'It was good to have this picture. I had two feelings….I was glad and sad at the same time…sad because she was premature.'"
Guillaume 2013	"Most parents described themselves as dependent on the staff to care for their baby and therefore necessarily subject to its authority"
Guillaume 2013	"'As we are in a place where everything is managed by others and we don't know, we have the impression that we have to ask for permission to touch him'"
Neu 1999	"'The nurses that we had really like me doing it [kangaroo care] because of her improved oxygen stats…They were really wonderful about me wanting to do it. I would have done it anyway, but it was easier because they were supportive and they made a fuss and thought it was wonderful that I did it.'"
Neu 1999	"The lack of appropriate support from the nursing staff also influenced the decision of some parents to discontinue skin-to-skin care."
Smith 2012	"Participating in the care of their child was a critical coping strategy….Activities such as diaper changes and feeding provided concrete skills and a sense of "knowing" their child, which boosted self-confidence and combated insecurities about their role as parents."
Smith 2012	"'It went from not holding her for a week to being able to hold her every couple days, and then slowly becoming a very active participant in her day. Just learning how to feed her, and hold her correctly, and bathe her.'"
Smith 2012	"Staff provided informal and formalized training on providing care, as well as opportunities for parents to practice. In addition, staff provided a welcoming

Study ID	Evidence
	environment and specific encouragement that parents needed to overcome anxieties about handling their child.”
Smith 2012	"'The nurses here don't care how much time I spend [trying] to change one diaper…they still let me try and …give me lots of tips…I learn a lot here.'"
Smith 2012	“One parent noted that it was helpful for staff to facilitate less intrusive visits by enforcing strict visiting rules with guests. Another said, the staff made note of a hospital Web site for NICU parents to provide standardized updates to friends and family, without having to interact individually.”
Smith 2012	"'They told me about a website… where I could post pictures of [my baby] and give daily updates. Because one of the things that was very draining was people asking all the time, "how's the baby, how's the baby?"'"
Smith 2012	“Often what gave parents confidence to leave was their belief that the NICU staff had not only medical expertise but also affection for their child.”
Wigert 2014	“The parents felt they were taken notice of when the staff responded to their need for information by listening attentively and calmly answering their questions… Parents also appreciated occasions when staff conveyed sensitivity to their need for consolation.”
Wigert 2014	"'We noticed that they were keeping an eye on the situation…They were hanging around, they were there and started talking a bit and could tell if you wanted to talk.'"
Gibbs 2016	“Their engagement was focused on both reclaiming involvement in caregiving occupations they anticipated prior to the baby's birth and participating in alternative occupations that still allowed them to experience closeness with their infant.”
Subtheme 2: Communication to Reduce Stress	
Falck 2016	“Transparent communication that provided information in a personalized and sensitive manner facilitated development of trusting relationships and minimized maternal anxiety”
Falck 2016	“Family meetings were valued as a forum for communication, shared decision making, and for parents to advocate for their child.”
Falck 2016	"'Dr. *** was really good about keeping us up to speed each day…when we didn't see her in person she called us, she was wonderful about it…we like it up front, not being blindsided'"
Falck 2016	"'I need good communication. I need to feel like our beliefs, what we expect and what need, are being respected.'"
Flacking 2016	“Knowing how care was provided (e.g. procedures, technical devices, staff routines), what was expected of them as parents, and understanding the infant's signals enabled parents to relax and be in the present…The knowledge of their infant's medical status, gained through the communication with and by spending time with their infant, made parents feel more confidence in the parental role.”
Flacking 2016	"'During the medical round when the doctor asked, how are your babies doing? I was very proud when I was able to tell them about my observations about the babies.'"
Gibbs 2016	“It was the intervention of a nurse that encouraged them to have hope for David's survival. Nell shared what the nurse said to them: ‘It's ok to have hope for him… despite the medical circumstances, you're his parents and it's ok to have hope for him'"
Gibbs 2016	“The importance of receiving information about their infant's condition underpinned all communications that the parents undertook with NICU staff.”
Gibbs 2016	“Facilitation was often twofold; it was about provision of information in a way that was accessible to the parents and the creation of opportunities for parents to participate in parenting occupations: ‘It was good to be encouraged to do that [diaper changing] by the nurses, and for them even to show you how to do it.'"

Study ID	Evidence
Guillaume 2013	“Some fathers reported that the staff spoke to them less than the mother, which seemed normal or more rarely, frustrating in their role of father.”
Guillaume 2013	“In the delivery room, mothers reported that they had needed explicit communication - words - about the baby's health, to be reassured that he was really alive: ‘As soon as I woke up, I asked: He's not dead? He's not dead?’"
Guillaume 2013	“Fathers and mothers both insisted on the need to warn them of changes such as intubation, changing the room, or placing a catheter.”
Guillaume 2013	"’If there is no problem with the examinations, the doctors don't come to tell you the results…If they tell us the results right away, whether they are good or bad, we know them and we can start to enjoy the child.’"
Guillaume 2013	“The telephone was described as a way of staying linked to the baby from home. Most parents reported feeling reassured by ritualized calls morning and evening…Some described calls more worrisome than reassuring, in cases where the phone rang repeatedly with no answer, and stressed the importance of always giving news, even succinctly.”
Guillaume 2013	“The fathers accompanied their child from the delivery room but frequently described an anxious wait at the ward entrance: ‘I would have liked it, when I arrived in the unit, for someone to come out and say to me, 'Your daughter is in good hands, we are going to take care of her,' just to reassure me that everything was all right.’"
Heinemann 2013	“The staff conveyed hope, without giving false expectations, which was perceived as essential.”
Holditch 2000	“The most helpful action was a nurse or other health care provider caring competently for the infant: ‘She thought maybe he was getting another little virus or something. She never said NEC. I don't think wanted to scare me until she had something to scare me about.’"
Pohlman 2009	“Fathers sometimes felt frustrated because the nurses did not fully inform them as to what they could or could not do with their infants during visits.”
Wigert 2014	“The parents felt that conversation with staff created the opportunity for a break from a reality that was difficult to live with.”
Wigert 2014	“The parents felt invited to communicate when the staff took the time to explain the child's care and treatment to them and invited them to participate in the child's care. The encouragement to care for the child strengthened parental bonding with the child.”
Wigert 2014	"’There is a communication together with us, [they] answer questions, provide support, tell us what we can do and what they will help with.’"
Wigert 2014	“The parents felt that they were dependent on communication with the staff to get information about their child and to get support from the staff to participate in their child's care.”
Wigert 2014	"’It would have felt good to have a review discussion there, what happened after the birth…because I have no idea of what happened there.’"
Wigert 2014	“The parents felt that, in their communication with the staff, they adapted to each member of staff's personality and their availability for conversation. They learned the different responsibilities of the various professionals and what roles they had in communicating with parents.”
Wigert 2014	“It could be difficult for parents to understand the doctor's information during the conversation, in which case the parents had to take the initiative to ask the nurse for an explanation of what had been said.”
Wigert 2014	"’Communication between the maternity ward and Neonatal could be improved. They had failed to schedule the hearing test. They didn't know if it was the maternity ward or Neonatal that booked it, so I had to check it myself.’"
Subtheme 4: Interpersonal Relationships	

Study ID	Evidence
Cescutti-Butler 2003	“Caring attributes: ‘Being genuinely concerned with you…Made you feel that your baby was important to them…The nurse would be there for you and give you a bit of confidence…You sort of got rapport with them, you feel more confident about asking questions’"
Cescutti-Butler 2003	“Relationships with families are central; skilled crisis intervention is needed, parents need assistance to interact with their very ill infants.”
Cescutti-Butler 2003	“The mother's relationship with the nurse was the single most important influence on mothering…The nurse was a key focus maybe because they were a constant feature of their [the parents'] time in the NICU.”
Gibbs 2016	“NICU staff were perceived as 'gatekeepers' to the infants, so this was an element of the NICU experience that parents took very seriously.”
Gibbs 2016	“The development of collaborative parent-staff relationships that underpin the provision of family-centered care also provides the platform for supporting parents to participate in meaningful caregiving occupations.”
Heinemann 2013	“Several participants expressed the need for confirmation of their concerns and for being treated with empathy…They appreciated that the staff fulfilled their role of being available for the parents and infants.”
Holditch 2000	"’The nurses meant a lot to us. The nurses were real special. They would answer our questions and be straight with us. And say, 'Well, this could happen.' They were real supportive.’"
Holditch 2000	"’I think about the social worker a lot. I remember her face and the good words that she used…She talked to me a lot. She helped me a lot. She got me in contact with a lot of people who could be of help to me.’"
Jackson 2003	“In a sense the mothers were negotiating their role both with their infants with the hospital personnel as the infants were gaining strength and independence from medical equipment and as the nurses were encouraging and supporting their entry into complex feeding and nurturing routines.”
Smith 2012	“Staff encouraged parent friendships by facilitating coffee hours or scrapbooking sessions as well as by arranging more structured relationships with graduate parents.”
Smith 2012	"’I would have found [it] helpful… if I would've been put in touch with somebody whose child was in the exact same situation.’"
Wigert 2014	“The parents felt supported when they were met with compassion…It was comforting to meet the human being behind the professional role: ‘The doctor listened, the doctor was also a person…she showed that she was also a fellow human being in the whole thing.’"
Subtheme 5: Continuity of Care	
Falck 2016	“For mothers, familiarity with nursing staff facilitated trust and confidence in nurses' abilities to care for their child. Assigning continuity attending facilitated smoother transitions and promoted maintenance of a consistent care plan.”
Falck 2016	"’I wish there were consistency in care between doctors…I feel they switch way too often and they don't always know the baby. They have different opinions on what's the right thing to do, and it gets frustrating.’"
Gibbs 2016	“The inconsistency in advice received from the nursing staff was problematic and had the potential to erode trust between parents and staff.”
Guillaume 2013	“Both parents also reported the supportive value of a visit by the paediatrician or the nurse to the mother's room, telling them about the baby's health.”
Guillaume 2013	"’For 3 days I wasn't able to see my daughter. The doctors came to see me and the nurse also. I found that encouraging: I was very glad to get news about her.’"
MacDonald 2003	“Two of the mothers expressed frustration over conflicting approaches and contradictory advice around feeding strategies. Much of the frustration observed was the result of gaps between theory and practice as nurses and lactation consultants gave advice to the mothers who were struggling”

Study ID	Evidence
Pohlman 2009	"'Almost every day there's a different nurse in there… And I can tell just by how the nurse acts and everything whether she's gonna be gentle with her or whatever. Usually they are pretty rough and I just get nervous.'"
Pohlman 2009	"Building rapport, and therefore trust (what would seem to be an essential ingredient to feeling emotionally supported), was difficult when fathers saw a new face almost every day. The lack of consistent caregivers was on the minds of several fathers and they found this 'discomforting.'"
Pohlman 2009	"He felt that having consistent nurses also allowed him the opportunity to get to know the nurses "a little bit better…which made it easier to talk with them, makes it easier for you to think 'well, what can I ask this person'?'"
Wigert 2014	"Having a designated doctor and nurse contact in the NICU for their child provided continuity and felt important to the parents."
Wigert 2014	"'We had our contact nurses…it felt really nice because we could come to them with these extra requests.'"

1 **Table 30: Theme 3: Parent-to-Parent Support**

Study ID	Evidence
Subtheme 1: Shared Experiences	
Ardal 2011	"Mothers tended to talk to parent-buddies: 'I would talk to her [the buddy] in more detail rather than to other people because she has had the same experience.'"
Ardal 2011	"Sharing culture and language facilitates the process of communicating feelings: 'In the same language, we can understand everything; also, the feelings, I believe, are the same in the same culture.'"
Ardal 2011	"Sharing a culture fostered an understanding not only of the preterm birth experience but also of its cultural context."
Ardal 2011	"Buddies were able to normalize their experience and reassure them that their feelings were natural under the circumstances."
Ardal 2011	"The parent-buddies reduced the new mothers' experience of isolation related to both preterm birth and language and cultural differences."
Ardal 2011	"Judicious use of the buddy's own experience in response to the mother's concerns appeared to have a profound impact. One mother reported, after hearing a buddy's account of her son, who had been so sick and was now healthy: 'That changed my world completely. From there on, I was a person who could do it.'"
Smith 2012	"Engagement with other NICU parents was a coping strategy that several parents found helpful because it provided them with information and perspective. Graduate NICU parents whose children had faced similar medical issues were especially helpful."
Smith 2012	"'Sometimes you want to talk to someone who's been there, who's experiencing the exact same thing.'"
Smith 2012	"'You're a member of a club and no one likes to be a member of that club, and no one likes to talk about it. And all of a sudden (sic) when people start to share it, you don't feel so alone in it. And I, I think it's just really helpful, and I think it's really hard to be the first one to kind of share or to break through that wall, but once you do it's really supportive.'"
Gibbs 2016	"The fostering of relationships with other parents seemed to stem from the mutuality of parent experiences… This support was highly valued by parents, and the shared camaraderie with other parents was a noticeable loss once their infants were discharged."
Subtheme 2: Observational Learning	

Study ID	Evidence
Feeley 2013	“In the two open-spaced NICUs where this study took place, fathers saw other parents holding or diapering their infants, and this led to the realisation that involvement was possible and permitted.”

Table 31: Theme 4: Hospital Environment

Study ID	Evidence
Subtheme 1: Need for Privacy	
Falck 2016	“Physical space limited the ability of mothers to feel comfortable expressing emotions…despite use of screens to partition the infant's space. In addition, participants emphasized that this lack of privacy impacted confidential communication with families.”
Falck 2016	"’It was touch and go, and we weren't sure if she was going to make it, so I am sobbing and everybody is walking by.’"
Falck 2016	"’It would be helpful to be presented with a choice...can we step outside to talk about this… it's good to have that option so the whole NICU doesn't hear what's going on with your kid.’"
Flacking 2016	“Parents in Sweden and Finland highlighted the importance of feeling and being a family when alone with their infant. This was facilitated when parents had their own room on the NICU which they could bring the infant into: ‘Yesterday, it was also a wonderful moment when the father came and we were allowed to be alone in the room, as a family, without nurses or other parents.’"
Heinemann 2013	“It became more complicated to take turns in performing KMC, as the parent who was not providing KMC had no private space to get some rest.”
Jackson 2003	“The mothers wanted privacy and wished to be with the baby in a private area.”
Neu 1999	"’To take off her clothes and mine wasn't anything I could do at the hospital. I'm not that modest, but I would have been right in the middle of that room!’"
Neu 1999	Conversely parents who discontinued skn-to-skin holding in the hospital were quite cognizant of a sterile, noisy, busy, or crowded environment, inadequate privacy, loss of control, and lack of nursing support that precluded a gratifying skin-to-skin experience.
Neu 1999	"It seemed hard to do because everything was so rush, rush in there."
Subtheme 2: Friendly, Homelike Environments	
Feeley 2013	“Fathers felt that because the appearance of the NICU did not resemble the home environment, this deterred their involvement.”
Feeley 2013	“One father thought that this was particularly important in the step-down unit and explained, 'More space and more chairs and nice décor - there is a bit of soul would help.'"
Feeley 2013	“Open visiting policies allowed fathers unlimited access to the NICU. As one father noted, 'I can come here whenever I want - 24 hours.'"
Heinemann 2013	“Parents who had the opportunity to stay overnight in a family room in the NICU felt that it simplified their life and made it possible to perform KMC for large parts of the day by taking turns.”
Heinemann 2013	“Several parents attributed difficulties of being present during nights to a high level of illumination and the noise from alarms and staff chatting in loud voices.”
Subtheme 3: Feelings of Security or Insecurity	
Falck 2016	“Re: open room design - Mothers described a feeling of safety, comfort, and security provided by the proximity of multiple caregivers in the room at all times”
Falck 2016	"’The NICU is not a privacy place…I don't want it closed off because he is so unpredictable…some days I need to look across the room and say, "Hey, what is going on with him?’"

Study ID	Evidence
Feeley 2013	“One father described how the 'tubes' and 'wires' made him reluctant to provide care for his infant, stating 'I was always afraid, you know… I tried once, she started desaturating and the nurse said "Let me take her from your arms.”"
Holditch 2000	“Sometimes, the appearance of the entire NICU - equipment, infants, and families - overwhelmed the mothers ‘The first time that their monitors went off, it terrified me! But the staff there was really good about explaining what was going on.’"
Holditch 2000	“Medical complications could further impair the appearance of the infant: ‘When he was in the ICU, they had him paralyzed then. He just wasn't moving then, because he had the respirator on. They don't look like real babies when they're paralyzed. Almost like they're dead.’"
Guillaume 2013	“To be at ease with their child, the parents reported that they needed to understand the environment: ‘The more I know, the more I am reassured. What I want to know are the upper and lower limits, because I watch the monitor and I have the impression I understand.’"
Subtheme 4: Participating in care	
Gibbs 2016	“The NICU environment has a significant impact on participation in parenting occupations… The presence of lines and the types of respiratory equipment limited how much of their infant they could actually see.”
Gibbs 2016	“The incubator served to reinforce the critical nature of their infant's condition and placed significant limitations on their involvement in providing nurturing for their infant.”
Gibbs 2016	"’Sometimes you'd feel like you were just sitting there watching everybody do everything for him.’"
Gibbs 2016	“The various policies and unwritten ground rules, also shaped parents' experiences, including visiting restrictions imposed during infection outbreaks, the ability to engage in skin-to-skin contact based on the infant's respiratory support needs, and the exclusion of parents from the unit during ward rounds”
Flacking 2016	“For many parents, holding the infant and/or being skin-to-skin was the first time they felt their infant was theirs… By being physically close the parent-infant bond was strengthened.”
Flacking 2016	“Doing simple and ordinary parenting tasks made them feel that the infant was theirs; changing diapers, putting on clothes and washing and bathing their infant were significant events.”
Flacking 2016	“Some parents also specifically referred to how their increasing involvement in caretaking duties had had a simultaneous influence on their growing sense of commitment and connection.”
Flacking 2016	"’During the following days, the commitment and connection strengthened, especially when I got to spend all three nights at the neonatal unit next to my baby although he was on a monitor.’"
MacDonald 2003	“Mothers whose infants were on respirators or C-PAP mentioned the difficulty of accessing infants for skin-to-skin cuddles and in seeing their infant's face. The monitors and monitoring devices made the babies less accessible and the routines more challenging.”

1 **Table 32: Theme 5: Employment Support**

Study ID	Evidence
Financial Support	
Feeley 2013	“Paternity or other types of employment leaves allowed for greater presence, contributing to greater involvement.”
Feeley 2013	"’When my company gave me two weeks off, I was here Monday to Friday’"

Study ID	Evidence
Jackson 2003	“Four of the fathers were on parental leave during the hospitalization and were able to participate in the care of the infants. However, others had problems getting time off from work, which depended to a great extent on the attitudes of their employers.”

Qualitative quotes and excerpts for question 6.3 What information, and in what format, is valued by parents and carers of preterm babies who are receiving respiratory support on the neonatal unit?

Table 33: Theme 1: Prenatal and Postnatal Information

Study ID	Evidence
Subtheme 1: Prenatal maternal and infant health	
Kavanaugh 2005	“Prenatally, all parents were able to recall the information that they were given about the treatment of the mothers' condition such as magnesium sulfate for preterm labor and options and rationale for route of delivery of their infant.”
Kavanaugh 2005	“Prenatally, all but one parent reported that they were given information on premature infants including morbidity and mortality for infants born at varying gestational ages by the maternal-fetal medicine specialist and or the neonatologist.”
Kavanaugh 2005	“Three parents …wanted more specific information on the treatment that their infant would likely need.”
Subtheme 2: Postnatal maternal and infant health	
Calam 1999	"'I would have liked a proper explanation. They had plenty of time while they waited for the doctor from [the maternity ward.]'"
Kavanaugh 2005	“Postnatally, all parents felt that they were informed of their infant's condition and treatment plans.”
Wigert 2014	“The parents explained that they got the most information from the staff at the beginning of the child's hospitalization but at that time it could be difficult to take in information because the mother was most often still recovering from the birth. As time went by, the amount of information and the number of discussions, mainly with doctors, declined after the child's condition stabilized.”
Wigert 2014	"'It would have felt good to have a review discussion there, what happened after the birth…because I have no idea of what happened there, I know that I've thought about that afterwards.'"

Table 34: Theme 2: Infant’s Health Status Information

Study ID	Evidence
Subtheme 1: Understanding Medical Condition	
Feeley 2013	“The medical jargon used by staff served as a barrier to involvement. When fathers did not understand what was said to them about their infants' medical condition or care, this deterred involvement as they were anxious about handling the infant.”
Gibbs 2016	“Information for the parents was an essential requirement of understanding their situation and assisted in alleviation of their concerns or anxiety. Understanding medical information allowed them to feel more integrated in the NICU experience…”
Gibbs 2016	“The importance of receiving information about their infant's condition underpinned all communications that the parents undertook with NICU staff.”
Wigert 2014	“The parents stated that they were often left waiting for some time for information about their child's illness. When the answer was uncertain, or conversations with the doctor were postponed or information failed to materialize, the parents suffered.”
Subtheme 2: Receiving Updates of Health Status	

Guillaume 2013	"'For 3 days I wasn't able to see my daughter. The doctors came to see me and the nurse also. I found that encouraging: I was very glad to get news about her. The information was clear; they told me that she is small but doing well.'"
Guillaume 2013	"Many mothers said that they were frustrated to have to rely on the child's father for new information: 'It would have been good if someone from the team had come down to see me, because my husband is not a physician.'"
Guillaume 2013	"They also described their need to not be kept waiting about exam results, such as ultrasound: 'If there is no problem with the examinations, the doctors don't come to tell you the results…'"

1 **Table 35: Theme 3: Caregiving Information**

Study ID	Evidence
Subtheme 1: Parenting Activities	
Feeley 2013	"When nurses provided information, encouragement to become involved and coaching, involvement was fostered."
Gibbs 2016	"Actions of the nurses could facilitate parent engagement in caregiving. Facilitation was often twofold; it was about provision of information in a way that was accessible to the parents and the creation of opportunities for parents to participate in parenting occupations."
Heinemann 2013	"The participants, especially those whose infants had been transferred to this NICU from another hospital, regarded information about caregiving activities and what was expected from them as parents as particularly important."
Heinemann 2013	"The participants expressed satisfaction with the guidance they received in taking care of their infants. The staff had shown patience when parents did not feel ready for learning a procedure and had invited the parents to learn step by step and gradually take over most of the infant's care."
Pohlman 2009	"Fathers sometimes felt frustrated because the nurses did not fully inform them as to what they could or could not do with their infants during visits…'We didn't feel as informed as we could have about our boundaries. I mean it was like our own child, but we didn't know what we could do with her.'"
Smith 2012	"Staff provided informal and formalized training on providing care, as well as opportunities for parents to practice…'The nurses were like, 'Okay, changing his diaper: this is how you do it.'""
Wigert 2014	"The parents felt that they were dependent on communication with the staff to get information about their child and to get support from the staff to participate in their child's care. When parents were not given information about their child's care and treatment, they felt themselves excluded in their parenting."
Subtheme 2: Changes in Care	
Guillaume 2013	"Fathers and mothers both insisted on the need to warn them of changes such as intubation, changing the room, or placing a catheter."
Subtheme 3: Understanding Behavioural Cues	
Guillaume 2013	"The mothers said more frequently than the fathers that they needed explanations of the baby's relational capacities and on the meaning of their reactions, to help them: 'It's important to understand her reactions, when she cries or seems nervous.'"
Subtheme 4: Breast feeding	
Kavanaugh 2005	"At one site, parents were given information on the nursery's breast-feeding program…Mothers reported that this information was very useful because it helped them make a decision about infant feeding and recognize their unique contribution to their infant's care."
Subtheme 5: Skin to skin care	
Neu 1999	"'When we did kangaroo care, I didn't know what I was going to do, but I thought I was going to do something wrong because she was so small. I was petrified that maybe I would dislodge her tube even though it was taped to her face.'"
Neu 1999	"Parents who expressed more anxiety about transferring their infant from the bed for skin-to-skin care preferred he nurse-to-parent transfer rather than the

	parent transfer. They explained that they were afraid that they would disconnect wires or tubing if they moved the infant themselves.”

Table 36: Theme 4: Future Information

Study ID	Evidence
Subtheme 1: Plans for Children in the Future	
Kavanaugh 2005	“Three weeks after her infant's death, she indicated that she wanted more information on the cause of death and advice for a subsequent pregnancy and that she wanted follow-up phone calls from hospital staff.”
Kavanaugh 2005	“Three mothers knew someone who had an infant born before 25 weeks' gestation who did well, and this information gave them hope.”
Subtheme 2: Decision Making	
Feeley 2013	“Fathers were involved in decision-making about the infant's care when staff shared information and provided the opportunity to ask questions.”
Kavanaugh 2005	“One of the parents who wanted to be involved explained, "Physicians have the information but parents have more faith." These parents felt that they needed information from the physician and then most needed the physician to make a recommendation.”
Kavanaugh 2005	“With adequate information, some parents felt very confident about decision making.”

Table 37: Theme 5: NICU Environment Information

Study ID	Evidence
Guillaume 2013	“In the first weeks in the NICU, access to regular explanations helped most of the parents to limit their feelings of helplessness and to be able to come see the baby day after day.”
Guillaume 2013	“To be at ease with their child, the parents reported that they needed to understand the environment: ‘The more I know, the more I am reassured. What I want to know are the upper and lower limits, because I watch the monitor and I have the impression I understand.’"
Pohlman 2009	“Dan recalled several situation where he was frustrated by the nurses' actions but was reluctant to confront them. For example, he did not fully understand why the nurses were so nonchalant about monitor alarms. He had to learn for himself that many of the beeps and buzzers were false alarms, but only after a few frightening experiences.”

Table 38: Theme 6: Formats

Study ID	Evidence
Subtheme 1: Telephone	
Guillaume 2013	“The telephone was described as a way of staying linked to the baby from home. Most parents reported feeling reassured by ritualized calls morning and evening: ‘It's very good to have news by telephone…it takes 15 seconds but afterwards, you feel so much better... then pfff! I pump my milk and I fill the bottle.’"
Smith 2012	“Getting routine information at home via an unexpected telephone call was often alarming because they often assumed that any phone call was bad news.”
Subtheme 2: Medical Team	
Heinemann 2013	“Information should be given by staff members who are sufficiently qualified to provide medical information.”
Smith 2012	“Staff answered questions and also encouraged parents to ask questions, proactively provided information, and recommended additional resources. Parents were grateful when staff tailored information to their emotional needs and technical abilities.”

Smith 2012	"'The more I can pick the brains of the nurses and the doctors that gives me comfort.'"
Subtheme 3: Nurses	
Kavanaugh 2005	"They reported that nurses were the ones who helped them understand information, especially when medical jargons were used."
Smith 2012	"Parents often felt the primary nurses knew their infants well and could provide the best day-to-day information."
Subtheme 4: Physician or Neonatologist	
Kavanaugh 2005	"'So I would say to any physician give as much information as needed. Allow the parents to ask. I don't care how silly it may seem to them, but allow them to ask the questions so they can better understand what's taken place.'"
Smith 2012	"However, some parents felt that technical or complex information was better conveyed by a physician. These parents wanted physicians to provide this information, even if they needed additional guidance from nurses afterward."
Subtheme 5: Timing and Consistency	
Calam 1999	"A high percentage of women had little or no recall of information provided about the complications in the pregnancy and the risk of preterm delivery prior to the birth and only one mother was able to recall what she considered to be a full explanation."
Calam 1999	"The overwhelming nature of the experience, and the difficulty inherent in absorbing information round this time was clear from the mother's comments…'They always gave you information, but I can't recall the details. I didn't listen a lot of the time.'"
Calam 1999	"There was a substantial proportion of mothers who did not recall or understand what they had been told…"
Guillaume 2013	"Several participants said that it had been difficult to comprehend the information that was given the first few days: to them, repeated, consistent and clear information about the infants' condition and care was important in the early postnatal period."
Kavanaugh 2005	"Parents stressed the importance of receiving honest, consistent information and that it was desirable to receive it from a limited number of professionals to avoid hearing conflicting information."
Kavanaugh 2005	"One mother indicated that initially she did not understand the information because of her emotional state. She said, 'Honestly when she (the obstetrician) told me, I really heard nothing that they said…All I heard was I'm here until the baby is born.'"
Kavanaugh 2005	"Her husband also indicated that he was feeling so faint that he also could not understand all of the information initially."
Smith 2012	"Parents were reassured by receiving similar information from all care team members."
Smith 2012	"One challenge to this strategy was absorbing information, especially in the beginning when parents were overwhelmed by their new life situation."
Smith 2012	"'Not only were we receiving too much [in the beginning], but I think you're going through so much that really you don't absorb as much as you would like to…even though you think you're absorbing everything… - you're trying to concentrate on every single word that's coming through the doctor's mouth.'"
Subtheme 6: Other Resources (including books, internet resources, friends and family)	
Smith 2012	"Gathering information was an iterative and ongoing process in which asking questions of staff was central, although parents also relied on books, online resources, and, in some cases, friends and family in the medical field."

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