Developmental follow-up of children and young people born preterm

NICE guideline: short version

Draft for consultation, February 2017

This guideline covers the developmental follow-up of babies, children and young people under 18 years who were born preterm (before 37^{+0} weeks of pregnancy). It includes recommendations about risk of developmental problems and disorders, and specifies when and how to assess development.

Who is it for?

- Healthcare professionals
- Education services
- Social care services
- Commissioners and providers
- Parents and carers of babies, children and young people who were born preterm

This version of the guideline contains the draft recommendations, context and recommendations for research. Information about how the guideline was developed is on the guideline's page on the NICE website This includes the guideline committee's discussion and the evidence reviews (in the full guideline), the scope, and details of the committee and any declarations of interest.

Contents

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Risk and prevalence of developmental problems and disorders

1.1.1 Be aware that children born preterm are at increased risk of developmental problems and disorders.

1.1.2 Be aware that for recommendations in this section:

- for some developmental problems and disorders there was an absence of evidence about overall risk and prevalence in children born preterm, and some papers included specific gestational ages at birth from which the committee was unable to extrapolate to other gestational ages
- for some developmental problems and disorders the evidence was underpowered to detect an effect
- other gestational ages and other factors not listed here might also be associated with increased risk of developmental problems and disorders.

Cerebral palsy

1.1.3 Be aware that children born preterm are at increased risk of cerebral palsy, and that:

- the following are independent risk factors:
  - grade 3 or 4 intraventricular haemorrhage

  - cystic periventricular leukomalacia
  - neonatal sepsis
  - bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age
  - antenatal steroids not given
  - postnatal steroids given to babies born before 32^{+0} weeks' gestation
- prevalence increases with decreasing gestational age.

See also the NICE guideline on cerebral palsy in children and young people under 25.

Motor problems

1.1.4 Be aware that children born preterm are at increased risk of motor problems, and that the following are independent risk factors:

- brain lesions (for example, grade 3 or 4 intraventricular haemorrhage, periventricular leukomalacia, infarct)
- necrotising enterocolitis that needed surgery
- neonatal sepsis
- severe retinopathy of prematurity.

1.1.5 Be aware that there is increased prevalence of developmental coordination disorder in children born preterm compared with the general population.

Intellectual disability

1.1.6 Be aware that children born preterm are at increased risk of intellectual disability, and that:

- the following are independent risk factors:
  - grade 3 or 4 intraventricular haemorrhage
  - cystic periventricular leukomalacia
  - neonatal sepsis in babies born before 28^{+0} weeks' gestation

  - necrotising enterocolitis that needed surgery in babies born before 33^{+0} weeks' gestation
  - bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age in babies born before 28^{+0} weeks' gestation
  - severe retinopathy of prematurity in babies born before 28^{+0} weeks' gestation
  - small for gestational age
  - postnatal steroids given to babies born before 33^{+0} weeks' gestation
  - mother from a low-income or disadvantaged background
- prevalence increases with decreasing gestational age.

Special educational needs and educational attainment

1.1.7 Be aware that children born preterm are at increased risk of having special educational needs, and that the following are independent risk factors:

- brain lesions detected by ultrasound
- male sex.

1.1.8 Be aware that children born preterm are at increased risk of low educational attainment at the end of the Early Years foundation stage and at key stage 1, and that:

- prevalence of low educational attainment increases with decreasing gestational age
- there is increased risk of low attainment for reading and numeracy particularly in children born before 26^{+0} weeks' gestation
- the following are independent risk factors for delayed numeracy in children born before 32^{+0} weeks' gestation:
  - intracranial haemorrhage
  - bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age.

Attention, impulsivity and hyperactivity

1.1.9 Be aware that children born before 33^{+0} weeks' gestation are at increased risk of symptoms of hyperactivity, impulsivity and particularly inattention at preschool and school ages.

1.1.10 Be aware that children born before 28^{+0} weeks' gestation are at increased risk of attention deficit hyperactivity disorder (ADHD), and that male sex is an independent risk factor.

Autism spectrum disorder

1.1.11 Be aware that children born before 28+0 weeks' gestation are at increased risk of symptoms of social communication impairment, which may suggest a problem in the autism spectrum.

1.1.12 Be aware that children born preterm are at increased risk of autism spectrum disorder, and that:

- the following are independent risk factors:
  - intracranial haemorrhage in babies born before 34+0 weeks' gestation
  - male sex
- prevalence increases with decreasing gestational age.

Emotional and behavioural problems

1.1.13 Be aware that children born preterm are at increased risk of emotional and behavioural problems, particularly internalising behaviours and passivity, at preschool and primary school ages, and that the following are independent risk factors:

- major brain lesions (for example, periventricular leukomalacia, parenchymal lesions)
- mother with mental health problems
- mother younger than 25 years
- mother from a low-income or disadvantaged background.

Speech, language and communication

1.1.14 Be aware that children born preterm are at increased risk of speech, language and communication problems and disorders, and that the following are independent risk factors for language disorder:

- grade 3 or 4 intraventricular haemorrhage
- cystic periventricular leukomalacia
- male sex.

Feeding problems

1.1.15 Be aware that children born preterm are at increased risk of oro-motor feeding problems, and that this increased risk persists until at least 6 years of age in children born before 26^{+0} weeks.

Sleep problems

1.1.16 Be aware that children born preterm are at increased risk of sleep apnoea up to 6 years of age.

Visual impairment

1.1.17 Be aware that the prevalence of visual impairment increases with decreasing gestational age in children born preterm, and that the following are independent risk factors:

- grade 3 or 4 intraventricular haemorrhage with a shunt
- neonatal sepsis in babies born before 33^{+0} weeks' gestation
- retinopathy of prematurity requiring treatment.

Hearing impairment

1.1.18 Be aware that the prevalence of hearing impairment increases with decreasing gestational age in children born preterm, and that neonatal sepsis is an independent risk factor in babies born before 28^{+0} weeks' gestation.

Executive function problems

1.1.19 Be aware that children born before 32^{+0} weeks' gestation are at increased risk of executive function problems at preschool and school ages.

Developmental problems

1.1.20 Be aware that children born preterm are at increased risk of developmental problems, and that the following are independent risk factors:

- small for gestational age
- male sex
- mother from a low-income or disadvantaged background
- black, Asian or other minority ethnic group
- multiple pregnancy.

1.2 Information and support for parents and carers of all preterm babies

Providing information and support

1.2.1 Provide information about the risk and prevalence of developmental problems and disorders to parents or carers of preterm babies, and discuss this with them.

1.2.2 Provide information to parents or carers of preterm babies that is tailored to their individual circumstances, taking into account:

- their child's potential developmental needs
- their level of education
- any social care needs they have
- any cultural, spiritual or religious beliefs
- the need for consistency in information sharing among healthcare professionals.

1.2.3 Follow the principles in the NICE guideline on patient experience in NHS services in relation to communication (including different formats and languages), information and shared decision-making.

1.2.4 Provide emotional and psychological support as needed to parents or carers of preterm babies.

1.2.5 Provide information to parents or carers of preterm babies about opportunities for peer support.

Information and support leading up to and on discharge

1.2.6 Before discharging a preterm baby:

- agree a discharge plan with the parents or carers
- ensure that the discharge plan includes clear information about any antenatal and perinatal risk factors for developmental problems and disorders (see section 1.1)
- share the discharge plan with parents or carers and with primary and secondary healthcare teams.

1.2.7 Help parents or carers to gain the knowledge, skills and confidence they need to look after their baby at home and to support the baby's developmental needs, taking into account that they are likely to be anxious about managing their baby's care after discharge. This may relate to:

- interaction with the baby
- managing feeding
- patterns of sleeping
- impact on day-to-day living, such as social isolation because of fear of infection.

1.2.8 Involve the social support networks (which may include partners, grandparents or other family members) of parents and carers of a baby born preterm when planning discharge and during follow-up.

1.2.9 Explain to parents and carers at the time of discharge that their child's developmental (corrected) age, which is calculated from their original due date (and not the date they were born), will be used for the first 2 years when assessing their functional and developmental skills (such as walking and talking).

1.2.10 Inform parents or carers of all preterm babies about the Healthy Child Programme, which includes national recommendations for all children about screening (for example, newborn hearing screening) and surveillance (including social, emotional, behavioural and language development).

Care, support and follow-up after discharge

1.2.11 Inform parents or carers about the routine postnatal care and support available as described in the NICE guideline on postnatal care up to 8 weeks after birth.

1.2.12 Healthcare professionals providing postnatal care and support in the community for babies born preterm should have the skills and knowledge to recognise and manage problems in these babies, including:

- providing feeding support
- addressing concerns about sleeping
- facilitating interaction between the parents or carers and the baby.

1.3 Enhanced developmental support and surveillance

Criteria for enhanced developmental support and surveillance up to 2 years (corrected age)

1.3.1 Provide enhanced developmental support and surveillance by a multidisciplinary team (see section 1.4) up to 2 years (corrected age) for children born preterm who have a developmental problem

or disorder, or are at increased risk of developmental problems or disorders based on the following criteria:

- born before 30^{+0} weeks' gestation **or**
- born between 30^{+0} and 36^{+6} weeks' gestation and has or had 1 or more of the following risk factors:
  - a brain lesion on neuroimaging likely to be associated with developmental problems or disorders (for example, grade 3 or 4 intraventricular haemorrhage or cystic periventricular leukomalacia)
  - grade 2 or 3 hypoxic ischaemic encephalopathy in the neonatal period
  - neonatal bacterial meningitis
  - herpes simplex encephalitis in the neonatal period.

1.3.2 Consider providing enhanced developmental support and surveillance by a multidisciplinary team (see section 1.4) up to 2 years (corrected age) for children born between 30^{+0} and 36^{+6} weeks' gestation who do not have any of the risk factors listed in recommendation 1.3.1 but are thought, using clinical judgement, to be at increased risk of developmental problems or disorders in the first 2 years of life and taking into account the presence and severity of risk factors (see recommendations 1.1.3 to 1.1.20).

1.3.3 Inform parents or carers of preterm babies who meet the defined criteria about the arrangements for enhanced developmental support and surveillance for their child.

Enhanced developmental support

1.3.4 Provide parents or carers of a preterm baby having enhanced developmental support with a single point of contact within the neonatal service for outreach care after discharge.

1.3.5 Use a range of approaches when providing enhanced developmental support and tailor the support to take account of individual preferences and needs. Approaches may include:

- face-to-face meetings, in clinics or in the home
- a telephone helpline
- electronic communication, for example by text message or email.

Enhanced developmental surveillance

1.3.6 For all children born preterm who are having enhanced developmental surveillance, provide:

- a minimum of 2 face-to-face follow-up developmental visits in the first 2 years of life **and**
- a developmental assessment at 2 years (corrected age) (see recommendation 1.3.11).

1.3.7 At each visit for a child born preterm who is having enhanced developmental surveillance:

- ensure that this is conducted by professionals with appropriate skills (see recommendations 1.4.2 and 1.4.3)
- ask parents or carers whether they have any concerns about their child's development
- include checks for developmental problems and disorders (see recommendation 1.3.8) .
- carefully assess and review any developmental concerns arising either from parent or carer report or at the visit itself
- correct for gestational age up to 2 years (corrected) when assessing development
- discuss any concerns with parents or carers
- consider further investigation or referral if a developmental problem or disorder is suspected or present
- refer the child to the appropriate local pathway if needed.

Checking for developmental problems and disorders

1.3.8 At each visit for a child born preterm who is having enhanced developmental surveillance up to 2 years (corrected age), and at the 4-year assessment (for children born before 28^{+0} weeks; see recommendation 1.3.134), check for signs and symptoms of developmental problems and disorders as appropriate, such as:

- cerebral palsy (see recommendation 1.3.9)
- global developmental delay
- autism spectrum disorder (see recommendation 1.3.10)
- visual impairment
- hearing impairment
- feeding problems
- sleep problems
- speech, language and communication problems
- motor problems
- attention, impulsivity and hyperactivity
- emotional and behavioural problems
- executive function problems
- special educational needs

1.3.9 Recognise the following as possible early motor signs of cerebral palsy:

- delayed motor milestones, such as late sitting, crawling or walking (correcting for gestational age)
- unusual fidgety movements or other abnormalities of movement, including asymmetry or paucity of movement
- abnormalities of tone, including hypotonia (floppiness) or spasticity (stiffness)
- persisting feeding difficulties.

See also the NICE guideline on cerebral palsy in children and young people under 25.

1.3.10 For guidance on recognising signs and symptoms of possible autism spectrum disorder, see the NICE guideline on autism spectrum disorder in under 19s: recognition, referral and diagnosis.

Developmental assessment at 2 years (corrected age)

1.3.11 Provide a developmental assessment at 2 years (corrected age) for children born preterm who are having enhanced developmental surveillance. This assessment should include:

- all aspects listed in recommendation 1.3.7
- at a minimum, using the Parent Report of Children's Abilities - Revised (PARCA-R) to identify if the child is at risk of global developmental delay, early intellectual disability or language problems:
  - if the PARCA-R is not suitable (for example, because of poor English language comprehension or the child being outside the validated age range of 22 to 26 months), use a suitable alternative
- ensuring that checks of vision and hearing have been carried out in line with national recommendations.

1.3.12 If findings from the developmental assessments at 2 years (corrected age) or 4 years (see recommendation 1.3.14) suggest any developmental problems or disorders:

- refer the child to an appropriate local pathway, which may involve child health and education services
- share information with:
  - parents or carers
  - primary and secondary healthcare teams
- ask parents or carers for permission to share the information with:
  - education services
  - social care services as appropriate.

Discharge from enhanced surveillance at 2 years

1.3.13 After the developmental assessment at 2 years (corrected age):

- advise parents or carers of all children that their child should continue to be followed-up in the healthy child programme **and**
- advise parents or carers of children born before 28^{+0} weeks' gestation that their child will also be offered a further developmental assessment at 4 years

Developmental assessment at 4 years for children born before 28^{+0} weeks' gestation

1.3.14 Provide a developmental assessment at 4 years for all children born before 28^{+0} weeks' gestation. This assessment should:

- be conducted by professionals with appropriate skills (see recommendations 1.4.2 and 1.4.3)
- take into account information provided by parent or carers (see recommendation 1.3.7)
- include a review of previous assessments and information from all other relevant sources
- include checks for developmental problems and disorders (see recommendation 1.3.8)
- use:
  - the Strengths and Difficulties Questionaire (SDQ) to check for social, attentional, emotional and behavioural problems
  - as a minimum, the Wechsler Preschool and Primary Scales of Intelligence 4th Edition (WPPSI) test, including subscales for verbal comprehension, visual spatial skills, fluid reasoning, working memory and processing speed:
    - ◊ if the WPPSI is not suitable (for example, because of sensory or motor impairment), use a suitable alternative
- include ensuring that the child has been offered orthoptic vision screening as recommended by the National Screening Committee.

1.3.15 Provide a comprehensive summary of the child's strengths and difficulties, including any developmental problems and disorders, after the 4-year assessment that:

- is in a format that is accessible to parents and carers
- if needed, informs the development of a plan for intervention and support, including educational support.

See also recommendation 1.3.12 about referral and information sharing.

1.4 Delivering enhanced developmental support and surveillance

1.4.1 Enhanced developmental support and surveillance for children born preterm who meet the defined criteria (see recommendations 1.3.1, 1.3.2 and 1.3.134) should:

- be provided as an integral part of a neonatal service working together with local health services
- empower parents and carers to be involved in decisions about their child's care
- be delivered by a multidisciplinary team with the necessary skills (see recommendation 1.4.2)
- record outcomes at specified time points for national audit (see section 1.5)
- be monitored by checking adherence to the recommendations in this guideline, including follow-up rates and outcomes, as part of the routine provision of neonatal care by neonatal operational delivery networks and commissioners.

1.4.2 Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should include professionals with knowledge and expertise in the following areas:

- neonatal care

- development of children born preterm, including developmental problems and disorders (see recommendation 1.3.8)
- providing support in the community, for example for feeding problems
- administering and interpreting results from questionnaires and standardised tests (such as the PARCA-R, SDQ and WPPSI)
- collating information from a range of sources to facilitate decision making and writing reports
- local care pathways, including Early Years education.

1.4.3 Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should include the following professionals:

- for follow-up to 2 years (corrected age):
  - neonatologist or paediatrician with expertise in neonatal care
  - occupational therapist or physiotherapist
  - outreach nurse or nurse with expertise in neonatal care
- for the assessment at 4 years (see recommendation 1.3.14):
  - clinical or educational psychologist
  - paediatrician with expertise in neurodevelopment.

1.4.4 Multidisciplinary teams delivering enhanced developmental support and surveillance for children born preterm should have access to the following professionals:

- community nurse
- occupational therapist
- physiotherapist
- paediatric neurologist
- paediatrician with expertise in neurodevelopment
- dietitian
- speech and language therapist.

1.5 Neonatal audit

1.5.1 Record the following information, as applicable, in the National Neonatal Research Database for every child born preterm who has enhanced developmental surveillance:

- whether the child had specialist neonatal care and details of discharge
- at the assessment at 2 years (corrected age) (see recommendation 1.3.11):
  - diagnosis of cerebral palsy
  - Gross Motor Function Classification System (GMFCS) score if cerebral palsy is present
  - PARCA-R score
  - epilepsy that is currently being treated
  - impairments of hearing, vision, speech and language, and motor skills[1]
- at the assessment at 4 years (see recommendation 1.3.14):
  - diagnosis of cerebral palsy
  - GMFCS score if cerebral palsy is present
  - WPPSI full scale IQ score, and subscale scores for verbal comprehension, visual spatial skills, fluid reasoning, working memory and processing speed
  - SDQ total difficulty score, subscale scores and impact score
  - any formal clinical diagnoses of a developmental disorder (for example, autism spectrum disorder)
  - epilepsy that is currently being treated
  - the presence of a hearing impairment, defined as profound deafness or impairment severe enough to need hearing aids or cochlear implant

[1] As defined in Figure 3 in Classification of health status at 2 years as a perinatal outcome, report of a BAPM/RCPCH working group, version 1.0, 8 January 2008.

- results of national orthoptic vision screening (see recommendation 1.3.14).

1.5.2 Record routine educational measures at key stage 2 (including special educational needs and disability [SEND]) on an operational delivery network-wide basis, to allow educational outcomes at 11 years to be linked to neonatal information.

Terms used in this guideline

Developmental problems and disorders

A group of problems that become apparent during child development and often occur together. They are characterised by impairments of personal, social, academic or occupational functioning, ranging from very specific limitations to global impairments of social skills or cognition, as measured by parent or teacher reports and surveillance tools. The term ‘disorder’ applies if the condition is severe, persistent and pervasive enough to meet the criteria for a disorder in the International Statistical classification of diseases and related health problems (ICD) or the Diagnostic and statistical manual of mental disorders (DSM).

Executive function

Executive functions are a set of inter-related cognitive processes that are used to organise and regulate thoughts and actions. These processes are important for guiding learning and behaviour, and comprise skills such as inhibition, impulse control, emotional control, working memory, cognitive flexibility and planning.

Intellectual disability

Intellectual disability (intellectual developmental disorder) is characterised by deficits in general cognitive abilities (such as reasoning and abstract thinking) and impairment of adaptive function that affects several aspects of daily life. In the ICD-10 this is defined as an IQ score more than 2 standard deviations below the mean.

Neonatal sepsis

Blood culture-positive sepsis that is treated with antibiotics for more than 5 days.

Putting this guideline into practice

[This section will be finalised after consultation]

NICE has produced tools and resources [link to tools and resources tab] to help you put this guideline into practice.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Context

This guideline focuses on the specialist developmental support and surveillance needed for the early identification of developmental problems and disorders in children born preterm.

The proportion of babies born preterm in the UK, defined as birth before 37 weeks' gestation, has remained steady for several years at 7.4%. In 2014 this amounted to 48,985 from a total of 656,957 live births, of which 2438 (5% of preterm births and 0.4% of all births) were before 28 weeks' gestation.

Preterm birth is associated with an increased risk of developmental problems and disorders. These include developmental challenges, physical, sensory, cognitive and learning disorders, and emotional and behavioural problems. These may extend into adolescence and, in some cases, be lifelong. In particular, the risk and prevalence of impairments that affect educational attainment rise sharply in children born before 28 weeks' gestation. Although most major disorders are detectable in the first 2 years of life, several developmental disorders and problems, particularly those that have an impact on the child's ability to participate and on their educational attainment, may not be apparent until they are older.

Identifying developmental problems and disorders in all children (born preterm or at term) is currently through the Healthy Child Programme, which incorporates nationally approved population screening programmes recommended by Public Health England. This guideline aims to improve the identification of developmental problems and disorders in children born preterm by setting standards for follow-up. This is expected to improve outcomes for these children by reducing variation in follow-up and enabling

benchmarking of neonatal care. Developmental surveillance up to and at 2 years (corrected age) is recommended for identifying major problems and disorders. A later developmental assessment for children at high risk aims to identify problems that are more apparent at school age, with a view to supporting education plans for the child.

More information

To find out what NICE has said on topics related to this guideline, see our web pages on intrapartum care, postnatal care, cerebral palsy, spasticity, autism spectrum disorder and mental health and wellbeing.

Recommendations for research

The guideline committee has made the following recommendations for research. The committee's full set of research recommendations is detailed in the full guideline.

1 Predictive accuracy of the WPPSI-IV at age 4 years for children born preterm

What is the accuracy of a Wechsler Preschool and Primary Scale of Intelligence 4th Edition (WPPSI-IV) assessment at age 4 years for predicting later educational difficulties in children of primary school age who were born before 28^{+0} weeks' gestation?

Why this is important

Children born before 28^{+0} weeks' gestation are at increased risk of intellectual disability, which may have an adverse impact on their learning and achievement at school, but may not be apparent at the 2-year developmental assessment. Determining the predictive accuracy of a WPPSI-IV assessment is key to providing parents or carers with accurate information about their child's likely development, so that educational support can be provided in order to reduce the risk of long-term intellectual disability.

2 Predictive accuracy of the PARCA-R for children born preterm

What is the accuracy of the parent-completed Parent Report of Children's Abilities-Revised (PARCA-R) questionnaire for predicting intellectual disability, language impairment and special educational needs at age 4 years for children born preterm?

Why this is important

Parent-completed questionnaires such as the PARCA-R are used to identify children at risk of developmental problems and disorders. Although the PARCA-R has good diagnostic accuracy for identifying children at risk of concurrent developmental problems at age 2 years (corrected), its accuracy for predicting later risk of intellectual disability, language impairment and learning difficulties is not known. Improved identification and provision of interventions are expected to lead to improved developmental outcomes for children born preterm.

3 Predictive accuracy of the ASQ-3 for children born preterm

What is the accuracy of the parent-completed Ages and Stages Questionnaire, 3rd edition (ASQ-3) for detecting concurrent intellectual disability and motor impairment between the ages of 2 years (corrected) and 4 years in children born preterm?

Why this is important

The ASQ is widely used to identify children at risk of developmental problems and disorders, and there are many versions of the questionnaire that span the preschool years. If the ASQ-3 was found to have sufficient predictive accuracy for detecting intellectual disability and motor impairment between the ages of 2 years (corrected) and 4 years, this developmental check could be considered for use in enhanced developmental surveillance.

4 Accuracy of the SDQ for predicting social, attentional, emotional and behavioural problems in children born before 28^{+0} weeks' gestation

What is the accuracy of the parent-completed Strengths and Difficulties Questionnaire (SDQ) for predicting social, attentional, emotional and behavioural problems in children born before 28^{+0} weeks' gestation?

Why this is important

Social, attentional, emotional and behavioural problems in children born preterm may go unnoticed, yet can have an adverse impact on a child's health and wellbeing, quality of life and school performance, as well as on their family. Identifying children at risk of these problems will enable intervention and family support to be provided in order to reduce their impact. In particular, identifying problems before school entry will support education planning and promote social and emotional development and attainment at school.

5 Impact of enhanced developmental support and surveillance for children born preterm on parents and carers

Does enhanced developmental support and surveillance improve outcomes for the parents and carers of children born preterm?

Why this is important

Enhanced developmental support and surveillance up to age 4 years for children born preterm who fulfil the necessary criteria is expected to increase the detection of developmental problems and disorders and improve outcomes for these children,. However, the acceptability of this approach to parents, carers and families also needs to be taken into consideration. A study that looks at the impact of enhanced developmental support and surveillance on parents and carers (for outcomes such as experience of services, satisfaction and anxiety) may help to identify where improvements can be made to future support and surveillance.