

# Developmental follow-up of children and young people born preterm

NICE guideline

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# Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should [assess and reduce the environmental impact of implementing NICE recommendations](#) wherever possible.

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This guideline is the basis of QS169.

## Overview

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 explains the risk of different developmental problems and disorders, and specifies what extra assessments and support children born preterm might need during their growth and development.

## Who is it for?

- Healthcare professionals
- Education services
- Social care services
- Commissioners and providers
- Children and young people born preterm and their parents and carers

# Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [NICE's information on making decisions about 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 Information and support for parents and carers of all preterm babies

### Providing information and support

- 1.1.1 Be aware that the majority of children and young people born preterm have a good developmental outcome and good quality of life.
- 1.1.2 Provide information about the risk and prevalence of [developmental problems and disorders](#) in babies born preterm (see section 1.2) to parents or carers, and offer to discuss this with them.
- 1.1.3 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.
- 1.1.4 Follow the principles in the [NICE guidelines on patient experience in NHS services](#) and [babies, children and young people's experience of healthcare](#) in relation to communication (including different formats and languages), information and continuity of care. Also see [NICE's guideline on shared decision making](#).
- 1.1.5 Provide emotional and psychological support to parents or carers of preterm babies as needed, recognising the significant potential impact of having a preterm baby on all the family. Times when support may be particularly valuable include:
- when the baby is transferred between units or hospitals
  - leading up to and on discharge home.
- 1.1.6 Provide information to parents or carers of preterm babies about opportunities for peer support.

## Information and support leading up to and on discharge home

### Discharge planning and support

- 1.1.7 Start discharge planning as soon as possible after the birth of a preterm baby, and involve parents or carers at all stages.
- 1.1.8 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 1.2)
  - share the written discharge plan with parents or carers and with primary and secondary healthcare teams.
- 1.1.9 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 caring for their baby after discharge. This may relate to:

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

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

### **Information before discharge about ongoing support and follow-up**

1.1.11 Inform parents or carers of all preterm babies about the routine postnatal care and support available, as described in the [NICE guideline on postnatal care up to 8 weeks after birth](#).

1.1.12 Explain to parents and carers of preterm babies about:

- universal services and national recommendations for assessing the development of all children through screening (for example, newborn hearing screening) and surveillance (including social, emotional, behavioural and language development) **and**
- whether their baby will also be offered enhanced developmental [support](#) and [surveillance](#) (see section 1.3) and plans for follow-up.

For more information on universal screening and surveillance services in England, see the [Healthy Child Programme](#).

1.1.13 Explain to parents or carers 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).

- 1.1.14 Advise parents or carers to talk to their health visitor or GP if they have any concerns about their child's development at any stage of childhood or adolescence.

## Care, support and follow-up after discharge

- 1.1.15 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
- helping parents or carers to interact with their baby.

## 1.2 Risk and prevalence of developmental problems and disorders

- 1.2.1 Be aware that children and young people born preterm are at increased risk of developmental problems and disorders.

- 1.2.2 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
- there was limited evidence about developmental problems and disorders in 11–18-year-olds
- for some developmental problems and disorders the evidence was underpowered to detect an effect
- some studies described specific gestational ages at birth, from which the committee was unable to extrapolate to other gestational ages

- other gestational ages and other factors not listed here might also be associated with increased risk of developmental problems and disorders.

## Cerebral palsy

1.2.3 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<sup>+0</sup> weeks' gestation
- prevalence increases with decreasing gestational age.

See also the [NICE guideline on cerebral palsy in under 25s: assessment and management](#).

## Motor function problems

1.2.4 Be aware that children born preterm are at increased risk of motor function 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.

1.2.5 Be aware that there is an increased prevalence of developmental

coordination disorder in children born preterm compared with the general population.

## Learning disability (intellectual disability)

1.2.6 Be aware that children born preterm are at increased risk of learning disability (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<sup>+0</sup> weeks' gestation
  - necrotising enterocolitis that needed surgery in babies born before 33<sup>+0</sup> weeks' gestation
  - bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age in babies born before 28<sup>+0</sup> weeks' gestation
  - severe retinopathy of prematurity in babies born before 28<sup>+0</sup> weeks' gestation
  - small for gestational age
  - postnatal steroids given to babies born before 33<sup>+0</sup> weeks' gestation
  - mother from a low-income or disadvantaged background
- prevalence increases with decreasing gestational age.

## Special educational needs and educational attainment

1.2.7 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.

1.2.8 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 (age up to 7 years), and that:

- prevalence of low educational attainment increases with decreasing gestational age
- children born preterm are at increased risk of low attainment for reading and maths, and this risk is greater in children born before 26<sup>+0</sup> weeks' gestation
- the following are independent risk factors for low attainment in maths in children born before 32<sup>+0</sup> weeks' gestation:
  - intraventricular haemorrhage
  - bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age.

## Executive function problems

1.2.9 Be aware that children born before 32<sup>+0</sup> weeks' gestation are at increased risk of executive function problems at preschool and school ages, and that prevalence increases with decreasing gestational age.

## Speech, language and communication

1.2.10 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.

## Attention, impulsivity and hyperactivity

- 1.2.11 Be aware that children born before 33<sup>+0</sup> weeks' gestation are at increased risk of symptoms of hyperactivity, impulsivity and particularly inattention at preschool and school ages.
- 1.2.12 Be aware that children born before 28<sup>+0</sup> weeks' gestation are at increased risk of attention deficit hyperactivity disorder (ADHD), and that male sex is an independent risk factor.

## Autism spectrum disorder

- 1.2.13 Be aware that children born before 28<sup>+0</sup> weeks' gestation are at increased risk of symptoms of social communication impairment, which may suggest a problem in the autism spectrum.
- 1.2.14 Be aware that children born preterm are at increased risk of autism spectrum disorder, and that the following are independent risk factors:
- intraventricular haemorrhage in babies born before 34<sup>+0</sup> weeks' gestation
  - male sex.

## Emotional and behavioural problems

- 1.2.15 Be aware that children born preterm are at increased risk of emotional and behavioural problems, particularly internalising behaviours and passivity, at preschool and 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.

## Feeding problems

- 1.2.16 Be aware that children born preterm are at increased risk of oro-motor feeding problems (for example, problems with sucking and chewing), and that this increased risk persists until at least 6 years of age in children born before 26<sup>+0</sup> weeks' gestation.

## Sleep problems

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

## Visual impairment

- 1.2.18 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<sup>+0</sup> weeks' gestation
- retinopathy of prematurity needing treatment.

## Hearing impairment

- 1.2.19 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<sup>+0</sup> weeks' gestation.

## Developmental delay

- 1.2.20 Be aware that children born preterm are at increased risk of developmental delay (identified using a range of tools), 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.

## 1.3 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<sup>+0</sup> weeks' gestation **or**
  - born between 30<sup>+0</sup> and 36<sup>+6</sup> 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 enhanced developmental support and surveillance by a multidisciplinary team up to 2 years (corrected age) for children born

preterm who do not meet the criteria in recommendation 1.3.1 but are suspected of being at increased risk of developmental problems or disorders, taking into account the presence and severity of risk factors (see [recommendations 1.2.3 to 1.2.20](#)).

## Criteria for enhanced developmental support and surveillance at 4 years (uncorrected age)

1.3.3 Provide a face-to-face developmental assessment at 4 years (uncorrected age) for all children born before 28<sup>+0</sup> weeks' gestation (see [recommendation 1.3.13](#)).

## Providing 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
- text messages, emails or similar.

## Providing enhanced developmental surveillance up to 2 years (corrected age)

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

- 2 face-to-face follow-up visits in the first year that focus on development, at the following corrected ages:
  - between 3 and 5 months **and**
  - by 12 months
- and**
- a detailed face-to-face developmental assessment at 2 years (corrected age) (see [recommendation 1.3.11](#)).

## Checks at each developmental visit and assessment

- 1.3.7 At each face-to-face follow-up visit and developmental assessment (see recommendations 1.3.6, [1.3.11](#) and [1.3.13](#)) for a child born preterm who is having enhanced developmental surveillance, professionals with appropriate skills (see section 1.4) should:
- discuss with 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)
  - measure length or height, weight and head circumference
  - carefully evaluate and review any developmental concerns reported by parents or carers or noted during the visit or assessment
  - correct for gestational age up to 2 years when assessing development
  - 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.
- 1.3.8 At each face-to-face follow-up visit and developmental assessment for a child born preterm who is having enhanced developmental surveillance, check for signs and symptoms of developmental problems and disorders as appropriate, such as:

- cerebral palsy (see recommendation 1.3.9)
- global developmental delay and learning disability (intellectual disability)
- autism spectrum disorder (see recommendation 1.3.10)
- visual impairment
- hearing impairment
- feeding problems
- sleep problems, including sleep apnoea
- speech, language and communication problems
- motor problems
- problems with inattention, impulsivity or hyperactivity
- emotional and behavioural problems
- executive function problems
- potential 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 (abnormal or absent) 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 under 25s: assessment and management](#).

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 face-to-face developmental assessment at 2 years (corrected age) for children born preterm who are having enhanced developmental surveillance. This assessment should include as a minimum:

- all aspects listed in [recommendation 1.3.7](#)
- using the Parent Report of Children's Abilities – Revised (PARCA-R) to identify if the child is at risk of global developmental delay, learning disability (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 parent questionnaire
- Gross Motor Function Classification System (GMFCS) score if cerebral palsy has been diagnosed
- ensuring that checks of vision and hearing have been carried out in line with national recommendations.

## Follow-up and assessment after 2 years (corrected age)

1.3.12 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 by universal screening and surveillance services for all children and young people **and**
- advise parents or carers of children born before 28<sup>+0</sup> weeks' gestation that their child will also be offered a further developmental assessment at 4 years (uncorrected age).

For more information on universal screening and surveillance services in England, see the [Healthy Child Programme](#).

## Further developmental assessment at 4 years (uncorrected age) for children born before 28<sup>+0</sup> weeks' gestation

1.3.13 Provide a face-to-face developmental assessment at 4 years (uncorrected age) for all children born before 28<sup>+0</sup> weeks' gestation that includes as a minimum:

- all aspects listed in [recommendation 1.3.7](#)
- using the following parent questionnaires, to be completed by parents or carers beforehand and the results discussed during the assessment:
  - the Strengths and Difficulties Questionnaire (SDQ), to check for social, attentional, emotional and behavioural problems
  - the Ages and Stages Questionnaire (ASQ) 48-month questionnaire, to check for various aspects of development
- reviewing previous assessments and information from all other relevant sources
- using a standardised test to assess IQ, such as the Wechsler Preschool and Primary Scales of Intelligence 4th Edition (WPPSI) test
- GMFCS score if cerebral palsy has been diagnosed
- ensuring that the child has been offered orthoptic vision screening as recommended by the [National Screening Committee](#).

1.3.14 After the 4-year assessment, provide a comprehensive summary of the child's strengths and difficulties, including any developmental problems and disorders, 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
- should be shared with the neonatal consultant.

## Information sharing and referral

- 1.3.15 If findings at any stage of developmental surveillance, including the assessments at 2 years (corrected age) and 4 years (uncorrected age) (see recommendations 1.3.11 and 1.3.13), suggest any developmental problems or disorders:
- share information with:
    - parents or carers
    - primary and secondary healthcare teams
  - refer the child to an appropriate local pathway for further assessment
  - ask parents or carers for permission to share the information with:
    - education services
    - social care services as appropriate.

## Later presentation of learning or behavioural problems

- 1.3.16 Primary and secondary education professionals should be aware that:
- preterm birth may be a factor in learning or behavioural problems
  - these problems can emerge at any point during a child or young person's education
  - prompt referral to educational support services may be needed.

## 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 to 1.3.3) 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 (for example, the PARCA-R, SDQ, ASQ and IQ tests such as the 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 enhanced developmental support:
  - neonatologist or paediatrician with an understanding of neonatal care and child development
  - outreach nurse or nurse with expertise in the development of babies born preterm
- for the surveillance assessments up to and including 2 years (corrected age) (see [recommendation 1.3.6](#)):
  - neonatologist or paediatrician with an understanding of neonatal care and child development
  - at least one of occupational therapist, physiotherapist and speech and language therapist
- for the surveillance assessment at 4 years (uncorrected age) (see [recommendation 1.3.13](#)):
  - educational or clinical 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 or health visitor
- occupational therapist
- physiotherapist
- speech and language therapist
- paediatric neurologist
- dietitian.

## 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 if so, relevant details
- the reasons for enhanced surveillance (see recommendations 1.3.1 to 1.3.3)
- at the assessment at 2 years (corrected age) (see recommendation 1.3.11):
  - diagnosis of cerebral palsy
  - 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 (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)

- at the assessment at 4 years (uncorrected age) (see [recommendation 1.3.13](#)):
  - diagnosis of cerebral palsy
  - GMFCS score if cerebral palsy is present
  - full scale IQ score
  - 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
  - results of national orthoptic vision screening.

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).

## **Enhanced developmental support**

Additional advice and interventions with skilled professionals for children and young people born preterm and their parents and carers. The aim is to support them after discharge from hospital, respond to their concerns, and reduce the impact of any developmental problems and disorders.

## **Enhanced developmental surveillance**

Active monitoring of a child's development, at set times and using specific tools, to detect developmental problems and disorders.

## **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.

## **Learning disability (Intellectual disability)**

Learning disability (intellectual disability) 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.

## **Small for gestational age**

Birth weight less than the 10<sup>th</sup> percentile for gestational age.

# Putting this guideline into practice

NICE has produced [tools and resources](#) to help you put this guideline into practice.

One issue was highlighted that might need specific thought when implementing the recommendations. This was raised during the development of this guideline. The issue is service organisation for implementing the developmental assessment at 4 years (uncorrected age).

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.

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 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 (uncorrected) 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 (uncorrected) for predicting later educational difficulties in children of primary school age who were born before 28<sup>+0</sup> weeks' gestation?

### Why this is important

Children born before 28<sup>+0</sup> weeks' gestation are at increased risk of [learning disability \(intellectual disability\)](#), 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 learning disability (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 carried out at age 2 years (corrected) for predicting learning disability (intellectual disability), language impairment and special educational needs at age 4 years (uncorrected) 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 learning disability (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 concurrent and predictive accuracy of the parent-completed Ages and Stages Questionnaire, 3rd edition (ASQ-3) for detecting concurrent learning disability (intellectual disability) and motor impairment between the ages of 2 years (corrected) and 4 years (uncorrected) 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 concurrent and predictive accuracy for detecting learning disability (intellectual disability) and motor impairment between the ages of 2 years (corrected) and 4 years (uncorrected), 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<sup>+0</sup> 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<sup>+0</sup> 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 4 years (uncorrected age) 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.

# Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the [NICE topic page on postnatal care](#).

For full details of the evidence and the guideline committee's discussions, see the [evidence reviews](#). You can also find information about [how the guideline was developed](#), including [details of the committee](#).

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).

## Update information

**October 2021:** We added a link to NICE's shared decision making guideline in recommendation 1.1.4.

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## Accreditation

