

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Guideline scope

### Developmental follow-up of preterm babies

#### *Topic*

The Department of Health in England has asked NICE to develop a clinical guideline on the developmental follow-up of preterm babies.

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the [context](#) section.

#### *Who the guideline is for*

- Parents and carers of babies, children and young people who were born preterm.
- Healthcare professionals in primary, secondary and tertiary care.
- Commissioners and providers of services for the developmental follow-up of preterm babies.

It may also be relevant for:

- Voluntary organisations.
- Educational services.
- Social care services.

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NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#).

### ***Equality considerations***

NICE has carried out an [equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

## **1 What the guideline is about**

### ***1.1 Who is the focus?***

#### **Groups that will be covered**

- Babies, children and young people under 18 years who were born preterm (less than 37 weeks of pregnancy).

### ***1.2 Settings***

#### **Settings that will be covered**

- All settings in which NHS or local authority commissioned healthcare is provided (including educational settings).

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### **1.3      *Activities, services or aspects of care***

#### **Key areas that will be covered**

- 1      The risk of developmental problems (such as feeding difficulties) and developmental disorders (such as cerebral palsy or autism) in relation to gestational age at birth for babies, children and young people who were born preterm, and other factors that might affect their risk.
- 2      Identifying developmental problems and disorders in babies, children and young people who were born preterm.
- 3      Providing information about the development of preterm babies for parents and carers and children and young people who were born preterm.
- 4      Providing support (for example, help with feeding difficulties, including continuing breastfeeding if appropriate, and with parent-child interaction) for babies, children and young people who were born preterm and their parents and carers.
- 5      Service delivery for developmental follow-up after preterm birth.

#### **Areas that will not be covered**

- 1      Diagnosing and managing developmental disorders such as autism and cerebral palsy. These areas are covered by existing NICE guidance on [autism diagnosis in children and young people](#) and [autism: the management and support of children and young people on the autism spectrum](#), and in guidance being developed on the [diagnosis and management of cerebral palsy in children and young people](#).
- 2      Reducing the risk of preterm birth.

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## **1.4 Economic aspects**

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS, educational and personal social services perspective, as appropriate.

## **1.5 Draft review questions**

While writing this scope, we have identified the following key issues, and review questions related to them:

- 1 The risk of developmental problems and disorders in relation to gestational age at birth for babies, children and young people who were born preterm, and other factors (for example, maternal, neonatal and societal factors) that might affect their risk:
  - What is the risk of developmental problems and disorders in babies, children and young people born preterm at different gestational ages?
  - What is the prognosis of specific developmental problems and disorders in babies, children and young people born preterm at different gestational ages?
  - What factors other than the degree of prematurity (for example, maternal, neonatal, socioeconomic and environmental factors) influence the prevalence and prognosis of developmental problems and disorders in babies, children and young people born preterm?

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- 2 Identifying developmental problems and disorders in babies, children and young people who were born preterm:
  - How often should babies, children and young people born preterm with different levels of risk be monitored to identify developmental problems and disorders?
  - Until what age should babies, children and young people born preterm with different levels of risk be monitored to identify developmental problems and disorders?
  - What is the diagnostic value of parents' and teachers' observations in identifying developmental disorders in babies, children and young people who were born preterm?
  - What is the diagnostic value of standard opportunistic assessments (for example, the [Healthy Child Programme](#) [Department of Health 2009]) and validated developmental screening and assessment tools (used in primary and secondary settings) in identifying developmental disorders in babies, children and young people who were born preterm?
  - What corrections, if any, should be made for gestational age when using developmental screening and assessment tools?
  - When should corrections for gestational age stop?
- 3 Providing information:
  - What information about the development of preterm babies should be given to parents and carers and children and young people who were born preterm?

- What information about follow-up arrangements of preterm babies should be given to parents and carers and children and young people?
  - What information should be shared (with consent) between those delivering NHS-commissioned care, and between the NHS and schools, on the developmental follow-up of babies, children and young people born preterm?
  - How should information be shared between those delivering NHS-commissioned care, and between the NHS and schools, on the developmental follow-up of babies, children and young people born preterm?
- 4 Support:
- What support (for example, help with feeding difficulties including continuing breastfeeding if appropriate, and with parent-child interaction) should be provided for parents and carers of preterm babies and for children and young people who were born preterm and their parents or carers?
- 5 Service delivery for developmental follow-up programmes:
- What is the most effective model (including staff and setting) of service delivery to identify developmental problems and disorders in babies, children and young people born preterm?

## **1.6 Main outcomes**

The main outcomes that will be considered when searching for and assessing the evidence are:

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- 1 Quality of life (both health- and social-related quality).
- 2 Social functioning.
- 3 Ability to carry out activities of daily living.
- 4 Educational attainment.

## **2 Links with other NICE guidance, NICE quality standards, and NICE Pathways**

### **2.1 NICE guidance**

#### **NICE guidance in development that is closely related to this guideline**

NICE is currently developing the following guidance that is closely related to this guideline:

- [Preterm labour and birth](#) NICE guideline. Publication expected November 2015.
- [Mental health problems in people with learning disabilities](#) NICE guideline. Publication expected September 2016.
- [Cerebral palsy](#) NICE guideline. Publication expected October 2016.
- [Intrapartum care for high risk women](#) NICE guideline. Publication expected January 2017.
- [Faltering growth](#) NICE guideline. Publication expected October 2017.
- [Social and emotional wellbeing in primary and secondary education](#) Publication date to be confirmed.

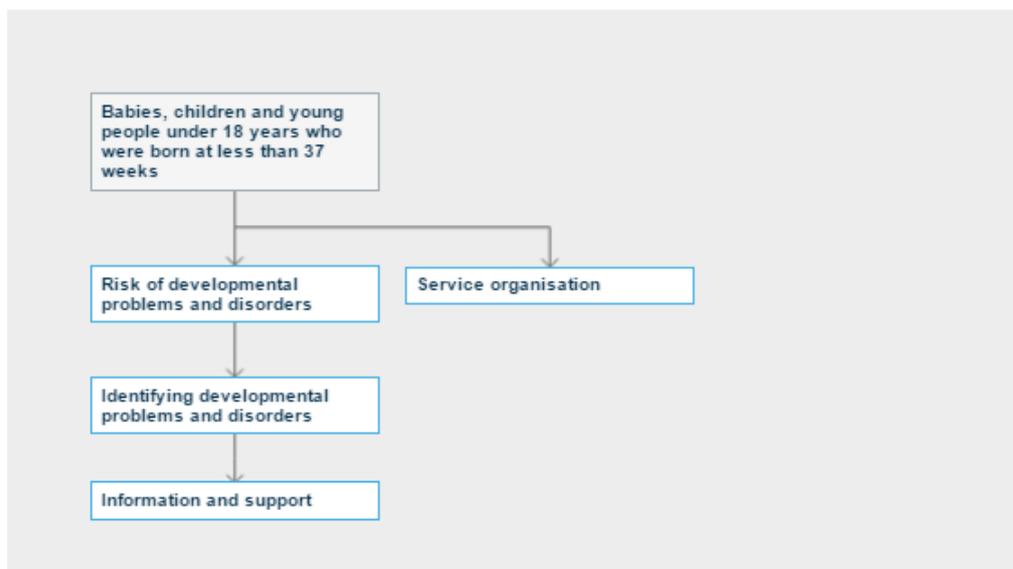
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## 2.2 NICE Pathways

When this guideline is published, the recommendations will be added to [NICE Pathways](#). NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

A draft pathway outline on developmental follow-up of preterm babies, based on this scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

### Developmental follow-up of preterm babies overview



Links will be made from other relevant pathways, for example, preterm labour and birth (when published) and [postnatal care](#).

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## 3 Context

### 3.1 *Key facts and figures*

Development in childhood is the process whereby children progress from a state of complete dependency to independent adult life. This encompasses a broad range of skills and their application in daily life: motor competencies, speech and language, communication, cognitive and learning skills, vision and listening skills, social, emotional and behavioural development applied both in self-regulation and interpersonal relationships, and self-help competencies such as feeding, sleeping and excretion.

Development typically progresses in a regular manner with skills (milestones) being attained in a predictable sequence. There is normal variation in the age at which milestones are reached and the median age is generally used for comparison. In addition, ages by which particular milestones would be expected to have been reached have been defined. Developmental follow-up is intended to monitor this progress.

Development is influenced by both genetic and environmental factors. Brain development begins early in gestation and progresses through early childhood and beyond. During intrauterine development and in the early years of life the brain is susceptible to injury, potentially leading to impairments that can affect development.

In 2012/2013 more than 7% of live babies were born preterm (less than 37<sup>+0</sup> weeks of pregnancy) in England ([Health and Social Care Information Centre: NHS maternity statistic 2012/13](#)).

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The consequences of preterm birth can be substantial with a wide range of possible physical, neurodevelopmental and behavioural sequelae. Compared with those born at term, preterm babies have more health problems, including higher rates of temperature instability, respiratory distress, apnoea, seizures, jaundice and feeding difficulties. They are also more likely to need re-admission to hospital. Neurodevelopmental problems, behavioural problems, cerebral palsy, sensory impairment and complex mixed neurodevelopmental problems affecting attention and academic progress have been linked to preterm birth.

It has been predicted that 4.2% of all surviving preterm babies will have a severe disability at 18 years, and that 18.5% will have a milder disability (Mangham LJ, Petrou S, Doyle LW et al. [2009] [The cost of preterm birth throughout childhood in England Wales](#). *Pediatrics* 123: 312-27). The [EPICure 1995 study](#) of children born very prematurely (between 20<sup>+0</sup> and 25<sup>+6</sup> weeks of gestation) showed that at the age of 11 years more than half had no or only minor impairments or health problems and 45% had moderate or severe impairments.

The greater the degree of prematurity, the higher the risk of both short-term and long-term complications. However, even babies born between 32<sup>+0</sup> and 36<sup>+0</sup> weeks of pregnancy are at higher risk of short- and long-term poor health outcomes or disability compared with babies born at full term. The [NHS atlas of variation](#) (Annual Report of the Chief Medical Officer 2012) Map 34 shows that impairment-free survival at 2 years for babies born at less than 30<sup>+0</sup> weeks of pregnancy in neonatal units ranges from 15.7-37.1% across the

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country, but 2-year health status data were available for only 40% of eligible babies. Local factors are likely to have a major influence on this.

Public sector annual cost for babies, children and young people up to 18 years of age who were born preterm is estimated to be £1.24 billion, with a total societal cost of £2.48 billion, including parental costs and lost productivity (Strelitz [2012] Annual Report of the chief Medical Officer). Most of the costs (92%) are incurred during the neonatal period (the first 28 days of life) and are largely attributable to neonatal hospitalisation. For those with severe disability, estimated at 4.2% of preterm babies, the costs are far greater and have been estimated as 10% of the total costs of disability in childhood.

### **3.2 Current practice**

Screening for developmental disorders can be inaccurate, both in terms of missing significant delays in development (false-negative results) and over-recognition. This trade-off between sensitivity and specificity has been seen as problematic and as a result screening is selective in some countries and universal in others.

In the UK the [Healthy Child Programme](#) (Department of Health 2009) is used as the basis for practice in supporting optimum development and identifying problems and disorders. This programme includes developmental reviews to aid early detection of developmental delay, and emphasises the importance of a review at 2.5 years. There is a core programme that applies to all children and additional elements for those at risk.

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In current practice, primary care practitioners (health visitors or GPs) ask questions about the child's development and any parental concerns at each visit. Standardised development screening tools are not currently used, and are not recommended by the [UK National Screening Committee](#) or the [Healthy Child Programme](#).

Preterm babies, especially those who are very premature (between 28<sup>+0</sup> and 32<sup>+0</sup> weeks of pregnancy) or extremely premature (less than 28<sup>+0</sup> weeks of pregnancy) are likely to be followed up in a secondary or tertiary care clinic, often with outreach nurses.

### **3.3 Policy, legislation, regulation and commissioning**

#### **Policy**

The [National service framework for children, young people and maternity services](#) (Department of Health 2004) aims for long-term and sustained improvement in children's health, and sets standards for health and social services for children, young people and pregnant women.

The [UK National Screening Committee](#) advises on evidence-based whole-population screening for conditions including congenital heart disease, cystic fibrosis, congenital cataracts and sensorineural hearing impairment.

The [Healthy Child Programme](#) (Department of Health 2009) is the key universal public health service for improving the health and well-being of children through health and developmental reviews, screening and health promotion, immunisation and parenting support.

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The NICE quality standard for [specialist neonatal care](#) (2010) includes the quality statement 'Babies receiving specialist neonatal care have their health outcomes monitored'. The associated measures include the proportion of babies born at less than 30 weeks of gestation and at less than 32 weeks of gestation and/or with a birth weight less than 1501 g, and receiving specialist neonatal care, who had a 2-year outcome form completed. However, variation in practice has been identified in the nature, frequency and duration of developmental assessments, and less than half of very premature babies have an assessment of their health outcomes at 2 years.

#### **4 Further information**

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in August 2017.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.