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.

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.

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 [add hyperlink in final version] during scoping. The assessment:

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

1 What the guideline is about

1.1 Who is the focus

Groups that will be covered

- Babies, children and young people under 13 years who were born preterm (less than 37 weeks of gestation).

Groups that will not be covered

- Babies, children and young people born at or after 37 weeks of gestation.
- Young people aged 13 years or older.

1.2 Settings

Settings that will be covered

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

1.3 Activities, services or aspects of care

Key areas that will be covered

1. The identification of developmental problems and disorders in babies, children and young people who were born preterm.
2. 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.
3. Provision of information about development for babies, children and young people who were born preterm and their parents and carers.
4. Provision of support (for example, help with parent-child interaction, such as guided interaction) for babies, children and young people who were born preterm and their parents and carers.
5. Service delivery for developmental follow-up following preterm birth (for example which healthcare professionals are responsible for the identification, assessment and follow-up arrangements of babies, children and young people who were born preterm).

Areas that will not be covered

1. Management of developmental disorders (such as cerebral palsy) associated with preterm birth.
2. Reducing the risk of preterm birth.

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 Key issues and questions

We have identified the following key issues, and key questions related to them:

1. The risk of developmental problems and disorders in babies, children and young people who were born preterm:
   - 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 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?
2. Methods of identifying developmental problems and disorders in babies, children and young people who were born preterm:
   - How frequently should babies, children and young people born at varying degrees of prematurity be monitored for the identification of developmental problems and disorders?
   - Until what age should babies, children and young people born at varying degrees of prematurity be monitored for the identification of developmental problems and disorders?

  - What is the diagnostic value of parental concern in the identification of developmental disorders in babies, children and young people who were born preterm?
  - What is the diagnostic value of validated developmental assessment tools (used in primary and secondary settings) in identifying developmental disorders in babies, children and young people who were born preterm?
  - What is the diagnostic accuracy of modified opportunistic assessments versus standard opportunistic screening (for example, the Healthy Child Programme [Department of Health 2009] in identifying developmental disorders in babies, children and young people who were born preterm?
3. Information provision:
   - What information about development and follow-up arrangements should be provided to parents and carers of preterm babies, and to children and young people who were born preterm and their parents or carers?
   - What is the most effective approach to share information between organisations delivering NHS commissioned health care and schools on the developmental follow-up of babies, children and young people born preterm?
4. Support:
   - What support (for example, help with parent-child interaction, such as guided interaction) should be provided to newborn babies, babies, children and young people who were born preterm and to their parents or carers?
5. Service delivery for developmental follow-up programmes:
   - What is the most appropriate model (including setting and personnel) for service delivery for the identification and assessment of 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:

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
5. patient experience
6. parent and carer experience.

2 Links with other NICE guidance and NICE Pathways

2.1 NICE guidance

NICE guidance in development that is closely related to this guideline

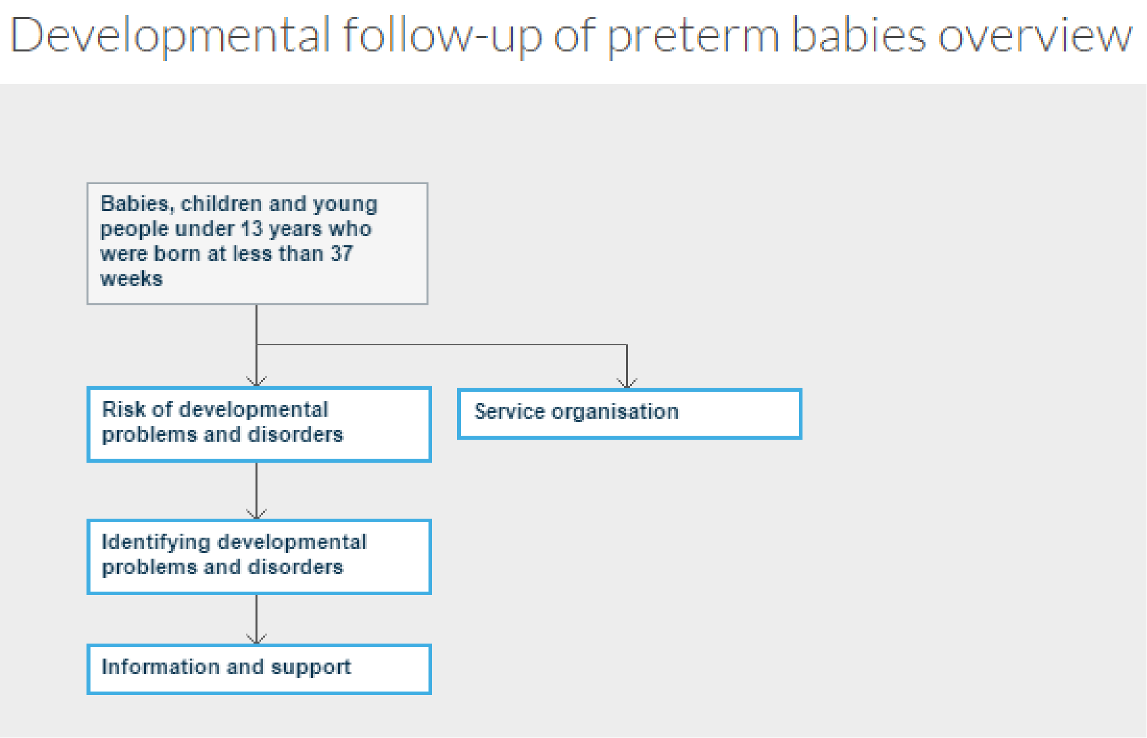
NICE is currently developing the following guidance that is closely related to this guideline:

- Challenging behaviour and learning disabilities NICE guideline. Publication expected May 2015.
- 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.
- Failure to thrive NICE guideline. Publication expected October 2017.

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 draft scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.



Other NICE guidance that may be included in this pathway includes Human growth hormone (somatropin) for the treatment of growth failure in children (NICE technology appraisal guidance 188), because it covers children who are small for gestational age.

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

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 in feeding, sleeping and excretion

Typical development 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 have been defined by which a particular milestone would be expected to have been reached. 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. Preterm birth can increase susceptibility to delayed or impaired development.

Preterm birth is defined as birth at less than 37 weeks of gestation. In 2010/2011 more than 7% of live babies were born preterm in England (Health and Social Care Information Centre: NHS maternity statistic 2010/11).

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 readmission 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 is 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 et al 2009). The EPICure 1995 study of children born very prematurely (between 20 and 25 weeks 6 days of gestation) in 1995 showed that at the age of 11 years more than half had no or only minor impairments or health problems, while 45% had moderate or severe impairment.

The greater the degree of prematurity, the higher the risk of both short-term and long-term complications. However, even babies born at 32 to 36 weeks of gestation are at higher risk of short and long-term poor health outcomes or disability compared with babies born at full term. The 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 under 30 weeks of gestation in neonatal units ranges from 15.7-37.1% across the country, but 2 year health status data was only available for 40% of eligible infants. 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). The specific long-term outcome from preterm birth of severe disability in children and young people aged 2-18 years accounts for 10% of the total public sector costs for severe disability among children and young people. Most of the costs (92%) are during the neonatal period (the first 28 days of life) and largely attributable to neonatal hospitalisation.

3.2 Current practice

Screening for developmental disorders can be inaccurate, both in terms of missing significant delay (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 and 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 facilitate 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.

In current practice, primary care practitioners (health visitors or GPs) opportunistically ask questions about the child's development at each visit, focusing on promotion of child developmental and parental concerns about behaviour, learning and development. Standardised development screening tools are not currently used, and are not recommended by the National Screening Committee or the Healthy Child Programme.

Preterm babies, especially those who are very premature (28-32 weeks of gestation) or extremely premature (less than 28 weeks of gestation) are likely to be followed-up in a secondary or tertiary care clinic, often with outreach nurses.

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 health and well-being of children through health and developmental reviews, screening and health promotion, immunisation and parenting support.

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 of developmental assessments, their frequency and duration, and less than half of very premature babies receive an assessment of their health outcomes at 2 years.

4 Further information

This is the draft scope for consultation with registered stakeholders. The consultation dates are 29 May to 26 June 2015.

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.