Developmental follow-up of children and young people born preterm

NICE quality standard

Draft for consultation

15 December 2017

This quality standard 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 describes high-quality care in priority areas for improvement.

It is for commissioners, service providers, health, public health and social care.

This is the draft quality standard for consultation (from 15 December 2017 to 19 January 2018). The final quality standard is expected to publish in May 2018.

Quality statements

Statement 1 Parents or carers of a preterm baby agree a discharge plan with maternity services.

Statement 2 Parents or carers of a preterm baby who is eligible for enhanced developmental support are provided with a single point of contact for outreach care within the neonatal service.

Statement 3 Children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up visits in the first year and an assessment at 2 years that focus on development.

Statement 4 Children born before 28^{+0} weeks' gestation have a developmental assessment at age 4 years.

Other quality standards that should be considered when commissioning or providing developmental follow-up of babies, children and young people under 18 years who were born preterm (before 37^{+0} weeks of pregnancy) services include:

- Cerebral palsy in children and young people (2017) NICE quality standard 162.
- Preterm labour and birth (2016) NICE quality standard 135.
- Autism (2014) NICE quality standard 51.
- Multiple pregnancy: twin and triplet pregnancies (2013) NICE quality standard 46.
- Attention deficit hyperactivity disorder (2013) NICE quality standard 39.
- Postnatal care (2013) NICE quality standard 37.
- Neonatal specialist care (2010) NICE quality standard 4.

A full list of NICE quality standards is available from the quality standards topic library.

Questions for consultation

Questions about the quality standard

Question 1 Does this draft quality standard accurately reflect the key areas for quality improvement?

Question 2 Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?

Question 3 Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Local practice case studies

Question 4 Do you have an example from practice of implementing the NICE guideline(s) that underpins this quality standard? If so, please submit your example to NICE local practice case studies on the NICE website. Examples of using NICE quality standards can also be submitted.

Quality statement 1: Discharge planning

Quality statement

Parents or carers of a preterm baby agree a discharge plan with maternity services.

Rationale

Many families can feel ill-equipped to care for their preterm baby after discharge, and they may experience high levels of anxiety after leaving the hospital. Involving families in planning discharge and agreeing a written discharge plan with information to help them can minimise this.

Quality measures

Structure

Evidence of local arrangements for healthcare professionals in maternity services to agree a discharge plan with parents or carers of a preterm baby before the baby is discharged.

Data source: Local data collection, for example, service protocols.

Process

Proportion of discharges for preterm babies where the parents or carers have a discharge plan.

Numerator – the number in the denominator where the parents or carers have a discharge plan.

Denominator – the number of discharges for preterm babies.

Data source: Local data collection, such as the child's personal folder or patient record systems.

Outcome

Proportion of parents or carers who felt prepared for their baby’s discharge from maternity services.

Data source: Local data collection, for example, parent or carer surveys. The Neonatal Survey 2014 includes a question on whether parents felt prepared for their baby's discharge from neonatal care.

What the quality statement means for different audiences

Service providers (maternity services, including neonatal and postnatal services) ensure that healthcare professionals have the time and resources to involve parents or carers of a preterm baby in discharge planning and provide them with tailored information before the baby is discharged.

Healthcare professionals (such as midwives, neonatal nurses and neonatologists) involve parents or carers of a preterm baby in discharge planning as soon as possible after the birth of the baby and at all stages. They agree a discharge plan with them that includes information tailored to their individual circumstances. It should cover risk factors for developmental problems and disorders, support available and follow-up arrangements. They share the written discharge plan with parents or carers and with primary and secondary healthcare teams.

Commissioners (NHS England and clinical commissioning groups) ensure that they commission services that have the capacity and resources to involve parents or carers of a preterm baby in discharge planning and provide a written plan that includes information tailored to their individual circumstances. They undertake contract monitoring and seek evidence that service providers have this in place.

Parents or carers of a preterm baby are involved in planning for going home from hospital as soon as possible after the birth of the baby and at all stages. They agree a written discharge plan that includes tailored information on risk factors for developmental problems and disorders, support available and follow-up arrangements.

Source guidance

Developmental follow-up of children and young people born preterm (2017) NICE guideline 72, recommendation 1.1.8

Definitions of terms used in this quality statement

Preterm baby

Babies born before 37^{+0} weeks of pregnancy. [NICE's guideline on developmental follow-up of children and young people born preterm]

Discharge plan

The plan should include clear information that is tailored to individual circumstances about:

- any antenatal and perinatal risk factors for developmental problems and disorders
- routine postnatal care and support available, as described in the NICE guideline on postnatal care up to 8 weeks after birth
- 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)
- whether their baby will also be offered enhanced developmental support and surveillance and plans for follow-up
- opportunities for peer support
- talking to their health visitor or GP if they have any concerns about their child's development at any stage of childhood or adolescence.

[Adapted from NICE's guideline on developmental follow-up of children and young people born preterm recommendations 1.1.3, 1.1.6, 1.1.8, 1.1.11, 1.1.12, and 1.1.14]

Equality and diversity considerations

People should be provided with information that they can easily read and understand themselves, or with support, so they can communicate effectively with health and social care services. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in NHS England's Accessible Information Standard.

Quality statement 2: Single point of contact

Quality statement

Parents or carers of a preterm baby who is eligible for enhanced developmental support are provided with a single point of contact for outreach care within the neonatal service.

Rationale

Many families can feel ill-equipped to care for their preterm baby following discharge, and they may experience high levels of anxiety after leaving the hospital. Being able to contact an expert in working with preterm children to ask questions or get reassurance can reduce this anxiety. It can also help with the identification and management of early developmental problems.

Quality measures

Structure

Evidence of local arrangements for a neonatal outreach team with expertise in the development of babies born preterm to be available through a single point of contact.

Data source: Local data collection, for example, service specifications.

Process

Proportion of preterm babies who are eligible for enhanced developmental support whose parents or carers are provided with a single point of contact for outreach care within the neonatal service.

Numerator – the number in the denominator whose parents or carers are provided with a single point of contact for outreach care within the neonatal service.

Denominator – the number of preterm babies who are eligible for enhanced developmental support.

Data source: Local data collection based on audits of patient care records.

Outcome

Level of satisfaction of parents or carers of a preterm baby with the outreach care provided by neonatal services.

Data source: Local data collection, for example, parent or carer surveys.

What the quality statement means for different audiences

Service providers (neonatal services) ensure that healthcare professionals with expertise in children born preterm are available to provide information and reassurance to parents or carers of a preterm baby having enhanced developmental support.

Healthcare professionals (such as neonatal nurses or specialist community nurses) are part of a neonatal outreach team that is available through a single point of contact. They are available to answer questions and reassure parents or carers of a preterm baby who is eligible for enhanced developmental support after discharge.

Commissioners (NHS England) ensure that they commission services that have capacity and staff with expertise in children born preterm to provide a single point of contact for outreach care within the service for parents or carers of a preterm baby who is eligible for enhanced developmental support. They undertake contract monitoring and seek evidence that service providers have this in place.

Parents or carers of a preterm baby who is having extra support know how to contact someone to speak to if they have any worries about looking after their baby.

Source guidance

Developmental follow-up of children and young people born preterm (2017) NICE guideline 72, recommendation 1.3.4

Definitions of terms used in this quality statement

Preterm baby eligible for enhanced developmental support

Babies born before 37^{+0} weeks of pregnancy 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.

[NICE's guideline on developmental follow-up of children and young people born preterm, recommendation 1.3.1]

Enhanced developmental support

Support that includes 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. The support should be tailored to take account of individual preferences and needs.

[NICE's guideline on developmental follow-up of children and young people born preterm, recommendation 1.3.5]

Single point of contact for outreach care

This could be a telephone helpline, e-mail address, or other messaging service. A single point of contact within the neonatal service will be staffed by experts in preterm development. Parents or carers can seek advice from this contact after discharge on issues such as feeding, breathing, crying and sleeping, and get reassurance.

[Adapted from NICE's full guideline on developmental follow-up of children and young people born preterm]

Quality statement 3: Enhanced developmental surveillance up to 2 years

Quality statement

Children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up visits in the first year and an assessment at 2 years that focus on development.

Rationale

Children who are born preterm are at increased risk of a range of developmental problems and disorders that may have an adverse impact on their health and well-being. Face-to-face follow-up visits and a developmental assessment during the first 2 years allow for early identification of problems and disorders and monitoring of progress. This means that appropriate support and intervention can be provided to improve a child's outcomes.

Quality measures

Structure

a) Evidence of local systems, such as BadgerNet, to record data on children born preterm and identify who needs enhanced developmental surveillance.

Data source: Local data collection, for example, service specifications.

b) Evidence of local systems to arrange 2 face-to-face follow-up visits in the first year and an assessment at 2 years (corrected age) that focus on development with children born preterm who are eligible for enhanced developmental surveillance.

Data source: Local data collection, for example, service protocols.

Process

a) Proportion of children born preterm who are eligible for enhanced developmental surveillance who have a follow-up visit between 3 and 5 months (corrected age) that focuses on development.

Numerator – the number in the denominator who have a follow-up visit between 3 and 5 months (corrected age) that focuses on development.

Denominator – the number of children born preterm who are eligible for enhanced developmental surveillance.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book') or a patient record system, such as BadgerNet.

b) Proportion of children born preterm who are eligible for enhanced developmental surveillance who have a follow-up visit by 12 months (corrected age) that focuses on development.

Numerator – the number in the denominator who have a follow-up visit by 12 months (corrected age) that focuses on development.

Denominator – the number of children born preterm who are eligible for enhanced developmental surveillance.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book') or a patient record system, such as BadgerNet.

c) Proportion of children born preterm who are eligible for enhanced developmental surveillance who have a face-to-face developmental assessment at 2 years (corrected age).

Numerator – the number in the denominator who have a face-to-face developmental assessment at 2 years (corrected age).

Denominator – the number of children born preterm who are eligible for enhanced developmental surveillance.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book') or a patient record system, such as BadgerNet. The National Neonatal Audit Programme includes data on clinical follow-up at age 2 years for babies born before 30^{+0} weeks' gestation.

Outcomes

a) Proportion of children born preterm who are eligible for enhanced developmental surveillance who have a follow-up visit between 3 and 5 months (corrected age) with a developmental outcome category recorded.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book') or a patient record system, such as BadgerNet.

b) Proportion of children born preterm who are eligible for enhanced developmental surveillance who have a follow-up visit by 12 months (corrected age) with a developmental outcome category recorded.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book') or a patient record system, such as BadgerNet.

c) Proportion of children born preterm who are eligible for enhanced developmental surveillance who have a face-to-face developmental assessment at 2 years (corrected age) with a developmental outcome category recorded.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book') or a patient record system, such as BadgerNet. The National Neonatal Audit Programme includes data on neurodevelopmental outcomes recorded at clinical follow-up at age 2 years for babies born before 30 weeks' gestation.

What the quality statement means for different audiences

Service providers (neonatal services) ensure that systems are in place to identify children born preterm who are eligible for enhanced developmental surveillance and to arrange at least 2 face-to-face follow-up visits in the first year and a face-to-face assessment at 2 years (corrected age) that focus on development.

Healthcare professionals (neonatologists, paediatricians, occupational therapists, physiotherapists and speech and language therapists) are either present at the 2 face-to-face follow-up visits in the first year and the assessment at 2 years (corrected age), or are available through referral for children born preterm who are eligible for enhanced developmental surveillance. At the visits they discuss with parents or carers whether they have any concerns and check for developmental problems and disorders. At the 2 year (corrected age) assessment they use screening tools to check for developmental problems and disorders and also ensure that vision and hearing checks have been carried out. If there are any suspected problems they investigate further or refer to the appropriate local pathway.

Commissioners (NHS England) ensure that they commission services that have the capacity and expertise to provide children born preterm who are eligible for enhanced developmental surveillance with the required follow-up visits and assessments that focus on development. They undertake contract monitoring and seek evidence that service providers have this in place.

Children born preterm having extra support have at least 2 face-to-face follow-up visits in their first year and an assessment at 2 years (corrected age). These are with a doctor and another health professional, such as a physiotherapist, occupational therapist or speech and language therapist. The purpose is to check their development and see if they have any problems. Their parents or carers will have a chance to talk about any concerns. If there are any suspected problems, the healthcare professionals will investigate further or refer them to local services.

Source guidance

Developmental follow-up of children and young people born preterm (2017) NICE guideline 72, recommendations 1.3.6 and 1.3.11

Definitions of terms used in this quality statement

Children born preterm eligible for enhanced developmental surveillance

Children born before 37^{+0} weeks of pregnancy 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.

[NICE’s guideline on developmental follow-up of children and young people born preterm, recommendation 1.3.1]

Enhanced developmental surveillance

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

[NICE’s guideline on developmental follow-up of children and young people born preterm]

Follow-up visits in the first year and an assessment at 2 years that focus on development

Face-to-face follow-up assessments that should involve the following professionals:

- neonatologist or paediatrician with an understanding of neonatal care and child development
- at least 1 of occupational therapist, physiotherapist and speech and language therapist

At each visit professionals should:

- discuss with parents or carers whether they have any concerns about their child's development
- include checks for developmental problems and disorders

- 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.

The assessment at 2 years (corrected age) should also include:

- 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), a suitable alternative parent questionnaire should be used
- 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.

[NICE’s guideline on developmental follow-up of children and young people born preterm, recommendations 1.3.6, 1.3.7, 1.3.11 and 1.4.3]

Equality and diversity considerations

The PARCA-R might not be suitable for people with poor English language comprehension. In these circumstances a suitable alternative parent questionnaire should be provided, depending on the needs of the child.

Quality statement 4: Developmental assessment at 4 years

Quality statement

Children born before 28^{+0} weeks' gestation have a developmental assessment at age 4 years.

Rationale

Children who are born before 28^{+0} weeks' gestation are at increased risk of a range of developmental problems and disorders that may have an impact on their health and well-being. Significant problems cannot always be reliably assessed at the 2 year assessment, or problems and disorders of a lesser severity may only become evident at this later age. A face-to-face developmental assessment at 4 years allows difficulties to be identified and gives an understanding of overall development. This allows appropriate support and intervention to be provided before a child starts school to improve a child's outcomes and school-based learning.

Quality measures

Structure

a) Evidence of local systems, such as BadgerNet, to record data on children born preterm and identify those born before 28^{+0} weeks' gestation.

Data source: Local data collection, for example, service specifications.

b) Evidence of local systems to arrange a developmental assessment at 4 years (uncorrected age) with children who are born before 28^{+0} weeks' gestation.

Data source: Local data collection, for example, service protocols.

Process

Proportion of children born before 28^{+0} weeks' gestation who have a face-to-face developmental assessment at 4 years (uncorrected age).

Numerator – the number in the denominator who have a face-to-face developmental assessment at 4 years (uncorrected age).

Denominator – the number of children born before 28^{+0} weeks' gestation.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book') or the child health information system.

Outcome

Proportion of children born before 28^{+0} weeks' gestation that have a developmental assessment at age 4 years (uncorrected age) with a developmental outcome category recorded.

Data source: Local data collection, such as the Royal College of Paediatrics and Child Health personal child health record ('red book') or the child health information system.

What the quality statement means for different audiences

Service providers (community paediatric services) ensure that systems are in place to identify children born before 28^{+0} weeks' gestation and to arrange a face-to-face developmental assessment at 4 years (uncorrected age).

Healthcare professionals (educational psychologists, clinical psychologists and paediatricians with expertise in neurodevelopment) attend a face-to-face developmental assessment at 4 years (uncorrected age) with children born before 28^{+0} weeks' gestation. At the visit they discuss with parents or carers whether they have any concerns and check for developmental problems and disorders. They use assessments to check for social, attentional, emotional and behavioural problems, and to check development and IQ. They ensure that orthoptic vision screening has been offered. If there are any suspected problems they investigate further or refer to the appropriate local pathway.

Commissioners (clinical commissioning groups) ensure that they commission services that have the capacity and expertise to provide children born before 28^{+0} weeks' gestation with the required developmental assessment. They undertake contract monitoring and seek evidence that service providers have this in place.

Children born before 28+0 weeks have a face-to-face assessment at 4 years (uncorrected age) with a doctor and a psychologist to check their development and see if they have any problems. Their parents or carers will have a chance to talk about any concerns. If there are any suspected problems, the healthcare professionals will investigate further or refer them to local services.

Source guidance

Developmental follow-up of children and young people born preterm (2017) NICE guideline 72, recommendations 1.3.3 and 1.3.13

Definitions of terms used in this quality statement

Developmental assessment at age 4 years

A face-to-face assessment that should involve the following professionals:

- an educational or clinical psychologist
- a paediatrician with expertise in neurodevelopment.

This assessment should include as a minimum:

- discussing with parents or carers whether they have any concerns about their child's development
- include checks for developmental problems and disorders
- measuring length or height, weight and head circumference
- carefully evaluating and reviewing any developmental concerns reported by parents or carers or noted during the visit or assessment
- correcting for gestational age up to 2 years when assessing developmental history
- considering further investigation or referral if a developmental problem or disorder is suspected or present
- referring the child to the appropriate local pathway if needed
- 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

  If the questionnaires are not suitable (for example, because of poor English language comprehension or the child being outside the validated age range), a suitable alternative parent questionnaire should be used
- 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
- Gross Motor Function Classification System (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.

[NICE's guideline on developmental follow-up of children and young people born preterm, recommendations 1.3.7, 1.3.13 and 1.4.3 and expert opinion]

Equality and diversity considerations

The questionnaires used at the assessment might not be suitable for people with poor English language comprehension. In these circumstances a suitable alternative parent questionnaire should be provided, depending on the needs of the child.

About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about how NICE quality standards are developed is available from the NICE website.

See quality standard advisory committees on the website for details of standing committee 1 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the quality standard's webpage.

This quality standard has been included in the NICE Pathway on developmental follow-up of children and young people born preterm, which brings together everything we have said on developmental follow-up of children and young people born preterm in an interactive flowchart.

NICE has produced a quality standard service improvement template to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- child development at 2 to 2.5 years
- child development at 4 years
- school readiness
- identification of developmental problems and disorders
- parent and carer satisfaction with services
- parent and carer wellbeing.

It is also expected to support delivery of the Department of Health's outcome frameworks:

- NHS outcomes framework 2016–17
- Public health outcomes framework for England, 2016–19.

Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact statement for the NICE guideline on developmental follow-up of children and young people born preterm to help estimate local costs:

Diversity, equality and language

During the development of this quality standard, equality issues were considered and equality assessments are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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