

Developmental follow-up of children and young people born preterm

Quality standard

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This standard is based on NG72 and NG194.

This standard should be read in conjunction with QS162, QS135, QS51, QS46, QS39, QS37, QS193 and QS197.

Quality statements

Statement 1 Parents or carers of a preterm baby have an agreed discharge plan.

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 appointments 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 4 years.

Quality statement 1: Discharge planning

Quality statement

Parents or carers of a preterm baby have an agreed discharge plan.

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 can minimise this and help them to feel prepared.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

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

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

Process

Proportion of preterm babies discharged from hospital whose parents or carers have a discharge plan.

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

Denominator – the number of preterm babies discharged from hospital.

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 hospital.

Data source: Local data collection, for example, parent or carer surveys. The [Picker Institute's 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 (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 from hospital.

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 before they leave hospital and with primary and secondary healthcare teams.

Commissioners 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. NICE guideline NG72 (2017), 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](#)
- 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
- signposting to local support services, such as [Bliss](#), [Twins Trust](#), [Scope](#) and [National Childbirth Trust](#)
- 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 support on non-acute issues can reduce this anxiety. It can also help with the identification and management of early developmental problems.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

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

Proportion of parents or carers of a preterm baby who felt they could access support for dealing with non-acute issues following discharge from 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 support to parents or carers of a preterm baby having enhanced developmental support while their baby is followed up by neonatal services.

Healthcare professionals (such as neonatal nurses, specialist community nurses, occupational therapists, physiotherapists, and speech and language therapists) are part of a neonatal outreach team that is available through a single point of contact. They are available to answer questions about non-acute issues and support parents or carers of a preterm baby who is eligible for enhanced developmental support after discharge and while they are followed up by neonatal services.

Commissioners 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. The outreach care should be available for parents or carers of a preterm baby who is eligible for enhanced developmental support while their baby is followed up by neonatal services. 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 while their baby is followed up by neonatal services.

Source guidance

Developmental follow-up of children and young people born preterm. NICE guideline NG72 (2017), 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, email address, or other messaging service. A single point of contact within the neonatal service will be staffed by experts in preterm development. While their baby is followed up by neonatal services after discharge from hospital, parents or carers can seek advice from this contact on non-acute feeding, breathing, crying and sleeping issues, and get support. [Adapted from [NICE's full guideline on developmental follow-up of children and young people born preterm](#)]

Quality statement 3: Enhanced developmental surveillance

Quality statement

Children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up appointments 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 appointments and a developmental assessment during the first 2 years (corrected ages) 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

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

a) Evidence of local systems, such as the BadgerNet electronic record system, 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 appointments in the first year and an assessment at 2 years (corrected ages) 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 appointment between 3 and 5 months (corrected age) that focuses on development.

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

Numerator – the number in the denominator who have a further follow-up appointment 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.

Outcome

a) 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.

b) Proportion of children born preterm with developmental problems and disorders identified at the appointments in the first 2 years (corrected ages) who have support provided.

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](#).

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 appointments in the first year and a face-to-face

assessment at 2 years (corrected ages) 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 appointments in the first year (corrected age), or are available through referral for children born preterm who are eligible for enhanced developmental surveillance. A neonatologist or paediatrician and at least 1 of occupational therapist, physiotherapist and speech and language therapist should be present at the assessment at 2 years (corrected age). At the appointments 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 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 appointments 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 appointments in their first year and an assessment at 2 years (corrected ages). 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. NICE guideline NG72 (2017), 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 appointments 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 appointment 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 appointment 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 assessment 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 assessments used at the 2-year review might not be suitable for people with poor English language comprehension. In these circumstances a suitable alternative assessment 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 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 to improve a child's outcomes and school-based learning.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

a) Evidence of local systems, such as the BadgerNet electronic record system, 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 with developmental problems and disorders identified at the developmental assessment at 4 years (uncorrected age) who have support provided.

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 as close to the child's fourth birthday (uncorrected age) as possible.

Health care professionals (educational psychologists, clinical psychologists and paediatricians with expertise in neurodevelopment) attend a face-to-face developmental assessment with children born before 28+0 weeks' gestation as close to the child's fourth birthday (uncorrected age) as possible. At the appointment 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 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 as close to their fourth birthday (uncorrected age) as possible 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. NICE guideline NG72 (2017), 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 takes place as close to the child's fourth birthday (uncorrected age) as possible 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 appointment 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 assessment 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 UK 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

assessment should be provided, depending on the needs of the child.

Update information

Minor changes since publication

April 2021: Changes have been made to this quality standard to update links and references to the updated [NICE guideline on postnatal care](#).

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 our [webpage on quality standards advisory committees](#) for details of our standing committees. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](#).

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 guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

During the development of this quality standard, equality issues were considered and [equality assessments for this quality standard](#) 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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Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Royal College of Nursing \(RCN\)](#)
- [Royal College of Occupational Therapists \(RCOT\)](#)
- [Bliss](#)
- [Association of Paediatric Chartered Physiotherapists](#)
- [Royal College of Paediatrics and Child Health](#)