

# **Cerebral palsy in children and young people**

## **NICE quality standard**

### **Draft for consultation**

May 2017

**This quality standard covers** diagnosing, assessing and managing cerebral palsy in children and young people under 25. It describes high-quality care in priority areas for improvement.

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

This is the draft quality standard for consultation (from 11 May to 8 June 2017). The final quality standard is expected to publish in October 2017.

## Quality statements

[Statement 1](#) Children with any risk factor for cerebral palsy have an enhanced multidisciplinary clinical and developmental follow-up programme from birth to 2 years.

[Statement 2](#) Children with delayed motor milestones are referred to a child development service.

[Statement 3](#) Children and young people with cerebral palsy have a personal folder.

[Statement 4](#) Children and young people with cerebral palsy are given information about how specialist teams will be involved if they are needed to manage comorbidities.

Other quality standards that should be considered when commissioning or providing cerebral palsy services for children and young people include:

- [Preterm labour and birth](#) (2016) NICE quality standard 135
- [Multiple pregnancy: twin and triplet pregnancies](#) (2013) NICE quality standard 46
- [Meningitis \(bacterial\) and meningococcal septicaemia in children and young people](#) (2012) NICE quality standard 19

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.

### ***Questions about the individual quality statements***

**Question 4** For draft quality statement 1: In order to measure whether an enhanced clinical and developmental follow-up programme has been provided, a schedule of appointments is needed. Please can you provide details of appointments and timescales that you would expect to be provided? If this is not possible, can you suggest how the statement could be measured?

### ***Local practice case studies***

**Question 5** Do you have an example from practice of implementing the NICE guideline 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: Follow-up for children at risk of cerebral palsy

### ***Quality statement***

Children with any risk factor for cerebral palsy have an enhanced multidisciplinary clinical and developmental follow-up programme from birth to 2 years.

### ***Rationale***

The signs of cerebral palsy might not be apparent at birth. Following up children with a risk factor for cerebral palsy for the first 2 years of life will help to identify and diagnose cerebral palsy as early as possible. Early diagnosis can guide interventions, inform prognosis and let family members know what to expect.

### ***Quality measures***

#### **Structure**

Evidence of enhanced clinical and developmental follow-up programmes for children with risk factors for cerebral palsy.

**Data source:** Local data collection

#### **Process**

Proportion of children with a risk factor for cerebral palsy who have an enhanced clinical and developmental programme by a multidisciplinary team from birth to 2 years.

Numerator – the number in the denominator who have an enhanced clinical and developmental follow-up programme by a multidisciplinary team from birth to 2 years.

Denominator – the number of children with a risk factor for cerebral palsy.

**Data source:** Local data collection, such as the Royal College of Paediatrics and Child Health [personal child health record](#) ('red book').

## **Outcome**

Children and young people with cerebral palsy who were diagnosed by age 2.

**Data source:** Local data collection.

## ***What the quality statement means for different audiences***

**Service providers** (such as secondary care services) work together to ensure the provision of multidisciplinary teams that provide an enhanced clinical and developmental follow-up programme for children from birth to 2 years (corrected for gestational age) who have a risk factor for cerebral palsy.

**Healthcare professionals** (such as midwives and neonatologists) can identify risk factors for cerebral palsy and refer children who have a risk factor for cerebral palsy to an enhanced clinical and developmental follow-up programme from birth to 2 years (corrected for gestational age) delivered by a multidisciplinary team.

**Commissioners** (such as clinical commissioning groups) ensure that they commission services that provide an enhanced clinical and developmental follow-up programme, delivered by a multidisciplinary team, for children from birth to 2 years (corrected for gestational age) who have a risk factor for cerebral palsy.

**Babies who have problems that might cause cerebral palsy** have their movement and development closely checked until they are 2 years old, because cerebral palsy is not always obvious at birth. Some common causes of cerebral palsy are problems in the way the baby's brain develops before birth, an infection in the baby before or shortly after birth, or a difficult or early (preterm) birth.

## ***Source guidance***

[Cerebral palsy in under 25s: assessment and management](#) (2017) NICE guideline NG62, recommendations 1.1.2 and 1.3.1.

## ***Definitions of terms used in this quality statement***

### **Risk factors for developing cerebral palsy**

The following are independent risk factors for developing cerebral palsy:

- antenatal factors:
  - preterm birth (with risk increasing with decreasing gestational age)
  - chorioamnionitis
  - maternal respiratory tract or genito-urinary infection treated in hospital
- perinatal factors:
  - low birth weight
  - chorioamnionitis
  - neonatal encephalopathy
  - neonatal sepsis (particularly with a birth weight below 1.5 kg)
  - maternal respiratory tract or genito-urinary infection treated in hospital
- postnatal factors:
  - meningitis.

[NICE's guideline on [cerebral palsy in under 25s: assessment and management](#), recommendation 1.1.1]

### **Enhanced clinical and developmental follow-up programme**

An enhanced clinical and developmental follow-up programme ensures that a child has their movement and development closely checked. This should happen at their routine appointments up to age 3 months. They should then have extra follow-up appointments to check for problems until they are 2 years old. This should be performed by a multidisciplinary team that can provide the following expertise:

- paediatric medicine
- nursing care
- physiotherapy
- occupational therapy
- speech and language therapy
- dietetics
- psychology.

[Adapted from NICE's guideline on [cerebral palsy in under 25s: assessment and management](#), recommendation 1.5.3]

***Question for consultation***

In order to measure whether an enhanced clinical and developmental follow-up programme has been provided, a schedule of appointments is needed. Please can you provide details of appointments and timescales that you would expect to be provided?

If this is not possible, can you suggest how the statement could be measured?

## Quality statement 2: Referral for children with delayed motor milestones

### ***Quality statement***

Children with delayed motor milestones are referred to a child development service.

### ***Rationale***

The diagnosis of cerebral palsy is typically based on observations and parental reports on the attainment and quality of motor milestones. Referral to a child development service will enable early diagnosis of cerebral palsy, guide interventions, inform prognosis and let family members know what to expect.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that children with delayed motor milestones are referred to a child development service.

**Data source:** Local data collection, such as the Royal College of Paediatrics and Child Health [personal child health record](#) ('red book').

#### **Process**

Proportion of children with delayed motor milestones who are referred to a child development service.

Numerator – the number in the denominator who are referred to a child development service.

Denominator – the number of children with delayed motor milestones.

**Data source:** Local data collection, such as the Royal College of Paediatrics and Child Health [personal child health record](#) ('red book').

#### **Outcome**

Children and young people with cerebral palsy who were diagnosed by age 2.

**Data source:** Local data collection.

### ***What the quality statement means for different audiences***

**Service providers** (such as primary care services) provide healthcare professionals with training to enable them to identify delayed motor milestones in children.

**Healthcare professionals** (such as GPs, practice nurses and health visitors) are aware of motor milestones in children and refer children with delayed motor milestones to a child development service for multidisciplinary assessment.

**Commissioners** (such as clinical commissioning groups) commission child development services which provide an urgent assessment in order to facilitate early diagnosis and intervention in children with delayed motor milestones.

**Children with unusual signs that suggest possible cerebral palsy** are referred to a specialist team at the local child development service for more checks to find out whether they have cerebral palsy. Examples of unusual signs are not sitting by 8 months, not walking by 18 months, or using one hand more than the other before 12 months.

### ***Source guidance***

[Cerebral palsy in under 25s: assessment and management](#) (2017) NICE guideline NG62, recommendation 1.3.6.

### ***Definitions of terms used in this quality statement***

#### **Delayed motor milestones**

The following are the most common delayed motor milestones in children with cerebral palsy:

- not sitting by 8 months (corrected for gestational age)
- not walking by 18 months (corrected for gestational age)
- early asymmetry of hand function (hand preference) before 1 year (corrected for gestational age).

[NICE's guideline on [cerebral palsy in under 25s: assessment and management](#), recommendation 1.3.5]

### **Child development service**

A service that offers multidisciplinary assessment for children. It provides the following expertise, as appropriate, through a local network of care:

- paediatric or adult medicine
- nursing care
- physiotherapy
- occupational therapy
- speech and language therapy
- dietetics
- psychology.

[Adapted from NICE's guideline on [cerebral palsy in under 25s: assessment and management](#), recommendation 1.5.3]

## Quality statement 3: Personal folders for children and young people with cerebral palsy

### ***Quality statement***

Children and young people with cerebral palsy have a personal folder.

### ***Rationale***

A personal folder will have information about the child or young person with cerebral palsy that can be shared with health, social care and education providers to ensure good communication. Having a personal folder can help children and young people with cerebral palsy, their families and carers to take control and make informed decisions about their lives and how their condition is managed.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that children and young people with cerebral palsy have a personal folder.

**Data source:** Local data collection.

#### **Process**

Proportion of children and young people with cerebral palsy who have a personal folder.

Numerator – the number in the denominator who have a personal folder.

Denominator – the number of children and young people with cerebral palsy.

**Data source:** Local data collection.

#### **Outcome**

a) Satisfaction of children and young people with cerebral palsy with the information received.

**Data source:** Local data collection.

b) Satisfaction of parents and carers of children and young people with cerebral palsy with the information received.

**Data source:** Local data collection.

### ***What the quality statement means for different audiences***

**Service providers** (such as health, social care and educational providers) ensure that systems are in place for children and young people with cerebral palsy to have a personal folder that can be shared with family members and carers, and used in health, social care and educational settings.

**All health and social care practitioners** help children and young people with cerebral palsy and their parents or carers to develop and maintain a personal folder.

**Commissioners** (such as clinical commissioning groups) ensure that they commission services that provide children and young people with cerebral palsy with a personal folder.

**Children and young people with cerebral palsy** have a personal file with information that is unique to them. The information could include their medical history, care plans, medicines, special needs, and who to contact in an emergency. Their care team helps them to put the information together and keep it up to date. The personal file can be in an electronic format or notes on paper, and can be shared with everyone who supports the family, including friends, other family members, health professionals, social workers and teachers.

### ***Source guidance***

[Cerebral palsy in under 25s: assessment and management](#) (2017) NICE guideline NG62, recommendation 1.6.5.

### ***Definitions of terms used in this quality statement***

#### **Personal folder**

A personal folder is a file that contains information about the child or young person with cerebral palsy that can be shared with family members and friends, and used in health, social care and educational. The file can be in an electronic format, or on

paper, whichever is preferred by the child or young person and their family or carers. It could include:

- early history
- motor subtype and limb involvement
- functional abilities
- interventions
- medication
- comorbidities
- preferred methods of communication
- any specialist equipment that is used or needed
- care plans
- emergency contact details.

[NICE's guideline on [cerebral palsy in under 25s: assessment and management](#), recommendation 1.6.5]

### ***Equality and diversity considerations***

Children and young people with cerebral palsy 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 should be culturally and age appropriate. Children and young people with cerebral palsy should have access to an interpreter or advocate if needed.

For children and young people with cerebral palsy who have 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 4: Information about specialist teams for children and young people with cerebral palsy**

### ***Quality statement***

Children and young people with cerebral palsy are given information about how specialist teams will be involved if they are needed to manage comorbidities.

### ***Rationale***

Specialist teams provide interventions for any comorbidities children and young people with cerebral palsy may have. This can help the child or young person to achieve their individual goals and gain functional independence.

### ***Quality measures***

#### **Structure**

a) Evidence of regionally defined referral routes to specialist teams involved in the management of associated comorbidities in children and young people with cerebral palsy.

**Data source:** Local data collection.

b) Evidence of multidisciplinary care teams that enable access to specialist teams within their local or regional networks.

**Data source:** Local data collection.

#### **Process**

Proportion of children and young people with cerebral palsy who are given information about how specialist teams will be involved.

Numerator – the number in the denominator who are given information about how specialist teams will be involved.

Denominator – the number of children and young people with cerebral palsy.

**Data source:** Local data collection, such as the child or young person's personal folder.

### **Outcome**

a) Functional independence of children and young people with cerebral palsy.

**Data source:** Local data collection.

b) Educational attainment of children and young people with cerebral palsy.

**Data source:** Local data collection. This information can be collected by regional education authorities.

### ***What the quality statement means for different audiences***

**Service providers** (such as child development services) are aware of referral routes for children and young people with cerebral palsy that provide access to specialist teams involved in the management of associated comorbidities. The multidisciplinary care team is best placed to provide access because they are familiar with local and regional referral routes.

**Healthcare professionals** (such as paediatricians, nurses, physiotherapists, occupational therapists, speech and language therapists, dietitians and psychologists) are aware of referral routes to specialist teams and provide information about how they will be involved in the management of comorbidities associated with cerebral palsy.

**Commissioners** (such as clinical commissioning groups) commission services that provide specialist teams involved in the management of comorbidities associated with cerebral palsy and ensure that referral routes are clearly defined..

**Children and young people children with cerebral palsy** are offered specialist treatment and support for any difficulties or conditions caused by their cerebral palsy.

### ***Source guidance***

[Cerebral palsy in under 25s: assessment and management](#) (2017) NICE guideline NG62, recommendations 1.5.4, 1.6.2 and 1.6.5.

## ***Definitions of terms used in this quality statement***

### **Specialist teams involved in the management comorbidities**

Specialist teams will include:

- paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and surgical specialist care
- orthopaedics
- orthotics and rehabilitation services
- social care
- visual and hearing specialist services
- teaching support for preschool and school-age children, including portage (home teaching services for preschool children).

[Adapted from NICE's guideline on [cerebral palsy in under 25s: assessment and management](#), recommendation 1.5.3]

### ***Equality and diversity considerations***

Children and young people with cerebral palsy 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 should be culturally and age appropriate. Children and young people with cerebral palsy should have access to an interpreter or advocate if needed.

For children and young people with cerebral palsy who have additional needs related to a disability, impairment or sensory loss, information should be provided as set out in NHS England's [accessible information standard](#).

## 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.

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 will be incorporated into the NICE pathway on [cerebral palsy in under 25s](#).

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:

- health-related quality of life of children and young people with cerebral palsy

- functional independence of children and young people with cerebral palsy
- educational participation of children and young people with cerebral palsy
- wellbeing of parents and carers of children and young people with cerebral palsy.

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

- [Adult social care outcomes framework 2015–16](#)
- [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 source guidance 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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