

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Health and social care directorate

### Quality standards and indicators

#### Briefing paper

**Quality standard topic:** Cerebral palsy in children and young people

**Output:** Prioritised quality improvement areas for development.

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## **1 Introduction**

This briefing paper presents a structured overview of potential quality improvement areas for cerebral palsy in children and young people. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

### **1.1 Structure**

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

### **1.2 Development source**

The key development sources referenced in this briefing paper are:

- [Cerebral palsy in under 25s: assessment and management](#) (2017). NICE guideline NG62
- [Spasticity in under 19s: management](#) (2012). NICE guideline CG145  
Review decision made November 2016 not to update the guideline.

## **2 Overview**

### **2.1 Focus of quality standard**

This quality standard will cover the diagnosis, assessment and management of cerebral palsy in children and young people under 25.

### **2.2 Definition**

Cerebral palsy describes a group of permanent, non-progressive abnormalities of the developing fetal or infant brain leading to disorders of movement and posture, causing 'activity limitation' and 'functional impairment'.

There are different types of cerebral palsy depending on how movement and muscles are affected. The most common is called spastic cerebral palsy, where the muscles are stiff and movements can seem jerky. Less common types, such as dyskinetic (dystonic) or ataxic cerebral palsy, lead to problems with the control of movement or balance. Mixed cerebral palsy is a combination of types.

## **2.3 Incidence and prevalence**

Cerebral palsy is the most common cause of physical disability in children and young people in the developed world, with a prevalence of around 2 to 2.5 per 1,000 live births.

Everyone with cerebral palsy is affected differently – symptoms vary widely and the effects can range from minor problems to severe disability. Around 1 in 3 children with cerebral palsy have epilepsy.

## **2.4 Management**

The management of cerebral palsy is a two-pronged approach, and is provided by a variety of multidisciplinary services with a focus on maximising individual function, choice and independence. The first of these is optimising movement and posture for optimal activity and participation while minimising potential secondary musculoskeletal deformity. The second is recognising and intervening to address the many developmental and clinical comorbidities that are associated with cerebral palsy.

See appendices 1 and 2 for the associated care pathway and algorithms from NICE clinical guideline NG62.

## **2.5 Resource impact assessment**

The resource impact statement for [NG62](#) did not expect the guideline to have a significant impact on resources; that is, it would be less than £1m per year in England (or £1,800 per 100,000 population). This is because where there is variation in practice, changes or improvements in care and patient and family experience will be achieved by using existing resources differently.

In addition the costing report produced with [CG145](#) found that while consideration had been given to the likely resource impact of interventions such as orthopaedic surgery and selective dorsal rhizotomy, it was not possible to quantify national cost of implementing the guidance.

As such none of the suggested improvement areas within this briefing paper are expected to have significant resource impact.

## **2.6 National outcome frameworks**

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

**Table 1 [Adult social care outcomes framework 2015–16](#)**

Domain	Overarching and outcome measures
<p>1 Enhancing quality of life for people with care and support needs</p>	<p><b>Overarching measure</b>                      1A Social care-related quality of life**</p> <p><b>Outcome measures</b>  <b>People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs</b></p> <p>1B Proportion of people who use services who have control over their daily life</p> <p>1C Proportion of people using social care who receive self-directed support, and those receiving direct payments</p> <p><b>Carers can balance their caring roles and maintain their desired quality of life</b></p> <p>1D Carer-reported quality of life**</p> <p><b>People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation</b></p> <p>1I Proportion of people who use services and their carers, who reported that they had as much social contact as they would like</p>
<p>3 Ensuring that people have a positive experience of care and support</p>	<p><b>Overarching measure</b>  <b>People who use social care and their carers are satisfied with their experience of care and support services</b></p> <p>3A Overall satisfaction of people who use services with their care and support</p> <p>3B Overall satisfaction of carers with social services</p> <p><b>Outcome measures</b>  <b>Carers feel that they are respected as equal partners throughout the care process</b></p> <p>3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for</p> <p><b>People know what choices are available to them locally, what they are entitled to, and who to contact when they need help</b></p> <p>3D The proportion of people who use services and carers who find it easy to find information about support</p> <p><b>People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual</b></p> <p>This information can be taken from the Adult Social Care Survey and used for analysis at the local level.</p>
<p><b>Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework</b>                      * Indicator is shared</p>	

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\*\* Indicator is complementary  
Indicators in italics in development

**Table 2 [NHS outcomes framework 2016–17](#)**

<b>Domain</b>	<b>Overarching indicators and improvement areas</b>
2 Enhancing quality of life for people with long-term conditions	<p><b><i>Overarching indicator</i></b>                      2 Health-related quality of life for people with long-term conditions**</p> <p><b><i>Improvement areas</i></b>  <b>Ensuring people feel supported to manage their condition</b>                      2.1 Proportion of people feeling supported to manage their condition</p> <p><b>Enhancing quality of life for carers</b>                      2.4 Health-related quality of life for carers**</p>
4 Ensuring that people have a positive experience of care	<p><b><i>Overarching indicators</i></b>                      4a Patient experience of primary care                      i GP services                      ii GP Out-of-hours services                      4b Patient experience of hospital care                      4c <i>Friends and family test</i>                      4d <i>Patient experience characterised as poor or worse</i>  <i>I Primary care</i>  <i>ii Hospital care</i></p> <p><b><i>Improvement areas</i></b>  <b>Improving people’s experience of outpatient care</b>                      4.1 Patient experience of outpatient services</p> <p><b>Improving hospitals’ responsiveness to personal needs</b>                      4.2 Responsiveness to inpatients’ personal needs</p> <p><b>Improving access to primary care services</b>                      4.4 Access to i GP services</p> <p><b>Improving children and young people’s experience of healthcare</b>                      4.8 <i>Children and young people’s experience of inpatient services</i></p>
<p><b>Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework</b>                      * Indicator is shared                      ** Indicator is complementary                      Indicators in italics in development</p>	

### 3 Summary of suggestions

#### 3.1 Responses

In total 12 stakeholders responded to the 2-week engagement exercise 25/01/17 – 08/02/17.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the committee.

Full details of all the suggestions provided are given in appendix 4 for information.

**Table 3 Summary of suggested quality improvement areas**

<b>Suggested area for improvement</b>	<b>Stakeholders</b>
<b>Multidisciplinary care</b>	BCTC, RCGP, SCM
<b>Management of spasticity</b> <ul style="list-style-type: none"> <li>• Principles of care</li> <li>• Physical therapy</li> <li>• Orthoses</li> <li>• Orthopaedic surgery</li> <li>• Selective dorsal rhizotomy</li> </ul>	BCTC, BSCOS, DMO, LTH, RCGP, SCM
<b>Difficulties associated with cerebral palsy</b> <ul style="list-style-type: none"> <li>• Speech, language and communication</li> <li>• Low bone mineral density</li> <li>• Visual impairment</li> </ul>	DMO, RCGP, RCO, RCSLT, VIPS
<b>Care needs</b>	BCTC, SCM
<b>Information and support</b>	ACP, SCM
<b>Additional areas</b> <ul style="list-style-type: none"> <li>• National register</li> <li>• Training</li> <li>• Dynamic spinal management</li> <li>• Transition to adults services</li> </ul>	ACP, BCTC, DMO, SCM
ACP, Action Cerebral Palsy BCTC, Bobath Children's Therapy Centre Wales BSCOS, British Society for Children's Orthopaedic Surgery DMO, DM Orthotics Ltd LTH, Leeds Teaching Hospital NHS Trust RCGP, Royal College of General Practitioners RCO, Royal College of Ophthalmologists RCSLT, Royal College of Speech and Language Therapists SCM, Specialist Committee Member(s) VIPS, Visual Impairment Paediatric Special Interest Group	

### **3.2      *Identification of current practice evidence***

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 134 papers were identified for cerebral palsy in children and young people. In addition, 2 papers were suggested by stakeholders at topic engagement.

Of these papers, 5 have been included in this report and are included in the current practice sections where relevant. Appendix 3 outlines the search process.

## 4 Suggested improvement areas

### 4.1 Initial assessment of cerebral palsy

#### 4.1.1 Summary of suggestions

##### Multidisciplinary care

Stakeholders identified that children and young people with cerebral palsy and their parents and carers should to be referred to a multidisciplinary team which included specialists in cerebral palsy. This included having a single point of contact as well as healthcare professionals in primary care being aware of referral routes.

#### 4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the committee’s discussion.

**Table 4 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Suggested source guidance recommendations</b>
Multidisciplinary care	<b>Multidisciplinary care</b> NICE NG62 Recommendations 1.5.1 to 1.5.5

##### Multidisciplinary care

###### NICE NG62 – Recommendation 1.5.1

Refer all children with suspected cerebral palsy to a child development service for an urgent multidisciplinary assessment, in order to facilitate early diagnosis and intervention.

###### NICE NG62 – Recommendation 1.5.2

Recognise that children and young people with cerebral palsy and their parents or carers have a central role in decision-making and care planning.

###### NICE NG62 – Recommendation 1.5.3

Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:

- is able to meet their individual needs within agreed care pathways

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- can provide 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
- can enable access to other services within their local or regional network as appropriate, including:
  - 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).

### NICE NG62 – Recommendation 1.5.4

Ensure that routes for accessing specialist teams involved in managing comorbidities associated with cerebral palsy are clearly defined on a regional basis.

### NICE NG62 – Recommendation 1.5.5

Recognise that ongoing communication between all levels of service provision in the care of children and young people with cerebral palsy is crucial, particularly involvement of primary care from diagnosis onwards.

## **4.1.3 Current UK practice**

### **Multidisciplinary care**

Building on an inquiry in 2014, Action Cerebral Palsy found, there was insufficient specialist-support amongst CCGs. Of 209 CCGs approached 92% failed to provide details of their pathway for children and young people with cerebral palsy and only 5% could provide a service framework. The report concluded that this lack of specialist support can lead to late-diagnosis and missed opportunities for early intervention<sup>1</sup>.

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<sup>1</sup> Action Cerebral Palsy (2016). [Variations in Care: An analysis of cerebral palsy provision](#)

## **4.2      *Management of spasticity***

### **4.2.1    Summary of suggestions**

#### **Principles of care**

Stakeholders highlighted the need to improve the management of spasticity in children and young people with cerebral palsy. In particular they highlighted the need for active monitoring and screening, to ensure that interventions have proved effective and prevent deterioration in physical abilities.

#### **Physical therapy**

Stakeholders recognised that there is variation in access to physical therapy rehabilitation for children and young people with cerebral palsy. In particular they highlighted there was variation in community settings.

#### **Orthoses**

Stakeholders felt that early intervention, such as using bracing for the management of scoliosis, required improvement. Children and young people who have improved postural care are also likely to improve communication.

#### **Orthopaedic surgery**

A stakeholder suggested that single-event multi-level surgery (SEMLS) in children and young people with cerebral palsy, can be used to correct a number of associated deformities. Using SEMLS will reduce the length of rehabilitation time compared to other types of orthopaedic surgery.

#### **Selective dorsal rhizotomy**

Stakeholders highlighted the use of selective dorsal rhizotomy to increase mobility in children and young people with cerebral palsy. This will improve the likelihood that the children and young person can maintain a level of independence.

### **4.2.2    Selected recommendations from development source**

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

**Table 5 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Suggested source guidance recommendations</b>
Principles of care	<p><b>Management programmes</b> NICE CG145 Recommendations 1.1.4 and 1.1.10</p> <p><b>Monitoring</b> NICE CG145 Recommendations 1.1.14 to 1.1.16</p>
Physical therapy	<p><b>Physical therapy</b> NICE CG145 Recommendations 1.2.2 and 1.2.4 to 1.2.7</p>
Orthoses	<p><b>Orthoses</b> NICE CG145 Recommendations 1.3.1 to 1.3.5</p>
Orthopaedic surgery	<p><b>Orthopaedic surgery</b> NICE CG145 Recommendation 1.7.8</p>
Selective dorsal rhizotomy	<p><b>Selective dorsal rhizotomy</b> NICE CG145 Recommendation 1.8.1</p>

**Principles of care**

NICE CG145 – Recommendation 1.1.4

Following diagnosis, ensure that all children and young people with spasticity are referred without delay to an appropriate member of the network team.

NICE CG145 – Recommendation 1.1.10

Help children and young people and their parents or carers to be partners in developing and implementing the management programme by offering:

- relevant, and age and developmentally appropriate, information and educational materials
- regular opportunities for discussion **and**
- advice on their developmental potential and how different treatment options may affect this.

NICE CG145 – Recommendation 1.1.14

Monitor the child or young person's condition for:

- the response to treatments

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- worsening of spasticity
- developing secondary consequences of spasticity, for example pain or contractures
- the need to change their individualised goals.

### NICE CG145 – Recommendation 1.1.15

The network of care should have a pathway for monitoring children and young people at increased risk of hip displacement.

### NICE CG145 – Recommendation 1.1.16

Recognise the following clinical findings as possible indicators of hip displacement (hip migration greater than 30%):

- pain arising from the hip
- clinically important leg length difference
- deterioration in hip abduction or range of hip movement
- increasing hip muscle tone
- deterioration in sitting or standing
- increasing difficulty with perineal care or hygiene.

## **Physical activity**

### NICE CG145 – Recommendation 1.2.2

Offer a physical therapy (physiotherapy and/or occupational therapy) programme tailored to the child or young person's individual needs and aimed at specific goals, such as:

- enhancing skill development, function and ability to participate in everyday activities
- preventing consequences such as pain or contractures.

### NICE CG145 – Recommendation 1.2.4

When formulating a physical therapy programme for children and young people take into account:

- the views of the child or young person and their parents or carers
- the likelihood of achieving the treatment goals
- possible difficulties in implementing the programme
- implications for the individual child or young person and their parents or carers, including the time and effort involved and potential individual barriers.

#### NICE CG145 – Recommendation 1.2.5

When deciding who should deliver physical therapy, take into account:

- whether the child or young person and their parents or carers are able to deliver the specific therapy
- what training the child or young person or their parents or carers might need
- the wishes of the child or young person and their parents or carers.

#### NICE CG145 – Recommendation 1.2.6

Ensure that any equipment or techniques used in the physical therapy programme are safe and appropriate, in particular for children or young people with any of the following:

- poorly controlled epilepsy
- respiratory compromise
- increased risk of pulmonary aspiration
- increased risk of bone fracture due to osteoporosis (for example, those who are unable to walk, malnourished or taking anti-epileptic therapy).

#### NICE CG145 – Recommendation 1.2.7

Encourage children and young people and their parents or carers to incorporate physical therapy into daily activities (for example, standing at the sink while brushing teeth in order to stretch leg muscles).

### **Orthoses**

#### NICE CG145 – Recommendation 1.3.1

Consider orthoses<sup>2</sup> for children and young people with spasticity based on their individual needs and aimed at specific goals, such as:

- improving posture
- improving upper limb function
- improving walking efficiency
- preventing or slowing development of contractures
- preventing or slowing hip migration
- relieving discomfort or pain
- preventing or treating tissue injury, for example by relieving pressure points.

#### NICE CG145 – Recommendation 1.3.2

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<sup>2</sup> An artificial device or appliance used to support, align, prevent, or correct deformities or to improve musculoskeletal function.

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When considering an orthosis, discuss with the child or young person and their parents or carers the balance of possible benefits against risks. For example, discuss its cosmetic appearance, the possibility of discomfort or pressure sores or of muscle wasting through lack of muscle use.

### NICE CG145 – Recommendation 1.3.3

Assess whether an orthosis might:

- cause difficulties with self-care or care by others
- cause difficulties in relation to hygiene
- be unacceptable to the child or young person because of its appearance.

### NICE CG145 – Recommendation 1.3.4

Ensure that orthoses are appropriately designed for the individual child or young person and are sized and fitted correctly. If necessary seek expert advice from an orthotist within the network team.

### NICE CG145 – Recommendation 1.3.5

Be aware when considering a rigid orthosis that it may cause discomfort or pressure injuries in a child or young person with marked dyskinesia. They should be monitored closely to ensure that the orthosis is not causing such difficulties.

## **Orthopaedic surgery**

### NICE CG145 – Recommendation 1.7.8

If a child or young person will need several surgical procedures at different anatomical sites to improve their gait, perform them together if possible (single-event multilevel surgery), rather than individually over a period of time.

## **Selective dorsal rhizotomy**

### NICE CG145 – Recommendation 1.8.1

Consider selective dorsal rhizotomy to improve walking ability in children and young people with spasticity at GMFCS level II or III:

- Patient selection and treatment should be carried out by a multidisciplinary team with specialist training and expertise in the care of spasticity, and with access to the full range of treatment options.
- Discuss the irreversibility of the treatment, the known complications and the uncertainties over long-term outcomes with children and young people, and their parents and/or carers (see also Selective dorsal rhizotomy for spasticity in cerebral palsy, NICE interventional procedure guidance 373).

- Teams offering selective dorsal rhizotomy should participate in a coordinated national agreed programme to collect information on short- and long-term outcomes on all patients assessed for selective dorsal rhizotomy, whether or not selective dorsal rhizotomy is performed. These recorded outcomes should include measures of muscle tone, gross motor function, neurological impairment, spinal deformity, quality of life and need for additional operations, with nationally agreed consistent definitions.

### **4.2.3 Current UK practice**

#### **Principles of care**

A study into provision of health care for children and young people with cerebral palsy in the North of England looked at variation in different areas of care<sup>3</sup>. Using “p values” it found that there was significant variation between centres in the provision of hip and spine surveillance and management.

#### **Physical therapy**

A national survey of the amount of physical therapy given to children with cerebral palsy in the UK was completed by physiotherapists in 2012<sup>4</sup>. It found that among a total of 245 physiotherapists interventions were provided for 1425 children aged 1-18 years. The children receiving the most interventions were those aged 1-6 years, (median 17.6 hours), and the children receiving the least intervention were aged 12-18 years, (median 2.3 hours). Across all ages, the therapy where the most time was spent were ‘Body Functions and Structures’ at 3.8 hours (median), with 2.9 hours (median) on ‘Activity’ and 1 hour (median) on ‘Participation’. The survey suggested that these results should not be regarded as a benchmark for the amount of physiotherapy that children with CP should be receiving.

Additionally Action Cerebral Palsy found that 72% of CCGs commissioned paediatric physiotherapy services<sup>5</sup>.

#### **Orthoses**

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

#### **Orthopaedic surgery**

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<sup>3</sup> Horridge et al (2015). [Variation in health care for children and young people with cerebral palsies: a retrospective multicentre audit study.](#)

<sup>4</sup> The Association of Paediatric Chartered Physiotherapists (2012). [A National Survey of the Amount of Physiotherapy Intervention Given to Children with Cerebral Palsy in the UK in the NHS.](#)

<sup>5</sup> Action Cerebral Palsy (2016). [Variations in Care: An analysis of cerebral palsy provision](#)

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The study into provision of health care for children and young people with cerebral palsy also found significant variation amongst the availability of orthopaedic surgeons<sup>3</sup>.

**Selective dorsal rhizotomy**

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

### **4.3 Difficulties associated with cerebral palsy**

#### **4.3.1 Summary of suggestions**

##### **Speech, language and communication**

Stakeholders highlighted that that speech, language and communication difficulties occur in around 50% of children and young people with cerebral palsy. There is variation in assessment, interventions (including augmentative and alternative communication) and parent training.

##### **Low bone mineral density**

A stakeholder suggested that the use of bisphosphonates would improve bone mineral density in children and young people with cerebral palsy. This in turn would reduce the risk of fractures.

##### **Visual impairment**

Stakeholders highlighted the need for children and young people with cerebral palsy to receive a comprehensive assessment of any ocular dysfunction or visual impairment. This includes referral to a specialist as well as communication between other healthcare professionals and family members and/or carers.

#### **4.3.2 Selected recommendations from development source**

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the committee’s discussion.

**Table 6 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Suggested source guidance recommendations</b>
Speech, language and communication	<b>Speech, language and communication</b> NICE NG62 Recommendations 1.9.1 to 1.9.10
Low bone mineral density	<b>Low bone mineral density</b> NICE NG62 Recommendation 1.12.8
Visual impairment	<b>Visual impairment</b> NICE NG62 Recommendations 1.17.3 to 1.17.7

##### **Speech, language and communication**

NICE NG62 – Recommendation 1.9.1

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Talk to children and young people and their parents or carers about communication difficulties that can be associated with cerebral palsy. Information that may be useful to discuss includes the following:

- communication difficulties occur in around 1 in 2 children and young people with cerebral palsy
- at least 1 in 10 need augmentative and alternative communication (signs, symbols and speech generating devices)
- around 1 in 10 cannot use formal methods of augmentative and alternative communication because of cognitive and sensory impairments and communication difficulties
- communication difficulties may occur with any functional level or motor subtype, but are more common in children and young people with dyskinetic or severe bilateral spastic cerebral palsy
- communication difficulties do not necessarily correlate with learning disability (intellectual disability).

### NICE NG62 – Recommendation 1.9.2

Regularly assess children and young people with cerebral palsy during routine reviews to identify concerns about speech, language and communication, including speech intelligibility.

### NICE NG62 – Recommendation 1.9.3

Refer children and young people with cerebral palsy for specialist assessment if there are concerns about speech, language and communication, including speech intelligibility.

### NICE NG62 – Recommendation 1.9.4

Specialist assessment of the communication skills, including speech intelligibility, of children and young people with cerebral palsy should be conducted by a multidisciplinary team that includes a speech and language therapist.

### NICE NG62 – Recommendation 1.9.5

Recognise the importance of early intervention to improve the communication skills of children and young people with cerebral palsy.

### NICE NG62 – Recommendation 1.9.6

Offer interventions to improve speech intelligibility, for example targeting posture, breath control, voice production and rate of speech, to children and young people with cerebral palsy:

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- who have a motor speech disorder and some intelligible speech and
- for whom speech is the primary means of communication and
- who can engage with the intervention.

### NICE NG62 – Recommendation 1.9.7

Consider augmentative and alternative communication systems for children and young people with cerebral palsy who need support in understanding and producing speech. These may include pictures, objects, symbols and signs, and speech generating devices.

### NICE NG62 – Recommendation 1.9.8

If there are ongoing problems with using augmentative and alternative communication systems, refer the child or young person to a specialist service in order to tailor interventions to their individual needs, taking account of their cognitive, linguistic, motor, hearing and visual abilities.

### NICE NG62 – Recommendation 1.9.9

Regularly review children and young people who are using augmentative and alternative communication systems, to monitor their progress and ensure that interventions continue to be appropriate for their needs.

### NICE NG62 – Recommendation 1.9.10

Provide individualised training in communication techniques for families, carers, preschool and school staff and other people involved in the care of a child or young person with cerebral palsy.

## **Low bone mineral density**

### NICE NG62 – Recommendation 1.12.8

Refer children and young people with cerebral palsy with reduced bone density and a history of low-impact fracture to a specialist centre for consideration of bisphosphonate therapy.

## **Visual impairment**

### NICE NG62 – Recommendation 1.17.3

Refer all children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis.

### NICE NG62 – Recommendation 1.17.4

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Talk to children and young people and their parents or carers about visual impairment that can be associated with cerebral palsy. Information that may be useful to discuss includes the following:

- around 1 in 2 children and young people with cerebral palsy will have some form of visual impairment
- visual impairment may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment.

### NICE NG62 – Recommendation 1.17.5

Talk to children and young people and their parents or carers about the different types of visual impairment that can be associated with cerebral palsy. Explain that these could include 1 or more of the following:

- problems with controlling eye movements
- strabismus (squint)
- refractive errors (short or long sighted or distorted image)
- problems of eye function, including retinopathy of prematurity
- impaired cerebral visual information processing (problems with seeing objects caused by damage to the parts of the brain that control vision)
- visual field defects (loss of the part of usual field of vision).

### NICE NG62 – Recommendation 1.17.6

If concerns about visual impairment are raised by parents, carers or members of the care team, consider referring the child or young person with cerebral palsy to a specialist team for evaluation of the whole visual system (including eye health, eye movements, refraction, squint and visual acuity), especially if there are communication difficulties.

### NICE NG62 – Recommendation 1.17.7

Regularly assess children and young people with cerebral palsy for signs of cerebral visual impairment, bearing in mind that this:

- occurs in around 1 in 5 children and young people with cerebral palsy
- may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment
- may be difficult to recognise in the early stages.

### **4.3.3 Current UK practice**

#### **Speech, language and communication**

A UK survey of 265 speech and language therapists found variation in practice carried out<sup>6</sup>. Areas of highest priorities were dysphagia, alternative and augmentative (AAC)/interaction and receptive language. However, there were also reports that varying techniques were used with some interventions having no evidence base. The report of the survey concluded that the adoption of a standard set of agreed clinical measures was required to benchmark service provision.

Additionally, Action Cerebral Palsy found that 72% of CCGs commissioned paediatric speech and language therapy<sup>7</sup>.

#### **Low bone mineral density**

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

#### **Visual impairment**

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

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<sup>6</sup> Watson et al (2015). [Assessment and management of the communication difficulties of children with cerebral palsy: a UK survey of SLT practice.](#)

<sup>7</sup> Action Cerebral Palsy (2016). [Variations in Care: An analysis of cerebral palsy provision](#)

## 4.4 Care needs

### 4.4.1 Summary of suggestions

Stakeholders highlighted the need to address care needs that are specific to children and young people with cerebral palsy. This included interventions that are family centred and goal orientated, reviews at regularly intervals and healthcare systems which do not contain any barriers.

### 4.4.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the committee’s discussion.

**Table 7 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Suggested source guidance recommendations</b>
Care needs	<b>Care needs</b> NICE NG62 Recommendations 1.18.1, 1.18.3, 1.18.4, 1.18.6, 1.18.8 and 1.18.9

#### **Care needs**

##### NICE NG62 – Recommendation 1.18.1

Assess the care needs of every child with cerebral palsy, and of their parents or carers, at diagnosis, and reassess regularly.

##### NICE NG62 – Recommendation 1.18.3

Provide information on the following topics, and direct families to where they can find further information, at diagnosis of cerebral palsy and as appropriate thereafter:

- social care services
- financial support, welfare rights and voluntary organisations]
- support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings)
- respite and hospice services.

##### NICE NG62 – Recommendation 1.18.4

Address and review the specific needs of the child or young person with cerebral palsy in relation to accessing their physical environment (for example, home, school, healthcare, workplace, community), in order to optimise their functional participation. Think about the following aspects:

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- mobility
- equipment, particularly wheelchairs and hoists
- transport
- toileting and changing facilities.

### NICE NG62 – Recommendation 1.18.6

When assessing care needs, take into account the role of any social, cultural, spiritual or religious networks that support the child or young person with cerebral palsy and their family.

### NICE NG62 – Recommendation 1.18.8

Explore with the child or young person and their parents or carers the value of respite services, such as carer support either at home or in another setting.

### NICE NG62 – Recommendation 1.18.9

Ensure that individual, tailored care pathways (including pain management, rehabilitation and equipment) are in place after any major surgical intervention for children and young people with cerebral palsy (see also the NICE guideline on spasticity in under 19s).

#### **4.4.3 Current UK practice**

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

## **4.5 Information and support**

### **4.5.1 Summary of suggestions**

Stakeholders highlighted the need for information and support for children and young people with cerebral palsy and their family and/or carers. This included the development of a national information source, similar to the personal child health record or “red book”, which would include details on prognosis, assessments and interventions, signs and symptoms to look out for, and signposting to support such as respite services.

### **4.5.2 Selected recommendations from development source**

Table 8 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 8 to help inform the committee’s discussion.

**Table 8 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Suggested source guidance recommendations</b>
Information and support	<b>Information and support</b> NICE NG62 Recommendations 1.6.1 to 1.7.3

#### **Information and support**

##### NICE NG62 – Recommendation 1.6.1

Ensure that information and support focuses as much on the functional abilities of the child or young person with cerebral palsy as on any functional impairment.

##### NICE NG62 – Recommendation 1.6.2

Provide clear, timely and up-to-date information to parents or carers on the following topics:

- diagnosis (see section 1.3)
- aetiology (see section 1.2)
- prognosis (see section 1.7)
- expected developmental progress
- comorbidities
- availability of specialist equipment
- resources available and access to financial, respite, social care and other support for children and young people and their parents, carers and siblings (see also recommendations 1.18.3 and 1.18.8)

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- educational placement (including specialist preschool and early years settings)
- transition (see section 1.19).

### NICE NG62 – Recommendation 1.6.3

Ensure that clear information about the 'patient pathway' is shared with the child or young person and their parents or carers (for example, by providing them with copies of correspondence). Follow the principles in the recommendations about communication, information and shared decision-making in the NICE guideline on patient experience in adult NHS services.

### NICE NG62 – Recommendation 1.6.4

Provide information to the child or young person with cerebral palsy, and their parents or carers, on an ongoing basis. Adapt the communication methods and information resources to take account of the needs and understanding of the child or young person and their parents or carers. For example, think about using 1 or more of the following:

- oral explanations
- written information and leaflets
- mobile technology, including apps
- augmentative and alternative communication systems (see recommendations 1.9.7 to 1.9.10).

### NICE NG62 – Recommendation 1.6.5

Work with the child or young person and their parents or carers to develop and maintain a personal 'folder' in their preferred format (electronic or otherwise) containing relevant information that can be shared with their extended family and friends and used in health, social care, educational and transition settings. Information 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 NG62 – Recommendation 1.6.6

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Ensure that the child or young person and their parents or carers are provided with information, by a professional with appropriate expertise, about the following topics relevant to them that is tailored to their individual needs:

- menstruation
- fertility and contraception
- sex and sexuality
- parenting.

### NICE NG62 – Recommendation 1.6.7

Provide information to the child or young person and their parents or carers, and to all relevant teams around them, about the local and regional services available (for example, sporting clubs, respite care and specialist schools) for children and young people with cerebral palsy, and how to access them.

### NICE NG62 – Recommendation 1.6.8

Provide information about local support and advocacy groups to the child or young person and their parents or carers.

### NICE NG62 – Recommendation 1.7.1

Provide the following information to parents or carers about the prognosis for walking for a child with cerebral palsy:

- The more severe the child's physical, functional or cognitive impairment, the greater the possibility of difficulties with walking.
- If a child can sit at 2 years of age it is likely, but not certain, that they will be able to walk unaided by age 6.
- If a child cannot sit but can roll at 2 years of age, there is a possibility that they may be able to walk unaided by age 6.
- If a child cannot sit or roll at 2 years of age, they are unlikely to be able to walk unaided.

### NICE NG62 – Recommendation 1.7.2

Recognise the following in relation to prognosis for speech development in a child with cerebral palsy, and discuss this with parents or carers as appropriate:

- Around 1 in 2 children with cerebral palsy have some difficulty with elements of communication (see recommendation 1.9.1).
- Around 1 in 3 children have specific difficulties with speech and language.
- The more severe the child's physical, functional or cognitive impairment, the greater the likelihood of difficulties with speech and language.

- Uncontrolled epilepsy may be associated with difficulties with all forms of communication, including speech.
- A child with bilateral spastic, dyskinetic or ataxic cerebral palsy is more likely to have difficulties with speech and language than a child with unilateral spastic cerebral palsy.

#### NICE NG62 – Recommendation 1.7.3

Provide the following information to parents or carers, as appropriate, about prognosis for life expectancy for a child with cerebral palsy:

- The more severe the child's physical, functional or cognitive impairment, the greater the likelihood of reduced life expectancy.
- There is an association between reduced life expectancy and the need for enteral tube feeding, but this reflects the severity of swallowing difficulties and is not because of the intervention.

#### **4.5.3 Current UK practice**

Action Cerebral Palsy found that 14% of CCGs commissioned conductive education services for children and young people with cerebral palsy. In Local Authorities, 30% included cerebral palsy in their local offer for information that is provided<sup>8</sup>.

A study into service use and family-centred care in young people with severe cerebral palsy looked at family's perception of services using a 7 point scale. The mean score for providing general information about cerebral palsy was 2.9, while providing specific information about the young person was 4.3<sup>9</sup>.

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<sup>8</sup> Action Cerebral Palsy (2016). [Variations in Care: An analysis of cerebral palsy provision](#)

<sup>9</sup> McDowell et al (2015). [Service use and family-centred care in young people with severe cerebral palsy: a population-based, cross-sectional clinical survey.](#)

## **4.6 Additional areas**

### **Summary of suggestions**

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 02 March 2017.

### **National register**

Stakeholders highlighted the requirement for a national registry to improve information around the incidence and prevalence of cerebral palsy in children and young people. The source guidance for this quality standard [Cerebral palsy in under 25s: assessment and management](#) does not provide recommendations on this area, and the establishment of a national registry is not within the remit of NICE.

### **Training**

Stakeholders suggested that services providing care to children and young people with cerebral palsy should be made up of skilled professionals and that training should be provided to all other healthcare professionals. Training and education is outside the remit of quality standards as it is expected all healthcare professionals involve in patient centred care will be appropriately trained.

### **Dynamic spinal management**

A stakeholder felt that dynamic spinal management in children and young people with cerebral palsy was an emerging area of practice that may replace historic rigid bracing in orthotics. The source guidance for this quality standard [Cerebral palsy in under 25s: assessment and management](#) and [Spasticity in under 19s: management](#) do not provide recommendations on this area.

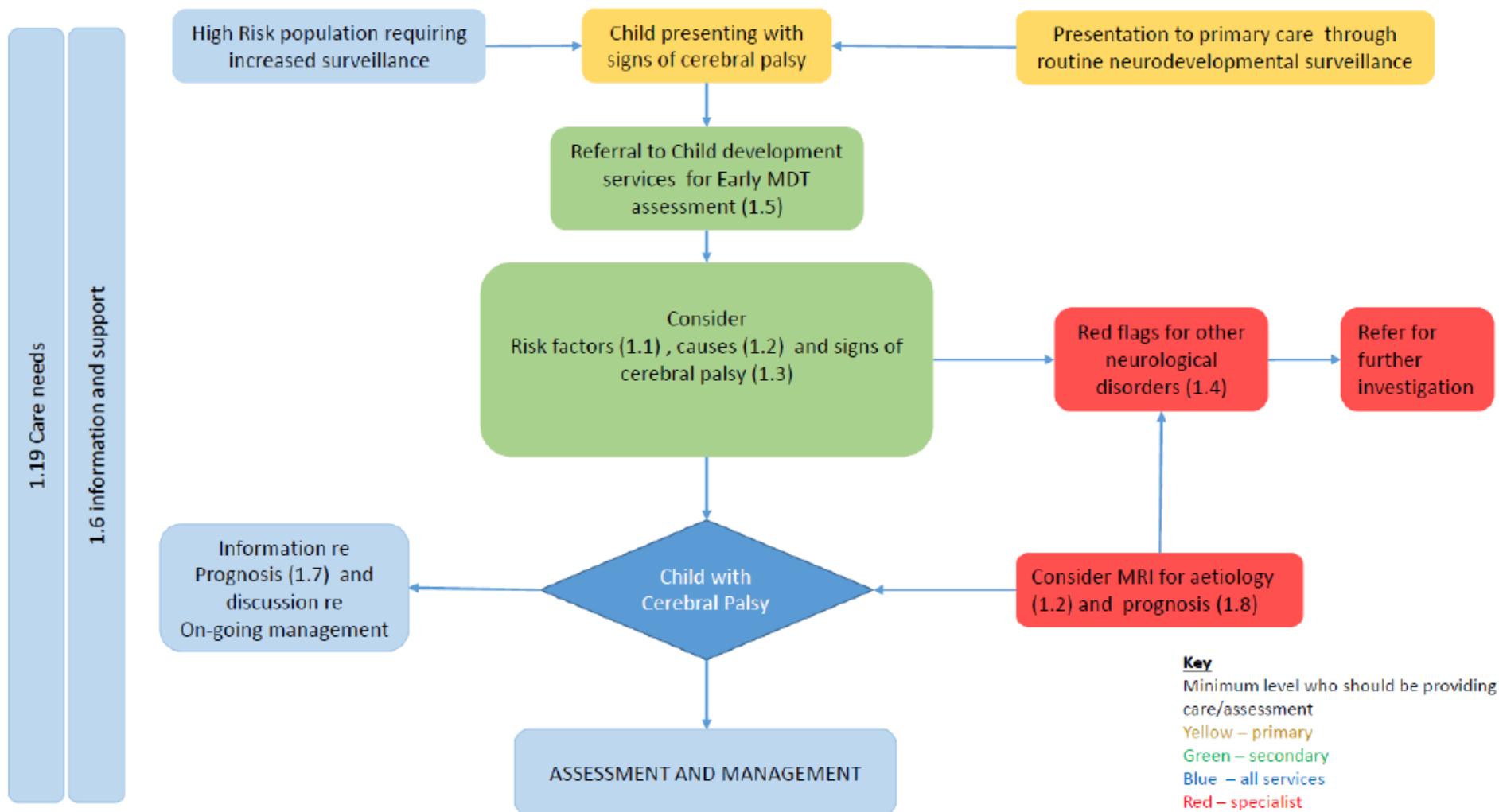
### **Transition to adult's services**

Stakeholders suggested that pathways for transition from children's services to adult services should be in place for people with cerebral palsy. This is a key period with a young person's life and continuity of care is often compromised. Recommendations within the source guidance for this quality standard [Cerebral palsy in under 25s: assessment and management](#) are to follow the NICE guideline on [transition from](#)

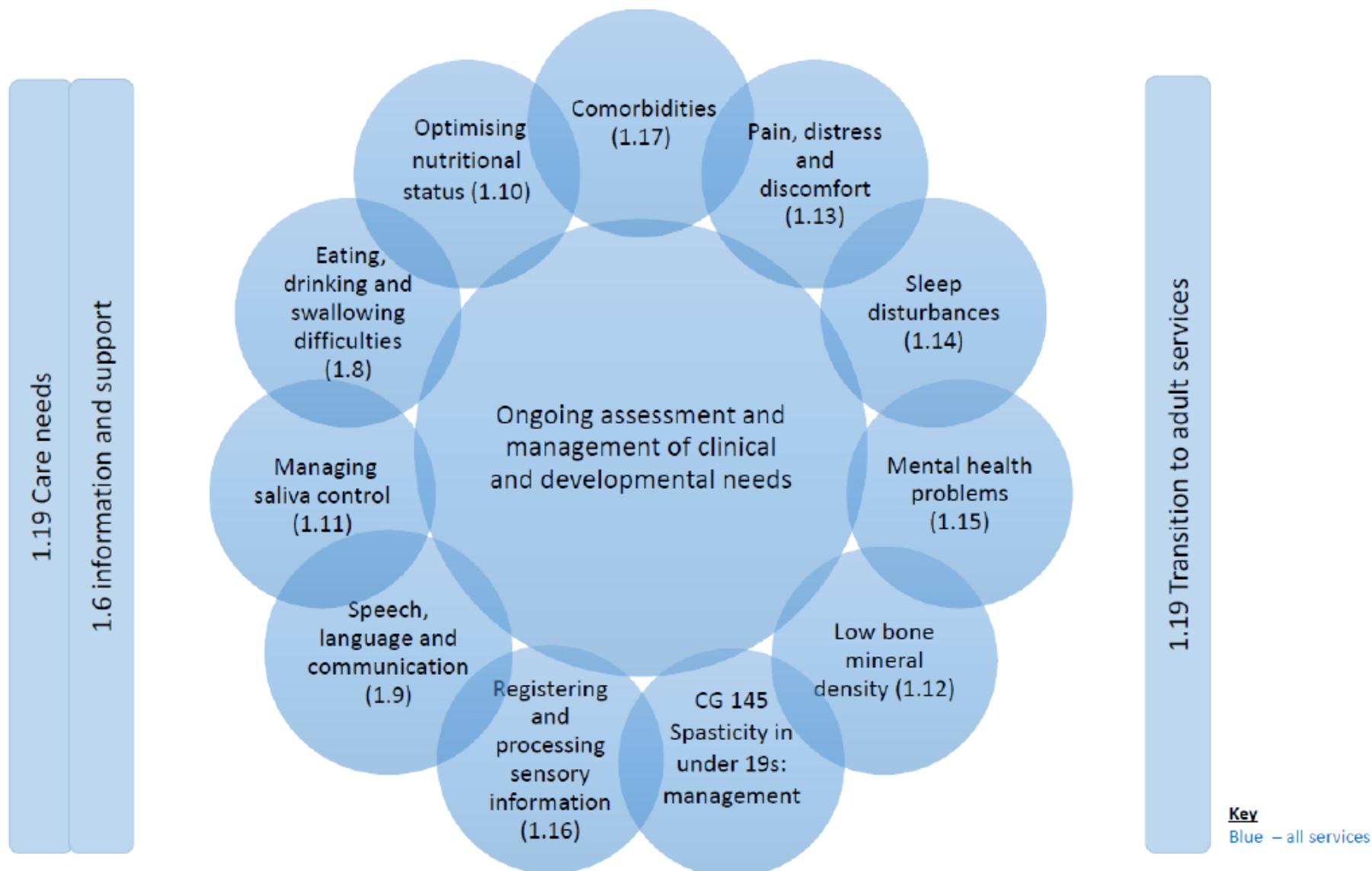
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[children's to adults' services for young people using health or social care services](#). A quality standard, [Transition from children's to adults' services](#) has been published using this guidance as its source.

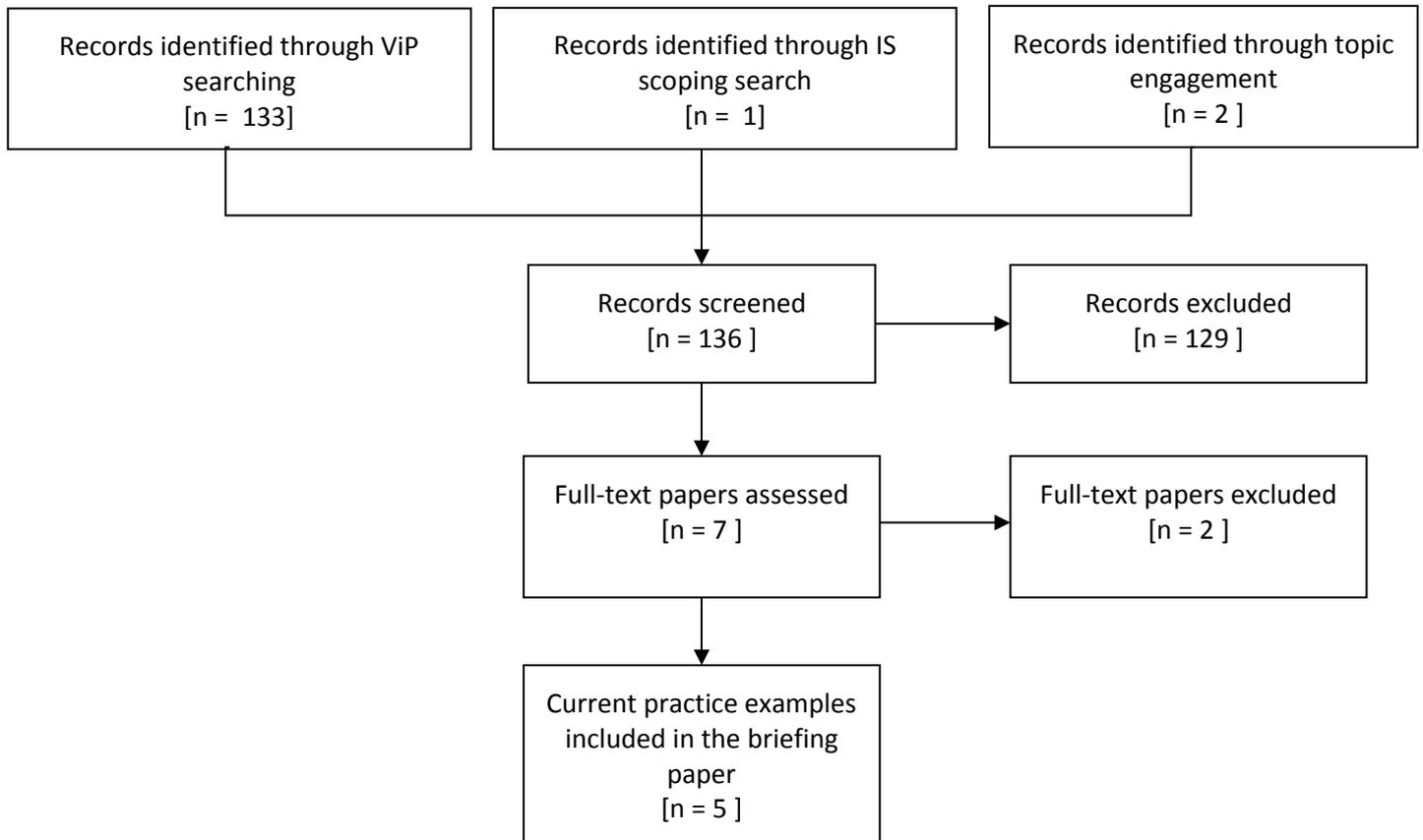
## Appendix 1: Cerebral palsy algorithm - identification



## Appendix 2: Cerebral palsy algorithm - management



### Appendix 3: Review flowchart



## Appendix 4: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
<b>4.1 Multidisciplinary care</b>					
001	Bobath Children's Therapy Centre Wales	Families need to have a reliable and consistent single point of contact who can act as an advocate for the family	In order to ensure effective communication and joined up care between health and social services and education.		Team around the Child. <a href="http://www.education.gov.uk/publications/.../LeadPro_Managers-Guide.pdf">www.education.gov.uk/publications/.../LeadPro_Managers-Guide.pdf</a>
002	Royal College of General Practitioners	Anticipating the physical and mental health needs of individuals affected by cerebral palsy. In particular how and what an integrated team of health care professionals offers to those affected	Multimorbidity is likely and particularly important to recognise what the red flags might be that warrant intervention	Regional variation in the offer of community based care depending on local provision. Similarly variation in access to specialist care such as orthopaedic scoliosis	
003	SCM1	Key area for quality improvement 3	To develop a network of consultants and health professionals with a specialist knowledge of Cerebral Palsy	Access to specialist tertiary care for children and young people is variable particularly in the regions and there is a lack of knowledge and expertise in the management of the condition outside of the few specialist centres.  As a result it is often very challenging for children and young people to access the specialist advice and support that would allow them to manage their condition effectively which can leave them isolated and increase the burden on the young	NICE Guideline on children and young people with cerebral palsy has recommended that children and young people have access to specialist consultants on a regional basis

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				<p>person and their parents and carers. Furthermore those specialist centres which do exist often receive referrals which might be better dealt with by a local specialist, increasing the pressure on these services unnecessarily.</p>	
004	SCM1	Key area for quality improvement 2	<p>Ensure that those health care professionals working in general practice have a knowledge of the referral routes for children and young people with Cerebral Palsy and the common issues that arise as a result of or alongside a diagnosis of cerebral palsy</p>	<p>Professionals in general practice are often the first point of contact for children and young people with cerebral palsy their parents and carers. They also act as gatekeepers to secondary and tertiary services. However those working in general practice very often have a limited knowledge of the expected clinical progression of Cerebral Palsy and associated co morbidities. Furthermore they often have a limited knowledge of the referral routes and services which are available. This often leads to inappropriate unnecessarily delayed.</p> <p>Ensuring those working in general practice have a general understanding of the expected presentation and progression of cerebral palsy over time will assist them in spotting deviations from the expected course of the condition which could necessitate inward referral.</p> <p>Providing those in general practice with concise information on the services and contacts will aid the referral process further.</p>	

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
005	SCM2	Key area for quality improvement 4	Supporting young people, their cares and families	Timely access to equipment and management programmes	
006	SCM2	Key area for quality improvement 1	Access to specialist development teams in a timely manner	Involving the right people early in the pathway so the best diagnostic test can be arranged and explained to the family, with a plan for surveillance if necessary.	
007	SCM3	<p>Key area for quality improvement 1</p> <p>Children, Young People and their parent/carers are referred to Multi-Disciplinary Team (MDT) and specialist teams to provide information and support following diagnosis including prognosis and management of co-morbidities and possible complications throughout childhood. This should be part of a known multi agency framework of care and supported by educational resources.</p>	<p>NICE spasticity guideline 2012 and Cerebral palsy guideline 2017 recommended information and support is given following diagnosis regarding prognosis, complications and life expectancy. This support should be on-going and a pathway should be developed by multi agencies with resources for child, families, and carers.</p>	<p>The Action CP 2016 report of variance in services for children with Cerebral palsy - showed huge discrepancies across commissioners and providers in England for recording population diagnosis and implementing a pathway of care. This was a recommendation from NICE guidelines in CP spasticity 2012.</p>	<p>Action CP variance report showed that there were real omissions on the part of local commissioning groups who were not able to provide local data regarding their prevalence of CP and the services they commission for this population.</p> <p>They also did not have information about their pathways of care.</p> <p>CP is a wide term with considerable spread of severity; not understanding the local population has major issues in terms of cost for care and therapy services.</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					<p>There has been considerable work coming out of population studies which has the potential to predict cost and resource needs. In England the discrepancies are increasingly apparent as local services are split and providers are not responsible for planning. The lack of shared data opportunities mean there are risks and poor understanding of responsibilities in this long term condition.</p>
008	SCM4	<p>Key area for quality improvement 3</p> <p>Identify a key worker in the multidisciplinary team.</p>	<p>Families/carers benefit and require on professional as a point of contact, who can ensure good communication throughout the patient journey.</p>	<p>Families regularly report that they do not know who to contact and communication between teams is variable across the country.</p>	<p>NICE Guidelines 1.5, 1.6 and 1.19.9</p>
009	SCM4	<p>Key area for quality improvement 1 Refer children at the time of diagnosis to local MDT Team.</p>	<p>All Children should have access at an early stage to physiotherapy, occupational therapy and community paediatrician.</p>	<p>Access and availability of an MDT Team which includes all key professionals is variable across the country. Families and children need this referral to maximise the child's quality of life.</p>	<p>NICE Guidelines 1.18.5 and 1.6.2</p> <p>Action Cerebral Palsy (2016) Variations in Care: An analysis of cerebral palsy provision</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
<b>4.2 Management of spasticity</b>					
010	Bobath Children's Therapy Centre Wales	Urgent need for more proactive monitoring and timely interventions.	Episodic periods of care are increasingly being delivered for children with cerebral palsy e.g. care aims model of delivery. There is little/no evidence for this and it may not be appropriate for complex, multifactorial, life-long conditions such as cerebral palsy, where proactive and routine monitoring of this condition is essential. Failure to do this may result in unnecessary deterioration in abilities and compounding family anxieties.		<a href="http://www.bacdis.org.uk/policy/documents/CPpathway.pdf">http://www.bacdis.org.uk/policy/documents/CPpathway.pdf</a>  <a href="http://www.bacdis.org.uk/policy/guidelines.htm">http://www.bacdis.org.uk/policy/guidelines.htm</a>
011	British Society for Children's Orthopaedic Surgery	Key area for quality improvement 3	Children with CP are at risk of hip displacement and dislocation. The risk is as high as 70-80% in the more severely affected children.	There is evidence that screening and early intervention prevents dislocation and the need for more extensive surgery. Screening programmes are already in place in Scotland but not in the rest of the UK.	<a href="http://apcp.csp.org.uk/publications/cerebral-palsy-integrated-pathway-scotland-cpips-dvd">http://apcp.csp.org.uk/publications/cerebral-palsy-integrated-pathway-scotland-cpips-dvd</a>
012	British Society for Children's Orthopaedic Surgery	Key area for quality improvement 2	Single-event multi-level surgery (SEMLS) in children with diplegic CP aims to correct all bone, joint and muscle deformities in one operation with one rehabilitation period. It is the most commonly used orthopaedic treatment for ambulant children with the condition. The SEMLS treatment consists of a single episode of	There are approximately 500 new cases of diplegic CP per year in the UK. The vast majority of these children would probably benefit from lower limb orthopaedic surgery - SEMLS. This would potentially limit the impact of their disability for a lifetime and would lead to major functional and socio-economic benefits. Good evidence (through good quality research) on the efficacy of SEMLS could lead to an expansion of the	Thomason P, Selber P, Graham HK. Single Event Multilevel Surgery in children with bilateral spastic cerebral palsy: a 5 year prospective cohort study. Gait Posture. 2013 Jan;37(1):23-8

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			multiple operations all undertaken under the same anaesthetic. It aims to correct complex lower limb deformities and allow a comprehensive rehabilitation lasting 18-24 months.	patient selection criteria opening it as an option to other CP subgroups and potentially to all children with neurological disability.	
013	British Society for Children's Orthopaedic Surgery	Key area for quality improvement 1	Hospitalisation of children with CP represents a major expenditure for the NHS involving longer lengths of stay, higher total costs and more procedures per admission than children with other pathology.	Improved orthopaedic management of CP in well organised specialist centres could result in improved functional outcomes for children and families and potentially decrease costs associated with hospitalisation and rehabilitation, along with potential to reduce annual lifetime cost.	Murphy NA, Hoff C, Jorgensen T, Norlin C, Young PC. Costs and complications of hospitalizations for children with cerebral palsy. <i>Pediatr Rehabil.</i> 2006 Jan-Mar;9(1):47-52
014	DM Orthotics Ltd	Key area for quality improvement 2	The incidence of spinal deformity in children with cerebral palsy is reported as 25 %, ranging from 5 % for bilateral-spastic to 74 % in quadrilateral-spastic presentations [6]. Children who are wheelchair dependent due to a neuropathic or neuromuscular disease have a 90 % increased risk of progressive spine deformities due to impairments in postural balance and motor control [7]	Very important for the achievement of sitting symmetry, pain management, pulmonary function and mastication.	Scoliosis is a major issues with children and young people with cerebral palsy which affects seating and quality of life in adult life. Surgery is often the only option often leaving the patient with a reduced quality of life. Tsirikos AI. Development and treatment of spinal defromity in patients with cerebral palsy. <i>Indian J Orthop.</i> 2010;44:148–58. Murans G, Gutierrez-Farewik EM, Saraste H.

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					Kinematic and kinetic analysis of static sitting of patients with neuropathic spine deformity. Gait Posture. 2011;34:533–8.
015	DM Orthotics Ltd	Key area for quality improvement 1	Sitting balance there is limited evidence in regard of the need for rigid bracing to manage scoliosis seen in	Early intervention is important to enable learning using proprioception to body image	Please see paper published in Scoliosis and Spinal disorders which provides a review of current clinical practice in 5 centres in Southern England using dynamic elastomeric fabric suit orthoses in the treatment of neuropathic onset scoliosis. <a href="http://scoliosisjournal.biomedcentral.com/articles/10.1186/s13013-016-0073-z">http://scoliosisjournal.biomedcentral.com/articles/10.1186/s13013-016-0073-z</a>
016	Leeds Teaching Hospitals NHS Trust	Key area for quality improvement 5	What should be the minimum standard of provision for children with CP for access to Community physiotherapy, occupational therapy & speech & language therapy.		
017	Leeds Teaching	Key area for quality improvement 3	What is the standard for rehabilitation after neurosurgery interventions?		

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
	Hospitals NHS Trust				
018	Leeds Teaching Hospitals NHS Trust	Key area for quality improvement 2	What is the Gold standard for rehabilitation after orthopaedic surgery interventions?		
019	Leeds Teaching Hospitals NHS Trust	Key area for quality improvement 1	There is a current lack of opportunity for rehabilitation / blocks of intensive therapy for children with CP. There are difficulties with Community therapy and with provision in hospital rehabilitation settings too. These need to be addressed with Quality Standards to target funding & improvement.		
020	Leeds Teaching Hospitals NHS Trust	Key area for quality improvement 4	How does Selective Dorsal Rhizotomy compare with Standard Therapeutic interventions for Children at GMFCS level 4 and level 5?		
021	Royal College of General Practitioners	Hip surveillance	Reduce hip dislocation and need for orthopaedic surgery		Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S.-A. and Goldsmith, S. (2013), A systematic review of interventions for children with cerebral

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ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					palsy: state of the evidence. Dev Med Child Neurol, 55: 885–910.
022	Royal College of General Practitioners	Postural Care	Pressure care is important to reduce contractures and improve mobility as well sitting	Children who can sit up straight are more likely to be able to maintain eye contact and communication	Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S.-A. and Goldsmith, S. (2013), A systematic review of interventions for children with cerebral palsy: state of the evidence. Dev Med Child Neurol, 55: 885–910.
023	Royal College of General Practitioners	Early Assessment for selective Dorsal Rhizotomy	Potential significant improvement in mobility and posture	Increased mobility will allow more independence	Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S.-A. and Goldsmith, S. (2013), A systematic review of interventions for children with cerebral palsy: state of the evidence. Dev Med Child Neurol, 55: 885–910.
024	SCM2	Key area for quality improvement 3	Information about on going monitoring	Monitoring interventions and ensuring appropriate involvement as needed	
025	SCM3	Key area for quality improvement 2	There is evidence that appropriate and timely surveillance by	There is no English CP integrated pathway with a CP register ensuring all children with	The Cerebral Palsy Integrated Pathway

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		<p>Children are offered regular reviews and enhanced surveillance for complications and co-morbidities of CP according to a national integrated framework of care.</p>	<p>appropriately trained therapy professionals improves outcomes and QOL, by helping families and children to anticipate and manage their condition. This allows them to make informed choices about their care and to reduce waste both in terms of emotional and resource costs.</p> <p>For example there is evidence from Scotland, Australia and Scandinavia that where clear integrated pathways for standardised musculoskeletal surveillance and onward specialist referral and treatment are implemented in the CP population, there is a reduction in complications such as hip dislocation and scoliosis. These complications have a direct impact on the child and family both acutely and in the longer term due to pain and the increasing complexity and cost of managing these if not picked up early.</p>	<p>CP are offered a basic standard of care for known risks related to the condition. Unlike Scotland, Iceland and all Scandinavian countries.</p>	<p>programme (Scotland) CPIPs, is showing where integrated pathways have been implemented there has been improved understanding and satisfaction for families. There is better understanding of expectations regarding prognosis and resource allocation; a clearer partnership between families and professionals; and feelings of empowerment in the process.</p>
026	SCM3	Key area for quality improvement 3	Children should receive tailored and timely equipment and adaptations, based on MDT	This was specified in Spasticity guideline 2012.	The association of Paediatric Chartered Physiotherapists survey

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		<p>Children and young people should be supported to be as active and independent as they can be and where possible to make their own life choices.</p>	<p>assessment. To facilitate care and dignity, to aid activity and communication, and to facilitate improved quality of life. This should be pre-empted during key stages of development with clear signposts for services available.</p> <p>Early therapy interventions are shown to have a positive effect on neuroplasticity and improve overall outcome for children with cerebral palsy and their families when they are part of an integrated pathway with tailored goals, set in partnership with children, their families/carers and MDT.</p>		<p>into therapy provision across the 4 nations showed huge discrepancies in physiotherapy provision across all health boards and providers.</p> <p>Orthotic provision has also come under scrutiny for discrepancies in provision.</p>
<b>4.3 Difficulties associated with cerebral palsy</b>					
027	DM Orthotics Ltd	Key area for quality improvement 3	Ability to communicate using various aids	Stabilisation of the spine	
028	Royal College of General Practitioners	Bisphosphonates	Improve bone mineral density	Decreased risk of fractures	<p>Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S.-A. and Goldsmith, S. (2013), A systematic review of interventions for children with cerebral palsy: state of the</p>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					evidence. Dev Med Child Neurol, 55: 885–910.
029	Royal College of Speech and Language Therapists	Key area for quality improvement 3 Intervention to improve the communication skills of children with cerebral palsy, provision of AAC	There is strong evidence of the impact of augmentative and alternative communication (AAC) to support independent communication for children and young people whose communication is limited by motor, cognitive and sensory impairments	A national survey showed that access to specialist AAC support is still lacking in some areas of the UK. Intensity of intervention to help children and young people learn their AAC systems varies widely.	
030	Royal College of Speech and Language Therapists	Key area for quality improvement 1 Assessment of speech, language and communication difficulties	There is evidence that intervention can improve the speech, language and communication skills of children and young people with cerebral palsy. Assessment of each of these areas of function is required to inform individualised intervention	A large UK survey (Watson and Pennington 2015) showed variation in the areas of function assessed by UK speech and language therapists and the methods used to do this. Many therapist relied on informal assessment and observation, which prevent comparison across children and time.	<a href="https://www.ncbi.nlm.nih.gov/pubmed/25652139">https://www.ncbi.nlm.nih.gov/pubmed/25652139</a>  Rose Mary Watson and Lindsay Pennington Assessment and management of the communication difficulties of children with cerebral palsy: a UK survey of SLT practice. INT J LANG COMMUN DISORD, MARCH–APRIL 2015, VOL. 50, NO. 2, 241–259
031	Royal College of Speech and Language Therapists	Key area for quality improvement 2 Intervention for address speech difficulties	There is developing evidence that speech intelligibility may be improved using motor learning	A large UK survey of speech and language therapists' practice (Watson and Pennington 2015) showed that therapists provide a wide variety of interventions to improve speech, including some that have no evidence and	See paper above  <a href="http://www.cochrane.org/C006937/MOVEMENT_speech-therapy-children-">http://www.cochrane.org/C006937/MOVEMENT_speech-therapy-children-</a>

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		associated with cerebral palsy (dysarthria)	therapies that target respiration, phonation and speech rate	lack a firm theoretical base. Interventions that have shown promise are provided in varying doses but generally at very low intensity, which does not fit with their evidence base. For example, strong evidence exists for the need for intensive practice to induce motor learning. Therapy for speech in UK is provided at most once a week, but often on a much lower intensity, which is probably insufficient to facilitate learning of new skills.	dysarthria-acquired-three-years-age Pennington L, Parker NK, Kelly H, Miller N. Speech therapy for children with dysarthria acquired before three years of age. Cochrane Database of Systematic Reviews 2016, Issue 7. Art. No.: CD006937. DOI: 10.1002/14651858.CD006937.pub3
032	Royal College of Speech and Language Therapists	Key area for quality improvement 4 Parent training to support communication development	Evidence on training parents to facilitate their children's communication development is developing and is available from indirect populations (samples of children with mixed developmental disorders)	Parent training is often provided by therapists but the content of the training, its method of delivery and its dosage varies widely. Training provided varies from published, validated programmes. Thus, it is not clear how effective the intervention actually provided is.	<a href="https://www.ncbi.nlm.nih.gov/pubmed/25652139">https://www.ncbi.nlm.nih.gov/pubmed/25652139</a>  Rose Mary Watson and Lindsay Pennington Assessment and management of the communication difficulties of children with cerebral palsy: a UK survey of SLT practice. INT J LANG COMMUN DISORD, MARCH-APRIL 2015, VOL. 50, NO. 2, 241-259

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033	The Royal College of Ophthalmologists	Key area for quality improvement 1	When a child or young person undergoes assessment of ocular health and visual function, a structured clinic letter should be produced which documents reported concerns and describes assessment findings.	Findings should be translated into terms that are meaningful for non-vision specialists and parents. Letters should be copied to all relevant professionals.	<p>See The Royal College of Ophthalmologists'</p> <p>Quality Standards &amp; Quality Indicators for Ophthalmic Care and Services for Children and Young People</p> <p><a href="https://www.rcophth.ac.uk/wp-content/uploads/2014/12/Paediatric-Ophthalmology-Quality-Standards-July-2013_2013_PROF_139.docx">https://www.rcophth.ac.uk/wp-content/uploads/2014/12/Paediatric-Ophthalmology-Quality-Standards-July-2013_2013_PROF_139.docx</a></p> <p>RCOphth 'Ophthalmic Services for Children'</p> <p><a href="https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2012_PROF_182_Ophthalmic-Services-for-Children.pdf">https://www.rcophth.ac.uk/wp-content/uploads/2014/12/2012_PROF_182_Ophthalmic-Services-for-Children.pdf</a></p> <p>Evidence synthesis e.g. Cochrane Reviews, Health Technology Assessment Reports, NHS Evidence,</p>

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					and other peer reviewed literature
034	Visual Impairment Paediatric Special Interest Group	Where follow up in the Eye clinic is deemed to be required, the reason for this should be clearly stated in the clinic letter	Parents are often uncertain as to the precise reason for follow up in an Eye clinic	A clinic appointment should have a clear purpose that is understood by both professional and patient	Information sheets used by the charity Seeability which explain what eye and vision tests have been carried out and what the test results mean have been well received by parents and professionals. These reports generally contain more detailed information than is usually included in an outpatient clinic letter.
035	Visual Impairment Paediatric Special Interest Group	Use of the term Cerebral Visual Impairment. This term should only cautiously be used when a child is young and other factors which may influence visual performance are not yet fully identified. An Ophthalmologist plays a key role in documenting ocular structure, visual acuity, eye movements and visual fields. However other aspects of	Currently, international agreement is lacking on which precise visual difficulties can be subsumed under a generic description of CVI. It is increasingly recognised that there is considerable overlap between reported symptoms of CVI and those of other developmental difficulties. Use of the term 'CVI' without due multidisciplinary attention may lead to the impact of non-visual factors being overlooked	Description of a child's reported functional difficulties will be more informative than use of the term 'CVI' with no further specification	<a href="http://www.vincyp.scot.nhs.uk/cerebral-visual-impairment-diagnostic-pathway/">http://www.vincyp.scot.nhs.uk/cerebral-visual-impairment-diagnostic-pathway/</a>

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		<p>abnormal visual performance may require evaluation by a Psychologist and Paediatrician: such assessment will establish a developmental framework within which reported visual difficulties can most effectively be understood</p> <p>A multidisciplinary approach to identification of possible cerebral visual impairment is therefore required in most children</p>			
036	Visual Impairment Paediatric Special Interest Group	<p>Adequacy of initial referral to Eye clinic AND Scope of baseline Ophthalmological assessment of CYP with cerebral palsy</p>	<p>Children and young people with Cerebral Palsy are known to be at increased risk of ocular dysfunction and visual impairment. Referral letters from GPs or Paediatricians may lack specific questions and assessment in the Eye clinic may not address all possible aspects of ocular and visual impairment leading to false beliefs that no problems are present when in fact assessment may be incomplete</p>	<p>A child's attendance at an Eye clinic may lead to an erroneous assumption that comprehensive assessment has been completed when in fact this is not the case</p>	<p>Woodhouse 2014 Ocular and Visual Status amongst children in special schools in Wales. ADC 2014 99(6) 500-504</p> <p>An Eye clinic could agree a proforma for an outpatient letter which clearly documents the reason for referral, any current concerns about eyes or vision, what examinations have been</p>

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					<p>completed, what examination has not been completed and why, and which provides clear functional explanations of all relevant findings that can be understood by parents and non-vision specialists</p> <p>A clinic leaflet or appendix to the letter could explain common terms such as squint, refractive error, visual acuity. Parents and non vision specialists may not sufficiently understand these terms.</p> <p>Clinic letters should be copied to parents and all professionals currently involved with the child including Paediatrician, Education staff, Therapists and GP, with parents permission.</p>
<b>4.4 Care needs</b>					
037	Bobath Children's	Service Delivery models should be family centred with goals of any	Effective collaboration within the wider team, which includes the family, needs to be paramount in		Raina P, O'donnell M., Rosenbaum P. et al. 2005. The health and well being

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	Therapy Centre Wales	intervention based on the families concerns.	order to ensure that every child maximises their individual potential.		<p>of of caregivers of children with cerebral palsy. Pediatrics. 115 (6): pp.e626-e636.</p> <p>McDowell BC1, Duffy C1, Parkes J2. Disabil Rehabil. 2015;37(25):2324-9. doi: 10.3109/09638288.2015.1019649. Epub 2015 Mar 4. Service use and family-centred care in young people with severe cerebral palsy: a population-based, cross-sectional clinical survey.</p>
038	Bobath Children's Therapy Centre Wales	All therapy intervention should be designed around and appropriate for the individual child and family.	As cerebral palsy does not affect any two children in the same way and the signs and symptoms of cerebral palsy evolve and change throughout life.		
039	SCM3	<p>Key area for quality improvement 4</p> <p>Children who require acute emergency or planned medical care are able to access this care with support for their,</p>	Children with CP are not consistently supported to access healthcare because of barriers caused by physical environmental access issues, attitudes and poor training for staff regarding the special needs across the spectrum.		

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		physical, communication, cognitive and emotional needs.			
040	SCM4	Key area for quality improvement 4  Children and families' needs should be reviewed on a regular basis.	Children who attend tertiary centres on a six monthly or yearly basis should have their needs reviewed so that there can be liaison with local services to improve levels of support.	My experience has shown me that families have not had their needs recognised at a local level and there is a need for paediatric Neurologists and their teams to elevate support needs to local services.	NICE Guidelines 1.5, 1.6, 1.18 and 1.19
<b>4.5 Information and support</b>					
041	Action Cerebral Palsy	Information on screening protocols for CP for parents and professionals	The 'toolkit' booklet could provide information on screening protocols, e.g. general movement assessments and/or MRI; and provide a record of all screening and assessment outcomes in relation to the child's developmental follow up programme. Screening protocols should include all domains of development: motor; feeding; sleeping patterns; play; regulatory state; communication etc.	Details of screening and assessment processes and the results of such processes in the document enable parents and professionals to build a full profile of the child's needs across all developmental domains. This facilitates joined up working and integrated strategies.	ACP's Variations in Care report found that only nine (6%) of local authorities were able to provide details on the training and advice provided to health visitors on identifying and referring children suspected of having cerebral palsy. Concerningly, five local authorities also described their training as "generic".
042	Action Cerebral Palsy	Early identification of CYP at risk of CP and corresponding page in the Personal Child Health Record (or 'red book')	For those infants who are not deemed to be at risk at the neonatal stage, and would therefore be issued with a normal 'red book', we would suggest that	As a nationally recognisable resource, the 'red book' would be a crucial resource to highlight risk factors/red flags for cerebral palsy. When combined with the detailed 'toolkit' booklet, this would give confidence	Evidence as given above.

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			<p>there could be a “red flag” trigger point in the developmental milestones in the existing ‘red book’. This would initiate referral to a MDT enhanced surveillance process and thence into the more detailed ‘toolkit’ booklet.</p>	<p>to parents that their child will receive timely, enhanced surveillance, follow up and intervention in line with national standards. Written, shared protocols would provide the transparency and partnership working that parents require prior to, at the time of diagnosis and throughout their child’s development.</p>	
043	Action Cerebral Palsy	<p>Early identification of CYP at risk of CP through a toolkit and resource booklet</p>	<p>For babies deemed to be at risk of CP from birth, ACP considers that a vital area for quality improvement would be around creating a “toolkit” and monitoring and resource booklet which would be issued to these children. This toolkit could incorporate (but would not be restricted to) the contents of a personal “folder”, described at 1.6.5 of the guideline (short), which would develop as the child matures. This would be one of the key components in establishing a national standard of care pathway for children at risk of developing CP.</p>	<p>Currently there is too much regional variation in levels of care available to children with cerebral palsy and their families. This booklet (akin to the existing “Red Book” issued to all neonates) would clearly set out national protocols for the enhanced surveillance programme to be carried out by neonatal and developmental services as recommended in the NICE guideline for infants, children, and YP who have any of the risk factors listed in the guidance.</p>	<p>ACP’s 2016 report Variations in Care: An analysis of cerebral palsy provision, based on FOIs sent to CCGs and LAs across England, concluded that more needs to be done to support CYP with CP, particularly during their first 24 months when intervention is most effective but also most likely to be absent. The biggest recurring issue was said to be “insufficient specialist support and a lack of awareness from health professionals as to how to access it.” Only 16.7% of CCGs were able to provide a specific timescale for referral for</p>

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					the diagnosis of cerebral palsy from the point of the formal identification of symptoms.
044	Action Cerebral Palsy	Integration of progress and development records and patient pathways for CYP with CP	<p>Before diagnosis of CP, the booklet could provide information for parents and professionals on typical and atypical development including signs of CP which will require follow up, and when and where to refer. The booklet could facilitate a detailed record of progress and development maintained by both parents and professionals which would inform and monitor further assessment and intervention. This would support inter agency working and communication.</p> <p>During the process of or after diagnosis, the booklet could provide a record of the child's history and medical interventions, and information given to parents which would minimise the need for parents to repeat information for multiple audiences and facilitate inter-agency communication. The booklet could also set out details of the "patient</p>	<p>Information about the signs of CP/atypical development would support improved awareness of CP for parents, health visitors and other professionals. It would also enable parents to flag up concerns to professionals in a timely manner.</p> <p>Currently there is a high level of variation in the level of information about care pathways and specialist support available to children with CP. To raise standards of care across the UK, there needs to be clear, accurate and detailed information about the child/young person and pathways of care to be expected, and the resources/support available, incorporated into one document.</p>	<p>ACP's 2015 report Enabling Potential – Achieving a New Deal for Children with Cerebral Palsy identified several means of improving signposting and support for families, including: The widespread use of "lead developmental therapists" to lead engagement with each child and provide a single point of contact for families; A web resource with information for families outlining information on disordered development and the cerebral palsies, local services available and minimum standards they should expect from statutory services; Counselling; and Proactive and timely advice on practical issues,</p>

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			<p>pathway” (1.6.3) that could be expected by the parent of child/young person; and provide clear, timely and up to date information to parents and carers on the topics set out at 1.6.2, 1.6.7 and 1.6.8 of the Guideline (short).</p> <p>The booklet could be used to record the strategies and goals which have been developed in partnership with parents and children/young people for interventions to improve eating, drinking and swallowing and record and monitor the management plan, and for other interventions in place for the child/young person. To improve the integration of and access to a child’s records, the booklet could be digitised.</p>		<p>such as feeding and sleeping.</p> <p>This report also describes the welcome given by respondents to ACP’s inquiry to the replacement of Statements of Special Educational Needs with Education, Health and Care Plans. It states that “If services for children and young people with cerebral palsies are to complement each other, then Plans should facilitate this by ensuring services are jointly commissioned and provision discussed in dialogue with parents.”</p>
045	SCM1	Key area for quality improvement 5	Development of a national information source for parents and carers of those with cerebral palsy	Information provided for parents and carers of children and young people is often poor in quality and comes from a large variety of desperate sources of varying quality. This means that many parents and carers are unaware of their entitlement to support and benefits and discover what support is available via the “£grapevine”	

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				<p>The development of a information hub of high quality accurate information would provide professionals with a single information source as well as somewhere they could signpost parents and carers to ensure they receive accurate information regarding the help and support to which they are entitled, thereby ensuring equality of access to services.</p>	
046	SCM2	Key area for quality improvement 2	Education of the young person, their carers and family	Named point of contact to help with signposting about services	
047	SCM4	Key area for quality improvement 2 Families and carers should be given information at the time of diagnosis on support available from social care.	Currently, many families are unaware of the support available and need signposting so that they can access support either initially or during the patient journey.	In my experience, families and carers struggle to cope both at diagnosis and during the patient journey and this is not always recognised by professionals.	NICE Guidelines 1.6, 1.18.1 and 1.18.3
<b>4.6 Additional areas</b>					
048	Action Cerebral Palsy	Recording incidence of cerebral palsy – creation of a national cerebral palsy register	<p>Aspects of information recorded within the booklet could be used to inform a national CP register and/or database, for example:</p> <ul style="list-style-type: none"> <li>•Incidence and prevalence of cerebral palsy type and presentation</li> </ul>	Currently there is very little information available about the incidence of cerebral palsy in England. Without information on the number of children with CP, the type and presentation, level and outcomes of screening, assessment and interventions together with information about their health and development, it will remain very difficult	The second report of the Australian Cerebral Palsy Register, Birth Years 1993-2006, provides an example of how a national register can be utilised to identify trends in CP prevalence and treatment.

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			<ul style="list-style-type: none"> <li>•Type of assessments carried out and outcomes</li> <li>•Type of intervention used and outcomes</li> <li>•Health</li> <li>•Medication</li> <li>•Equipment</li> <li>•Level of disability at baseline and at developmental stages</li> <li>•Educational attainment</li> <li>•Communication</li> <li>•Surgical interventions</li> </ul>	<p>to plan for and allocate resources effectively.</p> <p>A register would also facilitate vital research into CP and enhance our collective understanding of CP's prevalence, the impact of intervention and management, and improve how resources, including workforce training, are distributed.</p> <p>Action Cerebral Palsy continues to lobby for quality improvement in the areas outlined above and is grateful to NICE for the opportunity to express our recommendations in this document.</p>	<p>Of the 3,135 individuals identified with CP across this period, 5.6% developed during a "recognised event" more than 28 days after birth, while 94.4% were thought to have developed the condition during the prenatal or perinatal period of infant development. The register's data also identifies a significant proportion of children with CP being born prematurely or with a low birth weight (41.3% and 41.7% respectively).</p> <p>Despite the United Kingdom Cerebral Palsy Collaboration having previously compiled a similar register using various regional registers from across the UK, a concerted national effort to record CP prevalence and treatment has not been undertaken.</p>

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049	Bobath Children's Therapy Centre Wales	Specialist services made up of highly skilled professionals with relevant experience in this field	Due to the complex and multi-factorial nature of CP there is an urgent need for specialist services to support existing generic community services as well as provide the highly specialist advice and intervention that is required by children with cerebral palsy and their families		Myrhaug HT1, Jahnsen R2, Østensjø S3. J Child Health Care. 2016 Mar;20(1):109-19. doi: 10.1177/1367493514551312. Epub 2014 Oct 21. Family-centred practices in the provision of interventions and services in primary health care: A survey of parents of preschool children with cerebral palsy.
050	DM Orthotics Ltd	Additional developmental areas of emergent practice	Dynamic Spinal management to replace historic rigid bracing		<a href="http://scoliosisjournal.biomedcentral.com/articles/10.1186/s13013-016-0073-z">http://scoliosisjournal.biomedcentral.com/articles/10.1186/s13013-016-0073-z</a>
051	SCM1	Key area for quality improvement 4	Develop a structured process for the transition from paediatric to adult services	<p>Transition from paediatric to adult services is a key period for young people with Cerebral Palsy, their parents and carers. Often continuity of care is compromised as care becomes disjointed sporadic, increasing anxiety and stress for the young person, their parents and carers.</p> <p>The development of a quality standard for the planning and delivery of effective transition for children and young people will ensure that transition is planned and delivered in a structured way in consultation</p>	NICE Guideline on children and young people with Cerebral Palsy makes a number of key recommendations as to what should be included in a successful transition,

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				with the young person with Cerebral palsy as well as those health and social care professionals working with the young person both in paediatric and adult services. This will ensure that the young person receives the most appropriate support and treatment to allow them to reach their potential as an adult. It will support professionals as to the process which should be followed to ensure an successful transition.	
052	SCM1	Key area for quality improvement 1	Develop a national register of those children and young people with Cerebral palsy.	Consistent and accurate reporting and monitoring of the prevalence and severity of Cerebral Palsy in children and young people will mean that a more accurate assessment of current and future demands on the health and social care system as well as evaluating trends in cerebral palsy to help evaluate the effectiveness of current treatment modalities as well as providing an insight into the changing presentation and nature of Cerebral Palsy over time.	
053	SCM2	Key area for quality improvement 5	Smooth transition to adult services	Integration of teams with a network of local support	
054	SCM4	Key area for quality improvement 5 Transition pathway should be started at appropriate time with a key professional to	Parents report anxiety and lack of knowledge about services available following transition.	Young people need to feel empowered and obtain optimal advice about health and education as they move into adult services	NICE Guidelines 1.19 NICE Guideline Epilepsy in Children

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		support parents through the process.			
<b>General</b>					
055	DM Orthotics Ltd	Key area for quality improvement 4	Feeding		
056	DM Orthotics Ltd	Key area for quality improvement 5	Awareness of self	Study suggests imaging of the brain is offset	Kurz MB, Becker KM, Heinrichs-Graham E, Wilson TW: <b>Neurophysiological abnormalities in the sensorimotor cortices during the motor planning and movement execution stages of children with cerebral palsy.</b> <i>DevMedChild Neurol</i> 2014, <b>56</b> :1072-1077.
057	NHS England		Thank you for the opportunity to comment on the above Quality Standard.  We can confirm that there are no comments to be made on behalf of NHS England.		
058	Royal College of Nursing		This is to inform you that the Royal College of Nursing has no comments to submit to inform on		

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			the above topic engagement at this time.		
059	Royal College of Paediatrics and Child Health		Thank you for inviting the Royal College of Paediatrics and Child Health to comment on the NICE topic engagement exercise for quality standard on Cerebral palsy. Unfortunately, on this occasion we have not received any responses for this consultation		
060	Visual Impairment Paediatric Special Interest Group	<p>'Registering and processing sensory information'</p> <p>No suggestion has been made here for a Quality Standard regarding the above. This is because the condition being described has not been adequately defined</p> <p>It is recommended that functional difficulties in an individual child are NOT ascribed to 'difficulties registering or processing sensory information' since this putative</p>			

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		condition has not been defined			