NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

**Quality standard topic:** Cerebral palsy in adults

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

**Date of Quality Standards Advisory Committee meeting:** 11 June 2019

# Contents

[1 Introduction 2](#_Toc17961150)

[2 Overview 2](#_Toc17961151)

[3 Summary of suggestions 4](#_Toc17961152)

[4 Suggested improvement areas 6](#_Toc17961153)

[Appendix 1: Review flowchart 28](#_Toc17961154)

[Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders 29](#_Toc17961155)

1. Introduction

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

* 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. Development source

The key development source referenced in this briefing paper is:

[Cerebral palsy in adults](https://www.nice.org.uk/guidance/NG119) (2019) NICE guideline NG119.

1. Overview
   1. Focus of quality standard

This quality standard will cover care and support for adults with cerebral palsy. NICE has already published a quality standard on [cerebral palsy in children and young people](https://www.nice.org.uk/guidance/qs162). The published quality standard covers children and young people up to the age of 25.

* 1. Definition

Cerebral palsy is a lifelong condition caused by a problem in the developing fetal or infant brain. It mainly affects muscles and movement but can also affect how people see, hear, communicate, understand and think. Everyone with cerebral palsy is affected differently – symptoms vary widely and the effects can range from minor problems to severe disability. Most people with cerebral palsy live well into adulthood and many have independent and active lives. Although the brain injury that causes cerebral palsy does not get worse over time, its effects on the body change, so people often need different care and support as they grow older.

* 1. Incidence and prevalence

There are now more adults living with cerebral palsy than there are children with cerebral palsy. Around 1 in 400 adults have cerebral palsy, equivalent to approximately 109,000 people in England.

Adults with cerebral palsy have a wide range of abilities – from full independence in everyday life to needing 24‑hour care and attention. They tend to have less fluctuation in their motor skills than children. However, their mobility may decrease because of factors such as muscle tone, weakness and pain. Comorbid symptoms, such as pain, mental health problems, communication difficulties and nutritional problems can, individually and in combination, affect participation and quality of life. Some adults with cerebral palsy and associated comorbidities have difficulties with all aspects of health and daily living. Approximately 30% of adults with cerebral palsy have complex needs.

* 1. Management

Children with cerebral palsy have access to services specifically related to cerebral palsy. When they become adults there is no such service available to them. The care and support needs of adults with cerebral palsy depend on the severity of impairment and the presence or absence of comorbidities. There is significant variation in how services are currently provided to meet these needs. No single system is appropriate for all adults with cerebral palsy.

Adult’s with cerebral palsy may need access to appropriate specialist services such as rehabilitation medicine, neurology, speech and language therapy services, physiotherapy and occupational health. Those with learning disabilities can have an annual review of their needs. Adults with cerebral palsy, their family, or carers, may not be aware of their need for a specialist service, or know how to access that service.

As adults with cerebral palsy who have ongoing care needs grow older, there may be changes in their care arrangements. For example, it may not be possible for their parents to continue to be the main carers and other support may be needed, either in the community or a residential setting.

1. Summary of suggestions
   1. Responses

In total 11 stakeholders responded to the topic engagement exercise. Consultation initially ran for a 2-week period (21/03/19 to 04/04/19). An iterative process then began of contacting selected stakeholders who had not responded and extending the response deadline.

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 1 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 1 Summary of suggested quality improvement areas

| Suggested area for improvement | Stakeholders |
| --- | --- |
| **Multidisciplinary team** | ACPH, NHSE, SCM2, SCM3, SCM4 |
| **Access** |  |
| * Accessible facilities & equipment | RCOT, SCM1, SCM2, SCM3, SCM5, SCM6 |
| * Physiotherapy and physical activity | APCP, SCM1 |
| * Vocational skills and independent living | NHSE, RCOT, SCM3, SCM6 |
| **Pathways** | ACPH, APCP, SCM1, SCM2, SCM5, SCM6 |
| **Reviews** |  |
| * Annual reviews | ACPH, CM, NHSE, RCSLT, SCM1, SCM2, SCM3, SCM4, SCM5, SCM6 |
| * Main contact between reviews | SCM4, NHSE |
| **Communication and technology** |  |
| * Communication and assistive technology | CM, NHSE, RCSLT, SCM1, SCM2, SCM3, SCM5, SCM6 |
| * Other technology | ACPH, SCM2 |
| **Information sharing** | RCSLT, SCM2, SCM4, SCM5 |
| **Clinical complications and comorbidities** |  |
| * Mental health | RCSLT, RCOT |
| * Respiratory illness / failure and respiratory management | HR, RCSLT |
| **Additional areas** |  |
| * Training for clinicians | APCP |
| * Transition to adult services | ACP |
| ACP: Action Cerebral Palsy  ACPH: Adult Cerebral Palsy Hub  APCP: Association of Paediatric Chartered Physiotherapists  CM: Communication Matters  HR: Hill-Rom  NHSE: NHS England  RCOP: Royal College of Occupational Therapists  RCSLT: Royal College of Speech and Language Therapists  SCM1 to SCM6: Specialist committee members  **Responded with ‘no substantive comments’**  Department of Health and Social Care  Royal College of General Practitioners  The Neurological Alliance | |

* 1. Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 173 papers were identified for cerebral palsy in adults. In addition, 32 papers were suggested by stakeholders at topic engagement and 30 papers internally at project scoping.

Relevant evidence reviews for guideline NG119 were also searched for articles on current practice.

Of all these papers, 9 have been included in this report in the current practice sections. In many cases, the populations covered by the papers do not align fully with the target population of this quality standard. This is because there are no services specifically related to cerebral palsy for adults. Whilst the findings of the papers included may not be transferrable, they have been included as they provide context. Appendix 1 outlines the search process.

1. Suggested improvement areas
   1. Multidisciplinary team
      1. Summary of suggestions

A multidisciplinary approach with access to a specialist multidisciplinary team (MDT) was suggested by stakeholders as a key area for quality improvement. Many adults with cerebral palsy need ongoing specialist management. This is particularly important for people experiencing change or deterioration in function, and when surgical procedures are planned. Several stakeholders described many adults with cerebral palsy as having limited or no access to specialist teams. Some suggested that such teams needed to be available in primary and secondary care. Comments on MDT composition suggested the team should include allied health professionals; have experience in the management of neurological impairments; and expertise (or training) in neurorodisability / cerebral palsy.

* + 1. Selected recommendations from development source

Table 2 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 2 to help inform the committee’s discussion.

Table 2 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Multidisciplinary team | **Access to services**  NICE NG119 Recommendations 1.1.1, 1.1.2 |

### Access to services

NICE NG119 – Recommendation 1.1.1

Refer adults with cerebral palsy to a multidisciplinary team experienced in the management of neurological impairments if:

* their ability to carry out their usual daily activities deteriorates or
* a neurosurgical or orthopaedic procedure is being considered that may affect their ability to carry out their usual daily activities.

NICE NG119 – Recommendation 1.1.2

Recognise that reassessment by the multidisciplinary team may be needed by adults with cerebral palsy at different points in their lives to ensure that their changing needs are met (for example, pregnancy and parenting, decreased mobility due to hip arthritis, and loss of care and support from a parent).

* + 1. Current UK practice

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) published a review of the quality of care provided to patients aged 0-25 years old with cerebral palsy[[1]](#footnote-1). The review included an organisation survey (sent to every trust in the UK where children and young adults with cerebral palsy could be cared for); a patient and carer survey; and a clinical peer review using questionnaires and case notes. Although the age group covered by the review is different to that of this quality standard, the review did present some information on facilities available to adults.

One of the NCEPOD study questions asked if robust frameworks of multidisciplinary care are always available within service provision. The report states that every multidisciplinary team needs clear leadership, but found that details of a patient’s usual lead clinician for cerebral disability management was not always documented in case notes, and the position was worse for adults than it was for children: 63% of children (240/380) had details of their usual lead clinician in case notes compared to 23% of adults aged 18 to 25 (31/133).

NCEPOD case note reviewers reported evidence of regular physiotherapy to support and build function and prevent impairment in 221/309 (72%) patients. This varied with age and was lowest for adults aged 20-25 years, where only 31% (11/36) of case notes showed evidence of regular physiotherapy. The case reviewers assessed the quality of multidisciplinary care across four settings: paediatric inpatient care, paediatric outpatient care, adult inpatient care, adult outpatient care. Room for improvement was identified in all four settings, but there was greater room for improvement identified for all the adult service settings. Quality of multidisciplinary community care was not broken down by age.

A patient experience survey[[2]](#footnote-2) of members of The Neurological Alliance identified a wide range of professionals involved in providing neurology patient care. Over half of the 7,048 respondents (56%) felt that health and care professionals work well together at least some of the time, 20% feel this never happens. The results from this particular survey did not identify the proportion of respondents by type of condition. The previous Neurological Alliance patient experience survey of members found that 1% of respondents had cerebral palsy.

Service use and family-centred care in young people with severe cerebral palsy was assessed by a survey in a region of the UK[[3]](#footnote-3). Young people aged 4–27 years with severe forms of cerebral palsy were recruited via a case register in Northern Ireland and data were collected by questionnaire. Results from 123 people showed high levels of accessing specialist services in childhood with a considerable decrease in young adults. Use of generalist services remained relatively constant with age.

* + 1. Resource impact

Referring adults to an MDT was one of the main recommendations covered in a resource impact report for NG119. The report estimates the financial impact of implementing the recommendation for England at an indicative £1.2million. This figure is based on a scenario which assumes a 10% increase in referrals and uses an indicative unit cost of £112 per MDT referral. However, commissioners were encouraged to assess the impact locally as there was no clear evidence to support assumptions around current or future activity levels. A resource impact template was produced to allow costs to be calculated at a local level.

* 1. Access
     1. Summary of suggestions

### Accessible facilities & equipment

Stakeholders highlighted the importance of people physically being able to access services. Key areas suggested for quality improvement were access to buildings, and appropriate equipment to enable transfers and weighing of people who cannot weight bear. Comments state the latter is necessary to allow for regular weight checks and nutritional monitoring. One stakeholder suggested clarity and consistency regarding funding for equipment and adaptations to enable participation.

### Physiotherapy and physical activity

Rapid and appropriate access to physiotherapy and specialist seating when a person’s level of mobility changes was suggested by a stakeholder. Such access would help maintain independence and participation.

Improving access to physical activity for people with cerebral palsy was also suggested. Specifically, improving the expertise of those providing support for physical activities (sporting clubs, gymnasiums) through education so that such activity can be part of normal life rather than a ‘therapy’.

### Vocational skills and independent living

Access to specialist assessment for adults with cerebral palsy who are working, or who would like to work, from a professional with expertise in vocational skills was suggested. Stakeholders considered work as important for mental health, independence and participation in society. One stakeholder suggested access to specialist support and occupational therapy to promote self-management.

* + 1. Selected recommendations from development source

Table 3 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 3 to help inform the committee’s discussion.

Table 3 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Accessible facilities & equipment | **Access to services**  NICE NG119 Recommendation 1.1.8 |
| Physiotherapy and physical activity | **Physical activity**  NICE NG119 Recommendations 1.2.19, 1.2.20 |
| Vocational skills and independent living | **Vocational skills and independent living**  NICE NG119 Recommendations 1.2.11, 1.2.12 |

### Access to services

NICE NG119 – Recommendation 1.1.8

Recognise and address any physical and organisational barriers to accessing primary and secondary care for adults with cerebral palsy. For example, this may involve:

* improving physical access to buildings
* providing advice and information on accessible transport services, for example, local community transport services
* ensuring that appropriate equipment (for example, hoists and wheelchair weighing scales) and adequate changing and toilet facilities are available
* extending appointment times, if needed.

wheelchair services.

### Vocational skills and independent living

NICE NG119 – Recommendation 1.2.11

Refer adults with cerebral palsy who would like to live independently to a professional with expertise in independent living (for example, an occupational therapist). Give information and advice, which could include:

* adaptations to their home
* housing
* leisure activities
* statutory welfare benefits.

NICE NG119 – Recommendation 1.2.12

Refer adults with cerebral palsy who would like to work, or who are already working, to a professional with expertise in vocational skills and independent living (for example, an occupational therapist). Give information and advice, which could include:

* continued education
* job seeking or access to work schemes
* employment support to include workplace training and job retention
* occupational health assessment or workplace assessment
* statutory welfare benefits
* supporting a planned exit from the workforce if it becomes too difficult to continue working
* vocational rehabilitation

voluntary work.

### Physical activity

NICE NG119 – Recommendation 1.2.19

Provide information on accessible local services that support people with cerebral palsy to take part in physical activity.

NICE NG119 – Recommendation 1.2.20

Consider referring people with cerebral palsy to services with experience and expertise in neurological impairments that can provide support with physical activities (including sport) and tasks of daily living. Depending on local service provision and the person's needs, this may be to any of the following services:

* physiotherapy
* occupational therapy
* orthotic and functional electronic stimulation services
* rehabilitation engineering services
* wheelchair services.
  + 1. Current UK practice

**Accessible facilities & equipment**

No published studies on physical access to facilities were identified.

The NCEPOD review of quality of care provided to patients aged 0-25 years old with cerebral palsy [[4]](#footnote-4) shows that less than 50% of adult outpatient care providers reported having accessible scales to accurately weigh disabled patients, and less than 40% reported having access to hoists. Proportions recorded for emergency departments and adult inpatient services were lower still.

**Physiotherapy and physical activity**

The NCEPOD review4 reported evidence of regular physiotherapy to build function and prevent impairment in 72% (221 of 309) patient case notes. The review found that physiotherapy was less likely to be in place for older patients (31% of case notes of people aged 20-25 years had evidence of regular physiotherapy).

The Neurological Alliance Invisible Patients[[5]](#footnote-5) report provides information on neurological services based on a patient experience survey and commissioning audit. Patient experience information was gathered using an online survey of Neurological Alliance members. The commissioning audit was undertaken using freedom of information requests to all CCGs and NHS England in June 2014 (191 responses from CCGs were received). Of the 6,916 members who responded to the patient experience survey, 92% were aged 25 or over and 1% had cerebral palsy. 17% of all respondents reported having regular contact to help manage their condition from a physiotherapist.

No published studies on current practice were identified for physical activity and specialist seating.

**Specialist assessment from clinician with vocational skills**

No published studies on current practice were highlighted for this suggested area for quality improvement.

* + 1. Resource impact

Implementing the above recommendations was not expected to have a significant resource impact.

* 1. Pathways
     1. Summary of suggestions

Stakeholder comments indicated an absence of clear pathways for adults with cerebral palsy resulting in variability in access to care and treatment received. A contrast was made with children with cerebral palsy where there are services specifically for those with cerebral palsy, and also with other conditions (such as multiple sclerosis) where there are recognised pathways.

Several stakeholders suggested the focus for improvement should be delineated pathways for specialist management of movement disorders (spasticity and dystonia) for adults with cerebral palsy. These movement disorders were described as disabling but having treatable elements. However, stakeholders said there is variability in terms of access to specialist services and management strategies. Others suggested a pathway was needed to provide access to a wider range of services for all adults with cerebral palsy. Stakeholders described the referral process as being unclear, and there being variations in timely access to coordinated and appropriate care. A developmental area suggested by one stakeholder suggested that specialist cerebral palsy nurses could play an important role in coordinating how patients move along the pathways.

* + 1. 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

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Pathways | **Access to services**  NICE NG119 Recommendation 1.1.3 |

### Access to services

NICE NG119 – Recommendation 1.1.3

Commissioners and service providers should develop pathways that allow adults with cerebral palsy access to a local network of care that includes:

* advocacy support
* learning disability services
* mental health services
* orthopaedic surgery (and post-surgery rehabilitation)
* rehabilitation engineering services
* rehabilitation medicine or specialist neurology services
* secondary care expertise for managing comorbidities (for example, respiratory, gastrointestinal and urology services)
* social care
* specialist therapy services (for example, physiotherapy, occupational therapy, speech and language therapy, and dietetics)
* wheelchair services.
  + 1. Current UK practice

No published studies showing variation in practice on care pathways for adults with cerebral palsy were identified, but some were identified for children and young people. An NCEPOD organisational survey reported some information on pathways for children and young people[[6]](#footnote-6). An agreed written care pathway for the assessment, diagnosis and management of children and young people with cerebral palsy was not in place in 56/82 organisations providing paediatric outpatient care; in 42/81 organisations providing community paediatric care; and in 42/48 organisations providing adult outpatient care.

Action Cerebral Palsy carried out a Freedom of Information study into the provision of cerebral palsy services across England[[7]](#footnote-7). The freedom of information requests sought information on services commissioned by clinical commissioning groups; services provided by major local authorities; and services provided by NHS Trusts. Of 209 CCGs approached, 92% failed to provide details of their pathway for children and young people with cerebral palsy. Only 7% of CCGs reported that they had specific, tailored pathways. Out of 227 trusts, only 15% were able to provide a care pathway for children and young people with cerebral palsy.

A longitudinal study used mixed methods to assess how well services for young people deliver features to improve transition from child to adult health services[[8]](#footnote-8). The study found features proposed to improve transition to adult services were often lacking for those with cerebral palsy. One of the reasons suggested for the relatively poor organisation of supporting transition for young people with cerebral palsy was that it is often unclear to where to transfer the healthcare to.

* + 1. Resource impact

Implementing recommendation 1.1.3 was not expected to have a significant resource impact.

* 1. Annual reviews
     1. Summary of suggestions

### Annual reviews

Annual reviews of adults with cerebral palsy was suggested by several stakeholders. Such reviews could make sure that changing needs could be identified and addressed as people age. Comments described how cerebral palsy was previously seen as non-progressive, but that people can experience new problems as adults as well as changes in secondary conditions. As adults grow older, their function, posture and mobility can become more difficult. Some stakeholders said that annual reviews would help the transition from children’s services where young people would have had regular oversight, but after this can ‘go missing’ in the system. Some stakeholders emphasised the importance of annual reviews, as all recommendations in NICE guideline NG119 would flow from this. In terms of who should perform the review, some stakeholders suggested that adults with complex needs should be reviewed by a healthcare professional with expertise or experience in neurodisabilities.

### Main contact between reviews

Stakeholders suggested having a key professional who can be contacted between reviews by adults with cerebral palsy. People need to be able to access advice, care and support when it is needed, such as if their condition changes. One stakeholder suggested the key person should be a named contact.

* + 1. 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

|  |  |
| --- | --- |
| **Suggested quality improvement area** | **Selected source guidance recommendations** |
| Annual reviews | **Ongoing care**  NICE NG119 Recommendations 1.1.12, 1.1.13 |
| Main contact between reviews | **Ongoing care**  NICE NG119 Recommendations 1.1.16, 1.1.17 |

**Ongoing care**

NICE NG119 – Recommendation 1.1.12

Consider regular reviews for adults with cerebral palsy, tailored to their needs and preferences. Agree with the person the frequency of review and which services should be involved based on their needs and preferences.

NICE NG119 – Recommendation 1.1.13

Offer an annual review of the person's clinical and functional needs, carried out by a healthcare professional with expertise in neurodisabilities, for people with cerebral palsy who have complex needs (such as Gross Motor Function Classification System [GMFCS] levels IV and V) and any of the following:

* communication difficulties
* learning disabilities
* living in long-term care settings
* living in the community without sufficient practical and social support (for example, being cared for by elderly, frail parents)
* multiple comorbidities.

NICE NG119 – Recommendation 1.1.16

Identify who will be the main point of contact for the person with cerebral palsy (and their family and carers, if agreed) between reviews, and provide information on how to contact them.

NICE NG119 – Recommendation 1.1.17

If an adult with cerebral palsy chooses not to have regular reviews, offer the person (and their family and carers, if agreed) information on when to contact a healthcare professional and how to access the specialist services that they may need. Ensure that the person's GP and multidisciplinary team are aware that they do not want to be reviewed regularly (with the person's permission).

* + 1. Current UK practice

No published studies on current practice with regards to annual reviews for adults with cerebral palsy were identified. Adults with learning disabilities (including adults with cerebral palsy who have learning disabilities) can have an annual review of their needs. NHS Digital information collected from around half of GP practices in England[[9]](#footnote-9) shows that only 55.1% of patients with a learning disability had an annual learning disability health check in 2017/18. [The NHS long term plan](https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/) aims to increase uptake so that at least 75% of those eligible have a health check each year.

* + 1. Resource impact

Recommendation 1.1.13 was assessed as part of the NG119 resource impact report and template, and was considered not to have a significant impact on NHS resources overall. Using a unit cost of £172 per annual review and modelling a 10% increase in people having a review generated an indicative cost of £560,700 for England. This was expected to be offset by a reduction in emergency admissions for people with cerebral palsy and complex needs who also had additional risk factors such as communication difficulties or comorbidities. Organisations were advised to review their local circumstances and use the template to calculate costs and savings at a local level.

* 1. Communication and technology
     1. Summary of suggestions

### Communication and assistive technology

Communication was suggested as a key area by several stakeholders as it underpins the ability to engage in decision making and maintains participation in social, family and economic activities. Most comments on communication suggested the focus for quality improvement should be on access to speech and language therapy and assistive technology. For adults with cerebral palsy who have little or no functional speech, ongoing and appropriate input from speech and language therapy, and all other associated services (such as occupational therapy), was described as necessary to ensure that their communication needs are met. As well as speech and language therapy, several stakeholders suggested access to alternative and augmentative communication systems (AAC). Comments described the provision of AAC and necessary services as ‘very patchy’ and variable. Two stakeholders suggested a focus on communication between an adult with cerebral palsy and those providing care and support with consideration given to the time needed, means of communication (including electronic) and advocacy.

### Other technology

Population health management using predictive prevention to better support people to stay healthy and avoid illness, as proposed in the [NHS Long Term Plan](https://www.longtermplan.nhs.uk/), was suggested. This is an emerging area, as the plan aims to deploy population health management solutions, and systems to support it, over coming years.

Another stakeholder suggested use of technology to enhance communication (between professionals, patient access to notes, for appointments etc.) as a developmental area. Improved technology could help hospitals, GPs, community and social care providers join up people’s care, use resources more effectively and allow patients access to their information and empower them.

* + 1. 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

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Communication and assistive technology | **Access to services**  NICE NG119 Recommendation 1.1.7  **Communication**  NICE NG119 Recommendations 1.2.3, 1.2.4, 1.2.6  **Electronic assistive technology**  NICE NG119 Recommendations 1.2.13, 1.2.14 |
| Other technology | Not directly covered in NICE NG119 and no recommendations are presented |

**Access to services**

NICE NG119 – Recommendation 1.1.7

Recognise and address any personal barriers to accessing primary and secondary care for adults with cerebral palsy. For example, this may involve:

* ensuring healthcare professionals have the skills and training to overcome communication difficulties
* providing treatment and support for mental health problems
* ensuring that the person has an advocate, if needed
* providing support to help with social and emotional factors, such as fear of stigma, lack of motivation and exhaustion.

### Communication

NICE NG119 – Recommendation 1.2.3

Explore with the person with cerebral palsy who has communication difficulties whether they have a potential need for alternative and augmentative communication systems.

NICE NG119 – Recommendation 1.2.4

Ensure that training is provided for people with cerebral palsy using alternative and augmentative communication systems and their families, carers and other key communication partners in home, care, social or work environments.

NICE NG119 – Recommendation 1.2.6

Refer adults with cerebral palsy who have communication difficulties to speech and language therapy services to assess their need for intervention, which may include:

* use of alternative or augmentative communication systems
* intensive speech therapy to improve the intelligibility of their speech.

### Electronic assistive technology

NICE NG119 – Recommendation 1.2.13

Discuss with adults with cerebral palsy the potential role of electronic assistive technology if they have problems with participation and independence.

NICE NG119 – Recommendation 1.2.14

If adults with cerebral palsy have complex physical, cognitive, language or sensory needs, consider referring them to services providing information, assessment and provision of electronic assistive technology.

* + 1. Current UK practice

### Communication and assistive technology

A clinical review of case notes of patients aged 0-25 years old with cerebral palsy[[10]](#footnote-10) found that a preferred method of communication was only documented in the case notes of 35% of patients, and in a clinic letter for 38% of patients.

A survey to describe the assessment and intervention practices of speech and language therapists working with children and young people with cerebral palsy was undertaken in 2012[[11]](#footnote-11). The survey of 265 therapists found that the assessment and management of communication difficulties varies widely in the UK. Assessment practices were described by therapists as individualised and dependent on the needs of the person. 94% of therapists provided AAC interventions.

Communication Matters commissioned research to examine the need for, and provision of, AAC in the UK[[12]](#footnote-12). The report identified variations in AAC provision and funding through analysis of data returned from surveys of UK services. However, it predated NHS England guidance on AAC services[[13]](#footnote-13). Services for children and adults who need and use AAC are now commissioned as “specialised” and “local” AAC services. Specialised AAC Services are funded directly by NHS England and provide assessment, review and equipment for those with the most complex communication needs (likely to require a high-tech powered communication aid). An estimated 0.05% of the population will use these services. Most children and adults who need AAC will be supported by local AAC services. These are commissioned by CCGs, education and social care commissioners. Those accessing local AAC services are likely to be a group around 10 times larger than those using specialised AAC services (approximately 0.5% of the population).

A study exploring speech, communication and use of augmentative communication in young people with cerebral palsy was published in 2014[[14]](#footnote-14). The study included people aged 16–18, motor skills and speech were directly assessed, and both the parent/carer and the young person were asked about communication. Of 224 young people with bilateral cerebral palsy, the study found 33% had little or no speech, and 63% had some speech impairment. Of the total, 31% were provided with AAC (75% of those with moderate or severe speech impairment were provided with AAC). The most common form of AAC in use was graphic symbols (ranging from a small number of picture cards to displays of multiple symbols on the screens of sophisticated communication aids). 47% of the total with AAC had some form of Voice Output Communication Aid.

### Other technology

No published studies on the areas of other technology suggested were identified for cerebral palsy.

* + 1. Resource impact

These recommendations were not expected to have a significant resource impact.

* 1. Information sharing
     1. Summary of suggestions

Information sharing through use of ‘hospital passports’, portfolios and care plans was suggested. Adults with cerebral palsy often receive care and support from a range of professionals and carers in different disciplines and settings. Effective information sharing can help coordinate care and support for the person with cerebral palsy and ensure that their communication preferences and needs are known. This, along with access to information, can improve involvement of the person with cerebral palsy in decisions about care and treatment. One stakeholder suggested training and information should be provided to adults with cerebral palsy (such as on communication and self-management). Another stakeholder emphasised consistency in information sharing as important and suggested use of functional classification systems to ensure continuity of information about function.

* + 1. 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

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Information sharing | **Ongoing care**  NICE NG119 Recommendation 1.1.14, 1.1.15 |

### Ongoing care

NICE NG119 – Recommendation 1.1.14

Discuss with the person with cerebral palsy (and their family and carers, if agreed) what information should inform the regular or annual review, and who should receive clinical information following review (for example, their GP).

NICE NG119 – Recommendation 1.1.15

Record details of the person's review and share the information with relevant people (for example, healthcare professionals and social care practitioners), with the person's permission.

* + 1. Current UK practice

A patient experience survey of Neurological Alliance members with a neurological condition[[15]](#footnote-15) (7,048 respondents) identified that 85% of patients had not been offered a care plan. At the time of the survey, less than 10% of respondents had a care plan. The figures show a poorer patient experience than an earlier survey in 2014[[16]](#footnote-16) when 72% of patients had not been offered and care plan and 19% had one. Members were also asked how satisfied they were with the type of information received from healthcare professionals throughout living with their condition. Generally, more members were satisfied than unsatisfied with information received, but the proportion unsatisfied was often large. For example, 43% of respondents were unsatisfied with information received on contact details for a named healthcare professional in charge of their care; 45% were unsatisfied with information received about their condition, and 46% were dissatisfied with information received about their care and treatment options.

The NCEPOD review of quality of care[[17]](#footnote-17) included a clinical review of questionnaires sent to lead clinicians involved in a patient’s care as well as case notes. The report shows that leads for inpatient care for people with cerebral palsy did not have ready access to the patient’s community records and clinic letters (regarding their cerebral palsy) at the time of admission for 42/73 (57.5%) of patients aged 20-25. Communication with the patient’s wider multidisciplinary team about aspects of their health and wellbeing whilst they were inpatients was reported by case reviewers to be inadequate for 46/63 (73.0%) patients aged 20-25.

Case reviewers also found variation in the adequacy of communication on discharge from hospital. For patients discharged from inpatient and day case care, data showed that communication was relatively good with patients and their GP, but was lacking for the wider multidisciplinary team.

* + 1. Resource impact

No significant resource impact.

* 1. Clinical complications and comorbidities
     1. Summary of suggestions

### Mental health

One stakeholder described the key area for improvement as ‘mental and physical health are not disconnected’. The concern was that mental issues may be overlooked by assuming there is a physical cause. The quality improvement action would presumably be supporting people with combined mental and physical health in a more integrated way. Another stakeholder suggested access to mental health services and support as the key area for improvement.

### Respiratory illness / failure and respiratory management

Respiratory illness / failure and respiratory management were suggested by two stakeholders as key areas for quality improvement. However, the comments describe broad areas.

* + 1. 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

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Mental health | **Mental health problems**  NICE NG119 Recommendations 1.4.9 |
| Respiratory illness / failure and respiratory management | **Identifying and monitoring respiratory disorders**  NICE NG119 Recommendation 1.4.24  **Discussing the management of respiratory failure**  NICE NG119 Recommendation 1.4.30 |

### Mental health problems

NICE NG119 – Recommendation 1.4.9

Identify and address mental health problems alongside physical health problems. Recognise that the impact of mental health problems and emotional difficulties can be as important as physical health problems for adults with cerebral palsy.

### Identifying and monitoring respiratory disorders

NICE NG119 – Recommendation 1.4.24

Refer adults with cerebral palsy and persistent or multiple signs and symptoms of respiratory impairment, or risk factors for respiratory impairment (see recommendations 1.4.22 and 1.4.23) to specialist services.

### Discussing the management of respiratory failure

NICE NG119 – Recommendation 1.4.30

If a person with cerebral palsy has symptoms of respiratory failure, or is at high risk of developing respiratory failure, discuss their management plan with them (and their family or carers, if agreed), including:

* assessing the effectiveness and tolerability of treatment
* treatment goals and escalation plan of treatment
* managing complications
* options for managing progressive respiratory failure.
  + 1. Current UK practice

### Mental health

No published studies on mental health were identified for adults with cerebral palsy.

### Respiratory illness / failure and respiratory management

No published studies for this area were identified for adults with cerebral palsy.

* + 1. Resource impact

This area was not expected to have a significant resource impact.

* 1. 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 11 June 2019.

### Training for clinicians

The training of clinicians who are not specialists on the nature and complexity of cerebral palsy was suggested as an area of quality improvement. This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place. The committee is therefore asked to consider which components of care and support would be improved by increased training. Training may be referred to in the audience descriptors.

### Transition to adult services

Transition to adult services for young people with cerebral palsy has not been progressed as a statement. This falls outside of the scope of this quality standard. It was considered during the development of quality standard QS162 [cerebral palsy in children and young people](https://www.nice.org.uk/guidance/qs162). However, QSAC did not prioritise it for progression as a quality statement. [Transition from children’s to adults’ services](https://www.nice.org.uk/guidance/qs140) quality standard also covers this suggested area.

© NICE 2019. All rights reserved. Subject to [Notice of rights](https://www.nice.org.uk/terms-and-conditions#notice-of-rights).

# Appendix 1: Review flowchart

Records identified through topic engagement  
n = 32

Records identified through IS scoping search  
n=30

Records identified through ViP searching  
n = 173

Records excluded  
n = 218

Records screened  
n = 235

Full-text papers excluded  
n =8

Full-text papers assessed   
n =17

Current practice examples included in the briefing paper  
n = 9

# Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

| **Suggested area: Multidisciplinary team** | | | | | |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| 8 | SCM2 | **3. AHP’s available in primary care** with expertise in supporting those with neuro disability | Adults with CP have recognised co-morbidities re. communication/physical and emotional health.  EHCPs 0- 25 with aspirational goals requiring habilitation and will require SLT/OT/PT to enable them to both reach their potential, manage their condition most effectively and to manage secondary complications in a timely fashion in order to find solutions and be enabled to continue with Vocaton/participate fully.  Self-management and timely adjustments in support /activity in order to find solutions and maintain activity and participation  As review of spasticity management – 24 hour postural management | * Increased expectation/recognition that adults with CP benefit and have a right to achieve there potential re. EHCP – be active/ fully participate have aspirational goals. * Evidence that emotional well being is improved/secondary complications avoided by empowering people in managing their long term conditions – being ‘employed’ . being active and participating. * Increased likelihood of survival and need to address/manage secondary comorbidities. * Send Code of Practise.Children and Families Act 2014(moving into paid employment and higher education, independent living, having friends and relationships and being part of their communities, being as healthy as possible) * Review of postures/ support during activity and participation and self management approaches may avoid invasive – pharmacological/surgical . Also key adjunct to botox programmes OT/PT | Falls older people Quality standard [QS86] Balance programmes/home assessment  Low back pain and sciatica Quality standard [QS155] – self management  Quality standard [QS84]Physical Activity Staff/patients/carers Advice during health checks exercise.  CP Adults NICE guideline [NG119] Physical Activity  Tone management |
| 19 | SCM3 | 3. Adults with Cerebral palsy are able to access a specialist multidisciplinary team if required due to a deterioration in function or planned surgical procedure. | A specialist multidisciplinary team can improve the outcome for adults with cerebral palsy who are experiencing deterioration in function or recovering from surgery. | Adults with cerebral palsy do not all have access to specialist teams and may not be offered a service by some teams with appropriate expertise due to these team's exclusion criteria for long term conditions. | <https://www.nice.org.uk/guidance/ng119> |
| 26 | SCM4 | 5. Access to specialist multi-disciplinary teams | Many adults with CP need ongoing specialist management. In addition, their condition can change and early recognition and management can reduce the impact. Many though have limited access to specialist teams. |  | NICE CPA |
| 34 | Adult Cerebral Palsy Hub | 3. Multidisciplinary Approach | Rapid access to specialist multidisciplinary teams is particularly important when the person with cerebral palsy experiences a change or deterioration in their functional abilities.  There is wide variability in clinical needs that may also change over time.  Regular reviews are important to check for any new problems and ensure that people’s needs continue to be met. Regular reviews should be considered, tailored to the person’s needs.  The frequency of review was not specified because it will depend on  person’s needs and wishes | They recognised that the needs of adults with cerebral palsy may change over time and that services should be sufficiently flexible to manage these challenges.  Refer adults with cerebral palsy to a multidisciplinary team experienced in the management of neurological impairments if   * their ability to carry out their usual daily activities deteriorates or * a neurosurgical or orthopaedic procedure is being considered that may affect their ability to carry out their usual daily activities.   Reassessment by the multidisciplinary team and different clinical services may be needed by adults with cerebral palsy to ensure that their care meets their changing needs at different points in their lives.  Delivery of care by flexible teams working across primary care and local hospitals as proposed in the NHS long term plan ( Jan 2019) would greatly benefit the adult Cerebral palsy Community.  More joined up and coordinated care as advocated in the NHS long term plan ( Jan 2019) would:   * Break down traditional barriers between care institutions, teams and funding streams. * Support people with long term health conditions and connecting “episodes” of care. | Please see the NICE guidelines for Adults with Cerebral Palsy (published-Jan 2019).  Please see the NHS Long-term plan (published–Jan 2019) |
| 60 | NHS England | 2. Health Care Professions are available in primary and/or secondary care with expertise and training in Neurorodisability / cerebral palsy to provide assessment and management of any medical, physical, emotional or social changes. | [Additional information] It may be appropriate to consider timely access to outpatient neuro rehabilitation services which can vary widely for patient presenting with neurodisability. People with cerebral palsy who are experiencing deterioration in function can require prompt access to limit the impact.  In addition we would suggest that NICE may wish to consider Orthotics as well as Occupational Therapy, Orthotics, Physiotherapy and Speech and Language professions as they would have specific relevance to this group. |  |  |

| **Suggested area: Access** | | | | | |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| 18 | SCM3 | 2. Adults with Cerebral Palsy should be able to physically access services to monitor changes to BMI | Health services should be accessible to people with physical / neurological impairments and be responsive to changes in weight / eating ability to make appropriate onward referrals | The NICE guidelines state the need for nutritional monitoring and an appropriate means of weighing people who cannot weight bear must be available. | <https://www.nice.org.uk/guidance/ng119> |
| 2 | SCM1 | 2. Clinical Services for Adults with Cerebral Palsy should have physically accessible facilities with appropriate equipment to facilitate transfers and weighing. | Health services should be accessible to people with neurological impairments otherwise people with cerebral palsy are unfairly disadvantaged with consequences for their health. | The NICE guidelines state the need for nutritional monitoring and an appropriate means of weighing people who cannot weight bear must be available. Access to clinical services underpins any intervention that is being proposed outside an individual’s own home. | <https://www.nice.org.uk/guidance/ng119> |
| 10 | SCM2 | **5. Adjustments in place to support access** to health primary and secondary services | Routine Health Checks are as essential for this population and suitable provision re. Move and Handle Support – equipment – access buildings are often restrictive | * Pro-active management of secondary co-morbidities as well as ‘usual’ aging screening. * Adults with CP more likely to engage with health checks/monitoring. | Patient experience adults using NHS Clinical guideline [CG138]  Adjustments environment and utilisation of Hospital Passport  CP Adults NICE guideline [NG119]  Adjustments/availability of equipment |
| 28 | SCM5 | 2. Clinical Services for Adults with Cerebral Palsy should have physically accessible facilities with appropriate equipment to facilitate transfers and weighing. | Disabled people have a burden of untreated ill-health related to their inability to access health services both physical and communication wise. This cuts across both primary and secondary care.  Issues such as obesity/undernutrition, osteoporosis/cardiovascular risk factors are more prevalent in the disabled population. | Under the Equalities Act services should be accessible. There is concern regarding access to breast screening (Lancet 2013), similarly however cervical screening, cardiovascular screening and other preventative healthcare maybe an accessible. The NICE guidelines state the need for nutritional monitoring and an appropriate means of weighing people who cannot weight bear must be available. Access to clinical services underpins any intervention that is being proposed outside an individual’s own home. | <https://www.nice.org.uk/guidance/ng119>  Screening test for adults with intellectual disabilities [J Am Board Fam Med. 2007 Jul-Aug; 20(4): 399–407](https://www.ncbi.nlm.nih.gov/entrez/eutils/elink.fcgi?dbfrom=pubmed&retmode=ref&cmd=prlinks&id=17615421).  Barriers to access to cancer screening for people with learning disabilities Lancet volume 382 special issue 2013 |
| 54 | SCM6 | 2. Clinical Services for Adults with Cerebral Palsy should have physically accessible facilities with appropriate equipment to facilitate transfers and weighing. | Health services should be accessible to people with neurological impairments otherwise people with cerebral palsy are unfairly disadvantaged with consequences for their health. | The NICE guidelines state the need for nutritional monitoring and an appropriate means of weighing people who cannot weight bear must be available. Access to clinical services underpins any intervention that is being proposed outside an individual’s own home. | <https://www.nice.org.uk/guidance/ng119> |
| 68 | Royal College of Occupational Therapists | 4. Clarity and consistency regarding funding for equipment, adaptations and wheelchairs to enable participation |  |  |  |
| 5 | SCM1 | 5. Adults with cerebral palsy should have rapid and appropriate access to physiotherapy and/or specialist seating when there is a change in their level of mobility. | Many adults with cerebral palsy may have issues with mobility that arise from a variety of mechanisms. The appropriate restorative or compensatory approaches are important in maintaining independence and participation. | Different therapy services with specialist neurological oversight may have exclusion criteria for people with long term conditions even though these conditions can change with time and the development of comorbidities. Specialist seating is an area where change may be required over time to maintain posture and skin integrity. | <https://www.nice.org.uk/guidance/ng119> |
| 42 | Association of Paediatric Chartered Physiotherapists | 4. Improved integration into everyday activities | Despite the encouragement of people to engage in and be active there is some resistance to including ease of access to gymnastiams and sporting clubs. Education and fascilitation of this for adults with CP will improve rates of engagement in physical activity. | Managing functional issues and participation in people with cerebral palsy aged 25 and over NICE guidelines suggests providing information on accessible local services that support people with cerebral palsy to take part in physical activity. They also advise consideration of referring people with cerebral palsy to services with experience and expertise in neurological impariements that can provide support with physical activities and tasks of daily living. However it may be just as wise to consider improving the expertise of those providing support for physical activities (sporting clubs, gymnasiums) through education to reduce the ‘therapy’ aspect and change activity to being part of normal life. | Start active, stay active report on physical activity in the UK |
| 21 | SCM3 | 5. Adults with cerebral palsy who are working or who would like to work can access a specialist assessment from clinicians with vocational skills for assessment and advice. | Paid work / meaningful occupation is key in avoiding mental health difficulties. | This area may be overlooked / not addressed by professionals focused on physical impairment. | <https://www.nice.org.uk/guidance/ng119> |
| 56 | SCM6 | 4. Adults with cerebral palsy who are working or who would like to work can access a specialist assessment from clinicians with vocational skills for assessment and advice. | Work is a key area for maintaining health and offers the adult with cerebral palsy economic independence and participation in society. | Paid work / meaningful occupation is key in avoiding mental health difficulties. | <https://www.nice.org.uk/guidance/ng119> |
| 61 | NHS England | 3. Adults with cerebral palsy who are working or who would like to work can access a specialist assessment from a professional with vocational skills for assessment and recommendations to support employment. | [Additional information] The provision of vocational rehabilitation nationally is currently varied, it may be appropriate to seek further guidance from RCOT in relation to this subject area. |  |  |
| 65 | Royal College of Occupational Therapists | 1. Promoting self-management through access to specialist support/occupational therapy with a focus on strategies and enabling participation as well as provision of equipment and environmental adaptations. |  |  | RCOT is not aware of any reports/audits relating to adults with cerebral palsy and occupational therapy, although a Cochrane Review of interventions for unilateral CP in children was published today: <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004149.pub3/epdf/full> |
| 67 | Royal College of Occupational Therapists | 3. Access to support to enable productive lives (work, volunteering, continuing education) |  |  |  |

| **Suggested area: Pathways** | | | | | |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| 3 | SCM1 | 3. There should clearly delineated pathways for specialist management of movement disorders (spasticity and dystonia) for adults with cerebral palsy | There are different treatments used for spasticity and dystonia and an appreciation of the difference between them with the right level of knowledge to apply the required treatment would reduce the potential harms associated with utilising the wrong approach. | Teams and clinicians treating movement disorders may have great local variance with variable rates of access to specialist management strategies such as botulinum toxin and intrathecal baclofen. Equity of access to specialist review and management and standardisation of treatment approached in accordance with NICE guidelines and BSRM guidelines on treating spasticity. | <https://www.nice.org.uk/guidance/ng119>  <https://www.rcplondon.ac.uk/guidelines-policy/spasticity-adults-management-using-botulinum-toxin> |
| 7 | SCM2 | 2. Access and assessment by medical professional with appropriate level of training/expertise in a timely fashion.  Primary health care team/G.P have knowledge of C.P and individual needs and have clear pathways to **refer for specialist re. Neuro/orthopaedics/Respiratory/G.I /Mental Health**  CLEAR PATHWAYS. | Missed diagnosis and in-appropriate management are significant factors in mortality particularly those with complex conditions.  Secondary co-morbidities are identified and due to increased number surviving and life expectancy the prevalence is increasing. Respiratory a key …. | * Due to experiences in Paediatrics increased reliance on single professional – Paediatrician – lack of confidence/relationship with G.P young adults / carers are less likely to engage without support and positive/consistent experience. * Not appropriate or necessary for all adults with C.P to attend hospital routinely. Hospital is … * Important to identify those with higher need/ at point in progression or secondary complications that require specialist/hospital attendance.(Respiratory spec ) | The Accessible Information Standard (DCB1605 Accessible Information)  Heather Freeth  NCEPOD Each and Every Need |
| 29 | SCM5 | 3. There should clearly delineated pathways for specialist management of movement disorders (spasticity and dystonia) for adults with cerebral palsy | Spasticity and dystonia are both disabling and have treatable elements to it however individuals with a disabling condition can have a number of other complications which are driving spasticity and therefore need good diagnostic work up and good treating pathways. This is something that is often done badly and the roles of medications and various therapists is not always well understood. | There is marked inequalities across the country as to access to the specialist services and therefore variable rates of access to specialist management strategies such as botulinum toxin and intrathecal baclofen (the latter needs to be done in a centre with good level of competency particularly in individuals with CP, and good follow-up arrangements must be available for both). Moreover without good care pathways and understanding there can be capacity issues even in good services.  Timely access to good spasticity management can reduce the need for other services particularly surgical release of contractures, pressure sore management, difficulties with seating, pain services.  I would concur that access to specialist review and management and standardisation of treatment approached in accordance with NICE guidelines and BSRM guidelines on treating spasticity. | <https://www.nice.org.uk/guidance/ng119>  <https://www.rcplondon.ac.uk/guidelines-policy/spasticity-adults-management-using-botulinum-toxin> |
| 33 | Adult Cerebral Palsy Hub | 2.Care Pathways | Services are not always joined up to provide all aspects of care.  Commissioners and service providers should develop pathways that allow adults  with cerebral palsy access to a local network of care that includes:  -advocacy support  -learning disability services  -mental health services  -orthopaedic surgery and post- surgery rehabilitation  -rehabilitation engineering services  -rehabilitation medicine or specialist neurology services  -secondary care expertise for managing comorbidities (for example, respiratory, gastrointestinal and urology services)  -social care  -specialist therapy services (for example physiotherapy and occupational  -wheelchair services | Such pathways, the NICE guidelines (Jan 2019) committee noted, would lead to the more timely treatment and may prevent unplanned hospital admissions.  More joined up and coordinated care as advocated in the NHS long term plan ( Jan 2019) would:  -Break down traditional barriers between care institutions, teams and funding streams.  -Support people with long term health conditions and connecting “episodes” of care.  Delivery of care by flexible teams working across primary care and local hospitals as proposed in the NHS long term plan ( Jan 2019) would greatly benefit the adult Cerebral palsy Community. | Please see the NICE guidelines for Adults with Cerebral Palsy (published-Jan 2019).  Please see the NHS Long-term plan(published–Jan 2019) |
| 39 | Association of Paediatric Chartered Physiotherapists | 1. Improvement of Pathway of care for Adults with CP | When an adult with CP has not been requiring healthcare and a new issue arises, the pathway of care and onward referral process is often not clear. For conditions like Multiple Sclerosis and Stroke defined pathways are available for GPs to follow. The inconsistency of pathways of care can increase the time between presenting with an issue (eg pain) and receiving appropriate and timely care, and reduce the patient and NHS cost from inappropriate referrals. | NCEPOD described differences in accessing care in a timely manner for young people with cerebral palsy depending upon their location and disability. | NCEPOD 2018. Each and Every need; Chronic Neurodisability |
| 57 | SCM6 | 5. There should clearly delineated pathways for specialist management of movement disorders (spasticity and dystonia) for adults with cerebral palsy | Spasticity and dystonia are both disabling and treatable. There is a wide variability of access to specialist spasticity services. | There is variability in the UK in accessing specialist spasticity services leading to varied treatments. Spasticity has a number of treatment options including therapy, medication and surgical options. Intervention requires specialist MDT teams to offer treatment. This approach requires continuity and followup care. | <https://www.nice.org.uk/guidance/ng119>  <https://www.rcplondon.ac.uk/guidelines-policy/spasticity-adults-management-using-botulinum-toxin> |
| 37 | Adult Cerebral Palsy Hub | Developmental areas of emergent practice: Specialist Cerebral Palsy Nurses. | Specialist nurses have been shown to play a vital role in many other medical conditions  There is wide variability in clinical needs that may also change over time. | Having a specialist nurse to facilitate access to  such medical pathways, could lead to the more timely treatment / referrals and may prevent unplanned hospital admissions as well as reducing the feeling of isolation the patient may feel. | Please see the NICE guidelines for Adults with Cerebral Palsy (published-Jan 2019). |
| 32 | Adult Cerebral Palsy Hub | 1. Transition | Children with CP have access to services specifically related to CP. When they become adults there is no such service available to them  There is insufficient specialist service provision for adults, with variation and a lack of continuity in care. | Within the NICE guidelines (Jan 2019) based on their consensus, the committee agreed that the transition process from children’s disability services to general adult services may have a detrimental effect on meeting the specific needs that adults with Cerebral Palsy have.  There is also a need for transition of knowledge from paediatrics to adult colleagues to ensure continuity of in the quality of care. Evidence for the need for mentoring which now occur informally need to be formally established in the way of recognised mentorship programmes. Enabling upskilling and sub specialisations in adult services as is common within paediatrics  The NICE guidelines (Jan 2019) committee highlighted that it is important that services continue to meet the people’s needs when they move into adult services. | Please see the NICE guidelines for Adults with Cerebral Palsy (published-Jan 2019). |

| **Suggested area: Annual reviews** | | | | | |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| 14 | Communication Matters | 2.Ensuring that as adults with CP age their changing needs are taken account of and appropriately provided for. | CP is not an unchanging condition and as adults grow older, they can find that their function, posture and mobility (fine and gross) becomes more difficult due to years of possible abnormal patterns of movement. This can have huge implications for their access to AAC and may necessitate changing hardware, software, access methods of wheelchair seating and mounting. | The impact of ageing on CP has not been adequately addressed until quite recently and therefore it is very important that this developing understanding is carried through into all areas of the person's life, including communication. |  |
| 6 | SCM2 | **1. Annual Review** of changing Needs. Review of mental health alongside physical health  Primary and/ or Secondary Care depending on complexity of needs | To identify and manage or prevent secondary complications developing in a pro-active manner.  To maintain consistent link/support adult with CP can develop confidence in , increase likelihood of timely engagement if health deteriorates. | * Large variation in access to G.P services/consistent G.P .In equality re. annual reviews already offered / in place eg. LD annual review already offered. * No consistent level / availability of neurodisability/rehabilitation team currently available re. C.P * In equity in provision re. chronic and other neuro-disabilities either progressive or not ie. MD and Spina Bifida services re. adults. | [Mental health problems in people with learning disabilities](http://www.nice.org.uk/guidance/ng54) (2016) NICE guideline NG54  CP in Adults NICE guideline [NG119]  Patient experience adults using NHS Clinical guideline [CG138] – Consistency in staff |
| 17 | SCM3 | 1. Adults with cerebral palsy are offered an individualised annual review of their clinical and functional needs, carried out by a healthcare professional with expertise in neurodisabilities | Quality annual health checks would improve health and wellbeing for adults with cerebral palsy who take up the offer. | Adults with cerebral palsy are not routinely offered health checks which means they are likely to be missing out on services which can improve lives | <https://www.nice.org.uk/guidance/ng119> |
| 22 | SCM4 | 1. Offer an annual review for adults with cerebral palsy. For those with complex needs, this should be carried out by a healthcare professional with experience of neurodisability. | This was a key recommendation in the CPA guideline and. It would go some way to lessening the cliff edge when moving from children’s services and regular oversight by paediatricians into adult services and would also pick up age related changes in condition and abilities allowing these to be addressed at an earlier stage. | Offering annual reviews would be a change of practice in many cases although those with learning disabilities are offered an annual health check. | <https://www.nice.org.uk/guidance/ng119> |
| 27 | SCM5 | 1. Adults with Cerebral Palsy should be reviewed by a health professional at least yearly for a holistic overview of their health | I would regard this is the most significant area because all the other areas flow from it. There is evidence that health outcomes deteriorate because of loss of follow-up from discharge from paediatrics onwards. Clinical experience shows that people do experience deteriorations and that generic services do not always appreciate the significance of these. | Many of the other recommendations flow from this if for example there is annual review then implementation of guidelines were epilepsy, rapid referral for changing mobility, rapid referral to therapy teams can all be expurgated providing the person doing the review is skilled in knowing the local networks.  The NCEPOD audit into acute admissions to hospital for adults with cerebral palsy identified that there are issues with continuity of care and oversight of patient management. | <https://www.nice.org.uk/guidance/ng119>  <https://www.ncepod.org.uk/2018cn.html> |
| 59 | NHS England | 1. For an individual with moderate to complex needs having the opportunity for an annual holistic review including emotional wellbeing as well as physical health review would be appropriate. This group of people would also benefit from having an identified key professional/point of contact for advice between appointments. | [Additional information] It would be helpful if the output of the annual review was a care plan that could be shared across health and social care including the ambulance service to enable patient centred management of their condition.  Individuals with mild impairment, who are living independently in the community may not require the same support and are able to access to health and care when required, it may however be beneficial for the person with mild impairment to also have an identified key professional/point of contact for advice between appointments. |  |  |
| 1 | SCM1 | 1. Adults with Cerebral Palsy should be reviewed by a health professional at least yearly for a holistic overview of their health | This is a fundamental issue contained within the recent NICE guidelines and would be important in reducing the number of adults with cerebral palsy who “go missing” after transition from paediatric services | The NCEPOD audit into acute admissions to hospital for adults with cerebral palsy identified that there are issues with continuity of care and oversight of patient management. | <https://www.nice.org.uk/guidance/ng119>  <https://www.ncepod.org.uk/2018cn.html> |
| 53 | SCM6 | 1. Offer an annual review for adults with cerebral palsy. For those with complex needs, this should be carried out by a healthcare professional with experience of neurodisability. | This was a key recommendation in the CPA guideline. | Offering annual reviews would be a change of practice in many cases although those with learning disabilities are offered an annual health check. | <https://www.nice.org.uk/guidance/ng119> |
| 44 | Royal College of Speech and Language Therapists | 2. Continuity of care for people with CP throughout their lives | People with CP will access specialist services sometimes in their lives. The transition to adult services will lead to fragmentation of provision and limited opportunities for routine health reviews. There is something problematic about specialist community services being commissioned for people with CP only when they become unwell. Preventative work would take place in routine reviews by specialists teams. | Preventative work would take place in routine reviews by specialists teams as long as they include relevant disciplines working in interdisciplinary ways. E.g. pain may be impacting on participation in many aspects of someone’s life including safe and efficient eating/drinking. Improved posture management routines and equipment, increased opportunities to move, tone management, pain relief, mental health issues, etc. may be underlying “pain”. | Unfortunately the evidence base for this is not strong although anecdotal reports in support of this would be easy to find.  A service user fedback to say that when he was in hospital his parents stayed with him, on rotation, because the nurses had no idea of how to look after him. |
| 36 | Adult Cerebral Palsy Hub | 5. Recognition that needs of adults with CP can change over time. | Previously thought that Cerebral Palsy was a non progressive condition and however now understood it has a degenerative component. | Cerebral Palsy is known as a childhood condition, effecting movement, and other daily activities. Steady birth rates of children with cerebral palsy and near normal life expectancy means that there are now more adults than children with cerebral palsy. Although cerebral palsy is often perceived as an unchanging condition, adults with cerebral palsy commonly experience new problems in adulthood, such as pain and falls. Concerns have been raised about the lack of specialist healthcare services for adults with cerebral palsy.  There is growing evidence around the secondary conditions that are associated with cerebral palsy, and there is still a lot to be learned about the extent and complexity of these problems and the shortfalls in specialist healthcare services. | Understanding the lived experience of ageing with Cerebral Palsy.  Higher incidence of chronic physical and mental health conditions in Adults with Cerebral Palsy.  Examining the experience of physiotherapy from Perspectives of adults with Cerebral Palsy  All ongoing research via RADiCAL  <https://www.brunel.ac.uk/research/Projects/RADiCAL-Researching-health-and-well-being-of-adults-with-cerebral-palsy> |
| 25 | SCM4 | 4. Named contact/lead clinician | Whether or not the individual chooses to take up offered reviews, having a named contact would ensure that they would be able to have a first port of call if their condition changed, they would be able to find their way back in to the system and they would have a source of information. Named contacts/lead clinicains have been recommended in NCEPOD and NICE guidelines including CPA, transitions and others. | Those with more complex needs move from children’s services where their care has been overseen by a paediatrician to one in which they are managed by a range of specialists with ‘**general**’ practitioner having oversight. I believe that in many areas this would be a new but vital change of practice and so one which I would consider to be a key area. | NCEPOD  NICE CPA, transitions and others |

| **Suggested area: Communication and technology** | | | | | |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| 9 | SCM2 | **4. Communication** with adult with CP.  Effective – time and means allowed to understand and respond.  Advocacy where it is difficult to achieve and address possible conflicts where family members are carers? choice of adult with CP | Engagement of CP Population  Accuracy in diagnosis  Accuracy and effective advice/support | * Needs re. communication in adults with CP are for some changing. * Co-production of treatment plans addressing patient identified goals essential. | **Care Act 2014**  Transition Hospital to Home NICE guideline NG27- Communication  Patient experience adults using NHS Clinical guideline [CG138] – communication  CP Adults NICE 119 Advocacy/speech and changing need |
| 20 | SCM3 | 4. Adults with cerebral palsy who have communication difficulties are able to access alternative and augmentative communication systems Including- assessment, training for Individual their families and carers. | A significant number of adults with cerebral palsy have communication difficulties and can be helped by access to AAC or intensive speech therapy. | Communication underpins the ability to engage in decision making and maintain participation in social, family and economic activities. The NICE guidelines for the management of cerebral palsy has a number of relevant recommendations towards supporting communication impairment | <https://www.nice.org.uk/guidance/ng119>  Guidance for commissioning AAC services and equipment/Guidance for commissioning AAC services and equipment/March 2016 |
| 63 | NHS England | 5. People with cerebral palsy have access to the appropriate adaptation and electronic assistive technology to enable them to gain as much independence as is practicable. | [Additional information] May we also guide you to this case study example of the use of personal health budgets for wheelchairs which may be of use: <https://www.england.nhs.uk/blog/there-are-wheels-within-wheels/> |  |  |
| 13 | Communication Matters | 1.Ensuring that adults with Cerebral Palsy (CP) who have little or no functional speech have ongoing and appropriate input from Speech and Language therapy, and all other associated services (Occupational Therapy, wheelchairs etc.) to ensure that their communication needs are being met. | Without the ability to communicate effectively adults with CP cannot participate in everyday life including family, social, employment and managing their health. | People who use or need to use Augmentative and Alternative Communication (AAC) and their families/carers report a very patchy and variable provision of necessary services and support across the country. The majority of AAC users, especially lifelong, will have cerebral palsy |  |
| 47 | Royal College of Speech and Language Therapists | 5. Speech and Language Therapy services for adults with CP who have communication difficulties or differences (including AAC systems). | People with CP will experience limitations to movement which may impact upon communication. They may be reliant on others to advocate for them or enable them to communicate through AAC systems. People with CP may or may not have an Intellectual Disability.  20% of people with CP may benefit from using an Augmentative and Alternative Communication (AAC) system.  <https://www.communicationmatters.org.uk/sites/default/files/downloads/projects/aac_evidence_base/2013_AAC_Evidence_Base_Beyond_the_Anecdote.pdf> (page 18)  Cockerill et al article (2014) <https://www.ncbi.nlm.nih.gov/pubmed/23656274>, 32% of 16-18 year olds with CP were provided with 1 or more AAC system; 15% had a voice output communication aid (VOCA)  Judge et al article (2017) <https://www.ncbi.nlm.nih.gov/pubmed/28695784> Table 3 – Highest means number of individuals with a named medical condition known to be using a VOCA was Cerebral Palsy  Advocacy for people with CP | People with CP will experience limitations to movement which may impact upon communication. They may be reliant on others to advocate for them or enable them to communicate through AAC systems. People with CP may or may not have an Intellectual Disability.  20% of people with CP may benefit from using an Augmentative and Alternative Communication (AAC) system.  <https://www.communicationmatters.org.uk/sites/default/files/downloads/projects/aac_evidence_base/2013_AAC_Evidence_Base_Beyond_the_Anecdote.pdf>  (page 18)  Cockerill et al article (2014) <https://www.ncbi.nlm.nih.gov/pubmed/23656274>, 32% of 16-18 year olds with CP were provided with 1 or more AAC system; 15% had a voice output communication aid (VOCA)  Judge et al article (2017) <https://www.ncbi.nlm.nih.gov/pubmed/28695784>  Table 3 – Highest means number of individuals with a named medical condition known to be using a VOCA was Cerebral Palsy  Advocacy for people with CP | [See row below for supporting information for this comment] |
| **Supporting information for comment 47 (above)**  A service user feedback, to say that if he wasn’t on the board of NHS AAC services he wouldn’t know how to find an SLT if he needed one. He feels that Communication aids are vital to most people with cerebral palsy and he believes that there must be a problem if he didn’t know where to find a SLT.  Guidance identifies a research question around clinical and cost efficacy of AAC.  Young adults may leave paediatric services using AAC devices/techniques on which they depend to communicate opinions, needs, views, requests etc. to other. Staff may not receive sufficient training to support adults in using these AAC systems, systems may break or slip into misuse, rendering an adult with limited means of communication.  NICE Interactive flowchart for Managing functional issues and participation in people with cerebral palsy aged 25 or over: Communication <https://pathways.nice.org.uk/pathways/cerebral-palsy#path=view%3A/pathways/cerebral-palsy/managing-functional-issues-and-participation-in-people-with-cerebral-palsy-aged-25-or-over.xml&content=view-node%3Anodes-communication>  <https://www.communicationmatters.org.uk/sites/default/files/downloads/standards/aac_services_standard_aug_2012.pdf>  and  <https://www.communicationmatters.org.uk/sites/default/files/downloads/standards/AAC_Report_Final_comm_champion_nov_2011.pdf>  contain standards for local SLT/AAC services (as well as specialised AAC services – which have subsequently been funded by NHS England)  Also quality standards for Commissioners: <https://www.communicationmatters.org.uk/sites/default/files/downloads/standards/aac_quality_standard_for_commissioners_sept_2011.pdf>  NHS England Guidance for developing local AAC services is here: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/guid-comms-aac.pdf> – but there are many areas of the country without local AAC services still; see page 11: <https://www.communicationmatters.org.uk/sites/default/files/downloads/projects/aac_evidence_base/2013_AAC_Evidence_Base_Beyond_the_Anecdote.pdf>  NHS England has a Specialised AAC Services Working party to develop resources for SLT services to engage with commissioners to develop these – see Communication Matters Journal September 2017 “NHS England Specialised AAC Services: An Update”  With a UK incidence rate of around 1 in 400 births, or 1800 children per year, cerebral palsy is a condition that can affect those from all social backgrounds and ethnic groups. The condition is the most common physical disability in childhood with an overall level of prevalence that has remained unchanged for sixty years (McIntyre et al, 2011)1.  <https://www.nice.org.uk/guidance/ng119/evidence/evidence-review-d4-communication-pdf-239689926616>  Page 11 “the committee agreed healthcare professionals should ask the person with cerebral palsy and their families and carers about any changes in hearing, speech and communication at each review” – many adults with CP do not have any healthcare professional involvement either from Consultants or Allied Health professionals.  Page 12 “the committee noted that low-tech and low-cost options would be considered by the local augmentative and alternative communication services” – there are very few local AAC services in place, hence the publication of these documents:  See also: <https://www.communicationmatters.org.uk/sites/default/files/downloads/standards/AAC_Report_Final_comm_champion_nov_2011.pdf>  Links between communication breakdown and mental health issues also need exploration, alongside interacting factors that are part of CP. | | | | | |
| 4 | SCM1 | 4. Adults with cerebral palsy who have difficulty with communication should be able to access speech and language therapy and assistive technology where this is appropriate. | The ability to communicate may be affected by a variety of impairments consequent to cerebral palsy with different treatment approaches to ameliorate them. | Communication underpins the ability to engage in decision making and maintain participation in social, family and economic activities. The NICE guidelines for the management of cerebral palsy has a number of relevant recommendations towards supporting communication impairment. | <https://www.nice.org.uk/guidance/ng119>  <https://www.ncepod.org.uk/2018cn.html> |
| 30 | SCM5 | 4. Adults with cerebral palsy who have difficulty with communication should be able to access speech and language therapy and assistive technology where this is appropriate. | Communication in adults with cerebral palsy is absolutely vital, children with cerebral palsy often have people “speaking for them” and therefore for adults with CP their need for communication can be underestimated. Often inappropriate waiting lists/reduced resources/poor expertise can lead to people giving up on communication aids. | Communication underpins the ability to engage in decision making and maintain participation in social, family and economic activities. Effective communication enables an individual to access healthcare effectively and to direct their own care package and therefore other medical and social care interventions can be more effective with direct feedback. Moreover politically being seen as important to hear the voice of disabled people is likely to have all sorts of additional benefits | <https://www.nice.org.uk/guidance/ng119>  <https://www.ncepod.org.uk/2018cn.html> |
| 55 | SCM6 | 3. Adults with cerebral palsy who have difficulty with communication should be able to access speech and language therapy and assistive technology where this is appropriate. | The ability to communicate may be affected by a variety of impairments consequent to cerebral palsy with different treatment approaches to ameliorate them. | Communication underpins the ability to engage in decision making and maintain participation in social, family and economic activities. The NICE guidelines for the management of cerebral palsy has a number of relevant recommendations towards supporting communication impairment. | <https://www.nice.org.uk/guidance/ng119>  <https://www.ncepod.org.uk/2018cn.html> |
| 62 | NHS England | 4. People with CP who experience communication difficulties should be enabled to communicate with all professionals/services supporting them in a manner that they chose including email / text and other electronic means where applicable. |  |  |  |
| 11 | SCM2 | Developmental area: **Use of Technology to enhance communication** primary / secondary care , Patient access to notes  Appointments etc | Timely and ease of access to information will enhance and empower adults with CP.  Where communication difficulties/challenge present technology provides acceptable/usual alternative | Effective use of resources – finance and staff time- appointment booking / avoidance of face to face time.  Reduced travel/time re. consultations adults with CP  Opportunity to link with specialist teams for training / review of individuals with CP | Dept of Health and Social Care ‘All the services we build, buy or commission should start with user needs’.The future of Health care :our vision data and technology in health and care. Oct 2018  NHS Digital. (2018). General and Personal Medical Services. (Accessed: 17 September 2018) |
| 35 | Adult Cerebral Palsy Hub | 4. Population Health management, physical and mental health. | Using predictive prevention to better support people to stay healthy and avoid illness complications as proposed in the NHS long term plan (Jan 2019) would greatly benefit the adult Cerebral palsy Community. | Higher risk of depression and anxiety in adults with Cerebral Palsy.  Higher risk of chronic respiratory, cardiovascular , osteoporosis and osteoarthritis in adults with Cerebral Palsy | Smith KJ, Peterson MD, O’Connell NE, et al. Risk of Depression and Anxiety in Adults With Cerebral Palsy. JAMA Neurol. Published online December 28, 2018. doi:10.1001/jamaneurol.2018.4147  Ryan, Jennifer & Allen, Elizabeth & Gormley, John & A Hurvitz, Edward & Peterson, Mark. (2018). The risk, burden, and management of non-communicable diseases in cerebral palsy: A scoping review. Developmental  Medicine & Child Neurology. 60. 10.1111/dmcn.13737.  Please see the NHS Long-term plan (published–Jan 2019) |

| **Suggested area: Information sharing** | | | | | |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| 12 | SCM2 | Additional evidence sources for consideration  **Use of Care Plans/communication Passport** | CP Adults have numerous professionals/specialities involved in care in disconnected services/trusts.  Are likely to have increasingly complex and combined secondary comorbidities which impact on each other - important to consider fully effects of treatments offered on other symptoms at every contact with health service. | Communication between all professionals involved in support/review of adult with CP ,-centred around the individual will ensure most effective management / individuals choice / co-production. | Passport to Health 2016 (LD) Jim Blair, Kirsty Glaysher and Sue Cooper  JCN Sept 2017Ruth Northway PhD, [Stacey Rees MSc, BSc, RN](https://onlinelibrary.wiley.com/action/doSearch?ContribAuthorStored=Rees%2C+Stacey) ,[Michelle Davies BSc, RN](https://onlinelibrary.wiley.com/action/doSearch?ContribAuthorStored=Davies%2C+Michelle) ,[Sharon Williams BSc, RN](https://onlinelibrary.wiley.com/action/doSearch?ContribAuthorStored=Williams%2C+Sharon) : Hospital passports, patientsafety and person‐centred care   * Standardization / safety   NICE Guidleine 94: Emergency and acute medical vare in over 16s Quality standard 4 structured handover on transition  Transition Hospital to Home NICE guideline NG27 |
| 24 | SCM4 | 3. Adult with complex needs should hold clear care plan/hospital passport/ portfolio. | There are several recommendations in NCEPOD and NICE guidance (eg transitions, CP in children) for variations on the theme of care plans/hospital passports/portfolios in paper or digital formats to be held by the individual. Those with more complex needs see a range of health professionals and may be supported by care workers. These can be an important tool for communication and to ensure accurate information is available especially for unplanned hospital visits which can be more frequent in this population. It can also empower the individual to hold and control their own information. | Young people are surviving into adulthood with increasingly complex conditions and need those around them to be informed. Electronic patient records are far from universal and interoperable IT systems which can allow access to individuals and their support workers is a long way off although there is a govt strategy to achieve this (Digital roadmap 2020?) . Therefore, I see a focus on person held information to be key. | NCEPOD  In line with CP (Children) and transitions recs for portfolio |
| 31 | SCM5 | 5. Adults with complex needs should hold a clear care plan/hospital passport/portfolio | Length of stay in hospital for people with complex needs is frequently increased either because clinicians lack skills in understanding their condition/making diagnosis/meeting nursing needs and also delivering care within the hospital setting. Sadly this can happen for both planned and unplanned states. Individuals and their families/carers find this frightening and frustrating. Lack of generic skills regarding making discharge arrangements often lead to unacceptable levels of delay in discharge and consumption of resources. Prolonged hospital length of stay can lead to additional complications, moreover typically hospitals are an inaccessible and disabling environment  There are several recommendations in NCEPOD and NICE guidance (eg transitions, CP in children) for variations on the theme of care plans/hospital passports/portfolios in paper or digital formats to be held by the individual. | This is an area which can have massive impact on terms of healthcare spending and quality of care. The more detailed plan can be put in place prior to admission less likely somebody is to be delayed from an elective admission. Moreover a good previously negotiated plan of management (which specifies how care needs can be met) for for example chest care can prevent admission and expedite discharge. Moreover being able to admit to the correct clinical area will strongly influence length of stay as well as quality of care and potential complication. | <https://www.nice.org.uk/guidance/ng119> |
| 23 | SCM4 | 2. Adults with cerebral palsy and, where appropriate, their family members or care providers, should have access to information and training for example on communication, self management, barriers to participation | Those at the more complex end of the spectrum rely on carers and family to support their participation. Lack of skills/knowledge can therefore be an environmental barrier. Training of those around the person with CP could also make interventions more effective. Carer training is recommended in the CPA guideline (and others) and NCEPOD. | I don’t believe there is any accepted standards on this important area and therefore, it is my impression, there is much variation between services and areas. I feel this should be higher up on the agenda and a quality improvement standard would support this. | <https://www.nice.org.uk/guidance/ng119>  NCEPOD |
| 43 | Royal College of Speech and Language Therapists | 1. Consistency in information sharing | CP is a lifelong disability arising in childhood. People with CP and their families will have seen many professionals in numerous different contexts, some more expert than others. | Making use of functional classification systems recommended by NINDS and AACPDM to provide continuity of information about function across lifespan:  GMFCS, MACS, EDACS, VSS, CFCS  The standard references questions about changes to “usual ability” – usual ability may be a continuation of dysfunctional ability which is causing harm or person answering question may have no idea about what usual means.  This ensures a degree of consistency in sharing information between people rather than trusting on a single doctor (p37) to hold all the information. | Schiariti et al for NINDS and AACPDM  <https://onlinelibrary.wiley.com/doi/full/10.1111/dmcn.13723>  A service user fedback to say that on the few occasions when he needed an on call doctor, the on call doctor had no knowledge of cerebral palsy and admitted him to hospital as he clearly didn’t know how to deal with him.  He then went on to say when he was rushed in to A&E with pneumonia he was with his mum because he can’t talk, and she was helping him communicate. However, when he was put into a treatment bay, his mum was told to wait outside. He couldn’t tell the doctors anything and because of his involuntary movements they couldn’t do any tests. He believes if someone was more informed about CP he would have received the tests quicker. |

| **Suggested area: Clinical complications and comorbidities** | | | | | |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| 46 | Royal College of Speech and Language Therapists | 4. Mental and physical health are not disconnected | In adulthood, mental health issues may become apparent or be overlooked because the assumptions made that they have a physical cause | Checklists of questions / areas of concern for routine health reviews listed in guidance are helpful but really a tall order for most health professionals, especially if it is a single doctor | <https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-mental-physical-health> |
| 66 | Royal College of Occupational Therapists | 2. Access to mental health services/support |  |  |  |
| 15 | Hill-Rom | 1.Respiratory management, especially community respiratory physio input and admission prevention. | We as a company are working towards MTEP guidance for The Vest for complex neuro patients which will include CP and have a strong health economics argument, as well as clinical data to support the need for better management of this patient population across both adults and paeds. We a now aging population of the more complex CP patients more are surviving to adulthood and the services are just not there to meet their needs. |  | I am happy to share our unpublished data should it be required, as it has been submitted for publication. |
| 45 | Royal College of Speech and Language Therapists | 3. Respiratory illness and respiratory failure | Links between eating/drinking/swallowing difficulties (dysphagia) and respiratory illness have been identified and in some cases modifications can be made to reduce respiratory illness | There needs to be more work to determine whether:   * More could be done in childhood to reduce rates of dysphagia related respiratory illness in adulthood * Changes take place in the life course of someone with CP that need to be more closely monitored to reduce impact on respiratory health. Use of EDACS would more closely monitor this * Respiratory failure is likely for those who are most severely affected by CP e.g. GMFCS V and IV | So many unanswered questions here for this under researched population.  There are also important issues to be considered about when information is shared with people with CP and their families. Because it is a lifelong condition, certain discussions do not take place at certain ages because they are deemed not appropriate. Skilled use of door opening questions e.g. “what do you not want to happen” across the lifespan may help families and adults articulate their concerns and fears more clearly.  Bowtie model of supportive care could be used to enable health professionals to explore sensitive value laden areas with families  <https://www.jpsmjournal.com/article/S0885-3924(13)00609-X/abstract> |

| **Suggested area: Additional areas** | | | | | |
| --- | --- | --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Suggested key area for quality improvement** | **Why is this important?** | **Why is this a key area for quality improvement?** | **Supporting information** |
| 40 | Association of Paediatric Chartered Physiotherapists | 2. Teaching and assistance for GPs or named clinicians. | Adults with CP often have a complex presentation. Training for those who are the initial care providers (GPs) in the complexity of CP and the pathways of care could improve the health outcome for Adults with CP. | NCEPOD have recommended a named clinician for young people with CP. In many cases and those who require access to health services only on occasion, this will be the GP. With limited time for an appointment and poor pathways of care, training could improve the effectiveness of the GP time | NCEPOD 2018  Cerebral palsy in adults NICE guidelines 2019 |
| 41 | Association of Paediatric Chartered Physiotherapists | 3. Teaching and assistance for specialists not routinely involved in the care of adults with CP. | Many adults with CP will require the expertise of specialist clinicians (orthopaedic surgeons, gastroenterologist, neurologists, therapists) who see this group of patients irregularly. With an advocate for the patient who understands the condition and changes to their body as a result of their condition (muscle changes, rehabilitiation requirements) able to support the treating clinician and the patient may improve outcomes and improve the clinical decision making process. | Cerebral palsy in adults NICE guidelines 2019 Recommendations 1.4.1 to 1.4.8 There is a lack of awareness, both among adults with cerebral palsy and healthcare professionals, that people with cerebral palsy are at increased risk of bone and joint complications, and that musculoskeletal function may worsen over time.  Increasing awareness and discussing this with adults with cerebral palsy will enable early identification and management of these conditions. | Cerebral palsy in adults NICE guidelines 2019 |
| 38 | Action Cerebral Palsy | With a disproportionate amount of children with special needs leaving mainstream education, Action Cerebral Palsy believe a key area for quality improvement could be in ensuring effective and thorough planning prior to moving children with cerebral palsy into services. Ensuring there is a proper long-term transitional plan, for a young person living with cerebral palsy, to go into further education or work is essential to allowing full developmental, educational and workplace opportunities be afforded to them as they transition into adulthood.  This can only be achieved by proper provision, training and guidance for teaching staff and healthcare practitioners. Often, the ability of local authorities to adequately assess the special educational needs of children living with cerebral palsy are often overlooked. Local authorities are already subject to detailed record-keeping but often lack the appropriate checks and plans in order to identify the transitional challenges of children with cerebral palsy. Thus are unable to support them sufficiently prior to entering adulthood, be that moving into further education or the workplace. The solution is a heightening or up-skilling of practitioners to give them the specialist guidance and services so they can better plan provision and introduce systems to ensure children with cerebral palsy are able to access their full potential, moving into adult life. Action Cerebral Palsy recommends that practitioners should also be able to easily refer children to the correct agencies, for effective provision to be introduced into their education transitional plan and, if required, their education, health and care transitional plan. There is a cliff-edge between adult and childrens' services and a postcode lottery of provision and services available. Action Cerebral Palsy believe this could be alleviated with the introduction of a cerebral palsy register, to identify the gaps in provision and fully assess the level, prevalence and severities of cerebral palsies. | Action Cerebral Palsy believes this is key as, currently, too many children with cerebral palsy in the UK are being failed by provision that is fragmented and under-funded. Too few children receive the thorough and intensive transitional plan that can enable their full adult life potential. We believe that clear guidance for education and health professionals should be readily available to ensure that children with cerebral palsy have their needs identified and supported when moving into adulthood. |  |  |

| **Suggested area: General comments** | | | |
| --- | --- | --- | --- |
| **ID** | **Stakeholder** | **Type of comment** | **Comment** |
| 64 | NHS England | General | Healthcare Quality Improvement Programme commissioned The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) Each and Every Need report as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). This review of the quality of care provided to patients aged 0-25 years old with chronic neurodisability used cerebral palsies as examples of chronic neurodisabling conditions. As people with cerebral palsy age they will be included in audits such as falls, frailty, stroke etc.  We are unaware of any work being undertaken in this area specifically for adults with cerebral palsy, however work in relation to electronic assistive adaptations including communication should be considered along with work undertaken in relation to vocational rehabilitation. |
| 58 | NHS England | General | Thank you for providing the Chief Allied Health Professions Officer an opportunity to comment.  We understand that the Royal College of Speech and Language therapists have been identified as a stakeholder, and we would direct you to their response, for the detailed Speech and Language therapy perspective. We have also been in contact with the Royal College of Occupational Therapists (RCOT), who have provided some guidance for our response, however due to the significant role Occupational therapy has in vocational rehabilitation and adaptations it may be appropriate to contact them directly for further detail.  In identifying areas to be covered by the quality standards on review of the associated documentation including cerebral palsy in under 25s the associated age restrictions for the condition do create some challenges. Cerebral Palsy as a global condition can vary widely in symptoms from mild neuro musculoskeletal dysfunction through to significant learning and physical disabilities. The needs of people with cerebral palsy on this scale will vary significantly as will their need for health and social care intervention. Development of a quality standard that is appropriate for all these needs will require consideration. |

1. The National Confidential Enquiry into Patient Outcome and Death (2018) [Each and Every Need](https://www.ncepod.org.uk/2018cn.html) [↑](#footnote-ref-1)
2. The Neurological Alliance (2017) [Falling short How has neurology patient experience changed since 2014?](https://www.neural.org.uk/resource_library/falling-short/) [↑](#footnote-ref-2)
3. McDowell B.C. (2015) [Service use and family-centred care in young people with severe cerebral palsy: a population-based, cross-sectional clinical survey](https://www.tandfonline.com/doi/full/10.3109/09638288.2015.1019649) [↑](#footnote-ref-3)
4. The National Confidential Enquiry into Patient Outcome and Death (2018) [Each and Every Need](https://www.ncepod.org.uk/2018cn.html) [↑](#footnote-ref-4)
5. The Neurological Alliance (2015) [The invisible patients: Revealing the state of neurology services](https://www.neural.org.uk/resource_library/invisible-patients) [↑](#footnote-ref-5)
6. The National Confidential Enquiry into Patient Outcome and Death (2018) [Each and Every Need](https://www.ncepod.org.uk/2018cn.html) [↑](#footnote-ref-6)
7. Action Cerebral Palsy (2016). [Variations in Care: An analysis of cerebral palsy provision](https://www.actioncp.org/resources) [↑](#footnote-ref-7)
8. Colver et al (2018) [How well do services for young people with long term conditions deliver features](https://doi.org/10.1186/s12913-018-3168-9)

   [proposed to improve transition?](https://doi.org/10.1186/s12913-018-3168-9) [↑](#footnote-ref-8)
9. NHS Digital (2019) [Health and Care of People with Learning Disabilities: 2017-18](https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018) [↑](#footnote-ref-9)
10. The National Confidential Enquiry into Patient Outcome and Death (2018) [Each and Every Need](https://www.ncepod.org.uk/2018cn.html) [↑](#footnote-ref-10)
11. Watson et al (2015). [Assessment and management of the communication difficulties of children with cerebral palsy: a UK survey of SLT practice](https://www.ncbi.nlm.nih.gov/pubmed/25652139). [↑](#footnote-ref-11)
12. Communication Matters (2013) [Research Matters: an AAC Evidence Base - Beyond the Anecdote: Examining the need for, and provision of, AAC in the United Kingdom](https://www.communicationmatters.org.uk/sites/default/files/downloads/projects/aac_evidence_base/2013_AAC_Evidence_Base_Beyond_the_Anecdote.pdf). [↑](#footnote-ref-12)
13. NHS England (2016) [Guidance for commissioning AAC services and equipment](https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/guid-comms-aac.pdf) [↑](#footnote-ref-13)
14. Cockerill et al (2014) [Speech, communication and use of augmentative communication in young people with cerebral palsy: the SH&PE population study](https://www.ncbi.nlm.nih.gov/pubmed/23656274) [↑](#footnote-ref-14)
15. The Neurological Alliance (2017) [Falling short How has neurology patient experience changed since 2014?](https://www.neural.org.uk/resource_library/falling-short/) [↑](#footnote-ref-15)
16. The Neurological Alliance (2015) [The invisible patients: Revealing the state of neurology services](https://www.neural.org.uk/resource_library/invisible-patients) [↑](#footnote-ref-16)
17. The National Confidential Enquiry into Patient Outcome and Death (2018) [Each and Every Need](https://www.ncepod.org.uk/2018cn.html) [↑](#footnote-ref-17)