NATIONAL INSTITUTE FOR HEALTH AND
CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1. Quality standard title

Cerebral palsy in adults

Date of quality standards advisory committee post-consultation meeting: 22 October 2019

1. Introduction

The draft quality standard for cerebral palsy in adults was made available on the NICE website for a 4-week public consultation period between 2 September and 30 September 2019. Registered stakeholders were notified by email and invited to submit consultation comments. Due to a small number of responses having been received by close of consultation, selected stakeholders were chased-up and the consultation deadline extended. General feedback on the quality standard and comments on individual quality statements were accepted.

Responses were received from 11 organisations, which included service providers, national organisations, professional bodies and others. Of these, 2 professional bodies responded by saying they have no comments to make. Additional comments were received from NICE internal teams and an individual.

This report provides the quality standards advisory committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the committee as part of the final meeting where the committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the committee should read this summary alongside the full set of consultation comments, which are provided in appendices. Appendix 1 lists comments from registered stakeholders.

1. Questions for consultation

Stakeholders were invited to respond to the following general questions:

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

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

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

Stakeholders were also invited to respond to the following statement specific questions:

4. For draft quality statement 1: This statement includes a definition of a multidisciplinary team experienced in the management of neurological impairments. Is this definition appropriate?

5. For draft quality statements 3 and 4: Draft quality statement 3 refers to a professional with expertise in independent living. Draft quality statement 4 refers to a professional with expertise in vocational skills and independent living. In practice, is this likely to be the same professional?

6. Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details on the comments form.

1. General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

* The quality standard is important and overdue.
* All 5 statements cover areas that are important and need improvement.
* There is currently a gap in services for adults with cerebral palsy without a learning disability that the quality standard can address.
* The language used for each of the statements should be more patient / person-centred.

### Consultation comments on data collection

* Data could be collected through local systems and pathways.
* Systems are not in place to collect the data and would be a challenge to develop.
* National solutions to data collection would be better than relying on local data. Valid and reliable data collection would require standardisation of health informatics and structures across the UK. This has limited feasibility without investment.

### Consultation comments on resource impact

* Systems are not in place to resource this quality standard in primary care. If funding for the additional work was available, e.g. via the quality and outcomes framework then this could then be supported.
1. Summary of consultation feedback by draft statement
	1. Draft statement 1

Adults with cerebral palsy are referred to a multidisciplinary team if their ability to carry out usual daily activities deteriorates or may be affected by a procedure.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

* Stakeholders supported the aim of the statement, but stated that changes would be needed to achieve it.
	+ Services and pathways necessary for the statement are not established.
	+ GPs currently look after patients with cerebral palsy and refer to specific services for individual issues, but the availability of services varies and there are lengthy delays for some.
	+ GPs may not have the knowledge / expertise of when and where to refer on.
	+ Most areas have community teams to assess older people if their function changes, but few have the knowledge or skills to deal with adults with cerebral palsy.
	+ Some areas will have community neuro rehabilitation teams. These are likely to have the necessary knowledge and skills, but additional resources may be needed to set up MDT clinics (as they may have a ‘treat and discharge’ model and hold individual discipline waiting lists).
* Could care workers or other professionals who identify changes in normal daily activities refer directly to multidisciplinary teams rather than refer / steer to a GP to complete the referral?
* Comments on measures:
	+ The number of adults with cerebral palsy whose ability to carry out their usual daily activities deteriorates cannot be counted. The measure should be changed to cover only those who present to primary care; or it should focus on numbers referred demonstrating different pathways instead.
	+ Measuring those referred for procedures would be challenging as the procedures will be varied and identifying linkage would be difficult (e.g. cerebral palsy and carpal tunnel syndrome).
	+ Contrasting views were given on the outcome measure: How would a deterioration in normal daily activities result in unplanned admissions / unplanned hospital admissions is a good metric.
	+ Codes will need to be added to electronic patient systems

### Consultation question 4

This statement includes a definition of a multidisciplinary team experienced in the management of neurological impairments. Is this definition appropriate?

Stakeholders made the following comments in relation to consultation question 4. Other comments made about the composition of the MDT are also summarised here:

* Several stakeholders considered the definition appropriate.
* Potential changes suggested included:
	+ Specifying the range of disciplines, and the area and depth of expertise of the team members experienced in the management of neurological impairments.
	+ Include all of the medical specialists in the multidisciplinary team or add an expert medical generalist (which could be a GP with a specialist interest).
	+ Add a learning disability psychiatrist and social care professionals.
	+ Change management of neurological ‘impairments’ to ‘conditions’.
	+ A physician/surgeon may not be essential given the evolving roles of specialist and advanced practitioners.
* Multidisciplinary teams for adults with cerebral palsy do exist in some areas, but do not have full range of members set out in the definition.
	1. Draft statement 2

Adults with cerebral palsy who have complex needs have an annual review.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

* The concept of the statement was supported, described as a gold standard idea by one comment.
* Annual reviews are not routinely taking place for the target population and would need funding.
* Comments on how the statement could work in practice included:
	+ A sub-group of the target population, those with a learning disability, will have an annual health check which has funding attached to it. One stakeholder asked if these checks could be expanded to deliver the annual review; another said the annual review should avoid duplicating the annual health check.
	+ Rehabilitation Medicine specialists and their teams are suited to carrying out annual reviews.
	+ Good communication with primary care is essential.
	+ Home visits should be considered for some people.
	+ An annual review should be a minimum; a review every 6 months would be preferable.
* Some comments suggest the roles of primary care and secondary care are not clear in relation to annual reviews. For example, one stakeholder said systems are not in place to resource the statement in primary care but also said that people in long-term care settings will find it difficult to attend secondary care appointments.
* Comments on measures included:
	+ Collecting data from multiple people in different settings would be difficult.
	+ There is no coding for adults with cerebral palsy who have complex needs or unplanned admissions on primary care electronic systems.
	+ It is unclear how the statement will achieve the outcome of reducing unplanned admissions.
	+ A measure should be included on providing appropriate and accessible information about the annual review to the person with cerebral palsy.
	1. Draft statement 3

Adults with cerebral palsy who want support to live independently are referred to a professional with expertise in independent living.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

* The statement wording should say ‘occupational therapist’ instead of ‘professional with expertise in independent living’.
* Audience descriptors and measures are inconsistent in that they sometimes refer to a ‘professional with expertise in independent living’ and at other times to an occupational therapist.
* Concerns about facility and staff resources were raised. There are not enough suitable facilities to house everyone who wants to live independently, especially young people returning from college. Social workers and occupational therapists can help with independent living, but there are few of them available.
* The statement is dependent on better co-ordination between health and social services.
* Should the actions described for healthcare professionals be part of the annual review for the multidisciplinary team to address? Healthcare professionals may need training for these actions.
* An important success factor in establishing independent living for people with cerebral palsy is determination from the person and their parents.
* Comments on measures included:
	+ Referrals should be relatively easy to count where services exist.
	+ Adults with cerebral palsy who successfully live independently are likely to use less resources, but this will be challenging to measure.
	1. Draft statement 4

Adults with cerebral palsy who want support to work are referred to a professional with expertise in vocational skills and independent living.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

* Additional resources may be necessary:
	+ Investment in people with the skills to help, and in systems that enable people to access and retain work (or other purposeful employment).
	+ Neuro teams are often only commissioned to support people who are already in work, if they are commissioned to provide vocational rehabilitation at all.
	+ Support for adults with cerebral palsy with conditions like post impairment syndrome (a barrier to continued sustainability in the work force).
* Existing services are ‘patchy’, with many failing to help people who do not reach the threshold for traditional occupations.
* Comments on who can help implement the statement included:
	+ An occupational therapist who can help with adapting access, understand electronic assistive technology, and see different ways of doing things is crucial.
	+ Occupational therapists in general neuro teams are skilled in supporting people to maintain their current job, but job seeking would need to be addressed within teams and links established with employment services.
	+ Organisations like Scope can offer support to help an adult with cerebral palsy find a job and remain employed.
* Should the actions described for healthcare professionals be part of the annual review for the multidisciplinary team to address? Healthcare professionals may need training to undertake these actions.
* Flexible working may be necessary to accommodate an adult’s changing needs.
* Referrals would be relatively easy to count where services exist.

### Consultation question 5

For draft quality statements 3 and 4: Draft quality statement 3 refers to a professional with expertise in independent living. Draft quality statement 4 refers to a professional with expertise in vocational skills and independent living. In practice, is this likely to be the same professional?

Most stakeholders referenced the role of an occupational therapist in relation to both statements, but there were different views about whether it would be the same professional for both statements. Comments included:

* It is likely to be the same professional, an occupational therapist.
* It is likely to be occupational therapists with different skill sets (distinct home-based and vocational services) and from different services (social services, community neuro rehabilitation, vocational rehabilitation).
* It could be the same person, but does not always need to be an occupational therapist.
* Social services (especially social workers and social service employed occupational therapists) and charities also provide support to people with cerebral palsy.
	1. Draft statement 5

Adults with cerebral palsy who have communication difficulties are referred to speech and language therapy services to assess their need for intervention.

### Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

* Should the statement focus on the provision of support that follows referral rather than the referral itself?
* Resources were flagged as a possible barrier:
	+ Services for speech and language therapy are often under resourced (especially for alternative and augmentative communication) and overstretched.
	+ Speech and language therapists are best placed to support AAC but may require training to develop specialist skills.
	+ Resources are needed for provision of high and low-tech equipment to aid communication, and for allied services.
* Commissioning guidance for accessing specialist regional (hub) AAC support is being re-written and the quality standard should ‘dovetail’ with this. The term “complex needs” may be used differently.
* Measures:
	+ Referrals would be relatively easy to count where services exist.
	+ Referral rates as a measure of quality could be detrimental to services (by increasing therapists’ caseloads to a level they are unable to support).
	+ There may be resource savings, as people who communicate better may retain jobs, but this would be hard to measure.
1. Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

* Eating and drinking difficulties, or this could be addressed as a cross-cutting theme across quality statements.
* A treatment regime to maintain functionality across the transition from paediatrics.
* Management of spasticity and dystonia.

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# Appendix 1: Quality standard consultation comments table – registered stakeholders

| ID | Stakeholder | Statement / Question | **Comments[[1]](#footnote-1)** |
| --- | --- | --- | --- |
| 1  | RCGP | General | [Would your organisation like to express an interest in formally supporting this quality standard? ] No, not as it currently stands as the systems are not in place to resource this in primary care. If funding for the additional work was available e.g. via The quality and outcomes framework as learning disability checks are then this could then be supported in primary care |
| 2  | RCGP | General | There is a gap in services for adults with Cerebral palsy without a learning disability. If patients with cerebral palsy have a learning disability, they will already be on the GP practice register and receive annual checks as part of the quality and outcomes framework which has funding attached to it. The committee should take this into account to ensure duplication is not occurring, when deciding whether to proceed with annual checks, and who should be performing these.  |
| 3  | University College London Hospitals NHS Trust | General | This is a very important piece of work and long overdue for people living with CP. It is targeted and to the point. UCLH are well aware of deficiencies in the care of people with long term Neurological disorders and we are extremely happy that this has been prepared.We think all 5 statements are valid and important.At UCLH we have an MDT service for people with CP. Patients can be referred from their GP or other secondary care provider into an MDT clinic appointment. From there they have access to Physio, OT, SALT, Psychology and specialist nursing. All patients are offered long term care with at least an annual review. This may be face to face with the whole team or just with relevant professionals (eg joint OT/PT or SALT/ psychol/nursing). It may simply be an annual phone review with the Nurse specialist. The service also offers reviews by facetime or skype if preferred. Transition clinics are also run in conjunction with local community paediatric services. |
| 4 | BSRM | Question 1 | The quality standards cover the main areas that need improvement, with some exceptions. The quality standards do not mention establishing a good treatment regime that is in place from transition from paeds that maintains as high a function as possible, including the provision of a well-fitting wheelchair. The management of spasticity and dystonia and its attendant musculoskeletal deformities is implied in standards 1 and 2, but given the fact that this is such an issue for many people, I am surprised not to see it explicitly mentioned. Prevention of problems is easier than sorting out a disaster that has been allowed to happen – I think this is a major omission.Living independently is a huge deal for many people. I am pleased to see this acknowledged.Work is important to all of us – and I am pleased to see purposeful activity emphasised. I am pleased that communication is specifically mentioned. |
| 5 | RCOT | Question 1 | Yes we think the draft quality standard reflects the key areas for improvement. Although transition from paediatric to adult services is covered in a separate NICE standard and signposted to, could this quality standard cover/mention aspirations for services to support people transitioning from paediatric to adult services? |
| 6  | RCSLT | Question 1 | We are concerned that this quality standard omits anything regarding eating and drinking difficulties, which can be common for people with cerebral palsy. Given the risk of health and medical complications should these difficulties go unmanaged, we consider a quality statement on this to be essential for patients. This could and should be a cross-cutting theme throughout some of these quality statements, especially in statement 3 (independent living), but would be sufficient to be a quality standard itself. |
| 7 | BSRM | Question 2 | Systems are not in place to collect the data required.The systems required would be challenging to develop.The numerator (number of people with CP) is not accurately known at an individual population level.The denominator (people whose function has changed or who are contemplating a procedure) is also unknown.The procedures would be varied and many – and therefore looking for linkage (eg CP and carpal tunnel syndrome, CP and scoliosis surgery) would be challenging.Collecting the number of people with CP who have an annual review would be very difficult, as the people doing the review are a) scarce and b) from many different backgrounds. If a new service were to be set up, measures could be put in place.Where services exist, referrals to professionals for independent living advice, vocational advice and to communication specialists would be relatively easy to count, provided the coding of the electronic systems in place is robust and can be interrogated. |
| 8 | RCOT | Question 2 | It would appear that data could be collected through local systems and pathways.  |
| 9  | RCSLT | Question 2 | To obtain valid and reliable data about whether these quality measures are being met would require standardisation of health informatics and structures across the UK which the NHS does not yet currently provide. Locally, some services may be able to triangulate their data about these standards. However our experience is that technical support and information specialist skills required for these tasks can be variable and patchy with some data from some trusts being more easily obtained than others, but also of varying degrees of quality. There is value in local data but it may be more useful to invest in national solutions, the feasibility of which appears limited. |
| 10 | BSRM | Question 3 | Standard 1 asks that people with CP are referred to an MDT if their function changes or a procedure is planned.Most of the country will have community teams that are used to assessing older persons in this situation. Very few of them will have the knowledge or skills to deal with adults with CP. Some will have community neuro rehab teams in their area, who are more likely to have the knowledge and skills, but may have a ‘treat and discharge’ model that is at variance with the standard.To see people at these key stages, and to put in place treatment or care that meets their needs better than the current situation will need investment.It is tempting to suggest that better care will prevent the development of contractures, pain pressure sores and so on, and therefore reduce health care costs. However I am not aware of any evidence that this is so. Standard 2 requires that adults with complex CP have an annual review. This is not currently carried out and would require resource. Some people – for instance those with a coexisting Learning Difficulty will be having an annual review. This may need to be expanded to cover all the areas needed. Rehabilitation Medicine specialists and their teams are very suited to carrying out these reviews.Standard 3 (independent living) there are not enough facilities to house everyone who wants to live independently, and returning from 3-4 years living autonomously at college to live with parents is sadly very common. I am aware that a local college can give people independent flats, with the opportunity to book care from college staff. However when the young person returns to our area, there are very few suitable facilities for such a care package to be developed. Loneliness is a major issue in our society, and adults with CP who are unwisely housed can experience this very acute. There are social workers and OTs who can help with independent living, but they are relatively few and far between. SW and OTs who are part of a generic team may find specific problems challenging. Therefore there is likely to be a bricks and mortar investment needed, and a personnel investment. Adults with CP who successful live independently, or establish a successful relationship or flat share, are likely to be happier and use less resources – but this will be very challenging to measure. Standard 4 addresses vocational rehabilitation. Services are very patchy, and many fail to be able to help people who do not reach the threshold for traditional occupations. The involvement of an OT who can help with adapting access, understand electronic assistive technology, and see different ways of doing things is crucial. There would need to be investment in people with the skills to help, but also in systems that enable people to access work (or other purposeful employment) and then to retain that actively. Standard 5 addresses communication. Speech therapists at the moment are over stretched. Some services are unable to provide as much communication support as they’d like to. Specialist communication aid services do exist, but the willingness or expertise to integrate communication aids with (for instance) wheelchairs is lacking. There will need to be resource in skilled SLTs, but also in low and high tech communication aids, and in allied services. People who communicate better may retain jobs and therefore use less benefit – but this is hard to measure. |
| 11 | RCOT | Question 3 | Many community neuro teams, although multidisciplinary, hold individual discipline waiting lists, so although people are referred to both occupational therapy and physiotherapy for example, they would be seen at different times which would not be ideal. Additional resources may be needed to set up MDT clinics so that people can be assessed and supported in an integrated way. Additional resources will also likely be needed to review people yearly as this will be a new referral pathway.Additional resources will likely be needed for vocational support as this is not consistently commissioned across the country for people with neurological conditions. Neuro teams are often only commissioned to support people who are already in work, if they are commissioned to provide vocational rehabilitation at all. Occupational therapists in general neuro teams are often skilled in supporting people to maintain their current job, but job seeking is an area with different support skills needed (e.g. CV writing, interview skills, job coaching). This would need to be addressed within teams and links established with employment services. We agree that this standard would certainly improve quality of services for people with CP, but need to recognise the additional resources and perhaps up skilling needed for this.  |
| 12  | RCSLT | Question 3 | Local services for speech and language therapy are often under resourced especially for AAC services. SLTs are best placed to support an AAC but may require support for training to develop specialist skills. |
| 13 | BSRM | Question 4 | An ‘MDT experienced in the management of neurological impairments’ is a broad definition. On one level, it is crucial to make the distinction from generic rehabilitation teams who may not have the specific knowledge to deal with problems presented by people with CP. So I welcome the phrase ‘experienced in the management of neurological impairments’. The NICE guidance describes the network of people who will be needed around a person with CP. I suspect future iterations will be able to specify the range of disciplines, and specify what expertise and to what depth is expected. |
| 14 | RCOT | Question 4 | We agree that the definition of multidisciplinary team is appropriate. However, we wondered if it should read experienced in the management of ‘neurological conditions’ instead of ‘neurological impairments’. Also, the definition may be better if it describes pathways for people with cerebral palsy to access services with the appropriate expertise, skills and what should be delivered/offered. With the evolving roles of specialist and advanced practitioners the requirement for a physician/surgeon as part of the team may not be an essential nor efficient use of resources particularly in areas where recruitment/access to a Consultant in Rehabilitation Medicine or Consultant Neurologist is challenging. |
| 15  | RCSLT | Question 4 | The content within the definition appears largely appropriate however we strongly encourage NICE to use a patient/person-centred approach in their language and terminology. A MDT does not have experience in the management of ‘neurological impairments’. This is highly disempowering of the patient. The healthcare professionals in a MDT have experience in supporting people with neurological difficulties to manage their disability (or similar)  Similarly, ‘the composition of the team will vary depending on…’ should be changed to include ‘the needs and preferences of the patient/service-user’ (or similar) rather than reference to the level of impairment/disability. |
| 16  | University College London Hospitals NHS Trust | Question 4 | Is this definition appropriate?Yes we feel it is |
| 17 | BSRM | Question 5 | In my team (Solent Neuro Rehab Services) the two people identified in standards 3 and 4 are not the same. We have OTs who are skilled in independent living, and separate OTs who work in our vocational rehabilitation service. Colleagues in social services (especially social workers and social service employed OTs) provide essential support to people with CP.However we are unusual in having both specialities in one team, and I suspect that in many teams one person will be carrying both responsibilities. It is possible that charities may be able to meet some needs.In my experience the most important determinator of success in establishing independent living for people with CP is a determination on the behalf of the person that is matched by the determination of their parents to facilitate their long term goal. A determined mum or dad makes a very good case manager. |
| 18 | RCOT | Question 5 | No – although both occupational therapists they are likely to be from different services – for example an occupational therapist from social services, an occupational therapist from the community neuro rehabilitation team and/or an occupational therapist from a specialist vocational rehabilitation team. A health occupational therapist for example, would not be able to look at major adaptations which may be needed for independent living (this would be the social services occupational therapist), but they may have vocational rehabilitation skills. There may be several occupational therapists involved due to how services/agencies are organised. For example, environmental controls, wheelchair services, social services, spasticity management clinics, reablement team, community neurology, mental health, learning disability. They will likely have different skills sets, especially those focused on vocational support and job seeking as outlined above.  |
| 19 | RCSLT | Question 5 | We envisage there may be distinct home-based and vocational services therefore likely to be occupational therapists with different skill sets. |
| 20 | University College London Hospitals NHS Trust | Question 5 | Yes- an OT |
| 21 | BSRM | Question 6 | My service (Solent Neuro Rehab Service) meets some of the guidance, and could provide numbers for standards 3,4, and 5, for people known to the service. The service is not set up to capture standards 1 and 2, but is offering on-going review to some adults with CP. The degree of unmet need is not known. |
| 22 | RCOT | Question 6 | No |
| 23 | ACPH | 1 | This Statement does reflect what we would like to see happen, however this may be difficult to implement for the following reasons:-Cerebral Palsy is not registered as a primary diagnosis, this will challenge local data collection-Services are currently not established to allow for regular reviews so that access to these discussions is difficult.-GP’s do not have knowledge or expertise currently to know when and where to refer on.Improved knowledge and skills of primary care professionals, clear pathway access to specialists e.g. orthopaedic, neuro, who have experience, knowledge and skills with this client group.We think the definition of MDT is appropriate.We have an example of:Orthopaedic lead MDT – Robert Jones & Agnes Hunt Hospital , OswestryNeurological lead MDT – National Hospital of Neurology and Neurosurgery, London.Both are good examples of an attempt to meet some of the NICE guidelines, however both fall short, due to access to the full range of members of the MDT. |
| 24 | NHSE | 1 | Process measure: Possible issues around data collection in Primary care covering coding of ‘ability to carry out usual activities’ and ‘referral to MDT team’. |
| 25  | RCGP | 1 | GPs currently look after patients with cerebral palsy, referring to specific services for individual issues after assessment of the patient e.g. Speech and language therapist, dietician, neurology etc. Having a dedicated team to refer to in the event of deteriorating ability to perform normal daily activities would be useful as currently services vary across the country, with often lengthy delays for neurology and neurophysiotherapists/ occupational therapists or specialist orthopaedics clinics/ rehabilitation clinics.  |
| 26  | RCGP | 1 | The proportion of adults with adults whose ability to carry out normal daily activities that deteriorate will be difficult to measure. Not all of these patients will present to a service in order to receive a referral. Can the committee reword this as “The proportion of adults with cerebral palsy that present to primary care and whose ability to carry out normal daily activities has deteriorated are referred to a multidisciplinary team”The denominator should therefore read, the number of adults with cerebral palsy presenting in primary care whose ability to carry out their usual daily activities has deteriorated.Codes will need to be added to the electronic patient systems to enable this to be coded and then subsequent audits preformed.  |
| 27  | RCGP | 1 | It is not clear how the deterioration in normal daily activities would cause an unplanned admission can the committee expand on this? |
| 28  | RCGP | 1 | If care workers or other professionals pick up on the changes in normal daily activities and they meet the criteria for referral, the committee should consider direct referral to the multidisciplinary t teams, rather than referring to the GP to complete the referral form on their behalf. This would otherwise be a wasted GP appointment if it were simply to complete a referral on behalf of another professional. |
| 29  | RCGP | 1 | The spectrum of disorders within the cerebral palsy diagnosis is extensive and so any multidisciplinary would need all of the medical specialists involved from respiratory and rehab to neurology and neurosurgery. The risk otherwise would be a patient is referred for spasms and sees the consultant who is a respiratory physician and then needs onward referral. Alternatively, an expert medical generalist could be included in the multidisciplinary. This could be a GP with a specialist interest. Can the committee consider adding a learning disability psychiatrist to the multidisciplinary team list? |
| 30  | RCSLT | 1 | * We support the concept of this quality statement.
* Similarly to points raised above we would encourage a reconsideration of the phrasing to have a more patient/person-centred approach. For example, change: ‘Their care and support needs will vary depending on the severity of impairment and the presence of any comorbidities’ to ‘Their care and support needs will vary depending on their preferences and priorities.’
* We would also encourage that the rationale refers to an individual’s changing circumstances and the possible need to be referred to a MDT, e.g. if someone begins a new job or activity and requires a new kind of input or a change in their usual support, not just if they are ‘having difficulty’.
 |
| 31  | Scope | 1 | This statement recognises the need for a multidisciplinary approach. Most adults living with CP will experience a deterioration of the mobility and function and increase in pain or secondary impairments such as arthritis. This could be lessened by adhering to multidisciplinary action with clear communications between the medical professionals themselves and the person living with CP. |
| 32  | University College London Hospitals NHS Trust | 1 | Data collection will be difficult as though it is easy to count the number referred to an MDT it is impossible to know the number of people with CP who have deterioration in function. Data collection should be focussed on demonstrating referral pathways from local therapists/ GP’s etc. unplanned hospital admissions is a good metric and should be available provided centres code appropriately. |
| 33 | ACPH | 2 | We do not agree that “People with complex needs including multiple medical comorbidities, or cognitive or communication impairments would benefit most from an annual review” we think annual reviews are important to identify avoidable areas of medical deterioration regardless of their level of impairment. There is acknowledged deterioration that can occur in mobility for adults as they hit their 40’s and identifying underlying degenerative changes caught early can make a significant and cost effective impact on a person’s quality of life.“Medical issues that are almost unsolvable when patients come to us in their 40s could be averted if spotted earlier. While CP is not a progressive condition, it does necessitate ongoing medical treatment into adulthood to offset medical issues, such as early joint degeneration, that can extremely debilitating if left untreated.”Professor David Roye, Jr, MD, Leading paediatric orthopaedic surgeon, & the director of the Weinberg Family Cerebral Palsy Center, New YorkWe agree with statement however need to be established both regarding service and data collection. Annual review is an essential component in the care pathway of all adults with Cerebral Palsy. This can’t happen currently as many remain under the care of GP’s and don’t have access to specialist services. |
| 34 | NHSE | 2 | Structure measure: Some ambiguity as to whether ALL patients with CP require an annual review or just those with complex needs who need review by a specialist. Primary care will need clarity around coding of ‘complex’ needs in order to identify patients who have for example moved to a new geographical area. |
| 35 | NHSE | 2 | Outcome measure: Primary care will need support to ensure that ‘unplanned admissions’ are adequately coded for data collection |
| 36  | RCGP | 2 | An expert in neurodisabilities performing an annual review is a gold standard idea. Currently, annual health checks for patients with learning disabilities (including those with cerebral palsy and learning disability) are funded through the quality and outcomes framework in England for GPs to perform and then onward referral is made if required. Could CP be included in this indicator and funding follow this?When cerebral palsy patients are to be invited to a secondary care review each year, it is essential that all care, including blood tests and prescribing is carried out by the person performing the review and it is not passed to primary care without appropriate funding in place. |
| 37  | RCGP | 2 | The number of adults with cerebral palsy that have complex needs. There is currently no systematic coding for this on the primary care electronic systems and not all of these patients are under the care of specialists. If funded, and read codes added, these patients could be identified in primary care |
| 38  | RCGP | 2 | It is unclear how an annual review and a named contact will reduce unplanned admissions can the committee expand on this? |
| 39  | RCGP | 2 | Many patients who live in long term care settings or without adequate social support will find it difficult to attend secondary care appointments. Home visits should be considered for these patients by a member of the multidisciplinary team. |
| 40  | RCGP | 2 | It is important to consider the GP role in long term conditions, comorbidities and general health issues related to aging. Experts in neurodisabilities may not know how to diagnose and treat aging comorbidities such as diabetes and hypertension. These do not need secondary care in put, and so adequate and timely communication with primary care is essential. |
| 41  | RCSLT | 2 | * We support the concept of this quality statement.
* However, again similarly to points raised above we would encourage a reconsideration of the phrasing to have a more patient/person-centred approach. For example, change: ‘An annual review can identify changes’ to ‘An annual review presents an opportunity for the adult and the team around them to highlight changes’.
* We would encourage consideration of including: ‘providing appropriate and accessible information about the annual review to the person with cerebral palsy’ as a quality measure for this standard (not just being given a main contact).
 |
| 42  | Scope | 2 | Adults with complex needs must have an annual review as a minimum. I would suggest 6 monthly reviews. |
| 43  | University College London Hospitals NHS Trust | 2 | An annual review is an excellent idea and we applaud this. We note this reflects the guideline and is limited to GMFCS IV and V which is a shame. We would have like it to be all people with CP but this is a good start. At UCLH we have a service for all people with CP that offers ongoing care as needed with at least an annual review by telephone with a Nurse specialist in Cerebral Palsy. This is not high cost for the NHS and can save unnecessary appointments or problems occurring. |
| 44 | ACPH | 3 | We agree with this statement however it is dependent on better co-ordination between Health and Social services.We think that an expert in vocational skills and profession with experience in independent living could be the same person, however this doesn’t always need to be an Occupational Therapy. |
| 45 | NHSE | 3 | Process measure: Primary care will need support to ensure those with CP ‘who want to live independently’ are adequately coded. |
| 46 | NHSE | 3 | Outcome measure: As above. Coding for ‘feel they live independently’ will need addressing.  |
| 47  | RCGP | 3 | Asking health care professionals with no expertise to give information about assessments of vocational and independent living skills cannot be supported unless training and information is given to them which will be locality specific. Could this be part of the annual review for the multidisciplinary team to address? |
| 48  | RCSLT | 3 | * We support the concept of this quality statement.
* We are raising issues with the language again. We strongly encourage the removal of the words ‘as possible’ in the sentence ‘Adults with cerebral palsy should be able to live as independently as possible’. Language is powerful and this automatically implies limitation. People with cerebral palsy can and do live independently with the appropriate supports in place. Similarly ‘help them participate’ should be ‘enable them to participate’.
* Therapists do not assess a person’s goals. They work collaboratively with the individual to identify personal goals. There are similar language issues in the definitions (e.g. ‘professionals with expertise in independent living’.
 |
| 49  | Scope | 3 | Adults living with CP should supported in making the choice to live independently. |
| 50  | University College London Hospitals NHS Trust | 3 | This is the most disappointing standard; not because of its content but the way it is written. The standard is about occupational therapy. This is not disputed as in fact all the data collection suggested by NICE is explicitly about OT services however it repeatedly refers to a ‘professional with expertise in independent living’ and not an OT. I understand this is ‘NICE speak’ but it calls a speech therapist a speech therapist in standard 5, not a ‘professional with expertise in communication and swallowing’. It is meaningless jargon and insulting to OT’s. You wouldn’t go and see a ‘professional with expertise in teeth’ you would see a Dentist…Please change this to OT or if not you have to change all the data metrics in the Quality measures to be consistent and refer to; 1. *Evidence of local pathways that allow adults with cerebral palsy to be referred to ~~occupational therapy services.~~ professionals with expertise in independent living.*

However this looks ridiculous… but if you don’t change one of these a service could exist that has no OT’s but lots of experts in independent living and they would score zero on the quality measures.Commissioners are also being asked to commission OT’s not experts in independent living skills;***Commissioners*** *(such as clinical commissioning groups) commission occupational therapy services for adults with cerebral palsy who want support to live independently, and ensure that referral pathways are in place.* |
| 51 | ACPH | 4 | We agree with this quality standard however we consider that the lack of health care provisions to supports adults with Cerebral Palsy with conditions like post impairment syndrome, e.g. fatigue, osteoarthritis etc. need to be recognised as a barrier to continued sustainability in the work force.Consideration may be needed around flexible working to accommodate the adults changing needs. |
| 52 | NHSE | 4 | Process measure: Coding for ‘want support to start (or continue) work’ will need addressing [for primary care] |
| 53  | RCGP | 4 | Asking health care professionals with no expertise to give information and advice about education, securing work and employment support. Cannot be supported unless training and information is given to them which will be locality specific. Could this be part of the annual review for the multidisciplinary team to address? |
| 54  | RCSLT | 4 | * We support the concept of this quality statement.
* Phrasing is still an issue. Further disempowerment to service users given here in the sentence ‘Adults with cerebral palsy who want support to work’. Consider: ‘Adults with cerebral palsy in or seeking employment who would like support are referred….’
 |
| 55  | Scope | 4 | The great majority of adults living with CP are highly educated and motivated to take their place in society. They would also prove to be an asset to the work force. Organisations like Scope are well placed to offer the required support to help an adult with CP not only find a job but remain employed. |
| 56 | ACPH | 5 | We agree with this quality standard this is partly dependant on access to services, time length of support services are able to offer and having individuals with specialist knowledge and skills. |
| 57 | Communication Matters  | 5 | Very pleased to see that communication and AAC is being given a prominent position in guidelines for adults with cerebral palsy. The Commissioning Guidance for accessing specialist regional (hub) AAC support is currently being re-written and so it is important that these 2 sets of guidelines dovetail appropriately and in a way that both local services providers, and adults with cerebral palsy, can readily understand and follow. This is particularly necessary in relation to the use of the term “complex needs” as it may be being used in a slightly different way in both sets of guidance.  |
| 58 | RCSLT | 5 | * We support the concept of this quality statement and are delighted to see the inclusion of our online outcome tool as a source of data.
* **N.b. The following comments apply loosely to statements 3 & 4 also**. While it is a step forward to have a quality statement on assessment of communication difficulties, it appears a wasted opportunity to not include ‘provision of therapy’ in the statement. Measuring quality using referral rates for assessment isn’t entirely helpful and could actually be detrimental to services i.e. by increasing therapists’ caseloads that they are unable to support. Having a quality standard advocating for the subsequential provision of support (and outcomes associated to therapeutic gains) following assessment in addition to this statement would be more meaningful for delivery of quality care and encourage those who enforce the quality standards to properly resource services.
* We would also like to see some further changes in terminology. e.g. ‘Referral to speech and language therapy services enables adults with communication difficulties to be assessed and offered suitable interventions’ could be changed to ‘Referral to speech and language therapy services enables adults with communication difficulties to discuss any concerns around communication and jointly decide intervention approaches’.
 |
| 59 | Scope | 5 | Adults with CP that have communication difficulties should be referred to SLTs for assessment as to what equipment would aid communication. Funding should be made available for the provision of this most necessary piece of equipment.  |
| 60 | University College London Hospitals NHS Trust | 5 | This is an excellent standard though may be challenging for some areas to deliver. |
| 61 | RCSLT | Briefing paper | Refers to occupational health- is this supposed to be occupational therapy? We would also envisage a reference to dietetics would be key here. |
| 62 | RCSLT | Briefing paper | Since this makes reference to respiratory illness, it would be an opportunity to explicitly make a link to Dysphagia (eating and drinking difficulties). |

## Registered stakeholders who submitted comments at consultation

* ACPH: Adult Cerebral Palsy Hub
* BSRM: British Society of Rehabilitation Medicine
* Communication Matters
* NHSE: NHS England and Improvement
* RCGP: Royal College of General Practitioners
* Royal College of Occupational Therapists
* RCSLT: Royal College of Speech and Language Therapists
* Scope
* University College London Hospitals NHS Trust

## Responded with ‘no substantive comments’

* Royal College of Nursing
* Royal College of Physicians

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1. PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees. [↑](#footnote-ref-1)