NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARD CONSULTATION

SUMMARY REPORT

1 Quality standard title

Cerebral palsy in children and young people

Date of quality standards advisory committee post-consultation meeting:
6 July 2017.

2 Introduction

The draft quality standard for cerebral palsy was made available on the NICE website for a 4-week public consultation period between 11 May and 8 June 2017. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted. Comments were received from 15 organisations, which included service providers, national organisations, professional bodies and others. 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 appendix 1.

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

4 General comments

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

- Support for the quality standard in that it accurately reflects key areas for quality improvement.
- No particular areas of concern
- Additional areas for quality improvement were suggested.

Consultation comments on data collection

- Queries were raised over the availability of data to support cerebral palsy measures in general.
- The creation of national cerebral palsy register would help to inform measures and inform interventions.

Consultation comments on resource impact

- Mixed responses were received around resource impact. Some concern was raised over affordability with some uncertainty over how the statements would be costed. However other comments suggested, although additional resources would be required, these additional costs would be offset by the cost savings and improvements that early interventions would make.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

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

Consultation comments

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

- The statement was considered to be important to support early diagnosis and intervention.
- A timeframe of every 3 months from birth up to the age of 2 years was suggested.
- The enhanced clinical and developmental follow up programme does not address sharing of information which is an important aspect of follow up care.
- The MDT team in the child development service should include orthoptists.
- Therapy should be tailored to the needs of children at risk.
- Parents should receive information of alternative providers of follow up care due to the lack of provision of services within the NHS in some areas.

Consultation question 4

Stakeholders made the following comments in relation to consultation question 4:

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

- It was suggested that The Action cerebral palsy proposed clinical and developmental follow up programme for infants at risk of cerebral palsy could be referred to. This outlines what should be included in the follow up programme and also provides be included in the programme and some timeframes (outlined in appendix 1 comment 19).

5.2 Draft statement 2

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

Consultation comments

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

- Further clarity is required over how the children at risk of cerebral palsy are identified and monitored.
- Problems with the measurability of this statement were highlighted because delayed motor milestones depend on the specific diagnosis.
- The MDT team in the child development service should include orthoptists.
- Considerable overlap with statement 1 was highlighted.
- Current availability of services may make this hard to achieve.

5.3 Draft statement 3

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

Consultation comments

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

- Clear clarification required over what is included in the personal folder.
- Additional suggestions for what should be in the personal folder:
  - diagnostic results,
  - information on any comorbidities
  - current medication
  - type of cerebral palsy diagnosis
  - education
    cognitive and communication skills.
  - any visual impairments
- Information outlining the aims of the personal folder would make it more useful.
- Expand scope to include disordered developmental journeys.
- Potential overlap with existing health and social care services support tools for people with learning difficulties e.g. health passports, health action books.
- Different confidentiality policies and lack of funding may make this statement difficult to implement.
- Information on education, health and care plans that supports the special education needs of children with cerebral palsy should be linked with the personal folder.
- Measures should be feasible with existing data collection resources.

5.4 Draft statement 4

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

Consultation comments

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

- Alternative wording suggested due to varying implications for different audiences e.g. different timescales of specialist treatment and support services.
- Uncertainty over whether this would apply to all children with cerebral palsy or just those with more complex needs.
- Inconsistent evidence of defined referral pathways was highlighted as a potential barrier for the implementation of this statement. However this statement may improve clarity over referral pathways and help to ensure patient information on them is more widely available.
- The responsibility of the local care provider for specialist liaison and care coordination should be highlighted.
- Orthoptists should be added as a relevant professional group to who this applies within the audience descriptors.

6 Suggestions for additional statements

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

- Support for the family and carers of children with cerebral palsy.
- Managing urinary dysfunction.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments[1]
1	Department of Health	General	Thank you for the opportunity to comment on the draft for the above quality standard. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.
2	DM Orthotics LTD	General	There are no comments in regard to orthotics. Orthotics are used in conjunction with physiotherapy and occupational therapy to aid and enhance gait retraining, prevent range of movement by passive and active orthoses, and to provide stability and support pre and post surgery.
3	DM Orthotics LTD	General	Orthoses use different mechanisms :- dynamic, semi- rigid and rigid constructions
4	DM Orthotics LTD	General	Dynamic Elastomeric Fabric Orthoses (DEFO) are an emerging orthotic intervention often used in early years to provide both postural and proprioceptive inputs to facilitate learnt patterning to improve long term outcomes For instance it is now becoming apparent that early treatment with suits (both symmetrical or counter scoliosis) can prevent GMFCS Level 4 children requiring spinal surgery and in Level 5 the rate of curve progression can be slowed. Both of which save the NHS money (from surgery and support services) and can improve quality of life for the individual.
5	DM Orthotics LTD	General	Semi- rigid orthoses can include the use of thinner ankle foot orthoses (AFO) which provide more flexibility in foot position reducing orthosis rejection and non compliance due to discomfort.
6	DM Orthotics LTD	General	Rigid orthoses including carbon fibre ankle foot orthoses and rigid spinal control orthoses (used in the management of lower and upper limb presentation and spinal support including Scoliosis)
7	DM Orthotics LTD	General	Orthoses are a significant cost to the NHS orthotic budgets so require the provision of a directive on use with guidance based on current evidence.
8	Action Cerebral Palsy	General	ACP agrees that the draft quality standard accurately reflects the key areas for quality improvement, but as set out in the previous answers highlights the need to ensure the details of the implementation of each quality statement are set out fully.
9	Action Cerebral Palsy	General	ACP's view is that that the development of local data collection systems and structures is still in its early stages. ACP is calling for the creation of a national CP register to inform interventions and allocate resources accordingly.
10	Action Cerebral Palsy	General	Although ACP is aware that additional resources would be required to deliver this quality standard in areas with inadequate existing CP provision, the cost savings and improvements that early intervention can make to the lives of CYP with CP wholly outweigh these. Early intervention has been shown to contribute to infants' physical, cognitive, social and emotional development, thereby reducing the impact of CP on the child and their family, ensuring they can achieve their full potential. CP is the most common childhood motor disability and it is imperative that local services invest in services to reduce its impact on children and young people and their families as much as possible.

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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.

ID	Stakeholder	Statement number	Comments[1]
11	Barts Health NHS Trust	General	I would be keen to highlight in the response the need to specify Orthoptists as part of the child development service and for visual function to be included in the folder. There is a high incidence of visual problems in children (approximately 50%) with cerebral palsy and often these can be overlooked early on due to the focus on other needs. Untreated visual problems can have an impact on the child's overall development and potentially irreversible visual loss.
12	Royal College of General Practitioners	General	A sensible and comprehensive approach with awareness of Physical, Mental, Social, Educational and family/carer dimensions. The focus is predominantly on the younger child and it would be useful to have a quality standard(s) around the adolescent with cerebral palsy. This could cover bone health, pain or distress, sleep disturbance, saliva control, mental health or other co-morbidities. The regular review, shared records and mutual appreciation of roles in the multi-disciplinary team is essential and the identification of a key worker. Timing of reviews should be at least annually, but a review called for by a team member or carer on an "as required" basis. There are important research questions not yet answered-what works, long term effectiveness. Two problems with this quality standard: 1. The list of risk factors in the guideline (https://www.nice.org.uk/guidance/ng62/chapter/Recommendations#risk-factors) is quite long. Some items appear to be poorly defined (low birth weight; preterm delivery and it is not clear if the definitions will the same across the UK. For this reason, the denominator may be both quite difficult to measure and vary across different areas of the UK. When commenting on the guideline, 'maternal … infection treated in hospital' were likely to be a non-standard criterion. This has not been responded to in the published guideline. 2. Are NICE sure that the benefits of implementing this aspect of the guideline will outweigh the risks? Early diagnosis may have gains (though this too has not been quantified). It is quite likely that including all children where there was a single risk factor will include many without cerebral palsy. This may have effects of increasing anxiety in their parents, as well as incurring opportunity costs. A risk of over investigation and over diagnosis.
13	Royal College of Paediatrics and Child Health	General	We have reviewed the content of this document and have no particular areas on which to raise comment. This document seems very appropriate.
14	Royal College of Paediatrics and Child Health	General	No not in place - concern that we currently do not have any systems in place to measure the standards in way set out
15	Royal College of Paediatrics and Child Health	General	We are really concerned that costs not available, but no idea how to cost
16	Royal College of Paediatrics and Child Health	General	We understand that the standards cannot be comprehensive for all aspects of CP care; therefore the 4 standards need to reflect key performance indicators of a service.

ID	Stakeholder	Statement number	Comments[1]
			Consideration of the following to include within these 4 standards are • Ensuring that the enhanced developmental follow up translates into early diagnosis, support across all settings and opportunity for early intervention. • Spine or hip monitoring, although we are aware that this will be covered in the spasticity guideline, but if there is omission here – it must be included within the spasticity quality standards. • The importance of recording GMFCS level in all clinical correspondence and documentation. • The importance of documentation of function e.g. communication, upper limb function, self-care/ADL, participation and learning ability.
17	Action Cerebral Palsy	1	The 'enhanced clinical and developmental follow-up programme' does not address sharing of information, linking up with different services or communicating with different professionals. Many services use different systems for electronic notes or referral routes. Children may be missed if information not physically handed over by a professional for enhanced follow up. There is an assumption made children would be automatically picked up by community multidisciplinary team.
18	Action Cerebral Palsy	1	Action Cerebral Palsy (ACP) agrees with quality statement 1, that "Children with any risk factor for cerebral palsy have an enhanced multidisciplinary clinical and developmental follow-up programme from birth to 2 years." However, this statement could benefit from being quantified, perhaps by amending the wording to read "Each child with any risk factors should be assessed by the multidisciplinary team at least once every 3 months from birth to two years." However, in many areas of the country this level of assessment would not be possible due to a lack of therapists in each multidisciplinary team. A day clinic style approach may be most cost effective, although we imagine that getting all therapists in one place on the same day would be difficult (especially with many part time therapists within the NHS).
19	Action Cerebral Palsy	1	To respond to question 4 on this draft quality statement, ACP has produced a proposed clinical and developmental follow up programme for infants at risk of cerebral palsy (CP). This can be found below, but has also been passed on to NICE separately as a PDF attachment, and we would urge NICE to consider this attachment to fully understand the process outlined. **Step 1:** Risk factors noted, or high-risk population. **Step 2:** Assessment before 12 weeks. Assessment to include as appropriate: • GMs • NBAS/ NBO • Bayley • ADLS, including sleep, feeding and attachment **Step 3:** If no problems are noted, take the following steps: **Step 4:** Follow up and review maintained by child development centre at: **Step 4a**. 6 months

ID	Stakeholder	Statement number	Comments[1]
			Step 4b. 12 months **Step 4c**. 18 months **Step 4d**. 24 months If any developmental concerns are noted at steps 4a-4d, revert to step 2 – appropriate assessments. If a child is identified as being 'at risk' of developing CP, there could also be an option for parents to refer back for an assessment in between these six-month intervals rather than waiting, in order to maximise the window of neuroplasticity for intervention approaches). Alternatively, if at **step 3** assessments highlight a developmental issue, follow these steps: **Step 4:** Immediate referral (max. wait two weeks) for weekly hands on intervention from MDT/clinician as appropriate to address the highlighted issue/issues. This intervention should be child/family led. **Step 5:** Reassessment to take place after 8 weeks of intervention. If: **Step 5a:** If development now within normal limits, revert to follow up and review maintained by Child Development Centre at 6, 12, 18 and 24 months, with further developmental concerns addressed with appropriate assessments. **Step 5b:** If child reaches 24 months of age, community services should be contacted to provide further follow up. **Step 5c:** If developmental issues are still present, revert to step 3.
20	Action Cerebral Palsy	1	To respond to question 4 on this draft quality statement, ACP has produced a proposed clinical and developmental follow up programme for infants at risk of cerebral palsy (CP). This is included in the PDF attached with this consultation response. This flowchart made use of the following links: • https://bmcpediatr.biomedcentral.com/articles/10.1186/s12887-016-0711-x • https://clinicaltrials.gov/ct2/show/NCT02166801 To expand on the assessments and timelines included in this proposed programme, a number of things should be noted: • The nature of the assessments used to investigate potential CP should be based on clinicians' views of what would be appropriate. However, ideally all of these assessments should be undertaken to ensure the possibility of CP is fully explored. • This clinical and developmental follow-up programme should take a combined approach of therapists and parents delivering interventions, with training available to enable parents to continue interventions beyond a clinical setting. Research is indicating that the traditional model of hands-on treatment provided by therapists is not necessarily effective, and so support from therapists should aim to support parents in incorporating interventions into the daily family routine rather than concentrating efforts into a weekly therapy session.

ID	Stakeholder	Statement number	Comments[1]
			The very specific recommendations included – for example, to reassess the infant eight weeks after intervention – are crucial to avoid the “wait and see” attitude which is prevalent among many clinicians when concerns are raised about the potential for CP. These are also needed to allow local areas to provide therapy around the needs of children at risk.
21	Action Cerebral Palsy	1	ACP notes that for service providers, the implication of QS 1 is to highlight the importance of adequate availability of providers with suitable and appropriate experience of intervention, including those outside the NHS. This is based on the knowledge that NHS services are variable (as identified in ACP’s 2016 report *Variations in Care*), and so parents should receive information on alternative provision.
22	Action Cerebral Palsy	1	ACP would question which professional in the multidisciplinary team would be responsible for triggering intervention after concerns have been raised, and who would support the family throughout this process. We believe this responsibility could fall to a specialist health visitor if they are available, although it depends on the specific issue with the child. It would be best if this professional could be community-based with the ability to meet families on a regular basis without too much notice – delegating responsibility to a paediatrician in a secondary care setting, for example, could lead to families waiting too long for appointments which need to be held as soon as possible.
23	Action Cerebral Palsy	1	ACP is aware that there are examples of good practice in implementing the NICE guidelines on CP across the country, but would emphasise that these are not standard practice.
24	British and Irish Orthoptic Society	1	A visual assessment should be included for any child at risk of cerebral palsy aged 0-2 years and this visual assessment to be provided by an Ophthalmic team consisting of an Orthoptist and Optometrist / Ophthalmologist. Orthoptics to be added to list of available services as part of the multidisciplinary team.
25	Royal College of Paediatrics and Child Health	1	We agree that statement one is a key quality standard and it is welcome to see inclusion of the whole MDT as essential to care: including physio/OT/ SALT/psychology/ nursing and dietetics. This may support service resource in child development teams. We would like to highlight the importance of (and ask for inclusion of) early referral to the local disability expert, to support early diagnosis and consider early interventions.
26	Action Cerebral Palsy	1 and 2	ACP approves of the suggestion in these quality statements that the personal child health record, produced by the Royal College of Paediatrics and Child Health (RCPCH), could be used as a data source for local data collection on children at risk of CP or with delayed motor milestones. This idea was included in ACP’s original submission to the stakeholder engagement for this quality standard. ACP has recently approached the RCPCH on the possibility of trialling the inclusion of risk factors for and signs of CP in the electronic personal child health record, and while these discussions are in their very early stages, it is encouraging to see this suggestion being adopted by NICE.
27	Royal College of Paediatrics and Child Health	1 and 2	We have been contacted by a lead orthoptist in the hospital to say that they believe that as they see children with suspected CP both before 2 years then up to 7 years that they should be included in the multidisciplinary team in quality statements 1 and 2. We do recognise that visual and hearing services are mentioned on page 16 but not elsewhere
28	[Alder Hey Children’s NHS Foundation Trust	2	The multi-disciplinary team in the child development service should include orthoptists, Allied Health Professionals specialist in assessing children’s visual function. There is a wealth of evidence to support the surveillance of vision assessments in this group of children to treat visual disorders and prevent sight loss.
29	[SeeAbility]	2	Given 1 in 2 children and young people will have a problem with their vision, and vision is so crucial to a child’s development, and visual impairment is specifically discussed in the full guideline, and ongoing support, then it seems odd to not reference expertise through ophthalmologists, orthoptists and optometrists as part of multidisciplinary support under the Child Development Service.

ID	Stakeholder	Statement number	Comments[1]
30	Action Cerebral Palsy	2	This statement is hard to quantify, as delayed motor milestones can vary hugely depending on the specific diagnosis and condition. We would suggest changing the wording to: “Children with delayed motor milestones should be referred to a child development service and be seen within 2 months of referral. Each child should be reassessed at least once every 3 months and at least once a month if they have significant delay.” In reality, it would be difficult to meet this aim within the current NHS structure, although if the NHS changed their approach it may be possible. For example, the therapy which can be administered to address developmental delays is usually delivered in 30-60 minute sessions. If therapists saw children for longer periods of time, parents would be more confident in delivering the therapy themselves and it would be possible for them to be assessed less frequently.
31	Action Cerebral Palsy	2	Beyond the comment above, ACP’s response to QS 2 is broadly the same as the response to QS 1, as the same actions should be taken for children with any risk factors for CP as for those with delayed motor milestones that may indicate CP.
32	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	2	Refers solely to paediatric services – no comments received on feasibility of outcomes or measures
33	British and Irish Orthoptic Society	2	Orthoptist and Optometrist / Ophthalmologist to be included in the multidisciplinary team. Orthoptists provide valuable information to assist others in the multidisciplinary team to understand the important link between visual behaviour, movement and communication.
34	Royal College of Occupational Therapists	2	The statement is not specific enough in explaining how children at risk of cerebral palsy are identified and monitored. This is important for service providers, healthcare professionals and commissioners to ensure consistencies between different boroughs. Not sitting by 8 months (corrected for gestational age), not walking by 18 months (corrected for gestational age) and early asymmetry of hand function (hand preference) before 1 year (corrected for gestational age) may result in too many children perceived as being at risk which will drain resources. Disordered patterns of development would need to be considered alongside delayed development.
35	Royal College of Paediatrics and Child Health	2	This is also a key performance indicator and there is recognition of wider developmental assessment after motor concerns. We would recommend increasing the scope of the recommendation to ensure inclusion of not only delayed motor milestones, but to include disordered developmental journeys, including e.g. toe walking, and evidence of abnormalities of tone or posture on clinical examination.
36	[Alder Hey Children’s NHS Foundation Trust	3	The personal folder should include information about the vision of the child
37	[SeeAbility]	3	Given 1 in 2 children and young people will have a problem with their vision, and vision is so crucial to a child’s development, it would be helpful to include this information in the personal folder.
38	[SeeAbility]	3	There is also no link in the quality standard to the fact that some children with cerebral palsy will have an education, health and care plan that supports their special educational needs, and how this should provide link information to the personal folder.

ID	Stakeholder	Statement number	Comments[1]
39	Action Cerebral Palsy	3	ACP wholly welcomes QS 3, which reflects what ACP has been pushing for some time. Currently many of the parents we see complain of their child being assessed but not receiving any specific advice or instructions. It would be useful if all contact, frequency of input, advice and programmes were kept in a central personal folder to counteract this. Each child with cerebral palsy is an individual with a variety of different needs, which makes prescribing contact levels and other interventions only possible on an individual basis and with resources such as a personal folder. However, we would urge that the personal folder must be fit for purpose in its content, style and structure, and its contents should be informed by stakeholders, parents and children and young people (CYP) with CP when they are old enough to be involved in their care. It should also include information on expected pathways of care, local support and personal information on the child, covering information **for** the child and family and information **about** the child and family. This will enable the personal folder to fulfil its purpose of preventing families from having to repeat information about their child's care to different professionals, and enable joined up working between services.
40	Action Cerebral Palsy	3	Under the definition of the personal folder and its potential contents, ACP believes this list could be reordered and expanded to read as follows (p.13): • Early history • **Diagnosis and details of CP, with MRI results if available (as these are needed to know the type of CP to understand the impact it will likely have on the CYP)** • Motor subtype and limb involvement, **and level of motor and mobility skills, e.g. the Gross Motor Function Classification System** • Functional abilities, **including sensory impairment and sensory integration issues – e.g. sensory over or under responsivity to movement/auditory/touch/visual stimuli – and the type of support required, e.g. glasses or hearing aids** • **Educational and cognitive skills** • **Communication skills** • Preferred methods of communication • Interventions • Medication • Co-morbidities • Any specialist equipment that is used or needed • Care plans • Emergency contact details
41	Association for Family Therapy and Systemic Practice	3	Personal folders are more likely to be usefully employed if more guidance is given about the aims of their use. In the Rationale, one of the phrases: 'to contain information about the child or young person with cerebral palsy that can be shared' with professionals, contains language which is a bit objectifying – the child or young person are portrayed as passive in the

ID	Stakeholder	Statement number	Comments[1]
			communication. The phrases which follow frame the child or young person as more actively involved in choice and control and these phrases are preferable. Inclusion of family members as users of this folder would also be useful. It should also be borne in mind that children or young people may have different views and priorities than family members (and than professionals). A personal folder could also be a way to document, communicate and manage differences of opinion about management. Access to a professional with expertise in supporting families to discuss and negotiate differences of opinion or conflicts could be useful to support the child or young person growing in independence by facilitating the expression of different views. The outcome markers for this quality standard are portraying the folder as a means by which children and young people / parents and carers receive information. This again implies a passive position. The outcomes could instead measure how satisfied children, young people / parents and carers are that the folder supported their communication or helped their choices to be taken seriously.
42	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	3	Support from respondents for the concept of a personal folder, which would help with transition from children to adult services.
43	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	3	Many health and social care services already promote the use of personal folders/health passports/health action books for people with learning disabilities. It would be helpful to consider whether these existing tools would satisfy the quality standard for people with cerebral palsy and associated learning disabilities to reduce duplication of recording.
44	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	3	Depending on the number of patients, how extensive the personal folder is, and the frequency of updating the folder there may be some initial requirement for additional resources to implement the project successfully.
45	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	3	Data collection for outcomes should be feasible within existing resources providing the methodology does not require intensive support from health and social care practitioners (i.e. use of postal questionnaire/web-based surveys similar to existing friends and family test data collection).
46	British and Irish Orthoptic Society	3	A visual assessment including functional vision to be included in the personal folder under comorbidities section.
47	Royal College of Occupational Therapists	3	The intention of this quality standard is welcomed. A personal folder is child specific and would reduce duplication of information sharing from families to professionals. It would ensure a universal/consistent approach is used by the multi-agency team working with the child.

ID	Stakeholder	Statement number	Comments[1]
			The personal folder will, however, be hard to implement because of the high risk of miscommunication and inaccurate information. It would require a designated coordinator to collect information jointly with family members, professionals and all those involved. It will also require a process to ensure it is reviewed regularly within a team context and not just by individual professionals. There is also potential duplication with the digital records being developed with the 'red book' initiatives. Additionally, the personal folder will difficult to achieve due to different confidentiality policies within different agencies and services e.g. 'need to know basis'. If it is in paper format it may also get lost and if in electronic format where would it be stored? There is the potential for the family to be given responsibilities for its storage and maintenance which may not be possible or appropriate in all situations.
48	Royal College of Paediatrics and Child Health	3	Re Personal file- we are concerned as there is no funding for this. Some parents do keep their own files and they get copies of all reports and letters. There is no system or funding for setting up parent held electronic files and because of email fire walls we cannot email parents clinical information with the current systems. There is no funding for key workers. Note the support for funding for Early Support 2014 that then collapsed. We are concerned that systems and funding not in place to support this laudable objective
49	Royal College of Paediatrics and Child Health	3	This standard will aim to ensure equity of care; for all children, however it may be the most challenging to deliver. There needs to be clear guidance to clarify essential information to include in the personal folder. What are the core standards (and they may need to be very basic)? Each child/family/region/service may have different preferences for the format of the folder (paper/ electronic etc) and where it should be kept. There may be varied engagement from families if the folder remains with the child; and some could see this as an additional burden of care for the family. There will be confidentiality and data governance issues. A standard to reflect the core clinical information that is needed to be recorded for each child; with freedom of the service/ child and family to consider how to do this may be more appropriate. Core clinical information: • Background medical and birth history • GMFCS • Nature and distribution of motor pattern • Communication • Co-morbidities • Equipment needed • Care plans: emergency or advance care plans if they are in existence. • Current medication
50	Royal College of Paediatrics and Child Health	3	Vision should be included in personal folder. We suspect this may be the plan anyway.

ID	Stakeholder	Statement number	Comments[1]
51	[BSCOS – British Society for Children's Orthopaedic Surgery]	4	The access to specialist services is described as a passive process that addresses co-morbidities rather than an active and positive involvement of the specialist services in the prevention and monitoring of potential problems. BSCOS strongly believes that children with CP should be screened for orthopaedic problems and monitored through regional and national registries from a young age until transition to adult services. This would identify and manage problems such as scoliosis, hip dislocation, deterioration of mobility and pain early through minimal interventions rather than allowing them to develop and escalate. This is an example of a positive effort in this domain: http://apcp.csp.org.uk/cerebral-palsy-integrated-pathway-developing-uk-wide-programme
52	Action Cerebral Palsy	4	This quality statement has different implications for different audiences. It should entail service providers using their local offer to identify potential specialist providers and referral routes which can be of use to CYP in managing comorbidities. For CYP with cerebral palsy, ACP would suggest that the wording on the impact for this audience is amended to read "Children and young people with cerebral palsy are offered **prompt and timely** specialist treatment and support for any difficulties or conditions caused by their cerebral palsy, **in line with recommended timescales**."
53	Action Cerebral Palsy	4	A concern with this quality statement is that if these specialist teams do not have sufficient resources and time available, the child and family may be told that the teams are involved but may not receive the support described.
54	Action Cerebral Palsy	4	ACP believes the list of specialist teams involved in the management of comorbidities should be amended to include the following professionals (p.16): • Paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and surgical specialist care • Orthopaedics • Orthotics and rehabilitation services • Social care • **Family support services, including health visitors and voluntary sector providers** • Visual and hearing specialist services • **Speech and language therapy** • **AAC assessment and support** • Teaching support for preschool and school-age children, including portage
55	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	4	Support from respondents for clearer referral pathways, and accessible patient information to be widely available.
56	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	4	Inconsistent evidence of defined referral pathways in some areas of the UK. Examples referred to included: respiratory, falls and spasticity management within specialist services.

ID	Stakeholder	Statement number	Comments[1]
57	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	4	Query from respondents whether quality standard would apply to all children and young people with cerebral palsy or just certain sections of the population with more complex needs (e.g. GMFCS levels 4 and 5).
58	Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	4	Support for taking a more proactive approach with identifying and signposting patients for intervention to reduce costly intervention when physical presentation has progressed significantly (e.g. significant contractures and pain; risk of respiratory complications; risk of falls and fractures).
59	British and Irish Orthoptic Society	4	Orthoptists to be added to this list.
60	British and Irish Orthoptic Society	4	Orthoptists to be added as a professional group.
61	British Society for Paediatric Endocrinology and Diabetes	4	Recommendation 1.5.3 lists a number of specialist services which children and young people with cerebral palsy should be able to access but this does not include endocrinology; this should be specifically listed as well because of the potential problems with low bone mineral density and puberty. There is no mention anywhere in the document specifically about monitoring puberty and ensuring that children and young people with cerebral palsy go through puberty at a normal age. It is well recognised that children with cerebral palsy are at higher risk of precocious puberty and some children also have very delayed or absent puberty (which will markedly increase the risk of low bone mineral density if this is not recognised and appropriately managed).
62	British Society for Paediatric Endocrinology and Diabetes	4	Low bone mineral density: suggestion of using bisphosphonates to improve bone mineral density in children and young people with cerebral palsy. This should only be considered after consultation with paediatric bone specialists. Much more important to ensure optimal Vitamin D and calcium intake and that puberty occurs at an appropriate time.
63	British Society for Paediatric Endocrinology and Diabetes	4	There is a specific comment on page 20 referencing NICE NG62 – Recommendation 1.12.8 (Refer children and young people with cerebral palsy with reduced bone density and a history of low-impact fracture to a specialist centre for consideration of bisphosphonate therapy); waiting for fractures to happen is too late and more consideration needs to be given earlier to avoiding low bone mineral density in the first place.
64	Pennine Care NHS Foundation Trust	4	Children with Cerebral palsy have a much higher probability of suffering visual disturbance and oculomotility problems than their peers, thought to be up to 70%. It is therefore essential for their general development and to maximise on their potential, that vision and ocular problems are identified and managed as early as possible.
65	Pennine Care NHS Foundation Trust	4	The most appropriate and cost effective clinician to assess these children is an orthoptist with developed skills in working with children with complex needs.
66	Pennine Care NHS Foundation Trust	4	Each child development team should have an orthoptist as a core member and that person should be able to make direct referrals to optometrists and ophthalmologists as appropriate.

ID	Stakeholder	Statement number	Comments[1]
67	Pennine Care NHS Foundation Trust	4	There should be direct links and pathways to vision support services provided by social services, education and 3rd sector organisations.
68	Royal College of Paediatrics and Child Health	4	This standard should ensure that there is transparency of clinical care provision and networks with access to specialist services as needed. We wish to highlight that the local paediatrician (disability, community etc. or neurologist) would aim to manage as many of the associated conditions as possible, to reduce time away from education and the number of appointments the family have to attend. The statement focussing on parent entitlement to information is welcome; however care should be taken to ensure that this does not imply or take away from the fact that it is the responsibility of the local care provider who are responsible for specialist liaison and care co-ordination.
69	Alder Hey Children's NHS Foundation Trust	Additional statement	I cannot find any reference in the document to managing urinary dysfunction, which occurs in one third of children with cerebral palsy. Morbidity and mortality may occur due to urinary tract infection and renal damage The cost implication of faecal and urinary incontinence are huge. Combined with the impact on quality of life for the individual and carers, this issue should be covered by the guidance. There is just one sentence that mentions possible constipation.
70	Association for Family Therapy and Systemic Practice	Additional statement	A quality standard regarding support would reflect an additional key area for quality improvement. Families may need to make significant adjustments to their expectations when a child is found to have additional needs. For some this may include implications of significant long-term caring implications. Support may be required at different points in the family life cycle or different developmental stages of children and young people. Access to professionals with expertise in providing emotional support to the whole family should be considered. Aspects from previous NICE guidelines about family involvement might be useful. The autism guideline below regarding family assessment, information giving, emotional support etc could be useful to consider when framing a quality standard about support. CG170 – AUTISM IN UNDER 19S: SUPPORT AND MANAGEMENT 1. 2 Families and Carers 1. 2.1 Offer all families (including siblings) and carers verbal and written information about their right to: • short breaks and other respite care • a formal carer's assessment of their own physical and mental health needs, and how to access these. 1. 2. 2 Offer families (including siblings) and carers an assessment of their own needs, including whether they have: • personal, social and emotional support

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			• practical support in their caring role, including short breaks and emergency plans • a plan for future care for the child or young person, including transition to adult services. 1. 2. 3 When the needs of families and carers have been identified, discuss help available locally and, taking into account their preferences, offer information, advice, training and support, especially if they: • need help with the personal, social or emotional care of the child or young person, including age-related needs such as self-care, relationships or sexuality

Registered stakeholders who submitted comments at consultation

- Action Cerebral Palsy
- Alder Hey Children's NHS Foundation Trust
- Association for Family Therapy and Systemic practice
- Association of Chartered Physiotherapists for People with Learning Disabilities
- Barts Health NHS Trust
- British and Irish Orthoptic Society
- British Society for Children's Orthopaedic Surgery
- British Society for Paediatric Endocrinology and Diabetes
- Department of Health
- DM orthotics

- Pennine Care Foundation Trust
- RCGP
- RCPCH
- Royal College of Occupational Therapists
- SeeAbility