National Institute for Health and Care Excellence

Cerebral Palsy
Scope Consultation Table
7 July 2014 – 4 August 2014

ID	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1	British Paediatric Neurology Association (BPNA)	1	General	Our comments are as follows: The following areas are not mentioned in the document: Assessment, investigation and management of pubertal disorders, behavioural difficulties, sleep disorders, mental health conditions; assessment of psychological adjustment/wellbeing; maintaining optimal bone density. sleep disorders in cerebral palsy result from several causes in cerebral palsy including spasticity, hip dislocation, scoliosis, gastro oesophageal reflux and centrally mediated sleep disorder etc. This ideally should be included in the guideline.	Thank you for your comment. In light of stakeholder comments it has been agreed the scope will include the following additional key areas: identification, and assessment of behavioural and mental health problems; management of mental health problems; assessment and management of sleep disturbance; and interventions to reduce the risk of reduced bone mineral density and low impact fractures. Pubertal disorders will be included as part of the review question on co-morbidities.
2	British Paediatric Neurology Association (BPNA)	2	4.5	e) Our comments are as follows: It would be helpful for this review question include the optimal timing to an MRI scan and also the value of an MRI in determining the outcome of cerebral palsy	Thank you for your comment. The value of an MRI scan in determining both the cause and prognosis are covered in the scope as review questions, optimal timing of neuroimaging may be identified by the guideline development group as significant and included in the review question protocol during the development of guideline.
3	British Paediatric Neurology	3	4.5	l) Our comments are as follows: The question should include what **assessments** are effective in maintaining adequate nutritional	Thank you for your comment. Nutritional status is included in the guideline as a main outcome (section 4.5).

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	Association (BPNA)			status….	
4	British Paediatric Neurology Association (BPNA)	4	4.5	n) Our comments are as follows: The question should include what **assessments** are effective in managing problems associated with difficulties in sensory planning…	Thank you for your comment. The scope has been revised to say "processing of sensory and perceptual information".
5	British Paediatric Neurology Association (BPNA)	5	General	Our comments are: There was a general question relating to the document about what is meant by 'sensory planning and perception'?	Thank you for your comment. The scope has been revised to say "processing of sensory and perceptual information".
6	British Paediatric Neurology Association (BPNA)	6	General	Our comments are: It would be helpful to have the following additional questions to the scope: What tools are available to measure/quantify pain? What are the prognostic indicators for the individual child in respect to: • The ability to walk • The ability to talk • Life expectancy?	Thank you for your comments. In light of stakeholder comments, it has been agreed that the assessment and management of pain, discomfort, and distress will be covered in this guideline. We have also revised the review question (n) to include the clinical and developmental prognostic indicators for the ability to walk, talk and life expectancy.
7	British Paediatric Neurology Association (BPNA)	7	General	Reference to child development centre - often work as child development "teams" rather than in centres which implies a geographical physical base .	Thank you for your comment. The section you refer to has been revised to say "teams" taking into account that all members of multidisciplinary teams may not be all working from one location.
8	British Academy of Childhood Disability	1	3.1	e) Assisted conception should be mentioned amongst these risk factors for CP (although it is associated with other risk factors, namely prematurity and multiple births).	Thank you for your comment. This section is not intended to be an exhaustive list.
9	British Academy of	2	3.1	g) It should be clarified that reduced life expectancy is associated with more extensive and severe forms of cerebral palsy rather than	Thank you for your comment. The link between severity of cerebral palsy correlating to reduced life expectancy has

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	Childhood Disability			applying generally to those with cerebral palsy.	been added to section 3.1 (g) of the scope.
10	British Academy of Childhood Disability	3	3.2	c) Although the list of those working in a child development centre (CDC) is not intended to be exhaustive, it would be best not to mention just community paediatricians but to be more inclusive and mention community paediatricians and other paediatricians. There are a variety of paediatricians, who may not be community paediatricians, who are key members of some local CDCs (e.g. general paediatricians with a neurodisability interest).	Thank you for your comment. The sentence in section 3.2 which refers to community paediatricians is specific to work happening outside of a hospital environment therefore this wording will be retained. We have re-worded the section to acknowledge your comments.
11	British Academy of Childhood Disability	4	3.2	e) Difficulties with sleep should be included (even though this relates to some of the other problems mentioned in this section).	Thank you for your comment. In light of stakeholder consultation, it has been agreed that the common causes for sleep disturbance and interventions to manage these will be included in the scope. Additionally, the symptoms and signs of sleep disturbance for children and young people who are unable to communicate has also been included in the scope.
12	British Academy of Childhood Disability	5	4.3.1 (and 4.5)	A key management issue to be covered (and to be included in the review questions), should be managing sleep difficulties in those with cerebral palsy.	Thank you for your comment. In light of stakeholder consultation, it has been agreed that the common causes and interventions for sleep disturbance will be included in the scope. Additionally, the symptoms and signs of sleep disturbance for children and young people who are unable to communicate will be also included in the scope.
13	British Academy of Childhood Disability	6	4.3.1 (and 4.5)	A key management issue to be covered (and to be included in the review questions), should be managing the hip in those with cerebral palsy. This is an extensive topic and it is unlikely that all aspects can be covered but at least some advice on hip surveillance programmes would be very helpful.	Thank you for your comment. Management of the hip was covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG

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					145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
14	British Academy of Childhood Disability	7	4.5	o) Life expectancy should consider not only the (semi-) predictable reduced life expectancy of those with more severe cerebral palsy, but also the issue of sudden, unexpected death since the strategies for educating and supporting families differ for each of these circumstances.	Thank you for your comment. The link between severity of cerebral palsy correlating to reduced life expectancy has been added to the scope. The review question "what specific information and support is needed by children and young people with cerebral palsy and their family members and carers?" will highlight the areas where information is needed which is specific to cerebral palsy.
15	Royal College of Paediatrics and Child Health	1	3.1 (b) 'Associated disorders'	These are crucial in the overall management of CP	Thank you for your comment.
16	Royal College of Paediatrics and Child Health	2	3.1 (g) 'Prognosis'	Non-English speaking parents and older children must be catered for with relevant use of trusted interpreters.	Thank you for your comment. This is an issue that the guideline development group will consider when developing the recommendations for children and young people to ensure equality of access to relevant services.
17	Royal College of Paediatrics and Child	3	3.2 (c)	'Community' should be removed before Paediatrician, recognising that many/most recently appointed Consultants work across both community and hospital settings.	Thank you for your comment. The sentence in section 3.2 which refers to community paediatricians is specific to work happening outside of a hospital environment therefore

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	Health				this wording will be retained.
18	Royal College of Paediatrics and Child Health	4	3.2 (f) ' Transition '	This remains a difficult area despite several attempts to improve the process.	Thank you for your comment. The guideline will cross refer to the NICE social care guideline, "Transition from children's to adult services". Publication is expected February 2016."
19	Royal College of Paediatrics and Child Health	5	4.2 (a) 'Setting'	Should 'Educational placements' be included?	Thank you for your comment. The remit of this guideline is to cover the NHS and government funded social care. Therefore, the education sector is outside of the remit of this guideline.
20	Royal College of Paediatrics and Child Health	6	4.3 (l) 'Pain'	Assessment of pain/discomfort has always been difficult in the more severely affected children who, importantly are often more likely to suffer from this. I'm pleased to note that this is covered later in section 4.5 (m).	Thank you for your comments. In light of stakeholder comments, it has been agreed that the assessment and management of pain, discomfort and distress will be covered in this guideline.
21	Royal College of Paediatrics and Child Health	7	4.4 (d) 'Main outcomes '	'Social participation', in my view, is probably the most important.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.
22	Royal College of Paediatrics and Child Health	8	General	In addressing the 'bullet points' above, I have the following comments to make :- To reach 'Equal Opportunity' for **all** children and their families a number of 'hurdles' must be crossed. These include; Health, Social Services and Education are often managed in areas which are not 'Co-terminus'; Also, there are bound to be wide variations in the quality and standards of MDT care which may be due to both geographic and funding issues.	Thank you for your comment. The scope of this guideline is broad as it includes both clinical management and social care needs of the child and young person with cerebral palsy. In addition, transition between children and adult services and the role of the multi-disciplinary team will also be covered. As part of the development of the guideline, best models of clinical practice and appropriate recommendations will be made.

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23	Royal College of Paediatrics and Child Health	9	General	This is an excellent and timely appraisal of aetiology and management of cerebral palsy with the aim of identifying the evidence base for current practice. The scope is extensive and will require expertise from many disciplines. We note exclusion of spasticity management, reflux and respiratory complications – presumably because they have been addressed recently by NICE or in existing plans. It may be difficult to disentangle the issues which are specifically not covered eg life expectancy and ability to walk and quality of life may be affected by management of spasticity and management of respiratory complications. Will the scope include appraisal of "alternative" forms of treatment?	Thank you for your comment. Cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline. During the guideline development, the guideline development group may prioritise alternative forms of treatment when agreeing the protocols for the evidence reviews.
24	Royal College of Paediatrics and Child Health	10	General	The omission of the detection, assessment and management of behavioural and mental health problems in CP is a gaping hole that we should suggest be filled. Clinical experience suggests that emotional difficulties around adjustment for this group of children and young people are strongest around 6-8 years when children realise they have a permanent disability and of course during adolescence when disability impacts on their peer relationships , sexuality, self-esteem and self-identity etc . Robert Goodman is a lead researcher here and identifies psychiatric disorders, emotional and behavioural problems, episodic outbursts, social difficulties such as poor peer relationships, and family factors , such as	Thank you for your comment. In light of stakeholder comments, it has been agreed that the management of mental health problems will be prioritised for inclusion in the scope for the cerebral palsy guideline. The identification and assessment of behavioural and mental health problems will be covered under review question (g) (identification of comorbidities) of the key issues to be covered.

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				maternal depression, as having higher incidence in children with hemiplegia and cerebral palsy. This group is also another example of children who often miss out on CAMHS even though its meant to offer an inclusive service for all children.	
25	Nottinghamshire County Council	1	4.3 and 4.4	My comment is that it is crucial and essential for timely specialist seating assessment and provision in order to promote optimum postural management. (Nottinghamshire County Council has a seating pathway to enable such for all children with disabilities including children with CP). This is an essential precursor and will serve to enhance opportunities for greater overall functional ability. Good posture in seating plays a key role in management (4.3) and is therefore instrumental in aiding promotion of outcomes mentioned in 4.4	Thank you for your comment. Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
26	British Association of Prosthetists and Orthotists (BAPO)	1	4.3.1 q)	The individual roles and responsibilities of the MDT members needs to be defined and clarified here. Not just the role of the MDT in the care of children and young people with CP. This ensures everyone within the MDT knows their role and what they have to do and allow a care pathway can be established.	Thank you for your comment. The further detail of the constituency of the multi and inter disciplinary teams will be defined when reviewing the relevant evidence and formulating recommendations during the course of the guideline development.
27	British Association of Prosthetists and Orthotists (BAPO)	2	4.3.2 a)	The management (theraputic orthotic etc) of the movement disorders of dystonia and dyskinesia that are commonly observed in CP are neither covered in the current scope or in the previous guidance of spasticity in children and young people. Where are these going to be covered?	Thank you for your comment. Other motor disorders were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.

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28	British Association of Prosthetists and Orthotists (BAPO)	3	4.3.2 a)	The previous NICE guideline titled management of spasticity in children and young people with non-progressive brain disorders needs to be reviewed, edited and updated urgently. Many of the sections that relate to the orthotic management are either incomplete or incorrect and causing problems in clinical settings.	Thank you for your comment. Spasticity and other motor disorders (such as ataxia) were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
29	British Association of Prosthetists and Orthotists (BAPO)	4	4.4	The main outcomes are listed, but clinical guidance on the most appropriate outcome measure to use to evaluate each of these areas is required for each healthcare discipline. A core set of outcome measures needs to be included here to ensure that standardisation of results is possible throughout the NHS. This will then allow for evaluation of the NICE guidance/clinical pathway and falls inline with the recommendations for development of a clinical care pathway.	Thank you for your comment. This is not intended to be an exhaustive list of the outcomes which will be included as part of this guideline. A further breakdown of outcomes used will be agreed at protocol stage for each evidence review during the course of the guideline development.
30	British Association of Prosthetists and Orthotists (BAPO)	5	4.5 o)	Ability to walk: The question of prognosis to walk in children with CP is not a simple one and it is very difficult to answer. A child's ability to walk in GMFC levels 2 & 3 depends heavily on the timing and the access to orthopaedic surgery (SEMLS) neurological surgery (SDR), physiotherapy and orthotics. If one of these is missing or not available at the appropriate time it will greatly affect the prognosis of a child's ability to walk and hence have a negative affect on the prognosis. These areas need to be addressed in this guidance in order to be able to realistically provide guidance on the prognosis for a child to	Thank you for your comment. Most of the issues in your comment were covered by CG 145. How that ability to walk is altered by specific motor interventions was covered. Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.

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				walk.	
31	British Society of Paediatric Radiologists	1	4.5 e	We are pleased to note that the role of MRI in the management of cerebral palsy will be looked at as part of the Guideline development process and look forward to contributing to that process.	Thank you for your comment. The guideline development group constituency includes a position for expert advisor - Paediatric Radiologist. Once appointed this person will advise the guideline development group when this review question is discussed.
45	NHS England	1	General	I wish to confirm that NHS England has no substantive comments to make regarding this consultation.	Thank you for your comment.
46	European Academy of Childhood Disability	1	3.1 a	For practical purposes most clinicians consider 2 yrs as the upper limit of the etiological event and 5yrs for the diagnosis in prevalence studies. The wording 'lack of consensus about when the brain stops developing rapidly' seems a bit confusing. Need to have a definite definition for CP, including upper age limit of brain damage. The "boundary" between CP and other residual motor disorders/handicaps like TBI, postnatal stroke etc. need clear delineation (same point as above). The treatment outcome and strategies may differ. It should be emphasized more that CP is a developmental disorder which cannot be restored or re-habilitated, but perhaps "habilitated". This may lead to an understanding that CP is a lifelong condition needing consistent support, help, management etc. Supporting the notion of a developmental disorder, concerning motor outcome CP is fairly predictable (motor growth curves). 'Cerebral palsy is a syndrome of motor impairment that results from a lesion in the developing brain.' may be better as 'Cerebral	Thank you for your comment. The section you refer has been revised to read: "There is general consensus of an upper age limit of 2 years for onset of the non-progressive brain disturbance and 5 years for clinical or developmental diagnosis." Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.

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				palsy is a syndrome of motor impairment that results from a non-progressive interference, lesion or abnormality in the developing brain.'	
47	European Academy of Childhood Disability	2	4.1.1 b	For clinical guideline development it is essential that subgroups will be defined according to the issues that can have an effect on the implementation or effectiveness of the intervention - not only according to gross motor functional level or cognitive level but also on type of CP and distribution of impairment. Guidelines are used for clinical decision making where the unique values and difficulties of the patient will be weighted against the clinical experience and the existing evidence. As CP is a very heterogenous disorder the guidelines on management need to be specific (eg guidelines for oralmotor difficulties for a spastic CP don't necessarily work with a child with dystonic CP etc). There may be evidence on some issues only on eg spastic type but none on dystonic type. The guideline needs to be formulated so that clinicians can draw the conclusions that will serve their patients best	Thank you for your comment. We will be considering inclusion of appropriate subgroups when developing the evidence review protocols for relevant evidence reviews during the course of the development of the guideline.
48	European Academy of Childhood Disability	3	4.3.1 e and 4.5.e	Every child with CP merits a MRI. In addition to identifying etiology, MRI can be useful for confirming diagnosis and often used as a prognostic tool for future outcome (associated comorbidities)/understanding the child functions (eg damage on visual tract). The question should not be whether a MRI is useful but what is the optimal age to restrict need of repeated MRIs.	Thank you for your comment. We now have two review questions, under points (e) and (f), looking at the effectiveness of MRI in determining cause and prognosis in Cerebral Palsy. As part of this, optimal timing of MRI scanning will be considered by the guideline development group during the development of the recommendations.
49	European Academy of	4	4.3.1	This should also include 'management'. It should ideally say 'identification, assessment and management of pain, discomfort or distress'	Thank you for your comments. In light of stakeholder comments, it has been agreed that the assessment and management of

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	Childhood Disability		l and 4.5.m		pain, discomfort and distress will be covered in this guideline.
50	European Academy of Childhood Disability	5	4.3.1 m	Should also include identification and assessment of sensory planning and perception problems	Thank you for your comment. The scope has been revised to say "processing of sensory and perceptual information".
51	European Academy of Childhood Disability	6	4.3.1 n	The scope should aim to provide prognosis across the various types and sub-classes of CP. This is potentially a difficult area as the prognosis is changing constantly with advances in medicine, care and technology. Setting a specific figure runs the risk of reducing expectations and the guideline will need to be cognizant of this.	Thank you for your comment. The guideline development group will consider any appropriate subgroups during the development of the evidence review protocol for prognostic indicators.
52	European Academy of Childhood Disability	7	4.3.2 h	Exclusion of sensory impairments is puzzling. There is no current guidance. These deficits, esp visual, are common in CP and have major functional impact individually and across other domains	Thank you for your comment. The scope has been revised to say "processing of sensory and perceptual information".
53	European Academy of Childhood Disability	8	4.5 a	It may be useful to include recognition of 'developmental trajectories' as well as these can help clinical diagnosis	Thank you for your comment. Developmental disparity will be considered as part of the question on clinical manifestations of 'red flags' in the scope under point (d) of the review questions.
54	Nutricia Advanced Medical Nutrition	1	4.3.1 (f)	Please consider specifying some examples of comorbidities here such as gastro-oesophageal reflux, constipation, pain and bone fractures.	Thank you for your comments. In light of stakeholder comments, it has been agreed that the assessment and management of pain, discomfort, and distress will be covered in this guideline. The priority comorbidities to be included in the evidence review protocol will be agreed with the guideline development group.
55	Nutricia Advanced	2	4.3.1	Assume you will also signpost where to go for information about managing comorbidities in CP if	Thank you for your comment. Important comorbidities associated with cerebral palsy

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	Medical Nutrition		(f)	they are not going to be covered in this guideline?	and their prevalence will be covered in the guideline. Published NICE clinical guidance will be cross referenced and linked for the management of related comorbidities.
56	Nutricia Advanced Medical Nutrition	3	4.3.1 (h)	Please ensure that measures of nutritional status are considered here in addition to safety of swallow and functional eating ability.	Thank you for your comment. Nutritional status is currently listed as one of the main outcomes for the cerebral palsy guideline.
57	Nutricia Advanced Medical Nutrition	4	4.3.1 (h)	Please consider looking at screening and identifying red flags for feeding dysfunction which will indicate the need for further investigation and assessment (see Arvedson JC (2013) EJCN, 67, S9-S12). EDACS developed by Chailey Heritage School www.edacs.org could be considered for investigation of feeding dysfunction.	Thank you for your comment. The guideline will address which investigations are appropriate for assessing feeding difficulties (including clinical assessment, videofluoroscopic swallow studies and endoscopic examination).
58	Nutricia Advanced Medical Nutrition	5	4.3.1 (k)	Please consider expanding the wording to specify nutritional assessment, monitoring and management. EJCN; Vol 67; Suppl 2; Dec 2013 provides a complete update on nutritional assessment and management of children with CP based on available evidence and best practice.	Thank you for your comment. Nutritional status is included in the guideline as a main outcome (section 4.5).
59	Nutricia Advanced Medical Nutrition	6	4.4 (g)	Please consider specifying growth here, which can be measured using various anthropometric techniques. How best to monitor growth in children and young people with CP should be included within the guideline. Although growth will be different from neurotypical children/young people, standard growth charts are recommended and children/young people with CP should be expected to follow a growth curve. Poor growth is linked to poor health, reduced social participation and increased mortality so it is key to measure and monitor regularly.	Thank you for your comment. Nutritional status is currently listed as an outcome for the guideline and will cover measurement of height and weight of the child/young person.
60	Nutricia Advanced Medical	7	4.5	Please also consider this question from a nutrition and growth perspective	Thank you for your comment. Nutritional status is included in the guideline as a main outcome. Please see section 4.5.

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	Nutrition		(i)		
61	Nutricia Advanced Medical Nutrition	8	4.5 (l)	Please consider also including a question here about how growth and nutritional status can be most accurately measured and monitored (if not included under 4.5 i)	Thank you for your comment. As part of the scope, the following review question has been included: In children and young people with cerebral palsy what are the interventions that are effective in maintaining adequate nutritional status? It was not feasible to include an additional specific question on measuring and monitoring growth and nutritional status.
62	Department of Health	1	General	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation	Thank you for your comment.
63	British Association of Occupational Therapy	1	3.2 a	Play is an important part of the ICF for children and one of children's primary occupations.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.
64	British Association of Occupational Therapy	2	General	Play is important for children with CP but often needs to be adapted or re-defined Graham N, Truman J, Holgate H (2014) An exploratory study: expanding the concept of play for children with severe cerebral palsy. *British Journal of Occupational Therapy, 77(7),* 358–365. This links into children's quality of life and their occupation- particularly if they are a severely disabled child. How can therapists/ members of the MDT be supporting parents to help their children to access the primary occupation of play? Can we help parents to redefine play to include play from its initial sensory motor level in order that they can help their children be engaged and reach their developmental potential?	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.

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				Include how OT has a role within children's occupation and how play is an important occupation for all children. This could include how to best position children with CP for play to help them gain function.	
65	British Association of Occupational Therapy	3	4.3.1 m	Sensory planning and perception- it would also be helpful to include 'sensory processing' here.	Thank you for your comment. The scope has been revised to say "processing of sensory and perceptual information".
65	British Association of Occupational Therapy	3	4.3.1 m	Sensory planning and perception- it would also be helpful to include 'sensory processing' here.	Thank you for your comment. The scope has been revised to say "processing of sensory and perceptual information".
66	British Association of Occupational Therapy	4	4.4 b, d	Play is an important factor to include here.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.
67	College of Occupational Therapists	1	General	The College of Occupational Therapists welcomes this draft scope on the diagnosis and management of cerebral palsy and is pleased to note that the guidelines will be using the ICF, and having activity and participation as outcomes. Whilst this is mentioned in certain sections of the scope, there are points where we would recommend that the focus on outcomes should be strengthened as these are influenced by more than just the medical condition of the child/young person (Bult et al 2012, Chiarello et al 2012, Law et al 2011). • Bult MK, Verschuren O, Lindeman E,	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects. The studies you mention will be reviewed during the course of the guideline development.

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				Jongmans MJ, Westers P, Claassen A, Ketelaar M (2012) Predicting leisure participation of school-aged children with cerebral palsy: longitudinal evidence of child, family and environmental factors. *Child: Care, Health, & Development, doi: 10.1111/j*.1365-2214.2012.01391.x. [Epub ahead of print]. • Chiarello LA, Palisano RJ, Orlin M, Chang HJ, Begnoche D, An M (2012) Understanding Participation of Preschool Age Children with Cerebral Palsy. *Journal of Early Intervention, 34,* 3-19. • Law, MC, Darrah J, Pollock N, Wilson B, Russell DJ, Walter SD, Rosenbaum P, Galuppi B (2011) Focus on function: A cluster, randomized controlled trial comparing child- versus context-focused intervention for young children with cerebral palsy. *Developmental Medicine & Child Neurology, 53*(7), 621-629.	
68	College of Occupational Therapists	2	General	Whilst we appreciate the importance of speech and language therapy intervention in relation to feeding issues and dysphasia, the focus on outcomes in play and leisure, productivity and education, and self-care are also essential in the management of children and young people with cerebral palsy (Shikako-Thomas et al 2012). • Shikako-Thomas K, Dahan-Oliel N. Majnemer A, Shevell MI, Law M, Birnbaum R, Rosenbaum P, Poulin C (2012) Play and be happy? Leisure participation and quality of life in school-aged children with cerebral palsy. *International Journal of Pediatrics. vol. 2012, Article ID 387280,* 7 pages, 2012. doi:10.1155/2012/387280.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, educational, emotional and work aspects. The guideline will also be looking at functional independence, including self-care and independence in activities of daily living as another outcome. The studies you mention will be reviewed during the course of the guideline development.

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69	College of Occupational Therapists	3	3.1 a)	*"Patterns of movement disorder are generally subdivided into spastic, dystonic and ataxic forms*". The word *dyskinetic* rather than dystonic is consistent with the terminology suggested by the European surveillance of CP. Dystonic CP is included as a subtype of dyskinetic CP (Cans 2007). Should this be adopted, the terminology used would need to be consistent throughout the guideline. • Cans C (2007) Surveillance of cerebral palsy in Europe: A collaboration of cerebral palsy surveys and registers. *Developmental medicine & child neurology 2000, 42*: 816–824.	Thank you for your comment, we have updated section 3.1 to include both terms dystonic / dyskinetic and will ensure that terminology is consistent throughout.
70	College of Occupational Therapists	4	3.2 d)	We would suggest that the second sentence be expanded to include *'the spectrum of severity varies with regard to gross motor functioning, upper limb and hand function, sensory processing, communication and associated disorders'*. Appropriate assessments and interventions should, however, focus on the child's activities and participation as outcomes.	Thank you for your comment. The section you mention has been revised to say: "The spectrum of severity varies with regard to gross and fine motor functioning, bimanual manipulation, feeding, communication and associated disorders". Managing difficulties associated with the processing of sensory and perceptual information in children and young people with cerebral palsy is one of the key issues to be looked at in the cerebral palsy guideline.
71	College of Occupational Therapists	5	3.2 e)	The focus of this point should be around how the child is participating in home, school and community life, and not restricted to assessment and treatment of body functions. This should be including assessment of the child/young person's context (Bult et al 2012, Shikako-Thomas et al 2012).	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects. The guideline development group will consider the studies you have mentioned during the development of the evidence

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				• Bult MK, Verschuren O, Lindeman E, Jongmans MJ, Westers P, Claassen A, Ketelaar M (2012) Predicting leisure participation of school-aged children with cerebral palsy: longitudinal evidence of child, family and environmental factors. *Child: Care, Health, & Development, doi: 10.1111/j*.1365-2214.2012.01391.x. [Epub ahead of print]. • Shikako-Thomas K, Dahan-Oliel N. Majnemer A, Shevell MI, Law M, Birnbaum R, Rosenbaum P, Poulin C (2012) Play and be happy? Leisure participation and quality of life in school-aged children with cerebral palsy. *International Journal of Pediatrics. vol. 2012, Article ID 387280,* 7 pages, 2012. doi:10.1155/2012/387280.	reviews.
72	College of Occupational Therapists	6	3.2 e)	In addition to the treatment which may be needed for co-morbidities, could it also include autism, hydrocephalus or ocular-motor problems? In particular, visual-perceptual difficulties may affect participation in school/community activities.	Thank you for your comment. In light of stakeholder comments it has been agreed that the management of mental health problems (including autism) will be prioritised for inclusion in the scope for the cerebral palsy guideline. The prevalence of dental issues will be included in the protocol for the review question addressing co-morbidities. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects
73	College of Occupational Therapists	7	3.2 e)	Treatment should focus on enabling participation in self-care productivity/education, play and leisure.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, educational, emotional and work aspects.

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74	College of Occupational Therapists	8	3.2 f)	We agree that preparing the young person for transition into adulthood is an important aspect of the scope. We would suggest that the guideline also covers relationships and sexual activity (Wiegerink et al 2012). • Wiegerink DJ, Stam HJ, Ketelaar M, Cohen-Kettenis PT, Roebroeck ME, The Transition Research Group South West Netherlands (2012) Personal and environmental factors contributing to participation in romantic relationships and sexual activity of young adults with cerebral palsy. *Disability and Rehabilitation, 34(17),* 1481-1487.	Thank you for your comment. This is an important area and will be considered by the guideline development group when developing the evidence review protocol for the transition from paediatric and adult care. The study you have provided will be looked at when the evidence is reviewed during the development of the guideline.
75	College of Occupational Therapists	9	4.2 a)	The setting should also include nursery and educational settings in line with the *Children and Families Act 2014*.	Thank you for your comment. The guideline will work within the up to date commissioning structure for Health and Social Care. The remit of this guideline is to cover the NHS and government funded social care. Therefore, the education sector is outside of the remit of this guideline.
76	College of Occupational Therapists	10	4.3.1 g)	We would suggest including participation in play/leisure/social activities to this point.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.
77	College of Occupational Therapists	11	4.3.2 h)	An additional bullet point should be added which includes observation/assessment of the child/young person in their usual context.	Thank you for your comment. This has not been prioritised as a key clinical area to address in the scope.
78	College of Occupation	12	4.3.1	This point should not focus on '*managing difficulties'*. It should relate to '***enabling***	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy

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	al Therapists		m)	**participation**' in play and leisure, productivity and education, and self-care.	guideline and has been expanded to clarify that it will cover social, educational, emotional and work aspects.
79	College of Occupational Therapists	13	4.3.1 n)	The prognosis for children and young people should be in relation to participation in daily life and life expectancy, rather than the ability to walk and talk.	The scoping group discussed the aspects for which it would be a priority to assess prognosis, and it was agreed that walking, talking and life expectancy are of the greatest importance to children and young people and family members and carers who have a child with cerebral palsy. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, educational, emotional and work aspects.
80	College of Occupational Therapists	14	4.3.1	In addition, the scope should focus on: i. Effective assessment and intervention for activities of daily living, such as, dressing, toileting and bathing. ii. Effective assessment and intervention for developing hand functioning (the Manual Ability Classification Scale (MACS) published on http://www.macs.nu/ and constraint induced therapy may be helpful in facilitating a discussion around this.) iii. The effectiveness of early intervention and prevention, establishing lifelong habits of management; preventing learnt passivity on the part of the child and parents and so limiting aspirations (McIntyre et al 2013). iv. Dosage of intervention; how much and how done and where done. The support for home based working and for group work for some targeted time- limited	Thank you for your comment. At present the guideline has functional independence and psychological wellbeing as key outcomes. Regarding your comment on fine motor assessment, intervention and dosage of therapy, these were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.

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				programmes. v. The psychosocial element of the effects of CP on children and young people should also be considered (Kang et al., 2012). • Kang LJ, Palisano RJ, King GA, Chiarello L.A, Orlin MN, Polansky M (2012) Social participation of youths with cerebral palsy differed based on self-perceived competence as a friend. *Child: Care, Health and Development, 38(1),* 117-127. DOI:10.1111/j.1365-2214.2011.01222.x. • McIntyre S, Morgan C, Walker K, Novak I (2013) Cerebral palsy - don't delay. *Developmental Disabilities Research Reviews, 17*, 114–129.	
81	College of Occupational Therapists	15	4.4	An additional main outcome should focus on the productive or educational participation.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, educational, emotional and work aspects.
82	College of Occupational Therapists	16	4.4 d)	Play/leisure should be added to social participation.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.
83	College of Occupational Therapists	17	4.5 n)	This point should not focus on '*managing difficulties'*. It should relate to '***enabling* participation**' in play and leisure, productivity and education, and self-care.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, educational, emotional and work aspects.

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84	College of Occupational Therapists	18	4.5 n)	The use of equipment provision should also be reviewed, as this is considerable due to postural management needs, moving and handling issues and accessing functional daily living activities. Consideration should also be given to the use of interactive technology and the environmental controls for this group of children and young people.	Thank you for your comment. The use of postural equipment was discussed within CG 145. Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
85	College of Occupational Therapists	19	4.5	Other review questions pertinent to occupational therapy that need to be asked include: • What is the most effective intervention for carrying over repertoire of skills from one environment to another and where the best place for therapy to take place and why? • What therapy programmes (home, school, clinic, nursery, college) are effective in improving participation in activities of daily living? • What outcome measurements and standardised assessments are useful in evaluating the participation of children and young people with cerebral palsy in everyday life? • What is the most effective intervention depending on age and classification of cerebral palsy to address concerns both in short and long term?	Thank you for your comment. Participation and functional independence are covered in this guideline as outcomes. Other issues in your comment about therapy programmes were considered by CG 145. Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.

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86	College of Occupational Therapists	20	4.5 o)	The prognosis for children and young people should be in relation to participation in daily life and life expectancy, rather than the ability to walk and talk.	Thank your for your comment. The scoping group discussed the aspects for which it would be a priority to assess prognosis, and it was agreed that walking, talking and life expectancy are of the greatest importance to children and young people and family members and carers who have a child with cerebral palsy. In addition, throughout the development of this guideline the outcomes will be referred to which include functional independence, including self-care and independence in activities of daily living and participation (including social, educational and work).
87	Royal College of Pathologists	1	4.3.1	The draft document highlights the importance of 'red flags' in the identification of patients who might have a progressive disorder rather than cerebral palsy. However, no comment is made as to role of laboratory investigations in the routine investigation of patients with suspected cerebral palsy. My suspicion is that there is considerable national variability in how laboratory medicine is used in this context and this could be addressed as a question under section 4.5 e.g. "what is the role of routine laboratory investigation in the assessment and diagnosis of a patient with suspected cerebral palsy".	Thank you for your comment. We agree that MRI is of key importance. The need for other investigations may be determined by the review question which covers co-morbidities: "In children and young people what are the comorbidities associated with cerebral palsy and what is their prevalence including the prevalence in relevant subgroups".
88	Quality Standards	1	4.3.1 o)	Is it possible to expand on the types of social care issues that will be considered?	Thank you for your comment. Further detail can be found in the relevant review question under point (x) of the review questions.
89	Quality	2	4.3.2	I can understand the need to limit what the	Thank you for your comment. We have

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	Standards			guideline will cover. However, could it be checked that the associated guidelines that cover GORD or bladder dysfunction do cover the care of children with cerebal palsy. This would ensure that when we come to develop the associated quality standard we are able to draw on these guidelines to cover aspects not covered by this guideline.	checked and the GORD scope population includes children and young people with neurodevelopmental disorders, and cerebral palsy was included as a specific subgroup in review questions. In addition, the Urinary incontinence in neurological disease (CG148) covers children and adults and includes those with cerebral palsy.
90	British Association for Community Child Health	1	4.3.1 g), h) and k)	Eating and drinking assessment and management is closely linked with nutritional management. Even in children with safe swallowing, the effort required could limit intake and affect nutritional well-being, particularly during times of rapid growth e.g. at puberty. Therefore, it would be very helpful if NICE could include examining evidence base for methodologies of assessing growth and nutrition e.g. review of available growth charts, methods of estimating weight and height/length, which weighing scales are best for children with different degrees of disability, alternative methods of nutritional assessment using waist circumference/ upper arm circumference and skinfolds and bioelectrical impedance etc..	Thank you for your comment. Nutritional status is included in the guideline as a main outcome (section 4.5) and in a review question: "In children and young people with cerebral palsy what are the interventions that are effective in maintaining adequate nutritional status?"
91	British Association for Community Child Health	2	3.1 a)	Please refer to more comprehensive definition of cerebral palsy as quoted in Developmental Medicine and Child Neurology, Supplement No 109 (Feb 2007 Vol 49) ***'Cerebral Palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and***	Thank you for your comment. We have amended the text to add the definition in line with your suggestion.

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				behaviour, by epilepsy, and by secondary musculoskeletal problems. If possible, guidance about the upper age limit of brain injury that could result in cerebral palsy would be welcome.	
92	British Association for Community Child Health	3	General	There's no reference to the detection, assessment and management of behavioural and mental health difficulties. This is an important aspect of well-being and functioning and we would prefer for behaviour and mental health difficulties to be included in the scope of this guideline.	Thank you for your comment. In light of stakeholder comments it has been agreed that the management of mental health problems will be prioritised for inclusion in the scope for the cerebral palsy guideline. The identification and assessment of behavioural and mental health problems will be covered under review question g (identification of comorbidities) of the key issues to be covered.
93	British Association for Community Child Health	4	General	Guidelines around assessment of cognitive ability, which is a comorbidity, would be helpful. Conventional developmental assessment tools often cannot be used effectively in children with motor difficulties.	Thank you for your comment. The identification and assessment of cognitive disabilities will be covered under the identification of comorbidities, which is listed as one of the key issues to be covered.
94	British Association for Community Child Health	5	3.2 c	It is not clear whom the specialist therapists refers to. Arguably the therapists in the community are specialists in the management of cerebral palsy. The specialist therapists in the hospital tend to be specialist at feeding clinics and therapists doing botulinum toxin injections. Psychologists are based in the community and hospitals. Should we say paediatric orthopaedic surgeons and paediatric surgeons?	Thank you for your comment. This has been discussed and agreed that the summary of practitioners detailed in the scope will be retained. We acknowledge that the list is not comprehensive but have stated so within the scope document.
95	British Association for Community Child Health	6	3.2 e	Alongside oromotor problems, children with cerebral palsy can have a range of dental problems and often have difficulty accessing dental care. ENT surgeons are often involved for upper airway problems	Thank you for your comment. The guideline development group will consider dental problems when developing the evidence review protocol on identification of co-morbidities in cerebral palsy and subgroups most at risk.

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96	British Association for Community Child Health	7	4.3.1 n	Perhaps it will be helpful to qualify the **efficiency** of walking and functional speech. Prognosis for key mile stones rather walking and talking will be helpful. In every day practice we often focus on key functional goals such as movement transitions, establishing a yes/no response and so on.	The scoping group discussed the aspects for which it would be a priority to assess prognosis, and it was agreed that walking, talking and life expectancy are of the greatest importance to children and young people and family members and carers who have a child with cerebral palsy. More detailed analysis of motor outcomes and function would be more relevant to the spasticity guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015).
97	British Association for Community Child Health	8	4.3.2 a	It would be really helpful especially while commissioning services, to have better clarity on hip surveillance and use of various equipment such as the sleep system, motorised wheel chairs, etc	Thank you for your comment. Following consultation, it was agreed that the common causes and interventions for sleep disturbance will be included in the scope. Additionally, the symptoms and signs of sleep disturbance for children and young people who are unable to communicate will be included in the scope. The scope also includes a question relating to the specific social care needs of children and young people with cerebral palsy and their family members and carers which includes hoists and access to buildings and transport.
98	British Association for Community	9	4.3.1 e	Alongside MRI scans, guidelines for other baseline investigations, such as clotting disorders will be useful.	Thank you for your comment. We agree that MRI is of key importance. The need for other investigations may be determined by the review question which covers co-morbidities:

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	Child Health				"In children and young people what are the comorbidities associated with cerebral palsy and what is their prevalence including the prevalence in relevant subgroups".
99	British Association for Community Child Health	10	4.3.1 f	As the motor disorder evolves through out childhood, it will be useful to have guidance on age specific comorbidities and when to investigate.	Thank you for your comment. Age will be included as a relevant subgroup for when developing the protocol for the evidence review on co-morbidities.
100	British Association for Community Child Health	11	4.3.1 i	It will be really useful if these guidelines are made with the understanding that the care has to be provided mainly in the community.	Thank you for your comment. It is outlined in the scope that "The primary care service for most families is the local child development team that supports health visitors and GPs".
101	British Association for Community Child Health	12	4.5 e	It has medicolegal implications as well. Perhaps the question could be rephrased- " What is the value of an MRI scan in determining the cause and **timing** of cerebral palsy? Does MRI scan help with prognosis, what age should MRI be done and should it be repeated and if so when and why? Should preterm babies with ultrasound evidence of leukodystrophy also get an MRI?	Thank you for your comment. We have now two review questions on MRI: "What is the effectiveness of an MRI scan in determining the cause of cerebral palsy?"; and "In children and young people with cerebral palsy what is the effectiveness of an MRI scan in determining prognosis?".
102	British Association for Community Child Health	13	4.5 f	As mentioned already, age specific co-morbidities, where ever possible will guide clinicians in better monitoring and timely intervention	Thank you for your comment. Age specific subgroups have been included in the scope and will be considered where appropriate throughout the guideline development.
103	British Association for Community Child Health	14	4.5 g	Again guidance around timing of this therapeutic intervention will be important for clinicians. A preterm baby could stay for months in the hospital and actually miss out on developmentally appropriate intervention and become averse to oral feeding for a very long time. The role of	Thank you for your comment. Age specific subgroups have been included in the scope and will be considered where appropriate and will be considered throughout the guideline development.

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				occupational therapist and physiotherapists is also important.	
104	British Association for Community Child Health	15	4.5 And general	Guidance around early intervention to optimise motor development in high-risk babies (or babies showing an evolving motor disorder) would be really helpful. There are a number of independent practitioners in the community and it can be confusing for parents. This also has implications for neonatal units- some units provide developmental care and others don't.	Thank you for your comment. Other motor disorders were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
105	British Association for Community Child Health	16	4.5 k	Age related guidelines would be useful. It would be really helpful to know if there is evidence for effective early intervention by therapists to manage drooling. This will impact on use of resources in the community.	Thank you for your comment. Included in the scope, the guidelines will specifically be looking at what interventions are relevant in the management of poor saliva control.
106	British Association for Community Child Health	17	4.5 m	It would be really helpful if guidelines also include checklist of common pain sources to look out for.	Thank you for your comment. In light of stakeholder consultation, the symptoms and signs of pain, its causes and interventions will be covered in this guideline.
107	British Association for Community Child Health	18	4.5 n	Guidance on early intervention in anticipation for difficulties would be useful. There are very varying practices at present. Guidance on assessment of sensory planning, perceptions and proprioception would be helpful.	Thank you for your comment. The scope has been revised to say "processing of sensory and perceptual information".
108	British Association for Community	19	4.5 o	As mentioned above, it will be helpful to qualify the efficiency of walking and functional speech and other key developmental milestones, including efficient wheelchair use.	Thank you for your comment. The prognostic indicators in relation to the ability to walk and talk will be addressed as part of the scope of this guideline however the achievement of

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	Child Health				this through aids or management strategies has not been prioritised as it covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
109	British Association for Community Child Health	20	4.5 r	At present there are no equivalent adult clinicians who could take over from Community Paediatricians. As a result, care is fragmented and often information on the young person is not transferred. Perhaps the guidelines could look at best practice in this area and make recommendations.	Thank you for your comment. The guideline will cross refer to the NICE social care guideline, "Transition from children's to adult services". Publication is expected in February 2016. Additionally, the specific needs of young people with cerebral palsy transitioning to adult services will be addressed in the review question "What are the specific elements of the process of transition from paediatric to adult services that are important for young people with cerebral palsy and their family members and carers?"
110	British Association for Community Child Health	21	General	We are very pleased that NICE has taken up this guideline development. We agree with rest of the draft document	Thank you for your comment.
111	Royal College of General Practitioners	1	4.3.1	In my opinion the scoping document would be improved by widening the scope. 1. Mental health and well-being of the child with cerebral palsy and the families is not cited in	Thank you for your comment. In light of stakeholder comments, it was agreed that the management of mental health difficulties will be included in the scope for the cerebral palsy guideline. The identification and

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				either the inclusion section or the exclusion section 4.3.2. It is important to help children with CP, siblings and familes cope with their feelings about: being sick facing uncomfortable procedures handling pain taking medication preparing for surgery changes in friendships and family relationships managing school while dealing with an illness grief and loss It is important to teach healthy coping skills for the whole family and educate members of the medical treatment team about the relationship between physical illness and psychological distress 2. Postural care and sleep positioning does not appear to be specifically mentioned. This is vital to maintain mobility and reduce respiratory problems.	assessment of mental health problems will be covered under points (h) and (p) of the review questions. The guideline will also address what information and support is necessary to children and young people with cerebral palsy and their families. Thank you for your comment. The provision of specialist postural management and equipment was covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
112	Royal College of General Practitioner	2	4.5	Specific questions about surgical intervention would useful e.g. Intrathecal baclofen pump insertion, Selective dorsal rhizotomy and Stereotactic basal ganglia	Thank you for your comment. Surgical interventions were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to

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	s				the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
113	Allergan	1	General 4.3.2	We note that the management of spasticity and co-existing motor disorders is excluded from the draft scope for this guideline. Allergan agrees that this is a reasonable approach given that CG145 is relatively recent. However, we would emphasise the need for the new guideline to be consistent with 145 and to make cost-references to 145 wherever this is relevant	Thank you for your comment. Cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
114	Allergan	2	3.2 (f)	Allergan welcomes the attention given in the scope to the transition from services tailored to the needs of children or young adults to full adulthood services. We strongly concur that this is of critical importantce. We believe that the multi-disciplinary team for young adults (age 17 and upwards) should introduce adult rehab clinicians and neurologists, alongside paediatric specialists, in order to support ba phased transition as attention from paediatricians is withdrawn. Consistency with the NICE social care guideline on transition from children's to adult services (in development) will again be important here.	Thank you for your comment. Cross-reference to the social care guideline on transition from children's to adult services will be included in the cerebral palsy guideline as appropriate. This will be addressed during the development of the evidence review protocol and during guideline development group discussion.
115	Allergan	3	4.6	Any review of economic evidence carried out as part of the development of this guideline should be consistent with NICE's broader economic methodology, including the proposed introduction of value-based assessment into the HTA process. Although the HTA methodlogy is being developed	Thank you for your comment. A decision was made in September this year to do further work on value-based assessment before introducing this to the NICE methodology. We keep up-to-date with changes in NICE methodology and will

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				specifically for introduction into HTA, It is importasnt that NICE in its guidelines work does not reach a different view about the value of QALYs gained in any intervention for cerebral palsy than that which might be reached in an HTA assessment of a particular technology	incorporate the wider values into our analyses once the methods for value-based assessment have been finalised. We work alongside the technical advisers at NICE to ensure our work meets current NICE standards and this means our work, including QALY values, is consistent with the NICE programme.
116	Society for Research In Rehabilitation	1	General	Whilst noting that the remit will take in to consideration the NICE clinical guideline 145 on management of spasticity and co-existing motor disorders it may be difficult to develop guidance relating to eating and communication problems, pain, walking prognosis and equipment needs without considering their interaction with motor disorders. As indicated at the stakeholders scoping meeting it will be essential that links are created to existing guidelines and gaps in information/ knowledge rectified.	Thank you for your comment. Cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
117	Society for Research In Rehabilitation	2	3.2 c	Portage refers to a specific programme for preschoolers only available in some areas of the country; preschool teachers may use other methods thus a more generic term for preschool teachers/counsellors would be more inclusive.	Thank you for your comment. The scope has been updated to include "pre-school developmental teams" instead of portage workers.
118	Society for Research In Rehabilitation	3	4.2 and 4.5(p)	Many therapy services to children with cerebral palsy are provided within an educational setting. There can be issues regarding the provision of equipment for postural management that are required in home, school and other care settings. Guidance as to how this should be arranged may be useful. Currently neither the guideline development group nor expert advisors include any educationalist. The differing priorities of health and educational professions need to be	Thank you for your comment. The remit of this guideline is to cover the NHS and government funded social care. Therefore, the education sector is outside of the remit of this guideline.

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				integrated in optimising management of cerebral palsy.	
118		3	4.2 and 4.5(p)	Many therapy services to children with cerebral palsy are provided within an educational setting. There can be issues regarding the provision of equipment for postural management that are required in home, school and other care settings. Guidance as to how this should be arranged may be useful. Currently neither the guideline development group nor expert advisors include any educationalist. The differing priorities of health and educational professions need to be integrated in optimising management of cerebral palsy.	Thank you for your comment. The remit of this guideline is to cover settings in which NHS commissioned health and social care is provided. Therefore, the education sector is outside of the remit of this guideline.
119	Society for Research In Rehabilitation	4	4.5 (m)	Pain may be an issue for all children with cerebral palsy, not just for those who have communication difficulties. Consideration could be given to including all children and young people with cerebral palsy in this question.	Thank you for your comment. In light of stakeholder consultation it has been agreed that the symptoms and signs of pain, its causes and interventions will be covered in this guideline.
120	Society for Research In Rehabilitation	5	4.5 (r)	This question is important; but adult services themselves may require guidance as to how services for adults with cerebral palsy should be provided. The transition between primary and secondary education can be challenging. As the guideline will include people up to the age of 25 years it may be appropriate to consider the elements that are required for the transitions between primary, secondary, further education and employment that impact on health and social care teams. The GDG may wish to refer to https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/338195/Code_of_Practice_approved_by_Parliament_290714.pdf	Thank you for your comment. The remit of this guideline is to cover the NHS and government funded social care. Therefore the education sector is outside of the remit of this guideline. However, participation (including social, educational and work) is included as a main outcome.

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121	Society for Research In Rehabilitation	6	General	Although this guideline will consider equipment and the CG145 considers orthoses there does not appear to be any guidance of the use of assistive technologies including electrical stimulation or robotics. There is general guidance on the use of FES (IPG278) but this does not refer to children with cerebral palsy specifically; thus although such modalities may be considered as treatment to motor disorders these factors should be identified to facilitate updating of CG145.	Thank you for your comment. Cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline. Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015).
122	Society for Research In Rehabilitation	7	General	There are a number of protocols for potentially relevant systematic reviews registered with Cochrane Collaboration and those published give support to further research, highlighting the need for research into many aspect of the management of cerebral palsy. It is to be hoped that the GDG will make recommendations for such research.	Thank you for your comment. It is part of standard NICE process that research recommendations will be developed as part of the guideline development.
123	Association of Paediatric Chartered Physiotherapists	1	1	The title does not reflect the very limited scope of this guideline, which will not cover all people with CP, or all aspects of its management. It should certainly reflect the limitations of age, i.e. children and young people.	Thank you for your comment. The title of the guideline has now been changed to "Cerebral palsy: the diagnosis and management of cerebral palsy in children and young people"
124	Association of Paediatric Chartered Physiotherapists	2	3.1 a	'Patterns of movement disorder' would more accurately described as 'patterns of disorder of movement and posture'	Thank you for your comment. This section of the scope has been updated to say "motor disorder" as opposed to "movement disorder". However, the aspects of cerebral palsy addressed in this section are not postural.
125	Association of Paediatric Chartered	3	3.1 b	Cerebral palsy is primarily a motor disorder, but this paragraph appears to be saying that the associated disorders should be seen as more important – a more balanced wording might be to	Thank you for your comment. This section of the scope has been revised to say, "Recognising their interrelationship and managing these associated disorders is an

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	Physiotherapists			say that 'recognising and managing these associated disorders is an essential part of the overall management of cerebral palsy'	essential part of the overall management of cerebral palsy".
126	Association of Paediatric Chartered Physiotherapists	4	3.2 c	There are some notable absences from the services available, including orthotists and dieticians (particularly in view of the recognition of the importance of nutrition). Also, there appears to be an assumption that 'specialised therapists' and 'experts' are only available in the hospital setting.	Thank you for your comment. The scope has been revised to accommodate the specialists mentioned.
127	Association of Paediatric Chartered Physiotherapists	5	3.2 d	'bimanual manipulation' would be better described as 'fine motor function'	Thank you for your comment. This section of the scope has been revised to say "fine motor functioning" in addition to "bimanual manipulation".
128	Association of Paediatric Chartered Physiotherapists	6	4.3	Should this read 'Diagnosis and Management'?	Thank you for your comment. In this standard section of the scope, Management includes all aspects of care, including diagnosis. However the scope has been updated to divide the issues covered into the subheadings of diagnosis and assessment; and interventions.
129	Association of Paediatric Chartered Physiotherapists	7	4.3 n	Rather than prognosis for walking and talking, this should refer to prognosis for independent mobility and communication. The guideline proposes to consider the provision of communication aids, but does not mention timely provision of appropriate mobility aids, including wheelchairs, which is equally important to the desired outcomes of 'functional independence, including self care and independence in activities of daily living' and to 'social participation'.	Thank you for your comments. The scoping group discussed the aspects for which it would be a priority to assess prognosis, and it was agreed that walking, talking and life expectancy are of the greatest importance to children and young people; and family members and carers who have a child with cerebral palsy. The access and use of equipment will be looked at as part of the social care needs of children and young people in point (x) of the

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				There is a very narrow focus on the effectiveness of interventions, related to swallowing/eating/drinking and communication, while not considering the effectiveness of interventions to improve motor function. While recognising that spasticity has been covered in Guideline 145, not all limitations in motor function are related to spasticity. Many aspects of the motor disorder have not been adequately covered elsewhere, including: dystonia, ataxia, and problems related to postural control, balance and equilibrium, weakness, and motor selectivity. None of these aspects are covered in the existing Spasticity guideline, and this is a major gap in the proposed new guideline. The guideline should therefore consider the effectiveness of interventions to address problems with motor function that are not related to spasticity, including the effectiveness of approaches to therapeutic management, and the provision of appropriate equipment to reduce pain and spasm, improve posture, and enhance participation in play, learning and communication. The role of exercise in enhancing and maintaining physical fitness and endurance should be included. There is no mention in this section about management of psychological and emotional needs of the child and young person with CP, although psychological wellbeing is identified as an outcome. The role of parents has not been mentioned, and	review questions. Ataxia and other motor disorders were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline. The specific information and support that is required by family members and carers has been included in the scope as a review question under point (y). The role of the multi-disciplinary team in the care of children has been identified as a key issue to be addressed in the guideline.

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				a question about the provision of support and training for parents and carers needs to be included. Please also include a question about the structure and role of multidisciplinary team, and the specific role of therapists. There are sometimes several different teams (local, regional, and specialist centres) providing a range of services to the child or young person with CP at any one time, and the importance of open and clear lines of communication, with joint planning and goal setting, needs to be recognised.	
130	Association of Paediatric Chartered Physiotherapists	8	5	The management of dystonia and ataxia are not separately covered under related guidelines, and they are not included in the proposed scope of this guideline. This is a major omission.	Thank you for your comment. Ataxia and other motor disorders were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
131	British Association of Bobath Trained Therapists	1	3.1	Need to mention Ataxia. Need to mention dyskinetic, with dystonic and choreo being subgroups of this SCPE classification.	Thank you for your comment. Ataxia and other motor disorders were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015).

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					Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
132	British Association of Bobath Trained Therapists	2	3.1 (e)	To include maternal infection, drug and alcohol abuse.	Thank you for your comment. The list provided in section 3.1 is not intended to cover all possible risk factors. However we have updated 3.1 to include "maternal/foetal/neonatal infections".
133	British Association of Bobath Trained Therapists	3	3.1 (b)	MSK problems are secondary and develop as the skeletal system develop and persistent postures and movement patterns become more established.	Thank you for your comment. We recognise the importance of stressing that the musculo-skeletal abnormalities are secondary to the central neurological problems and have updated 3.1 to include this.
134	British Association of Bobath Trained Therapists	4	3.2 (a)	Need to mention limiting pain and deformity and how this may impact in the present and in the future on function and participation.	Thank you for your comment. In light of stakeholder comments, it has been agreed that the assessment and management of pain, discomfort and distress will be covered in this guideline.
135	British Association of Bobath Trained Therapists	5	3.2 (b)	Acknowledge the possible concerns reported by parents to health care professionals involved regarding their child's development.	Thank you for your comment. We acknowledge the importance of this and will consider these during the development of recommendations with the lay members that are part of the guideline development group.
136	British Association of Bobath Trained Therapists	6	3.2 (c)	There are also specialist centre's which provide interventions and support for children who have cerebral palsy. Some of these are based in the voluntary sector.	Thank you for your comment. The remit of this guideline is to cover the NHS and government funded social care. Therefore, the voluntary sector is outside of the remit of this guideline.
137	British Association of Bobath Trained Therapists	7	3.2 (d)	Appropriate assessment and interventions differ depending on the SCPE classification of the child also.	Thank you for your comment. We believe this section is clear as it stands and the wording will not be altered.
138	British	8	3.2	Visual motor difficulties need to be dealt with	Thank you for your comment. We believe

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	Association of Bobath Trained Therapists		(e)	specifically here as they are linked to the primary motor disorder in the same way as oromotor difficulties.	this section is clear as it stands and the wording will not be altered.
139	British Association of Bobath Trained Therapists	9	3.2 (f)	As part of the lifelong perspective aging should also be considered as part of a life long condition.	Thank you for your comment. The scope for this guideline will focus on children and young people with cerebral palsy until 25 years of age to cover the transition between children and adult services.
140	British Association of Bobath Trained Therapists	10	4.1.1 (a)	A guideline entitled 'the diagnosis and management of cerebral palsy' must deal with the condition through the entire lifespan not to stop at 25 years.	Thank you for your comment. The title of the guideline has now been changed to "Cerebral palsy: the diagnosis and management of cerebral palsy in children and young people". The scoping team concluded that it would not be feasible to extend the age range of the scope while also covering the wide range of clinical issues that have been included in the scope.
141	British Association of Bobath Trained Therapists	11	4.1.1 (b)	People who have cerebral palsy of all levels of cognitive ability should be included. As well as functional levels, the differing SCPE classifications should also be considered as many of these have specific differing service requirements.	Thank you for your comment. All levels of cognitive abilities are included. GMFCS is given as an example of subgroups that may be considered but the guideline development group may consider SCPE classification subgroups if this is appropriate for specific review questions.
142	British Association of Bobath Trained Therapists	12	4.1.2 (a)	The guideline should not limit it's remit to 25 years, it is crucial that this is extended through the life span.	Thank you for your comment. The title of the guideline has now been changed to "Cerebral palsy: the diagnosis and management of cerebral palsy in children and young people".
143	British Association of Bobath	13	4.3.1	Need to recognise early risk factors such as osteopenia and osteoporosis.	Thank you for your comment. We now have included the following review question: "In children and young people with cerebral

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	Trained Therapists				palsy what are the risk factors for reduced low bone mineral density and low impact fractures?
144	British Association of Bobath Trained Therapists	14	4.3.1 (f)	ADITIONAL KEY ISSUE: Determining the effectiveness of interventions to improve breathing and postural control in children and young people who have cerebral palsy.	Thank you for your comment. Physical therapy was covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
145	British Association of Bobath Trained Therapists	15	4.3.1 (f)	ADDITIONAL KEY ISSUE: Determining the effectiveness of interventions in improving gross and fine motor skills in children and young people with cerebral palsy.	Thank you for your comment. Fine motor skills were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
146	British Association of Bobath Trained Therapists	16	4.3.1 (i)	Need to assess the effectiveness of pain management in this population.	Thank you for your comments. In light of stakeholder comments, it has been agreed that the assessment and management of pain, discomfort and distress will be covered in this guideline.
147	British Association of Bobath Trained	17	4.3.1 (m)	Need to determine the effectiveness of interventions in managing difficulties with sensory/motor planning and perception in children and young people with cerebral palsy	Thank you for your comment. The scope has been revised to say "processing of sensory and perceptual information".

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	Therapists				
148	British Association of Bobath Trained Therapists	18	4.3.1 (n)	This should not be in a list format and it should include ability to manage self care, ability to communicate, ability to transfer, ability to live independently etc. The emphasis on these very narrow categories are misleading as the are not the only markers which reflects a person's ability to participate and their quality of life.	Thank you for your comment. The list format is part of the standard NICE scope template. Many issues could be considered here but ability to talk, ability to walk, and life expectancy were considered to be the most important issues for children and young people and their family and carers. Ability to communicate, transfer, live independently, etc. are reflected in the outcomes (4.5) and will be reported where possible for every topic.
149	British Association of Bobath Trained Therapists	19	4.3.2 (h)	Visual motor difficulties should definitely be included as they are an integral part of the primary motor problem.	Thank you for your comment. We will look at visual problems as part of the review question on co-morbidities.
150	British Association of Bobath Trained Therapists	20	4.4 (b)	The presence of 'functional independence, including self-care and independence in activities of daily living' in outcomes reinforces the importance of including this in the prognosis section.	Thank you for your comment.
151	British Association of Bobath Trained Therapists	21	4.4 (c)	The presence of 'communication' here reinforces it's inclusion in the prognosis section.	Thank you for your comment.
152	British Association of Bobath Trained Therapists	22	4.5	How effectivel is clinical therapy at focusing on activities of daily living with people with cerebral palsy?	Thank you for your comment. Functional independence, including self-care and independence in activities of daily living is included in this guideline as outcomes.
153	British Association of Bobath Trained	23	4.5	How effective is clinical therapy at affecting long term participation in people with cerebral palsy?	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, educational,

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	Therapists				emotional and work aspects.
154	British Association of Bobath Trained Therapists	24	4.5 (i)	How effective is clinical therapy at improving a persons ability to use these communication systems?	Thank you for your comment. This guideline will address the effectiveness of using communication systems in improving communication in children and young people with cerebral palsy.
155	British Association of Bobath Trained Therapists	25	4.5	How effective is clinical therapy at improving functional mobility in people with cerebral palsy?	Thank you for your comment. Functional independence is an important outcome for this guideline. Please also note that cross-references to CG 145 will be included as appropriate in the cerebral palsy guideline.
156	British Association of Bobath Trained Therapists	26	4.5	How effective is clinical therapy at managing or preventing pain and discomfort in people with cerebral palsy?	Thank you for your comment. In light of consultation it has been agreed that the symptoms and signs of pain, its causes and interventions will be covered in this guideline.
157	British Association of Bobath Trained Therapists	27	4.5 (o)	This should not be in a list format and it should include ability to manage self care, ability to communicate, ability to transfer, ability to live independently etc. The emphasis on these very narrow categories are misleading as the are not the only markers which reflects a person's ability to participate and their quality of life.	Thank you for your comment. The list format is part of the standard NICE scope template. Many issues could be considered here but ability to talk, ability to walk, and life expectancy were felt to reflect the concerns most likely to be expressed by parents and carers at first diagnosis. Ability to communicate, transfer, live independently, etc. are reflected in the outcomes (4.5) and will be reported where possible for every topic.
158	British Association of Bobath Trained Therapists	28	General	There appears to a bias to Speech and Language Therapy in this guideline. Considering how important the multi-disciplinary team involvement is in the diagnosis and management of cerebral palsy it is of paramount importance that the	Thank you for your comment. We agree with the importance of the multi-disciplinary team and will be looking at its role in the care of children and young people with cerebral palsy. We consider that the scope balances

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				guideline is balanced, and looks thoroughly into the role and effectiveness of interventions such as physiotherapy and occupational therapy.	key health and social care issues for children and young people with cerebral palsy and an assessment of the effectiveness of interventions will be covered as part of the guideline development. Please note that physiotherapy and occupational therapy interventions were covered in CG145. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015).
159	British Association of Bobath Trained Therapists	29	General	There is no mention of access to work, which is an important step for many people with cerebral palsy.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.
160	British Association of Bobath Trained Therapists	30	General	There is no mention of 'leisure'	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.
161	Royal College of Speech & Language Therapists	1	General	**Omission:** Would welcome the inclusion of Communication and Swallowing as important issues of concern in all appropriate sections.	Thank you for your comment. Communication and swallowing have been listed as key issues covered in the cerebral palsy guideline.
162	Royal College of Speech & Language Therapists	2	General	**Omission:** Identification of the need and possible benefits of Alternative and Augmentative Communication needs to be included.	Thank you for your comment. This area will be covered in the review question; "What communication systems (alternative or augmentative) are effective in improving communication?"

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163	Royal College of Speech & Language Therapists	3	General	**Omission:** The need for re-evaluation at regular intervals throughout life, should be included	Thank you for your comment. As part of the guideline development we will be ensuring that all stages of the patient pathway from foetal development to age 25 are assessed, this will include the need for regular re-appraisal of social, clinical and developmental state.
164	Royal College of Speech & Language Therapists	4	General	**Omission:** Issue of establishing mental capacity needs should be under consideration for the guidance	Thank you for your comments. It is part of standard NICE process that if someone does not have capacity to make decisions, healthcare professionals should follow the code of practice that accompanies the Mental Capacity Act and the supplementary code of practice on deprivation of liberty safeguards.
165	Royal College of Speech & Language Therapists	5	General	**Omission:** Guidance required for healthcare working in educational settings	Thank you for your comment. The remit of this guideline is to cover the NHS and government funded social care. Therefore, the education sector is outside of the remit of this guideline.
166	Action Cerebral Palsy	1	3.1 b	This section should be amended to reflect that associated disorders tend not to be independent of one another, and as such, the management of these disorders must also address the ***interrelationship*** between them. It should also be highlighted that the interrelationship between associated disorders must also be fully understood and appropriately addressed.	Thank you for your comment. This section has been revised to say "recognising their interrelationship and managing these associated disorders is an essential part of the management of cerebral palsy."
167	Action Cerebral Palsy	2	3.1	The clinical guideline should also recognise the following factors as being contributory to a risk of cerebral palsy:	Thank you for your comment. The guideline development group will consider these when developing the protocol for the evidence

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			e	**1. Increased exposure to viruses during pregnancy including cytomegalovirus (CMV), group B streptococcus and rubella** Sources: Carlson, A; Nortwitz E.R; Stiller, R.J (2010) "Cytomegalovirus Infection in Pregnancy: Should All Women Be Screened?" Rev Obstet Gynecol. 2010 Fall; 3(4): 172–179. Available: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3046747/ NHS Choices: What are the risks of GBS (group B streptococcus) infection during pregnancy? Available: http://www.nhs.uk/chq/pages/2037.aspx?categoryid=54 Schendel, D.E (2001) "Infection in pregnancy and cerebral palsy" J Am Med Womens Assoc. 2001 Summer;56(3):105-8. Available: http://www.ncbi.nlm.nih.gov/pubmed/11506145 **2. the use of certain drugs during pregnancy such as cocaine excessive alcohol intake during pregnancy** Sources: Kronstadt, D. (1991) "Complex Developmental Issues of Prenatal Drug Exposure" Journal Issue: Drug-Exposed Infants Volume 1 Number 1 Spring 1991. Available:	review on risk factors.

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				http://www.princeton.edu/futureofchildren/publications/docs/01_01_03.pdf Abel, E.L (2010) "Cerebral Palsy and Alcohol Consumption during Pregnancy: Is There a Connection?" Alcohol and Alcoholism (2010) 45 (6): 592-594. doi: 10.1093/alcalc/agq063 Available: http://alcalc.oxfordjournals.org/content/45/6/592.full	
168	Action Cerebral Palsy	3	4.2 a	As of September 2014, clinical commissioning groups (CCGs) and local authorities will be required to work together under the Children and Families Act 2014 to make joint commissioning arrangements for children with SEND – including those with cerebral palsy. Given this development, section 4.2.a should be updated accordingly.	Thank you for your comment. The guideline will work within the up to date commissioning structure for Health and Social Care.
169	Action Cerebral Palsy	4	4.3.1 m	The term "sensory planning" should be more correctly, "sensory processing".	Thank you for your comment. The section in the scope has been revised to say "processing of sensory and perceptual information".
170	Action Cerebral Palsy	5	4.3.1	The following key issues should be covered in the clinical guideline: • addressing difficulties with motor function and control and • addressing musculoskeletal issues for children and young people with dyskinetic cerebral palsy (if not spasticity) Failure to address these issues will negatively impact on the main outcomes specific in section	Other motor disorders were covered as part of the scope of the Spasticity clinical guideline (CG 145). Your comments have been passed to the NICE Surveillance review team as CG 145 will be regularly reviewed. The next scheduled NICE Surveillance review for CG 145 is due to publish in Q4 (Jan to March 2015). Please also note that cross-references to CG 145 will be included as appropriate in the

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				4.4, in particular (but not restricted to) functional independence, including self-care and independence in activities of daily living.	cerebral palsy guideline.
171	Action Cerebral Palsy	6	4.3.1 o	The key issue in section 4.3.1.o should be expanded to account for the social and emotional needs specific to children and young people with cerebral palsy and their families.	Thank you for your comment. Participation is one of the outcomes for the cerebral palsy guideline and has been expanded to clarify that it will cover social, emotional and work aspects.