NICE National Institute for Health and Care Excellence

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	10	1	It would be beneficial to include the management of the risk factors for respiratory complications in people with Cerebral Palsy. This would include the proactive management of dysphagia, reflux, constipation, saliva management difficulties, airway clearance dysfunction, poor oral hygiene and thoracic deformity and the impact this has on reducing the signs and symptoms of respiratory complications. It the signs and symptoms of respiratory distress that results in reduced quality of life and function, as well as, increases care burden and access to primary and secondary healthcare services.	Thank you for your comment. We believe key question 3.3 about prophylactic treatments for respiratory infections could include the management of risk factors for respiratory complications in adults with cerebral palsy.
Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	10	24	It would be beneficial for NICE to consider the most effective tests to identify pain in people with severe cognitive impairment that impacts on their ability to understand and communicate pain. This may include tools such DisDAT and Paediatric pain profile.	Thank you for your comment. We have included key question 5.1 on the most effective sequence of tests to identify causes of pain in an adult with cerebral palsy. This question is likely to cover which methods of identifying pain are most effective (including tools for people with severe cognitive impairment) and as well as their optimal sequence.
Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	10	8	It would be beneficial for the NICE to consider and recognise that function for people with severe Cerebral Palsy (GMFCS level 4 and 5) with severe and profound learning disabilities are likely to be more basic level goals, such as comfort, elimination, sleep, simple communication of needs, breathing, etc.… Therefore, it would be beneficial for NICE to consider interventions that maximise these lower level	Thank you for your comment. People with severe Cerebral Palsy (GMFCS level 4 and 5) is a group that we have already recognised as a specific subgroup in the scope. We have also added this group to our Equalities Assessment Impact form for specific considerations to promote equality of care in this group. Most of the interventions in the scope are aimed to maximise

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			functional goals including modalities such as postural management, special seating, intensive interaction, etc….	functional goals and if the evidence allows we will have subgroups by functional levels where possible.
Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	10	8	In the above guideline 24-hour posture management is missing. Cerebral palsy and associated neurological impairments such as altered muscle tone and movement disorder causes asymmetrical movement patterns. Asymmetrical movement pattern predisposes for the postural issues such as spinal deformities, hip displacement etc. this affects the balance function [due to altered COG and line of gravity], independent mobility and at risk of fall. In wheelchair-dependant clients, postural issues such as spinal deformity and extensor posturing can affect: · Eating and drinking posture, and increased risk of aspiration · Increased risk of respiratory complications due to aspiration · Increased risk of developing constipation	Thank you for your comment. A number of the key questions suggested in the scope could incorporate posture management if the Guideline Committee prioritise it as an intervention.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
			· Asymmetrical weight bearing and risk of developing pressure sore · Risk of developing secondary deformities from poor positioning · Discomfort and pain, affecting behaviour pattern & mental health · Reduced hand eye coordination and upper limb function 24-hour posture management (e.g. exercise, walking with and without mobility aids, therapeutic standing and walking, spinal supports, supportive wheelchair/chair, sleep systems, specialist bath aids and showering equipment) along with the pharmacological and non-pharmacological management can help to prevent/delay the development of the above risks, and help to minimise hospital admission/A&E visits, whilst also helping to improve the quality of life.	
Association of Chartered Physiotherapists	3	4	It would be beneficial to consider the differences in commissioning and provision of specialist services for	Thank you for your comment. One of the protected characteristics we have included in the Equality Impact

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
for People with Learning Disabilities (ACPPLD)			adults with Cerebral Palsy with and without a Learning Disability. Locally there is a gap in the provision of services for people with severe Cerebral Palsy (GMFCS 4 and 5) who do not have a learning disability.	Assessment (EIA) form is disability. The EIA form is used to: • Record equality issues raised in connection with the guideline by anybody involved • demonstrate that these issues have been given due consideration – by explaining what impact they have had on the guideline's recommendations, or why there was no impact • Give assurance that the recommendations will not discriminate against any equality group • highlight recommendations aimed at advancing equality of opportunity or fostering good relations. We will also include those with and without a learning disability as subgroups in the review protocols. As a result, this will be covered in all review questions thereby ensuring equal access to services.
Association of Chartered Physiotherapists for People with Learning	5	12	The draft scope proposes to address the management of muscle tone in adults over the age of 19 with Cerebral Palsy with the rest of the document addressing adults with Cerebral Palsy over the age of 25. Although I recognise the reason for covering these different age ranges, it will result in the management of	Thank you for your comment. This issue may be resolved when the cerebral palsy in under 25s guideline and spasticity in under 19s guideline are updated. NICE pathways are proposing combining adult and children's cerebral palsy pathways to improve ease of reference.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Disabilities (ACPPLD)			adults with Cerebral palsy between the ages of 19-25 being covered in two sets of guidelines which could result in some confusion. This is during the time the young person transitions from paediatric to adult services.	
Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	5	15 - 19	The draft scope currently proposes to cover pharmacological and neurosurgical management of muscle tone in adult with Cerebral palsy over the age of 19. It would be beneficial to cover Physical therapy (physiotherapy and/or occupational therapy) as covered in NICE guidelines on Spasticity in under 19s: management (CG145)	Thank you for your comment. We will look at this specifically in how to maintain/improve function and participation. This covers physical therapy (physiotherapy and/or occupational therapy) as suggested and covered by NICE guidelines on Spasticity in under 19s: management (CG145)
Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	5	20	NICE proposes to cover the assessment and monitoring of complications and co-morbidities associated with CP. It would also be very beneficial for NICE to cover the treatment and management of these areas within the guidelines.	Thank you for your comment. We will look at management of those complications which are a specific problem in adults with CP where guidance has not already been provided by NICE. Elsewhere, we will cross-refer to other guidelines when appropriate.
Association of Chartered	5	26	The draft scope uses the term respiratory disorders associated with CP. It would be beneficial to expand	Thank you for your comment. In this guideline we would consider respiratory disorders which are a specific

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Physiotherapists for People with Learning Disabilities (ACPPLD)			on this term further and acknowledge the disorders covered. It would be useful to clarify the difference between respiratory disorders and respiratory complications such as pneumonia or aspiration pneumonia. Page 9 line 29 also discusses assessment and monitoring of respiratory health. Therefore, it would be beneficial to define these terms in more detail. There are a number of risk factors that increase the risk of people with Cerebral Palsy developing respiratory complications (dysphagia, reflux, constipation, saliva management difficulties, airway clearance dysfunction, poor oral hygiene and thoracic deformity). It would be beneficial to include the assessment and management of these risk factors within the guidance because they are contributory factors to the develop of respiratory problems. Thus respiratory health in people with Cerebral Palsy cannot be addressed effectively without managing these areas of a person presentation.	complication of CP, for example: recurrent aspiration pneumonia, respiratory failure related to scoliosis. We believe key question 3.3 about prophylactic treatments for respiratory infections could include the management of risk factors for respiratory complications in adults with cerebral palsy.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			Guy's and St Thomas' NHS Foundation Trust have developed a specialist respiratory services for adults with complex physical and learning disabilities via Lane Fox Unit. A number of the people accessing this service have severe Cerebral Palsy (GMFCS level 4 and 5). The service provides identification of individuals at risk of developing respiratory complications; comprehensive assessment; individualised respiratory treatment and management; long-term monitoring of the person's respiratory health; and the development of acute crisis management, admission prevention and escalation of care plans. The service is headed by Prof. Nicolas Hart, clinical and academic director Lane Fox Respiratory Unit. Therefore, it may be beneficial for NICE to consider liaising with him regarding this section of the guidelines.	
Association of Chartered Physiotherapists for People with Learning	9	1	The draft guidelines propose to review pharmacological and surgical treatment of spasticity and movement disorders in people with Cerebral Palsy. It would be beneficial to cover physiotherapy, occupational therapy, postural management, role of	Thank you for your comment. We will look at this specifically in how to maintain/improve function and participation. This covers physical therapy (physiotherapy and/or occupational therapy) as suggested and covered by NICE guidelines on Spasticity

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
Disabilities (ACPPLD)			splinting, orthotics, special seating and other management approaches used by Allied Health Professionals in the management of muscle -over-activity in people with Cerebral Palsy.	in under 19s: management (CG145). We will be covering physical therapy and it has been indicated at more than one place in the guideline
Association of Chartered Physiotherapists for People with Learning Disabilities (ACPPLD)	**General**		NICE proposes to cover the assessment and monitoring of disorders of bones and joints, mental health problems and nutritional problems. It would be beneficial for NICE to include the assessment, monitoring and treatment of bowel problems in the document. In particular, constipation, which is a huge concern for a high proportion of the people with Cerebral Palsy especially those with severe Cerebral Palsy (GMFCS level 4 and 5). Constipation has a significant impact on respiratory function, epilepsy, general health, pain, sleep and the care burden.	Thank you for your comment. Recognition of the problem was prioritised for this guideline. We recognise the concerns regarding constipation in adults with cerebral palsy and hope that this will be covered in the question about gastrointestinal pain.
Association of Paediatric Chartered Physiotherapists	10	26	Considerations of the impact for someone with CP GMFCS IV and V with and without a severe learning disability (LD). Currently those with a LD have an ongoing annual assessment / monitoring service that people without LD cannot access.	Thank you for your comment. This is one of the protected characteristics we have included in the Equality Impact

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				Assessment (EIA) form is disability. The EIA form is used to: • Record equality issues raised in connection with the guideline by anybody involved • demonstrate that these issues have been given due consideration – by explaining what impact they have had on the guideline's recommendations, or why there was no impact • Give assurance that the recommendations will not discriminate against any equality group • highlight recommendations aimed at advancing equality of opportunity or fostering good relations. We will also include those with and without a disability and GMFCS levels as subgroups in the review protocols. As a result, those subgroups will be integral to all recommendations to ensure we do not adopt a "one size fits all" recommendation.
Association of Paediatric Chartered Physiotherapists	10	8	Consider postural management approaches and access to equipment to maintain and optimise physical functioning for all adults with CP.	Thank you for your comment. We will be covering physical therapy and it has been indicated at more than one place in the guideline.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Association of Paediatric Chartered Physiotherapists	10	8	For example: strengthening or fitness / training; rehabilitation also very important to mention as omitting this leaves out a huge aspect of the role of therapists with adults with CP. Rehabilitation is broader and not necessarily covered by strengthening and training. e.g. rehabilitation following a fracture to return to previous functional level is key and will improve quality of life. Rehabilitation will take longer than those without CP.	Thank you for your comment. The scope of this guideline will cover interventions that would be incorporated into a rehabilitation programme.
Association of Paediatric Chartered Physiotherapists	4	27	dependent on level of functional disability as well as level of learning disability	Thank you for your comment. The type of disability is integral to the recommendations and will be stated in the review protocols. It is also one of the protected characteristics we have included in the Equality Impact Assessment (EIA) form is disability. The EIA form is used to: • Record equality issues raised in connection with the guideline by anybody involved • demonstrate that these issues have been given due consideration – by explaining what impact they have had

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				on the guideline's recommendations, or why there was no impact • Give assurance that the recommendations will not discriminate against any equality group • highlight recommendations aimed at advancing equality of opportunity or fostering good relations.
Association of Paediatric Chartered Physiotherapists	6	1	Consider 24 hour postural management approaches to improve comfort and function for Gross Motor Function Classification System (GMFCS) levels IV and V	Thank you for your comment. We will be covering this at more than one place in the guideline and it is identified as an important subgroup in the scope.
Association of Paediatric Chartered Physiotherapists	6	1	access to leisure and sports is important to include as is key in enabling function and participation as well as the potential health benefits. Access to this is currently an issue and is not equitable.	Thank you for your comment. Access is one of the key issues in the scope and is not limited to area 6.2 on the access to primary and secondary care for adults with cerebral palsy. People with cerebral palsy who have particular difficulties in accessing services will be a disadvantaged group that we will consider separately, as outlined in the Equality Assessment Impact Form. Furthermore, to ensure access to leisure and sports is considered fully, we will include access as a subgroup in the review protocol.
Association of Paediatric	6	9	Equal access for all to the multidisciplinary team(MDT). Following transition access to the MDT varies	Thank you for your comment. Access is one of the key issues in the scope and is not limited to area 6.2 on the access to primary and secondary care for adults with

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Chartered Physiotherapists			across the country and is severely lacking in some areas.	cerebral palsy. People with cerebral palsy who have particular difficulties in accessing services will be a disadvantaged group that we will consider separately, as outlined in the Equality Assessment Impact Form. Furthermore, to ensure access to the MDT following transition is considered fully, we will include access as a subgroup in the review protocols.
Association of Paediatric Chartered Physiotherapists	8	15	Clients with severe Cerebral Palsy (CP) with a learning disability are more likely to live in a residential care setting, than the general population. Their equipment needs are often higher than adults who acquire an impairment in adulthood. Current Fair Access to Care criteria mean that these clients cannot always access equipment to support them in lying, sitting and standing through their community equipment store because of their residential status. The residential homes will not buy the equipment and the individual does not have funds to be able to do this. There is an economic argument to be made to ensure ring fenced monies for equipment for adults with CP to manage their physical functioning and secondary physical problems.	Thank you for your comment. If equipment is found to be clinically effective and cost effective, we will make recommendations in favour of equipment, for those indications. NICE guidelines make recommendations for the NHS, local authorities and organisations commissioned by public bodies to follow; however, we cannot enforce the private sector to follow our recommendations. The Equality Impact Assessment form also states that "People with cerebral palsy living in residential care who no longer have family members able to act as their advocates may have particular difficulties in accessing services and may therefore be a disadvantaged group that we will consider." For this reason, different

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				recommendations may be made for those subgroups to remove inequalities.
Association of Paediatric Chartered Physiotherapists	9	31	Important to highlight the role of sleep studies in identifying sleep apnoea and other risk factors that can impact onto respiratory health.	Thank you for your comment. We believe key question 3.2 in the scope, about assisted ventilation, could include this issue of sleep apnoea adults with cerebral palsy.
Bobath Centre for Adults with Neurological Disability	1	25	Pain should be added to this list as it is a significant complication	Thank you for your comment. We agree and have added pain to this list.
Bobath Centre for Adults with Neurological Disability	1	27	Perhaps something added about chronic conditions, and increased incidence in CP potentially related to sedentary behaviour	Thank you for your comment. We believe this concept is covered by the current wording "significant complications and comorbidities".
Bobath Centre for Adults with Neurological Disability	10	33	What are the causes / associations with fatigue in CP, and how best to manage fatigue?	Thank you for your comment. Fatigue is recognised in the scope as an important factor affecting quality of life and participation in adults with cerebral palsy. The guideline group will take this into account when formulating the specific protocol questions and outcomes.
Bobath Centre for Adults with	10	4	Add in: Which outcome measures are clinically useful for measuring mobility levels and function (e.g. ability	Thank you for your comment. Although it is useful, outcome measures for measuring mobility levels is outside the remit of this guideline. We will take account

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Neurological Disability			to perform activities of daily living) for adults with cerebral palsy?	of tests that are commonly used for adults with cerebral palsy
Bobath Centre for Adults with Neurological Disability	10	4	Add in: What are the barriers to exercise for adults with CP?	Thank you for your comment. Access to primary and secondary care was prioritised for this area. However, we will consider access as a specific consideration in other review protocols such as the area on interventions that improve participation. As outlined in the Equality Assessment Impact Form, people with cerebral palsy who have particular difficulties in accessing services will be a disadvantaged group that we should consider separately.
Bobath Centre for Adults with Neurological Disability	11	12	And frequency of GP visits	Thank you for your comment. The list of outcomes included in the scope is not exhaustive; hence, we will consider including other outcomes such as the frequency of GP visits in the review protocols.
Bobath Centre for Adults with Neurological Disability	12	1	These are early onset (not late onset) disorders of bones and joints	Thank you for your comment. We have reworded this section and removed the term late onset.
Bobath Centre for Adults with Neurological Disability	5	1-2	This needs clarification; spasticity is separate to movement disorders, although both can be associated with Cerebral Palsy	Thank you for your comment. We agree that spasticity is not a movement disorder. There are movement disorders not uncommonly found in people with spasticity from a non-progressive pathology as in CP – dystonia, ataxia,

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				chorea etc. It would have therefore been incorrect if we had stated "other movement disorders" rather than "associated movement disorders". However, as it stands we feel that this does not require a change.
Bobath Centre for Adults with Neurological Disability	5	23	Include 'secondary neurological damage' such as cervical myelopathy	Thank you for your comment. We have added the issue of cervical instability leading to cervical myelopathy to key question 2.1.
Bobath Centre for Adults with Neurological Disability	6	3	'Neurophysiotherapy', or 'specialist exercise programmes', should be stated here rather than simply stating 'exercise programmes' which underestimates the complexity of the movement intervention that is usually required.	Thank you for your comment. This key area describes categories of possible interventions. The Guideline Committee, however, will consider evidence according to individual interventions, which could include the suggested movement interventions.
Bobath Centre for Adults with Neurological Disability	**General**		Post Impairment Syndrome	Thank you for your comment. This could be considered for inclusion in a number of our topics, particularly those related to complications (such as disorders of bones and joints).
Bobath Centre for Adults with Neurological Disability	**General**		Management of fatigue	Thank you for your comment. Fatigue is not a symptom that is specific to Cerebral Palsy and was therefore not prioritised in the scope.
British Society for Children's	5	22	A common site of pain and deformity in adult individuals with cerebral palsy is the foot. We believe	Thank you for your comment. We have included key question 5.1 on the most effective sequence of tests to

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Orthopaedic Surgery - BSCOS			this should be explicitly mentioned and discussed as access to adult Foot/Ankle specialist orthopaedic surgeons is often required.	identify causes of pain in an adult with cerebral palsy. This question is likely to cover common sites of pain if they are identified in the review of the evidence.
British Society for Children's Orthopaedic Surgery - BSCOS	6	3	Access to physiotherapy in order to support ongoing exercise programmes and access to orthotic services for long-term provision of orthotics/splints/braces could be added	Thank you for your comment. Access to primary and secondary care was prioritised for this area. However, we will consider access as a specific consideration in other review protocols such as the area on interventions that improve participation. As outlined in the Equality Assessment Impact Form, people with cerebral palsy who have particular difficulties in accessing services will be a disadvantaged group that we should consider separately.
British Society for Children's Orthopaedic Surgery - BSCOS	6	7	Perhaps it would help to clarify that it is often challenging to diagnose whether or not pain is present and to identify the site and cause of pain (particularly in non-verbal individuals)	Thank you for your comment. We have included key question 5.1 on the most effective sequence of tests to identify causes of pain in an adult with cerebral palsy. This question is likely to cover which methods of identifying pain are most effective (including tools for people with communication difficulties) and as well as their optimal sequence.
British Society for Children's Orthopaedic	9	16	Again it is relevant to list foot pain and deformity as one of the most frequent musculoskeletal complaints. It is also relevant to discuss the fragmentation of adult orthopaedic services: children with cerebral palsy are	Thank you for your comment. We consider that, although not specifically mentioned, foot pain and deformity are covered by a number of the key issues mentioned in the scope. We anticipate that the issues of access to adult

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Surgery - BSCOS			looked after by paediatric orthopaedic surgeons who normally address any musculoskeletal problem. Adult orthopaedic surgeons, however, specialise in specific areas of the body (e.g. hip, knee, foot). Adults with cerebral palsy usually have a multitude of musculoskeletal problems which fall within multiple areas of orthopaedic expertise. A triage system needs to be in place, ideally supervised by a "champion" for adult cerebral palsy individuals.	orthopaedic services and the coordination of care by professionals with a special interest in adult cerebral palsy should be addressed within key issue 6 (the configuration of services for adults over 25 with cerebral palsy).
College of Occupational Therapists	10	31	Should this also include barriers to workplace and community services?	Thank you for your comment. Access to primary and secondary care was prioritised for this area. However, we will consider access as a specific consideration in other review protocols such as the area on interventions that improve participation. As outlined in the Equality Assessment Impact Form, people with cerebral palsy who have particular difficulties in accessing services will be a disadvantaged group that we should consider separately.
College of Occupational Therapists	10	6-7	There should be examination of the interventions based on psychological approaches, which in turn improve physical function and participation. Will the guideline therefore also cover the interventions focusing on self-worth, emotional regulation,	Thank you for your comment. We anticipate that the key question 4.1 could cover psychological approaches if the Guideline Committee agree they are a priority.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			confidence building and social participation and their effect on physical function?	
College of Occupational Therapists	11	7	This should include vocational and pre-vocational activities (in functional independence list) particularly as this has been mentioned in section 3.5 (p.10, line 6-7) under key areas and questions.	Thank you for your comment. This has been addressed in a key areas that will be covered under interventions that improve function and participation for adults over 25 years with cerebral palsy
College of Occupational Therapists	5	18/19	Will non-pharmacological management e.g. positioning and standing programmes, splinting be covered in the guideline?	Thank you for your comment. We will look at this specifically in how to maintain/improve function and participation. This covers physical therapy (physiotherapy and/or occupational therapy) as suggested and covered by NICE guidelines on Spasticity in under 19s: management (CG145)
College of Occupational Therapists	5	20	Will mental health assessment include cognitive assessment and relevant assessment of need re: learning disability? The College would be concerned if the only focus is on mood, etc.	Thank you for your comment. Cognitive assessments and assessments of need regarding learning disabilities, should be undertaken in paediatric services, prior to transition. When we review the area on mental health assessment tools, we will outline the full list of mental health issues and assessment tools in the review protocol.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
College of Occupational Therapists	6	10	Given that some people require input from multiple services / agencies, further definition of specialist services is required as this could be extensive. Is this referring to specialist clinical services e.g. Orthopaedics or is this intended to incorporate a range of agencies and service providers e.g. Bobath Scotland?	Thank you for your comment. The Guideline Committee will further define specialist services when agreeing the protocol evidence review. The guideline covers any setting where NHS care is provided - so would apply to agencies providing NHS funded care.
College of Occupational Therapists	6	1-6	Will there be scope to include equipment other than mobility equipment that assists with activities of daily living? Why is there not an examination within the scope about the impact that adaption to the home makes on improvements in function and participation?	Thank you for your comment. When we review the area on equipment to help with mobility, we will outline the different types of equipment in the review protocol. The impact of home improvements was not prioritised for this guideline as adaptions may not be commissioned by the NHS or local authority.
College of Occupational Therapists	6	4	It would appear that equipment to help with independent living is included in addition to AAC equipment. It would also be helpful to have some specific definitions of exactly what this will include, e.g. environmental controls, telehealth and telemedicine, computer access/tablets etc, to allow people with cerebral palsy to participate in wider communications	Thank you for your comment. When we review the area on interventions to improve communication, we will outline the full list of interventions in the review protocol.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			through social media? This is potentially a huge area if not specified.	
College of Occupational Therapists	6	6	Where it states vocational needs, will this include further education and vocational rehabilitation? This is an area where people with cerebral palsy have real difficulties moving from further education into meaningful employment. It would be helpful to understand which strategies are successful, if any.	Thank you for your comment. We reflected on this and came to the conclusion that we will not add this since it is not specific to cerebral palsy.
College of Occupational Therapists	9	1-12	Will there be a review of non-pharmacological management of abnormal muscle tone, e.g. positioning and standing programmes, splinting?	Thank you for your comment. There will be review of non-pharmacological management under interventions that improves function and participation of adults with cerebral palsy. The details has been added to reflect this
Department of Health	**General**		I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.
DM Orthotics Ltd	9		Key issue 1 - The draft scope currently considers pharmacological and surgical interventions for the management of abnormal muscle tone, but does not consider the use of dynamic or static orthotics. We feel they should be considered in this section because they	Thank you for your comment. As far as we are aware, orthotics do not treat increased tone. However, orthotics will be looked at for their role in improving mobility

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			are currently being used in practice to help with abnormal muscle tone with children and adults with cerebral palsy.	
DM Orthotics Ltd	9		Key issue 2 - The draft scope considers monitoring complications and co-morbidities, but does not consider their management. Orthotic management, for example, of spinal deformities with rigid and dynamic bracing is currently in use. We feel this should be included in the guidelines.	Thank you for your comment. Orthotics will be looked at for their role in improving mobility.
DM Orthotics Ltd	**General**		Dynamic orthoses might reduce risk of falls through improved proprioception, pelvic and core stability.	Thank you for your comment. Orthotics will be looked at for their role in improving mobility, improved proprioception and stability.
DM Orthotics Ltd	**General**		Dynamic orthoses could delay the need for spinal surgery, through their effect on proprioception, muscle tone and spinal alignment.	Thank you for your comment. Orthotics will be looked at for their role in improving mobility, improved proprioception and stability
Medtronic Ltd	5	15	This line states *"Management of abnormal muscle tone in **adults over 19** with cerebral palsy"*. This should read ***"adults aged 19 and over"*** in line with page 1 lines 9-10 of draft scope which states that the guideline will cover adults aged 19 and over with cerebral palsy.	Thank you for your comment. We have reworded this section accordingly and checked for consistency throughout.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			Patients aged 19 years are not covered by CG145: "Spasticity in under 19s: management"	
NHS England	**General**		We can confirm that there are no comments to be made on behalf of NHS England.	Thank you.
Royal College of General Practitioners	10	26	6.1 What are the necessary components (for example, an adult cerebral palsy multidisciplinary team [MDT], requisite skills for doctors with an interest in cerebral palsy in adults) in the network of care and support for adults with cerebral palsy? Wright et AL (2016) reviewed services in Scotland and found after transition from paediatric services young people with CP can either be referred to an adult Learning Disability Team (LDT), a rehabilitation service or discharged back to their GP.[1] Criteria for access to adult LDTs (where available) varied and included the educational setting of the young person, the complexity of their needs, and a having a formal diagnosis of a Learning Disability (LD). Although the	Thank you for your comment. We anticipate that the issues of access to adult CP services and the coordination of care can be addressed within key issue 6 (the configuration of services for adults over 25 with cerebral palsy).

[1] Wright, Alice E., James Robb, and Morven C. Shearer. "Transition from paediatric to adult health services in Scotland for young people with cerebral palsy." Journal of Child Health Care 20.2 (2016): 205-213

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			input from adult LDT was normally multi-disciplinary and well coordinated, general health care for adults with CP was described as being more uncoordinated than in paediatrics. Participants reported that this was, in part, due to no longer having a school to bring health care professionals together. Furthermore, health care in adult services was often provided as required for specific problems rather than the adult receiving regular general review unless there was a specific medical reason for review. There was also considerable debate as to whether GPs were in a position to take over the co-ordination of the medical needs of young people with CP.	
Royal College of General Practitioners	10	31	6.2 What are the barriers to access to primary and secondary care for adults with cerebral palsy? 1. Lack of General Practice services Currently General Practice across the UK is overstretched due to underinvestment. It is vital to improve the patient with CP experience by • Easier to make a GP appointment for patients	Thank you for your comment. Access to primary and secondary care was prioritised for this area. However, we will consider access as a specific consideration in other review protocols such as the area on interventions that improve participation. As outlined in the Equality Assessment Impact Form, people with cerebral palsy who have particular difficulties in accessing services will be a disadvantaged group that we should consider separately.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			• More GP services will be available within the community • Reduction in the number of unnecessary hospital admissions • Improved continuity of care • Safer more convenient care for patients • More emphasis on prevention, helping patients to stay active longer • Getting to see the right person more quickly • Helping patients to manage their own care • Protection from local practice closure • More modern healthcare environment • Action to tackle health inequalities	
Royal College of General Practitioners	10	31	2. Lack of co-ordination and leadership of health care for adults with CP This needs to start with • Effective standardised transition planning. • The adult Learning Disability Team (LDT) and rehabilitation services need generalist health	Thank you for your comment which highlights the need for service guidance in this area. The configuration and access to services is going to be covered in by this guideline.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			input and to be based in the community, preferably in general practice. • The criteria based bureaucratic referral pathways to LDT lead to considerable referral delays, gaming and disputes over boundaries with other services. There needs to be a single point of access with effective care management • Standardised care planning 3. Lack of General Health care knowledge about adults with CP and access to specialist care. A large challenge is access to specialized care, as CP therapy is currently only available centered in pediatric care settings. Therapies in adults include providing adaptive equipment as capabilities change, targeted treatment for a specific deficit, or focusing on generalized strength and fitness. Adaptation, targeted physical therapy, and exercise are some specific examples. Prevention and management of secondary damage are important additional goals. Specific	

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			counseling and guidance must be directed at social factors such as employment in adults. [2] 4. Diagnostic overshadowing 5. Isolation, avoidance, inertia and neglect 6. Lack of Commissioner knowledge 7. Lack of health regulators knowledge 8. Lack of standardised data collection	
Royal College of General Practitioners	5	11	3.3. It would be useful to perform a systematic review of inventions of adults for adults with cerebral palsy to identify those interventions that work, those that don't and those that require further research. Noval et al	Thank you for your comment. The guideline will focus on improving quality of life, function and participation. As in children, there are a huge number of interventions that have been used for adults with CP for which there is little or no evidence. The guideline will emphasise the positive

[2] Magill-Evans J, Galambos N, Darrah J, Nickerson C. Predictors of employment for young adults with developmental motor disabilities. Work 2008;31:433–442.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			2013 performed a systematic review for children and identified interventions that work (green) as well as those that did not (red).[3] Green interventions included anticonvulsants, bimanual training, botulinum toxin, bisphosphonates, casting, constraint-induced movement therapy, context-focused therapy, diazepam, fitness training, goal-directed training, hip surveillance, home programmes, occupational therapy after botulinum toxin, pressure care, and selective dorsal rhizotomy. Red interventions included craniosacral therapy, hip bracing, hyperbaric oxygen, NDT, and sensory integration have all been shown to be ineffective in children with CP, and are therefore not recommended for standard care. It would be helpful to replicate the bubble charts used in this paper to assist with comparative clinical decision-making amongst intervention options for the same desired outcome,	interventions, rather than providing a text book on all interventions that could be used in this population.

[3] Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S.-A. and Goldsmith, S. (2013), A systematic review of interventions for children with cerebral palsy: state of the evidence. Dev Med Child Neurol, 55: 885–910.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Royal College of General Practitioners	5	24	3.3.2 Mental Health Under 3.3 the draft scope specifically includes mental health under 3.3.2 but contradicts on page 6 line 14 that the mental health will not be covered. The RCGP support parity of esteem and advocates that a holistic approach is required promoting mental health equally and in partnership with physical health.	Thank you for your comment. The assessment of mental health problems was prioritised for this guideline as the management of those problems (not specific to CP) has been covered elsewhere by NICE. For this reason, we will cross-refer to other guidelines to address the management of mental health problems.
Royal College of General Practitioners	8	26	***3.5 Key issues and questions*** The World Health Organization's International Classification of Functioning, Disability and Health (ICF), 2001 that has redefined the way clinicians understand about Cerebral Palsy and think about intervention options. The field of disability has chosen a philosophical shift away from almost exclusively redressing physical impairments underlying functional problems to adopting an additional focus on maximising the person's environment, their independence in daily activities, and their community participation. This feel this fits well with our general practice approach of personalising care and managing multimorbidity. Clinicians applying the recommended	Thank you for your comment. We agree that your key issues and questions are relevant. We have concluded that the majority of your questions will be addressed, as the same recommendations can be achieved when the question is phrased in a different way. Please note that fatigue is not a symptom that is specific to cerebral palsy and was therefore not prioritised in the scope.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			goal-based approach seek to choose interventions guided by what would best help the person and their family achieve their goals. This approach is not consistent with these key issues. There needs to been consistent standard long term care planning that aims to help people take more control over their own health and to stay well. This requires care navigation. The key questions should include: 1. How is Integrated Long term Care planning best implemented to support adults with CP? 2. What are the best models for care navigation for adults with CP? 3. Can a lifestyle intervention programme improve physical behaviour among adolescents and young adults with spastic cerebral palsy? 4	

[4] Slaman J, Roebroeck M, Dallmojer A, et al. Can a lifestyle intervention programme improve physical behaviour among adolescents and young adults with spastic cerebral palsy? A randomized controlled trial. Dev Med Child Neurol 2015; 57: 159–66.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
			4. What weight management and physical activity interventions to prevent and treat fatigue in this population?5 5. What occupational support and interventions are effective in helping with securing and maintaining employment for people with CP? 6 6. What sleep management interventions help reduce fatigue? What postural care improves sleep and reduces deformities?	
Royal College of General Practitioners	**General**		The Royal College of General Practitioners (RCGP) welcomes draft scope guidelines for cerebral palsy in adults.	Thank you.
Royal College of Nursing	**General**		This is to inform you that the Royal College of Nursing has no comments to submit to inform on the above consultation at this time.	Thank you for your comment.

[5] McPhee, P. G., Brunton, L. K., Timmons, B. W., Bentley, T. and Gorter, J. W. (2016), Fatigue and its relationship with physical activity, age, and body composition in adults with cerebral palsy. Dev Med Child Neurol. doi:10.1111/dmcn.13306

[6] Magill-Evans J, Galambos N, Darrah J, Nickerson C. Predictors of employment for young adults with developmental motor disabilities. Work 2008;31:433–442.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
			Thank you for the opportunity.	
Society of British Neurological Surgeons	General		No Comments	Thank you.
University College London Hospitals NHS Foundation Trust	1	9-14	Clear age delineation fitting with previous guidelines is very useful	Thank you for your comment.
University College London Hospitals NHS Foundation Trust	10	16	Important to highlight all equipment- wheelchair provision for people with CP can be patchy around UK, similarly standing frames etc	Thank you for your comment. If equipment is found to be clinically effective and cost effective, we will make recommendations in favour of equipment, for those indications. NICE guidelines make recommendations for the NHS, local authorities and organisations commissioned by public bodies to follow; however, we cannot enforce the private sector to follow our recommendations. The Equality Impact Assessment form also states that "People with cerebral palsy living in residential care who no longer have family members able to act as their

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				advocates may have particular difficulties in accessing services and may therefore be a disadvantaged group that we will consider." For this reason, different recommendations may be made for those subgroups to remove inequalities.
University College London Hospitals NHS Foundation Trust	10	18	Regarding Communication it refers mainly to technological interventions but it is essential this guideline reviews all needs not just focussing on assistive technology; including current systems whether oral or technical, speech, opportunity as well as social and communication support.	Thank you for your comment. When we review the area on interventions to improve communication, we will outline the full list of interventions in the review protocol.
University College London Hospitals NHS Foundation Trust	10	24, Q 5.1	The question is rather vague as a sequence of tests will be a clinical decision based on that particular patient presentation. Not sure the evidence will support this. May be better to look at the commonest causes of pain and then extrapolate what tests to use	Thank you for your comment. We agree that the appropriate sequence of tests will depend on the particular presentation and anticipate that the evidence review should also provide information about common causes of pain in this group.
University College London Hospitals NHS Foundation Trust	10	26 Q 6.1	Would be useful to include palliative care in the network	Thank you for your comment. The list of specialties is specified in key question 6.1 and is not exhaustive and we agree that palliative care would be a component of the network of care and support for adults with cerebral palsy.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
University College London Hospitals NHS Foundation Trust	10	31	This is a really important issue as many people with CP cannot access basic healthcare (such as breast screening) due to their mobility issues	Thank you for your comment. Access is one of the key issues in the scope and was included in the Equality Assessment Impact form to be considered as a subgroup in the review protocols.
University College London Hospitals NHS Foundation Trust	5	15	In areas of application to Management of Muscle tone, we appreciate there is a section below for exercise, but we should also consider non-pharmacological management of tone in this section such as exercise, splinting, positioning etc.	Thank you for your comment. The review of the evidence for management of muscle tone may include comparison of pharmacological with non-pharmacological interventions, if the Guideline Committee consider it relevant. There is also a key question about non-pharmacological interventions for maintaining physical function in adults with cerebral palsy which could include muscle tone as an outcome.
University College London Hospitals NHS Foundation Trust	9	23	Anxiety is a big problem in people with CP; hopefully this question can explain which mental health issues are common as well as looking at tools to assess?	Thank you for your comment. When we review the area on mental health assessment tools, we will outline the full list of mental health issues and assessment tools in the review protocol.
University College London Hospitals NHS Foundation Trust	9	25	Regarding Dysphagia it will obviously come under the nutrition bit but swallowing does change and reserve changes with wellbeing, medication etc issues. We didn't see a swallow review section and perhaps this needs to be a section on its own for review?	Thank you for your comment. We have updated the key question to include the assessment of feeding problems.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

Cerebral palsy in adults

Consultation on draft scope
Stakeholder comments table

Tuesday 29/11/16 to Thursday 05/01/17

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

Stakeholder	**Page no.**	**Line no.**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
University College London Hospitals NHS Foundation Trust	**General**		**Does the use of Sativex delay or negate the need for an intrathecal baclofen pump?**	Thank you for your comment. The list of interventions in the scope is not exhaustive and we will specify the full list of interventions when we agree on the details of the systematic review protocol. We will raise this point in the discussion of the relevant protocol.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.