Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Action Cerebral Palsy	Short	General	General	We are concerned that, without a national register of young people with cerebral palsy, important information on patient history, as well as data on the number and type of young adults or those transitioning to adult services, remains unavailable. The relatively uncommon occurrence of cerebral palsy compared to other disabilities, its multiple presentations and diverse pathways, make it a complex condition to study and to target intervention. Without a register, it is difficult to plan provision of health and social care across the range needs which may be required by young people transitioning in to adult services. The recommendations and guidelines presented in this document may be of little use if there is not the detection in place to ensure that young people and adults with cerebral palsy are diagnosed and monitored as early as possible, thus ensuring a seamless transition in to treatment, and between children's and adult services.	Thank you for your comment. The issue of transitioning to adult services is covered in the Cerebral palsy in under 25's (NG62) NICE guideline. NG62 also includes a recommendation related to a national register for children and young people up to the age of 25, This was outside the scope of the current guideline which focused more on access to services and assessment and monitoring. The committee therefore were unable to make a direct recommendation related to this. The discussion of a national registry came up in the context of selective dorsal rhizotomy as a treatment for spasticity. The committee agreed that even though the setting up of national registry for all adults with cerebral palsy was outside the scope of this guideline, the registry proposed by the NICE guideline on spasticity in under 19s may also help to inform future guidance. This is captured in the related 'rationale and impact' section.
Action Cerebral Palsy	Short	General	General	There is evidence to show a lack of care pathways and timescales from NHS Trusts regarding cerebral palsy care, especially amongst young people transitioning in to adult care, resulting in those with the disorder suffering from delays when trying to access neurological and physical assessments by multidisciplinary teams. The charity Action Cerebral Palsy is currently undertaking a series of Freedom of Information (FOI) requests, and has found that over 50% of responses thus far from NHS Trusts	Thank you for your comment. The issue of transitioning of young people with cerebral palsy to adult services is covered in other NICE guidelines on cerebral palsy in under 25s and transition from children's to adults' services for young people using health or social care services and the committee cross-referenced these to signpost the reader to relevant recommendations. The committee were aware that access to services for

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				indicate they have no single pathway or timescale for diagnosing and treating cerebral palsy. To avoid delays, NHS Trusts should ensure they have a pathway and timescale in place to adequately ensure those with cerebral palsy are treated as quickly as possible. Individual pathways should be developed prior to any treatment beginning, in order to ensure a seamless journey for those undergoing treatment.	adults with cerebral palsy was variable and they therefore made specific recommendations about services and ongoing care to promote equality. The committee decided that they could not be prescriptive about timescales because these would depend on individual needs. However, in the guideline we made recommendations about regular and annual reviews as well as referral and re-assessment which the committee believed would lead to earlier recognition and management, and possibly prevention of problems. This would then avoid delays and would encourage earlier intervention. The reasoning behind the recommendations and how they would lead to better access to services and assessments can be found in the 'rationale and impact' section and its subsections of the guideline (see for instance moving into services and access to services as well as ongoing care).
Action Cerebral Palsy	Short	5	11	The rationale is to create a person-centred approach, and thus it is beneficial to ensure that those transitioning to adult services will be considered as equal partners, and that their views and needs will be fully taken in to account. As indicated in NICE guideline 1.1.6 in the 'Transition from children's to adults' services for young people using health or social care services', service managers in adult services should proactively identify and plan for young people in their locality with transition support needs. Thus, in regards to cerebral palsy, these recommendations should explicitly make clear the necessity of service managers to ensure that care plans are in place for those young people entering	Thank you for your comment. The committee agreed that transition from children to adults services can be challenging and they have therefore signposted to the existing NICE guidelines that have already covered this (cerebral palsy in under 25s and transition from children's to adults' services for young people using health or social care services).

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				adult services, and that they should have access to contacts should they need assistance.	
Action Cerebral Palsy	Short	7	1	We are concerned that there is no information here on how any regular review should be conducted. The minimum expected frequency of a review should be stated, and it should be made clear that a review should commence at the request or either a clinician or the client.	Thank you for your comment. The committee decided that they could not give instructions on how to conduct the review since this would depend on too many different factors (such as setting, who is conducting the review, what the needs and preferences of the person with cerebral palsy are). They therefore left this to clinical judgement. In relation to frequency of reviews, given the clinical and economic evidence, the committee chose not to make a strong recommendation around the frequency of reviews for all people with cerebral palsy but suggested that reviews should be regular (recommendation 1.1.12). It was also taken into account that people with cerebral palsy have a wide range of abilities and disabilities and that it is difficult to provide a minimum frequency that would be applicable to all and that the frequency would need to be tailored to the individual person. However, an annual review is specifically recommended for people with cerebral palsy who have complex needs (recommendation 1.1.13). The reasoning for this is documented in the 'rationale and impact' section.
Action Cerebral Palsy	Short	22	9	The outcome of discussing difficulties eating, including food refusal, should be the offer of an assessment of oromotor and swallowing skills (dysphagia).	Thank you for your comment. We have revised recommendation 1.4.21 by adding two examples of 'relevant clinical specialist'. It now reads 'Refer adults with cerebral palsy to a relevant clinical specialist, such as dieticians and speech and language therapists, if assessment suggests they have difficulties with eating or

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					malnutrition'. These specialists would then be able to assess oromotor and swallowing skills.
Action Cerebral Palsy	Short	22	16	We are concerned that pain and depression have been classified together as something which may affect an individual's appetite, eating habits and weight. It is our view that pain and depression should be considered as separate issues and thus should be classified under two separate bullet points. Dental care should also be added as a reason which can affect an individual's appetite	Thank you for your comment. The recommendation was revised and now pain and depression are two separate bullet points. Dental care was considered a too specific example to be added to the list. However, it is not an exhaustive list and if dental care is affecting the appetite of a particular person then the recommendation does not preclude this from being discussed and explored.
Action Cerebral Palsy	Short	26	15	There is evidence that individuals with cerebral palsy have difficulty registering their communicative difficulties, and so reference should be made to those wo struggle to register and thus communicate they are in pain.	Thank you for your comment. The committee acknowledged that some adults with cerebral palsy may be experiencing pain but be unable to communicate this, even after all efforts and adjustments have been made to enable communication. In these situations the committee thought that observational pain measures - where pain is assessed by an observer may be appropriate and have included this in their recommendation. Studies of autonomic measures of pain (for example heart rate and galvanic skin response) were searched for but there was insufficient evidence to recommend these techniques.
AFTSP (UK)	Short	5	16-18	1.1.7 "Recognise and address barriers to accessing primary and secondary care for adults with cerebral palsy". This statement presumes barriers. It would be better to state " Recognise and address any barriers…"	Thank you for your comment. We have revised this accordingly.
AFTSP (UK)	Short	9	13-15	1.2.11	Thank you for your comment. We have now revised the order of the recommendations in this section. This has

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				"If an adult with cerebral palsy finds it difficult to participate in a chosen activity, assess their physical and mental health and address any factors identified that may be affecting participation, if possible". This statement focuses on internalised ideas, whereas, as stated earlier in this document, barriers can also be external, for example social stigma, building design, travel difficulties, and this statement would be more balanced if it reflected this.	made it clearer that there are two separate recommendations, one related to external factors (recommendation 1.2.8) and one related to internal factors (recommendation 1.2.9) that may affect participation. We have added to the rationale and impact section that removal of external barriers would add costs but that this should be done to comply with government policy and legislation.
AFTSP (UK)	Short	10	Dec-14	1.2.16 "Be aware that using electronic assistive technology may mean that the person with cerebral palsy needs less contact with their carers, which may reduce their social interaction". This is an important issue, and the statement may benefit from a further statement to motivate action, such as: "If this is the case then explore with the person other ways they can find opportunities for social interaction".	Thank you for your comment. The committee agreed that this should be emphasised more and have reordered this section to move this above what is currently recommendation 1.2.16 which talks about adults who are 'already using electronic assistive technology'. The committee agreed that this should be explored at an earlier stage and that once aware it would then directly link in with the following recommendation related to a discussion of 'potential changes in their needs' which may include a need for more social interactions'. Challenges related to social integration are highlighted elsewhere in the guideline, such as in recommendation 1.1.7 (providing support to help with social and emotional factors such as fear of stigma, lack of motivation and exhaustion) and the section on 'vocational and independent living skills' (recommendations 1.2.8 to 1.2.13).
AFTSP (UK)	Short	20-21	6 (p.20) – 23	The mental health section again takes an internalised perspective of mental health, and we feel a relational perspective would be beneficial. The skills of Family and Systemic therapists could be useful in working together	Thank you for your comment. This section was specifically related to assessment and monitoring rather than interventions for mental health problems. The committee could therefore not make specific recommendations about

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			(p.21)	with people and their carers to think about how the caring system can best support the person, and address any stresses within the system which might be impacting upon care or the quality of relationships.	systemic therapy because this was not the topic of the review.
APCP	General	General	General	The use of the GMFCS classification is only validated under 18 years of age, is this acknowledged in the document (have not found this)?	Thank you for your comment. We have amended the GMFCS definition (please see the 'terms used in this guideline' section).and the rationale and impact section to acknowledge that this is not validated in the adult population and described the reasons for why this was mentioned in some of the guideline's recommendations.
APCP	Short	9	2-7	Access to services: 1.1.4 Please add: Access to accessible exercise facilities Pathways for access to speech and language therapist specialist in dysphagia for eating and drinking issues and training of carers Pathways to access for on-going need for replacement of orthoses	Thank you for your comment. Specific recommendations for physical activity, communication and eating as well as training of carers are covered in other sections of the guideline. See for example 1.2.19 to 1.2.22 related to physical activity. We have now added that information should be provided about 'accessible' local services that support people with cerebral palsy to take part in physical activity (recommendation 1.2.20). Other recommendations already address referral to orthotic services and recommendations 1.2.4 and 1.2.6 related to referral to speech and language therapy services and training as well as 1.4.21 which addresses referral to dieticians or speech and language therapy services if assessment suggests difficulties with eating or malnutrition.
APCP	Short	33	20	Ongoing care: 1.1.10 – Suggest regular review with or involving multi-disciplinary team	Thank you for your comment. The committee decided that 'involving the multidisciplinary team' would not be appropriate for every person with cerebral palsy. They have therefore intentionally worded this recommendation in two parts: one sentence relates to the reviewing and the

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				Suggest consideration of referral to specialist wheelchair services for adults with complex seating needs (GMFCS IV and V) 1.1.11 – Change 'people with CP who have complex needs (such as GMFCS IV and V) and any of the following' to 'and/or' any of the following 1.1.16. - ? Specify with GP or organised by GP – to make sure it happens!	second sentence to agreeing the frequency and services being involved in this. If it is agreed that a number of services would be involved then most likely that would be a multidisciplinary team approach. In the section on 'access to services' it is stated that 'commissioners and service providers should develop pathways that allow adults with cerebral palsy access to a local network of care that includes wheelchair services as one of the services' (see recommendation 1.1.4). Furthermore, recommendation 1.2.21 in the 'physical activity' section of the guideline states that referral to wheelchair services can be made depending on local service provision and the person's needs. The committee decided that this was sufficiently covered. The recommendation related to 'annual review' was supported by an economic model which relied on an average reduction of one fewer emergency admission per year. It was therefore not considered cost effective to provide an annual review for all or a large proportion of people with cerebral palsy (i.e. all people with communication difficulties or all people in long-term settings). The committee agreed that an annual review was a very important recommendation in the guideline and wanted to make sure that those who most needed it would receive this at a minimum yearly frequency. This does not preclude it from happening more often if a need arises (as suggested in recommendations 1.1.2 on referral to a

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					multidisciplinary team and recommendation 1.1.3 on re-assessment). With regard to recommendation 1.1.18, the committee did not want to be too prescriptive about who in primary care would organise this or carry this out (to leave it open that a specialist nurse could do this). The details of this are described in the related NHS England information and the two NICE guidelines which are signposted in this recommendation.
APCP	Evidence Review E1	General	General	Pain is so often under recognised in this group, especially as there is no clear pathway/service for adults with CP. The guideline needs to be clearer regarding pain during daily activities and comfort in equipment (aggravating or relieving). Asking about functional daily activities is so important and it helps us to decide whether tone management options such as Botulinum toxin injections would be helpful. It can also help to identify when there is a need to see other specialists e.g. wheelchair services to review seating; orthopaedics to consider surgery etc.	Thank you for your comment. The committee agreed pain is an important factor when considering treatment options for spasticity or dystonia (see recommendations 1.3.4 and 1.3.6) and also when considering referral to a musculoskeletal specialist or an orthopaedic surgeon (recommendation 1.2.22) if participation in physical activities is limited by pain or joint problems that do not respond to any other treatments. The committee acknowledged the importance of assessment of the individual's usual daily activities and recommended referral to a multidisciplinary team experienced in the management of neurological impairments if there was any deterioration in ability to carry out usual daily activities (recommendation 1.1.2).
APCP	Evidence Review D2	26	10	Table 9 (FES- related guidance) suggest: NMES neuro muscular electrical stimulation as this includes FES. Warrants more coverage in the document as is increasingly used.	Thank you for your comment. Table 9 is the review protocol which outlines our plan for reviewing the literature. We did not identify any comparative FES or NMES studies in adults with cerebral palsy, however the committee acknowledged the use of FES in this population and so

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					have updated recommendation 1.2.21 to include referral to orthotic and functional electronic stimulation (FES) services if needed.
APCP	Evidence Review D2	23	37	Powered instead of powdered	Thank you for your comment. The spelling mistake has been corrected.
APCP	Evidence review D1	General	General	We would like to add the importance of adults with CP being able to have sexual relationships and potentially families of their own. We are concerned that this is often completely overlooked due to its sensitive nature.	Thank you for your comment. The committee agreed that sexual relationships and potential families are important topics but they were outside the scope of the guideline. 'Pregnancy and parenting' have now been added to recommendation 1.1.3 as examples of changing needs that can lead to re-assessment by a multidisciplinary team. However, we could not comment in detail about the sexual health and sexuality because no specific evidence review was conducted that addressed this. NICE is also currently developing a Quality Standard on sexual health which does not exclude any group with protected characteristics. The standards in this will therefore also be relevant to people with cerebral palsy.
Bobath Scotland	Short	General	General	We would strongly recommend offering an annual review for all adults with cerebral palsy with a physician, PT/OT/SLT, nurse specialist as appropriate because: • Regular reviews are likely to result in increased responsibility for and awareness of their own health, leading to greater success of self-management of issues related to living with a long term condition • There may be adults with cerebral palsy within GMFCS levels 1-3 without perceived associated difficulties who may in effect present with 'hidden'	Thank you for your comment. The committee considered the topic carefully including both clinical and cost effectiveness. The committee considered the limited clinical evidence, uncertain economic evidence and potential resource impact of this recommendation and did not think it was appropriate to make a strong recommendation around a minimum frequency of these reviews for all people with cerebral palsy. The committee highlighted that there should be some flexibility in the frequency of these reviews to allow for tailoring to the individuals needs as well as their

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				difficulties or barrier such as visual perceptual difficulties, emerging mental health difficulties/changes/deterioration • Postural alignment tends to alter with secondary ageing across the entire population with cerebral palsy which can have significant consequences on function, health, pain and quality of life. If identified early, these consequences can be minimised significantly whilst if left until they become severe, are likely to result in much more serious difficulties, possible contractures or deformities and accompanied pain that will be far more difficult to address at that time with the obvious results for people's overall health, function and ability as well as the potential economic impact on services.	preferences. This is documented in the 'Rationale and Impact' section. Even though the committee were unable to recommend a minimum frequency of clinical reviews for all people with cerebral palsy due to resource impact, they acknowledged that mental health problems and postural alignment (and its effects on bones and joints) are important topics and have therefore dedicated specific sections to these. These sections include recommendations related to raising awareness about these issues and identifying them. The committee believed that raised awareness of mental health or postural problems will improve early identification and treatment.
Bobath Scotland	Short	General	General	There are no recommendations for the management of adults with athetosis which we believe to be an error as these adults are at increased risk of wear and tear of their cervical spine and should be included in the recommendations.	Thank you for your comment. This is covered under recommendation 1.4.7 relating to cervical instability and spondylosis and we have added it as an example under the second bullet. The reasons for adding this are described in the 'committee's discussion of the evidence' section in evidence chapter B1.
Bobath Scotland	Short	4	9	We welcome the recommendation to refer adults with cerebral palsy to a multi-disciplinary team but we are concerned that the definition of what constitutes a multi-disciplinary team can vary from area to area. We would recommend that at the most basic level for adults with cerebral palsy teams should consist of physiotherapists, occupational therapists and speech and language therapists, whilst recognising that other therapists such as	Thank you for your comment. The committee were aware that multidisciplinary teams experienced in the management of neurological impairments already exist. However, the committee could not be too prescriptive about the constituency of the specific multidisciplinary team because the needs of people with cerebral palsy vary widely. They acknowledged that in order to adequately address the needs of people with cerebral palsy,

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				dieticians, orthotists and psychologists may also be required.	commissioners should develop pathways that allow adults with cerebral palsy access to a local network of care that includes services that can be tailored to the individual (see recommendation 1.1.4). The committee wanted to emphasise that the recommendations refer individuals to services which are already established (with skills in general management of neurodisabilities) and that a major component of the rationale for these recommendations is establishing equality in access to these services in line with the Human Rights Act 1998 and the Equality Act 2010.. Both of these have been extensively referenced throughout the rationale and impact sections.
Bobath Scotland	Short	4	10	It is important that the team is experienced in the management of cerebral palsy and not just in neurological conditions in general. There are a vast range of neurological conditions, many of them requiring very different therapeutic knowledge and approaches for treatment. If no such team exists in an area they should be able to link/liaise with other teams or centres of expertise for training and/or consultation.	Thank you for your comment. The committee were aware that multidisciplinary teams experienced in the management of neurological impairments already exist and would therefore not require a significant implementation cost. There was no evidence that re-organising services into specific dedicated multidisciplinary teams for people with cerebral palsy (which would be a change to current practice) would be cost effective. Specific training needs and expertise was outside the scope of this guideline. However, the committee agreed that good access to the full range of services is important. They acknowledged that in order to adequately address the needs of the people with cerebral palsy commissioners should develop pathways that allow adults with cerebral palsy access to a local network of care that includes services that can be tailored to the individual (see recommendation 1.1.4). It is assumed

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					that setting up such networks would rely on links between them and services liaising with each other.
Bobath Scotland	Short	4	11	Consider adding to the referral criteria to a multi-disciplinary team the following: • If a person reports discomfort or pain • If a person identifies new goals or areas of interest (e.g. to become more independent in a specific aspect of homecare, to explore a new avenue of work or study) • If there has been a change in environmental or social situation (e.g. new housing, new care team)	Thank you for your comment. In this specific section the committee's aim was to set out some general principles for service organisation and access to services. The committee recognised that pain is an important factor in the lives of people with cerebral palsy and therefore have dedicated a specific section to this topic (see recommendations 1.4.36 to 1.4.39). The committee also emphasised that vocational and independent living skills are very important for people and there is also a section in the guidance related to this topic (see recommendations 1.2.8 to 1.2.13) including when to refer. The committee acknowledged that re-assessment by a multidisciplinary team may be necessary at different points in the adult's life to ensure that their changing needs are met. The committee has now provided some specific examples, such as decreased mobility due to hip arthritis, pregnancy and parenting, loss of care support from an elderly parent, to highlight some of the needs that may change throughout the person's life. These examples are not an exhaustive list and therefore situations such as change in housing may also apply. The committee decided that environmental and social situations could also be barriers to access that may need to be addressed and have reworded and split one recommendation into two (recommendations 1.1.7 and 1.1.8) to highlight such barriers and how they could be addressed.

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Bobath Scotland	Short	4	18	Include access to Orthotics	Thank you for your comment. The committee agreed and the document was amended to include 'orthotic and functional electronic stimulation (FES) services' in the list of services in recommendation 1.2.21 in the 'physical activity' section.
Bobath Scotland	Short	6	11	Other organisational barriers to accessing primary and secondary care include: • Previous equipment and strategies from paediatric services may not be transferred with the person or may not be available to the person or their carers • Regular changes in personal care teams can result in loss of information or information not being passed on or shared	Thank you for your comment. The committee agreed that joined-up services are very important particularly in the time of transitioning from children to adult services. They therefore signposted to the NICE guidelines on cerebral palsy in under 25s and transition from children's to adults' services for young people using health or social care services which specifically cover this. The committee agreed that loss of information and the lack of joined-up services was a barrier and therefore already recommended in 1.1.14 that details of the person's review should be recorded and that the information should be shared with relevant people. They also highlighted that there should be a main contact between reviews as this would improve how information is passed on and shared.
Bobath Scotland	Short	6	13	As stated above, a minimum frequency should be specified in the guidelines rather than just "regular". We would recommend annual reviews.	Thank you for your comment. Given the clinical and economic evidence the committee chose not to make a strong recommendation around the frequency of reviews for all people with cerebral palsy but suggested that reviews should be regular (recommendation 1.1.12). It was also taken into account that people with cerebral palsy have a wide range of abilities and disabilities and that it is difficult to provide a minimum frequency that would be applicable to all and that the frequency would need to be tailored to the individual person. However, an annual

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					review is specifically recommended for people with cerebral palsy who have complex needs (recommendation 1.1.13). The reasoning for this is documented in the 'rationale and impact' section.
Bobath Scotland	Short	6	18	We would like the reference to 'clinical team' to be expanded to read 'a member of the clinical team who has experience of cerebral palsy in adults'.	Thank you for your comment. The committee wanted to emphasise that the recommendations refer individuals to services which are already established (with skills in general management of neurodisabilities) and that a major component of the rationale for these recommendations is establishing equality in access to these services in line with the Human Rights Act 1998 and the Equality Act 2010. Both of these have been extensively referenced throughout the rationale and impact sections.
Bobath Scotland	Short	8	10	Refer adults to specialist speech therapy services.	Thank you for your comment. We have now revised recommendation 1.1.4 to include speech and language therapy as an example of specialist therapy services to which adults with cerebral palsy can access when needed.
Bobath Scotland	Short	8	13	Referral on should not only be for assessment purposes but also for review of current skills and provision, for updates required for the system a person is using (for example a new vocabulary required for a new job/course) or for up-skilling (for example needing to link what they have with a new computer).	Thank you for your comment. The committee recommended that 'at every review' people with cerebral palsy should be asked about their hearing, speech and communication (recommendation 1.2.2). It should also be explored whether there is a potential need for alternative and augmentative communication systems (recommendation 1.2.3). The committee therefore decided that both the aspects of review and provision are already covered in the existing recommendations.
Bobath Scotland	Short	9	4	Would like to see referrals to specialist occupational therapy services	Thank you for your comment. We have now added to recommendations 1.2.12 and 1.2.13 an occupational therapist as an example of 'a professional with expertise in

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					vocational and independent living skills'. However, this can be delivered by other professionals and there was insufficient evidence to justify the cost of restricting this to 'specialist occupational therapy services'.
Bobath Scotland	Short	9	28	Include 'physical burn out' as an important topic to provide information on	Thank you for your comment. As a general barrier to access to services 'exhaustion' is one of the examples that is mentioned (see recommendation 1.1.7). It could then be explored whether 'physical burn out' could be a possible reason for the persons' 'exhaustion' and relevant support can then be provided as is recommended.
Bobath Scotland	Short	11	11	Consider contacting national, third sector, specialist services for further information to inform decision making and advice given or consider referring to specialist services for direct input.	Thank you for your comment. In recommendation 1.2.20 the committee recommended that information should be provided on local services that support people with cerebral palsy to take part in physical activity. The committee intentionally did not want to be too specific about the details for these services because the relevant services depend on the individual's needs and goals. In recommendation 1.2.21 referral is then recommended to specialist services that can provide support with physical activities and some examples of these services are provided. The committee therefore decided to leave it to clinical judgement to provide information or referral to the most relevant service be it national, third sector or specialist.
Bobath Scotland	Short	12	20	Other factors to include are: • Amount of effort being exerted in an activity • Physical factors such as fatigue or menstrual cycle	Thank you for your comment. The committee agreed that physical factors should be considered too, before considering drugs or more invasive options. They have therefore added 'and review the person with cerebral palsy's physical management programme' to the recommendation 1.3.5. The factors that may exacerbate

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					spasticity or dystonia in recommendation 1.3.4 are not an exhaustive list. The committee wanted to capture the main examples and decided that the suggested additional factors were too specific. They agreed that any such physical factors would be picked up in the review of the physical management programme.
Bobath Scotland	Short	14	9	If they have previously received injections, some crucial factors need to be taken into account i.e. effect of previous injections as well as number of previous injections as it was observed in children with CP that the effect of BTX-A tends to wane with repeated injections (Molenaers et al., 2013, J Child Orthop Nov;7(5))	Thank you for your comment. The committee recommended botulinum toxin type A treatment if a tone management specialist agrees that treatment targeted to focal muscle groups is likely to improve function and symptoms (see recommendation 1.3.11). The committee could not cover the details of all of the considerations in relation to this treatment but it was agreed that a tone management specialist in their assessment of whether or not it is likely to improve function would explore whether it was previously used. Molenaers 2013 was not included in the evidence review because it related specifically to children and not adults with cerebral palsy and therefore did not match the guideline population.
Bobath Scotland	Short	19	27	There is a closed bracket that has been missed after the word lordosis	Thank you for your comment. We have revised this recommendation accordingly.
Bobath Scotland	Short	20	20	Add 'burn out' to the list of common health problems	Thank you for your comment. The list that is provided is a list of examples and is not exhaustive. The committee decided that 'burn out' overlaps with many other factors that are already mentioned in the list (such as mood, behaviour, social interaction and general level of function). The committee decided that these are broad examples and that 'burn out' even though not explicitly stated could

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					nonetheless feature in the discussion with the person if they have particular concerns about to this.
Bobath Scotland	Short	21	4	Add to list of concerns to explore the person's level of autonomy or perception of autonomy	Thank you for your comment. The list of examples is not exhaustive and only some general factors were listed. The suggested new factors were not added because they were considered to be too specific for this section. However, if the person has concerns about any other issues that are not specifically listed but that affect their mental wellbeing then this recommendation would not preclude this from happening.
Bobath Scotland	Short	26	15	Even if a person had significant communication difficulties, unless they have a significant learning difficulty, before resorting to discussion with their family and carers it should be established if the person has a reliable yes/no. This could be through vocalisation, gesture, facial expression, eye-point or eye-gazing. In cases where a person does have a reliable yes/no, discussions should only include yes/no questions.	Thank you for your comment. The committee agreed that enabling adults with cerebral palsy to actively participate in their care is particularly important as they may have frequent and ongoing contact with healthcare services. The underlying principles for establishing effective communication in situations like this are outlined in the NICE patient experience in adult NHS services guideline. These principles are common to many health conditions and for this reason the guideline committee has chosen to refer directly to patient experience in adult NHS services guideline within recommendation 1.4.38. For example it is recommended that healthcare workers should "Establish the most effective way of communicating with each patient and explore ways to improve communication. Examples include using pictures, symbols, large print, Braille, different languages, sign language or communications aids, or involving an interpreter, a patient advocate or family members."

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	**Document**	**Page No**	**Line No**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
Bobath Scotland	Short	34	17	It is unclear how this would be organised? Whilst recognising the importance of bringing together the relevant professionals to review it is important that service providers set up a framework for this to be implemented. Would the person have a lead/co-ordinating professional as the link?	Thank you for your comment. The committee intentionally were not prescriptive about who and how this would be organised since the abilities and needs of people with cerebral palsy vary widely. However, they agreed that continuity of care is important and they therefore recommended (1.1.16) that it should be discussed with the person with cerebral palsy (and their family and carers, if agreed) who will be their main point of contact (which could be a department or service) between reviews to support ongoing care.
Bobath Scotland	Short	34	28	There is a "to" missing between and "access" and "specialist services"	Thank you for your comment. We have now revised this accordingly.
Bobath Scotland	Short	40	22	Orthotic devices are also used to reduce discomfort, to aid in-hand hygiene, to support in-hand skin integrity and to reduce pain.	Thank you for your comment. There was no evidence identified on the effectiveness of orthotic devices for adults with cerebral palsy. This section therefore describes why a research recommendation was drafted. The research recommendation directly refers to upper limb orthoses. We have therefore added 'in-hand hygiene and in-hand skin integrity' to the list of outcomes that should be measured in the proposed research.
Bobath Scotland	Short	40	25	Where a splint has been provided, the person should be issued with a written note of what has been provided, the rationale for provision and how to use and clean the splint. Information should also be provided regarding indications of the review requirements and who to contact for this.	Thank you for your comment. We have added orthotic and functional electronic stimulation (FES) services to the list of services to which people could be referred depending on local service provision and the person's needs. However, the specific details of what would be recorded in case a splint is provided was outside the scope of this question.
Bobath Scotland	Short	42	11	Given the fact that no evidence was identified on using baclofen for treating spasticity in adults with cerebral palsy and there is even limited evidence of effectiveness in	Thank you for your comment. The committee agreed that this was an error and added 'drug' before treatment. It is made clear elsewhere in the 'initial management of

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Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				children and young people, we urge for enteral baclofen NOT to be considered as a first-line treatment for generalised spasticity causing functional impairment, pain or spasms. We strongly recommend that the first line of treatment should be non-invasive, for example assessing whether the use of a person's own activity and routine change of position within maximum possible alignment has the potential to improve function, prevent or reduce pain and/or spasms. This will also aid to address and reduce risk of reduced respiratory function and infections, in addition to preventing possible side-effects from the medication.	spasticity and dystonia' section (recommendation 1.3.5) that the first step is to address any modifiable factors identified that may be exacerbating the person's spasticity or dystonia and review their physical management programme before discussing further management options with the adult with cerebral palsy. To review the physical management programme' was added since consultation to emphasise that this should be done prior to discussions about further management options. The related rationale and impact section was revised accordingly to emphasise this point.
Bobath Scotland	Short	43	Dec-21	Lack of recommendation for post-infiltration management; increased frequency physiotherapy and casting optimise the impact of BTX-A interventions. e.g. ref in Molenaers et al., 2013, J Child Orthop Nov;7(5) ; Love SC et al. (2010) Eur J Neurol Aug (17) suppl 2:9-37	Thank you for your comment. There was limited evidence (both in quality and quantity) for the use of Botulinum Toxin A injections and how they should be administered. The reference that is provided is related to children and therefore did not meet the inclusion criteria for our review of the evidence. We have now revised the research recommendation to include 'frequency of post-infiltration physiotherapy and casting' as an outcome so that this can be measured to inform future guidance.
Bobath Scotland	Short	44	28	The document refers to "selective dorsal rhizotomy" but we are assuming you mean to refer to "intrathecal baclofen"?	Thank you for your comment. This section has been redrafted and it no longer includes this text which did mistakenly refer to 'selective dorsal rhizotomy' rather than 'intrathecal baclofen'.
Bobath Scotland	Short	46	19	As acknowledged, assessment of 'problematic dystonia' is a specialist clinical area. It will always have some impact on functioning. We would urge that these adults are assessed by an experienced specialist team that can	Thank you for your comment. It is made clear elsewhere in the 'initial management of spasticity and dystonia' section (recommendation 1.3.5) the first step is to address any modifiable factors identified that may be exacerbating the

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				assess whether improvement can be achieved through non-invasive management before medication is considered.	person's spasticity or dystonia and review their physical management programme before discussing further management options with the adult with cerebral palsy. To review the physical management programme' was added since consultation to emphasise that this should be done prior to discussions about further management options. The related rationale and impact section was revised accordingly to emphasise this point.
Bobath Scotland	Short	50	24	Regular X-rays should be considered. Although the adult is not 'growing' we continue to see progression in back curves and hip alignment due to weakness, imperfect postural management, ageing etc.	Thank you for your comment. The committee agreed that because of abnormal musculoskeletal development, adults with cerebral palsy are more likely to have bone and joint disorders (see recommendation 1.4.6). However, it is known that over-exposure to x-rays is harmful and therefore ongoing surveillance was not considered appropriate unless the person is in pain or their posture or function is affected. We have made this more explicit in the 'committee's discussion of the evidence' section in the related evidence report.
Bobath Scotland	Short	52	28	Difficulties in eating and nutrition can also be linked with: • Difficulties in or changes in abilities to self-feed • Difficulties with or changes in abilities to prepare nutritious meals, (can be due to lack of knowledge, poor environmental set up, lack of opportunity to develop skills).	Thank you for your comment. The committee agreed that people with cerebral palsy should be asked whether there are 'changes in their ability to feed themselves' (see recommendation 1.4.17). They have also cross-referred to the NICE guideline nutrition support for adults which includes further examples of what to do to screen for malnutrition. The committee believed that 'changes in abilities to prepare nutritious meals' would be a subset of 'changes in their ability to feed themselves and it is also not an exhaustive list. Therefore the recommendation does not

Stakeholder	**Document**	**Page No**	**Line No**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
					preclude this being explored during a review if concerns are raised.
British Dietetic Association	General	-	-	We welcome this guideline and feel it starts to fill a vital gap in guidance for adults with CP who are very vulnerable nutritionally. We feel they will help raise awareness of the role of nutrition and its possible complications in CP; impacting patients' quality of life and raising awareness of nutrition symptoms e.g. reflux, vomiting, delayed gastric emptying, to other healthcare professionals. In response to the overriding questions: 1. **Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** We feel the area which will have the biggest impact is: a) Purchase and upkeep of the necessary equipment for weighing non-ambulant adults in the community would be of great use in the identification of changes in nutritional status and early intervention to prevent severe malnutrition. However the cost of the equipment, storage, training of staff in use and upkeep has a cost element that means that they are not universally available. Making them	Thank you for your comment. These barriers will be tackled by the accompanying NICE implementation tool. The committee did consider this issue but thought it was likely to be only isolated pockets where this equipment was not available (due to the fact that many older people with mobility problems may also need such equipment). With regard to the development of resource tools by your organisation, NICE routinely produce baseline assessment and resource impact tools. To encourage the development of other practical support tools, we run an endorsement scheme aimed at encouraging our partners to develop these in alignment with NICE recommendations. Eligible tools are assessed and if successful, will be endorsed by NICE and featured on the NICE website alongside the relevant guideline.

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				available will involve cost to community providers. 2. **Would implementation of any of the draft recommendations have significant cost implications?** Please see above – we are unsure how significant the cost of scales and hoists are. 3. **What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** Please see comments above – we would be keen to help to develop resources to make nutrition screening and implementation in this population easier for first line non-specialised professionals.	
British Dietetic Association	Short	General	General	We would suggest that the guideline recommends assessing patient's hydration status.	Thank you for your comment. This is not an area that was prioritised in the scope of this guideline. It was agreed that nutrition was a higher priority for people with cerebral palsy because of mobility issues that could affect digestion and as a side effect of medication. Hydration status is less specific to having cerebral palsy. It means that no evidence review was conducted and hence no recommendations could be made in relation to hydration status.
British Dietetic Association	Short	General	General	There is limited evidence around best practice for nutrition in CP, we therefore recommend that this guideline encourages further research into this area.	Thank you for your comment. The evidence review looked at the assessment and monitoring of nutritional status rather than the effectiveness of interventions or nutrition support. Therefore a search for evidence on 'best practice'

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					was not conducted. A research recommendation could therefore not be made.
British Dietetic Association	Short	6	01-Mar	Lack of access to equipment to weigh individuals with mobility difficulties is a huge barrier to effective nutrition monitoring and assessment so we welcome this issue being raised here. Lack of access to weighing hoists and wheelchair scales is widespread in community services, as well as sometimes in hospitals too. Question 1: How can this be best addressed?	Thank you for your comment. The committee believed that this recommendation reinforces current best practice and that where lack of equipment is creating a barrier the costs to overcome this would be outweighed by the savings from avoiding complications, injuries and maintaining a wider range of abilities. NICE also publish implementation tools in parallel with the guideline. Your comments will be considered by NICE where relevant support activity is being planned.
British Dietetic Association	Short	21-22	25-26, 1-2	We are concerned that use of BMI evaluation alone may lead to 1) under-recognition of obesity in individuals with proportionally lower muscle mass – as is commonly seen in individuals with cerebral palsy (this issue is highlighted in this article Peterson et al 2014 Obesity Misclassification and the Metabolic Syndrome in Adults with Functional Mobility Impairments: NHANES 2003–2006 (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3934754/): 2) Inability to evaluate individuals for whom it is not possible to measure height and or weight, which is commonly an issue for wheelchair users due to lack of appropriate weighing equipment (see previous comment). The first part of our concern may be mitigated by recommendation 1.2.2 in the linked NICE obesity guideline "Use BMI as a practical estimate of adiposity in adults.	Thank you for your comment. The committee agreed that the focus on BMI was too narrow and have revised this recommendation to now include 'anthropometric measures' to address these concerns. A definition of this is also provided in the section listing the 'terms used in the guideline'.

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				Interpret BMI with caution because it is not a direct measure of adiposity" Suggested recommendation (to encompass other anthropometry): Offer adults with cerebral palsy a regular weight check and BMI evaluation, nutritional screening using an appropriate validated screening tool or alternative anthropometry and identify people who may be at risk of undernutrition or obesity. Interpret BMI and other anthropometry with caution due to body composition differences in people with CP. Refer patients to a qualified dietitian for expert intervention on nutrition.	
British Dietetic Association	Short	21-22	25-26, 1-2	We are concerned that this recommendation overlooks micronutrient status. Common nutritional issues seen in adults with CP include vitamin D insufficiency and iron deficiency anaemia. Additionally adequate vitamin D and calcium intake are key in preventing fractures related to osteoporosis. We would suggest including the following additional recommendation: Assess dietary intake in adults with cerebral palsy, in particular calcium, vitamin D and iron alongside overall dietary adequacy. We are aware that first-line nutrition assessment and advice is complex in adults with CP and so could be challenging in practice. We would be really keen to work with NICE in developing an information sheet for adults and their families advising on adequate intake of these key	Thank you for your comment. The aim of this review was to identify any tools that could be used as a method of nutritional assessment for adults with cerebral palsy. The evidence was limited in quantity and quality. It was therefore not possible to be prescriptive about specific assessments. However, the details of generic nutritional assessment and monitoring (including laboratory monitoring of vitamin D) are covered in the NICE guideline on nutrition support for adults to which we cross refer. NICE routinely produce baseline assessment and resource impact tools. To encourage the development of other practical support tools, we run an endorsement scheme aimed at encouraging our partners to develop these in alignment with NICE recommendations. Eligible tools are assessed and if successful, will be endorsed by NICE and

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				nutrients that could aid first line advice and assessment, alongside an online training module for first line staff.	featured on the NICE website alongside the relevant guideline.
British Dietetic Association	Short	22	13-18	Recommendation 1.4.18 "Discuss if any of the following factors might be affecting the person's appetite, eating habits or weight" Clinical experience is that gastrointestinal symptoms such as; vomiting, bloating, diarrhoea, abdominal discomfort, reflux, delayed gastric emptying and particularly constipation are all major factors that contribute to reduced appetite in adults with CP. We suggest that this recommendation also includes the gastrointestinal symptoms mentioned above. We recognise that these could be encompassed in pain and/or medication side effects but as these symptoms, in particular constipation is so common in CP and can cause a loss of appetite even in the absence of pain, we feel they warrant inclusion.	Thank you for your comment. The list is not exhaustive and therefore not all gastrointestinal symptoms are captured as examples. However, the committee agreed that 'constipation' in particular was an important example to highlight and have amended this recommendation accordingly.
British Dietetic Association	Short	22	25	1.4.21 Refer adults with cerebral palsy to a relevant clinical specialist if assessment suggests they have difficulties with eating or malnutrition. We would suggested changing the recommendation to: Refer adults with cerebral palsy to a relevant clinical specialist if assessment suggests they have difficulties with eating, dysphagia or are at risk of malnutrition.	Thank you for your comment. We have revised recommendation 1.4.21 by adding two examples of 'relevant clinical specialist'. It now reads 'Refer adults with cerebral palsy to a relevant clinical specialist, such as dietitians and speech and language therapists, if assessment suggests they have difficulties with eating or malnutrition'. These specialist would then be able to assess oromotor and swallowing skills as well as nutritional factors.

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
British Dietetic Association	Evidence Review B4	11	41	“prevent ill health” after this, we would recommend including: by appropriately trained health care professionals e.g. Dietitian or speech and language therapist.	Thank you for your comment. This section of text describes why the committee made their recommendations. In response to your comment the guideline committee discussed this area and have changed recommendation 1.4.21 to "Refer adults with cerebral palsy to a relevant clinical specialist, such as dietitians and speech and language therapists, if assessment suggests they have difficulties with eating or malnutrition".
BSRM	Short	General	General	Deteriorating ability and reduced appetite With respect to deteriorating ability/reduced appetite a recognition of the higher SMRs for certain carcinomas in persons with CP	Thank you for your comment. If 'reduced appetite' was suggestive of malnutrition the committee decided that referral to specialist services is recommended (see recommendation 1.4.21). This would lead to further assessment. It is hoped that this may also have downstream effects on improving care for people with cerebral palsy with other conditions causing loss of appetite. However, specific reduction of standardised mortality rates for certain carcinomas in people with cerebral palsy was outside the scope of this guideline. The committee could therefore not directly comment on this.
BSRM	Short	General	General	In Accessing Services or Independent Living In accessing services (or Ind living) - an acknowledgment re sexual health/family planning and parenting. I certainly find the patient cohort I have seen in recent years has particular challenges to face in the sexual health/family planning/sex education arena.	Thank you for your comment. The committee agreed that sexual health/family planning/sex education are important topics but they were outside the scope of the guideline because they are not necessarily clinical problems. It has now been acknowledged as an important topic in the 'context' section of the guideline where the following text was added: Adults with cerebral palsy and associated comorbidities may have difficulties with all aspects of health and daily living. However, this guideline has not been able to look at the evidence and develop recommendation for all

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					areas of care. Areas that are not covered include bowel and bladder continence, sexual health and dental health. The principles of access to services, providing information and appropriate referral, discussed in the guideline, apply not only to areas directly addressed but also equally to other areas of care.' NICE is also currently developing a Quality Standard on sexual health which does not exclude any group with protected characteristics. The standards in this will therefore also be relevant to people with cerebral palsy.
BSRM	Short	12	16	Pain 1.3.3 General Comment: This is a really comprehensive document on the management of cerebral palsy in adults. It takes a very balanced approach on all treatments available for spasticity and dystonia. There is a cautious review of selective dorsal rhizotomy. The review of respiratory components was also very helpful. Here are some specific comments: Consider dental examination for dental caries as a cause of tooth ache/pain in people with learning disability with cerebral palsy.	Thank you for your comment. The committee agreed that dental examination is an important area but it was outside the scope of the guideline. However, the committee believes that this would fall into the remit of other guidelines that are specifically focused on dental care which mention 'physical and sensory impairments' and 'protected characteristics' and do not exclude people with cerebral palsy (such as the NICE guidelines oral health promotion: general dental practice, dental checks: intervals between oral health reviews and oral health for adults in care homes). Dental care is also mentioned in a NICE guideline on learning disabilities – see care and support of people growing older with learning disabilities (however since dental care was not one of the topics in the scope we could not directly cross refer to this).
BSRM	Short	13	-	Enteral Muscle Relaxants	Thank you for your comment. In recommendation 1.3.1 the committee highlight that a discussion should take place which should include information on 'the benefits and risks

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				When considering enteral muscle relaxants, caution patients and their carers about increasing dysphagia, particularly on escalating dosages of Baclofen	of treatments (for example, the risk of deterioration in function) as part of their multidisciplinary treatment strategy'. It is therefore assumed that the healthcare professional will explain adverse effects as part of the decision making on choosing treatments.
BSRM	Short	14	9	Botulinum Toxin Type A injections Consider the updated RCP guidelines from 20/03/2018 on dosages: https://www.rcplondon.ac.uk/guidelines-policy/spasticity-adults-management-using-botulinum-toxin Prior to injections of Botulinum Toxin, check that patients with cerebral palsy have not received Botulinum Toxin from another clinic within the previous three months (bladder botulinum Toxin or Salivary Botulinum Toxin).	Thank you for your comment. The committee recommended botulinum toxin type A treatment if a tone management specialist agrees that treatment targeted to focal muscle groups is likely to improve function and symptoms (see recommendation 1.3.11). The committee could not cover the details of all of the considerations in relation to this treatment but it was agreed that a tone management specialist in their assessment of whether or not it is likely to improve function would explore whether it was previously used.
BSRM	Short	14-15	-	Neurosurgical treatments Consider a high risk anaesthetic assessment in advance of intrathecal baclofen pump surgery, in patients with respiratory dysfunction.	Thank you for your comment. This is a specialised treatment which would take place after assessment in a tone or spasticity management service (recommendation 1.3.12). It is also recommended to 'Refer adults with cerebral palsy and persistent or multiple signs and symptoms of respiratory impairment, or risk factors for respiratory impairment (see recommendations 1.4.22 and 1.4.23) to specialist services' (recommendation 1.4.24). The committee therefore agreed that all the relevant specialists would be involved in relation to this particular case. However, they decided it is too specific for this to be added as a new recommendation.
BSRM	Short	27	-	Advanced Care Plan	Thank you for your comment. We have now emphasised in the related evidence review that such planning needs to

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Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	**Document**	**Page No**	**Line No**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
				Consider the use of a hospital passport, particularly in people with cerebral palsy and learning disability: http://www.easyhealth.org.uk/sites/default/files/null/Health%20Care%20Passport%20-%202017.pdf	take account of the individual's abilities and difficulties and have added a link to the hospital passport into the related evidence review (committee's discussion of the evidence section). It was also added that, even though the details of care planning are outside the scope of the guideline, the committee have cross-referenced the NICE patient experience in adult NHS services to highlight general principles in supporting people to actively participate in their care and shared decision-making.
BSRM	Short	33	1	Screening Another specific example is difficulty performing cervical screening in patient with cerebral palsy and lower limb spasticity.	Thank you for your comment. We have added this as another example to this section as suggested.
BSRM	Short	42	10	Enteral Muscle Relaxing Drug Treatments Page 42/60 line 10 In the drug treatments for spasticity, there was support for enteral Baclofen as a first line treatment for spasticity. There was no evidence for any other medicines. Could second line treatments be one of the key recommendations for research?	Thank you for your comment. The committee recommended that further treatment options (which would not necessarily be second line drug treatments) would be provided after referral to specialist services. The committee decided not to prioritise second line drug treatment for further research since these drugs have different benefits and harms profiles and would need to be tailored to the individual. It was agreed that further research was unlikely to change this conclusion at the moment and therefore other research was considered to have a higher priority.
BSRM	Short	46	-	Enteral anti-dystonic drug treatments Similarly, for dystonia there was limited evidence on treating dystonia in adults with cerebral palsy. Could first and second line enteral treatments be one of the key recommendations for research?	Thank you for your comment. The committee recommended that further treatment options (which would not necessarily be second line drug treatments) would be provided after referral to specialist services. The committee decided not to prioritise second line drug treatment for

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					further research since these drugs have different benefits and harms profiles and would need to be tailored to the individual. It was agreed that further research was unlikely to change this conclusion at the moment and therefore other research was considered to have a higher priority.
LTHT	Short	5	30	1.1.7 a major barrier is likely to be lack of (eg vocational rehab) or inadequate provision of specialist rehab services to be able to deliver these recommendations in a timely manner. This should be in main recommendation section too.	Thank you for your comment. This section is specifically related to service organisation and access to primary and secondary care. We have reworded and divided recommendation 1.1.7 into two separate recommendations to highlight particular types of barriers to accessing services and how they may be overcome (see recommendation 1.1.7 and 1.1.7). The committee agreed that vocational rehabilitation was an important aspect in the lives of people with disabilities and the committee dedicated a separate section to this matter (see recommendations 1.2.8 to 1.2.13). They therefore believed that this was sufficiently covered and that repeating recommendations in different sections would be confusing for readers.
LTHT	Short	13	9	1.3.7 It is debatable if we leave medication titration to GP and patients' discretion depending on dose response to achieve optimum dose in a timely manner	Thank you for your comment. This is a recommendation consistent with standard information in the British National Formulary BNF). This is described in the rationale and impact section that is related to this recommendation. The committee agreed that it was clear that this recommendation is for the prescribing healthcare professional rather than the patient because they would not start 'themselves' on any starting dose. This would be prescribed for them in line with standard instructions.

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
LTHT	Evidence not found	General	General	No guidelines found for contraceptive methods, menstrual suppression and pregnancy management	Thank you for your comment. The committee agreed that contraceptive methods, menstrual suppression, in particular, are important topics but they were outside the scope of the guideline because inclusion of these would imply that these topics would always be clinical issues requiring re-assessment by a multidisciplinary team. However, the committee agreed that 'pregnancy and parenting' is a topic that requires clinical consideration and have now added this to recommendation 1.1.3 as examples of a changing need that can lead to re-assessment by a multidisciplinary team.. However, we could not comment in detail about the sexual health and sexuality because no specific evidence review was conducted that addressed this. NICE is also currently developing a Quality Standard on sexual health which does not exclude any group with protected characteristics. The standards in this will therefore also be relevant to people with cerebral palsy.
LTHT	Evidence E1	General	General	No guidelines for bowel, bladder management	Thank you for your comment. We searched for evidence on assessment of gastrointestinal issues but did not find any, so this area was omitted from the original recommendation. Having discussed your comment the committee agreed that bowel function can influence nutritional status and have updated recommendation 1.4.17 to ask adults with cerebral palsy at every review if there have been any changes in bowel function or any issues with constipation. We did not search for evidence on bladder function or urinary incontinence: the committee noted existing NICE guidance

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					on urinary incontinence in neurological disease and prioritised other areas for evidence review. The guideline recommends assessment of bladder problems as a potential contributory factor to spasticity or dystonia in recommendation 1.3.3. The treatment of bowel or bladder problems (once identified) was not prioritised for coverage within this guideline, a paragraph has been added to the context section to explain why we did not cover bowel and bladder continence. This states that the principles of ensuring access to services, providing information, and referring when appropriate discussed in the guideline would apply equally to bowel and bladder continence.
LTHT	Evidence D1	5	16	Links to community accessible facilities for leisure and support groups	Thank you for your comment. This table is a summary of the review protocol which sets out how we searched and reviewed the published evidence for this topic. The committee acknowledged the importance of accessible facilities (see the section of the short guideline - vocational and independent living skills).
LTHT	Evidence C3	General	General	No specific guidelines for skin care and skin pressure ulcer prophylaxis	Thank you for your comment. The issues of skin care and skin ulcer prophylaxis were not prioritised for coverage within this guideline. A paragraph has been added to the context section of the short guideline noting that adults with cerebral palsy and associated comorbidities may have difficulties with all aspects of health and daily living. This guideline has not been able to look at the evidence and develop recommendation for all aspects of having cerebral palsy. The principles of ensuring access to services, providing information, and referring when appropriate discussed in the guideline would apply equally to those

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Stakeholder	**Document**	**Page No**	**Line No**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
					areas of health and daily living which we have not been able to cover in detail.
LTHT	Evidence C1	12	13	No specific advice on secretion management, dental hygiene, special dentistry care management	Thank you for your comment. In the sections on 'difficulties with eating and nutritional problems' and 'respiratory disorders' reference is made to referral to a speech and language therapist in case initial assessment identifies problems with swallowing or eating (see recommendation 1.4.21 and 1.4.29) it is also then explained in the rationale and impact section that 'Effective swallowing (and saliva control) is important to prevent respiratory infections in adults with cerebral palsy' and that therefore referral to a dysphagia-trained speech and language therapist should be considered. The committee agreed that dental health is an important area but it was outside the scope of the guideline. However the committee believes that this would fall into the remit of other guidelines that are specifically focused on dental care which mention 'physical and sensory impairments' and 'protected characteristics' and do not exclude people with cerebral palsy (such as the NICE guidelines oral health promotion: general dental practice, dental checks: intervals between oral health reviews and oral health for adults in care homes). Dental care is also mentioned in a NICE guideline on learning disabilities – see care and support of people growing older with learning disabilities (however since dental care was not one of the topics in the scope we could not directly cross refer to this or the other guidelines mentioned above).

Stakeholder	**Document**	**Page No**	**Line No**	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
LTHT	Evidence Review B1	11	11	No specific details about contracture management. Needs a specific plan for post surgical rehabilitation plan	Thank you for your comment. This issue was covered in evidence report D2. The committee noted that the evidence for orthopaedic surgery was very low quality with uncertainty around the outcomes. For this reason, the committee did not make a strong recommendation for orthopaedic surgery, instead they recommended considering referral to a specialist orthopaedic surgeon with experience and expertise in managing musculoskeletal pain in adults with cerebral palsy, if participation in physical activities is limited by pain or joint problems resistant to other measures. The committee noted that there is currently limited access to orthopaedic surgeons with expertise in cerebral palsy. Based on their knowledge and experience the committee agreed that a general orthopaedic surgeon may refer adults with cerebral palsy onwards to others with specific technical expertise (for example hip arthroplasty) within regional networks, but the referring surgeon would usually look after the rehabilitation aspects.
LTHT	Evidence A1	14	2	Botulinum toxin is commonly administered by rehabilitation medicine specialist in the outpatient clinic	Thank you for your comment. This has now been noted in the relevant section.
LTHT	Evidence A1	22	15	Combination treatment of oral anti spasticity agents not discussed	Thank you for your comment. There was insufficient evidence to recommend specific combination enteral anti-spasticity treatments. However recommendation 1.3.8 acknowledges that if enteral baclofen is ineffective or not tolerated by adults with cerebral palsy and generalised spasticity, other drug treatment options could be discussed with a tone management specialist. These options could include combination treatment if appropriate.

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Medtronic Ltd	Short	General	General	As the search criteria was limited to cerebral palsy, some key papers on ITB in broader spasticity treatment have been excluded. The ITB cerebral palsy literature on its own is limited, as noted in the review. The recent SISTERS RCT may be relevant to the evidence review. ***Creamer M, Cloud G, Kossmehl P, et al. J Neurol Neurosurg Psychiatry 2018;89:642–650.***	Thank you for your comment. When planning the literature searches the committee agreed that the guideline should be based on evidence from studies in adults with cerebral palsy. For this reason studies like the SISTERS trial were not included, because they were not done in adults with cerebral palsy. The SISTERS trial was also published after our literature searches had been completed and so was not listed as an excluded study.
Medtronic Ltd	Short	General	General	The following recently published RCT may be relevant to your evidence review. The study is an11-year retrospective assessment of procedure-and device-related complications after implantation of an ITB-pump in a large patient cohort. ***Pucks-Faes E, Hitzenberger G, Matzak H, et al. Eleven years' experience with Intrathecal Baclofen – Complications, risk factors. Brain Behav.2018;8:e00965. https://doi.org/10.1002/brb3.965***	Thank you for your comment. This study was published after our literature searches had been completed and so was not listed as an included or excluded study in the guideline. However, the findings of study are consistent and would support our conclusions and recommendations.
Medtronic Ltd	Short	4	1	Should this read "prescribing medicines ***and medical technologies*** (including off-label use)"?	Thank you for your comment. This standard paragraph is related to making decisions using NICE guidelines and the link is to a webpage with specific information about this and prescribing. The webpage does not include information about medical technologies so including 'medical technologies' would be inconsistent with the content. We have therefore not made this change.
Medtronic Ltd	Short	14	16	Section 1.3.13: we suggest the addition of an additional bullet point – "setting patient specific goals to be achieved with ITB treatment" as therapeutic goals are patient specific and should be determined in advance.	Thank you for your comment. The whole section on 'managing abnormal muscle tone' starts with a recommendation on agreeing goals for treatment'. This is intentionally an overarching recommendation because this

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Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					should be the first step throughout the management process. The committee, however, agreed that an additional recommendation is needed in the intrathecal baclofen section to specifically highlight in the context of the intrathecal baclofen test. They have therefore rephrased a recommendation 1.3.16 in this section to read 'Discuss with the adult with cerebral palsy (and their family and carers, if agreed) their views on the response to the intrathecal baclofen test and the likelihood of achieving their treatment goals' to explicitly capture this.
Medtronic Ltd	Short	14	26	"A review of 24 hour postural needs" – we are unclear why this has been listed in the Intrathecal Baclofen section as it's not specific to ITB. It is unclear why this statement is underlined?	Thank you for your comment. Posture is mentioned in one of the overarching recommendations in the first section related to this topic. The committee decided that a specific review of 24 hour postural needs' is particularly important for intrathecal baclofen pumps since this is an invasive procedure and the 'review of 24 hour postural needs' will provide information about whether or not it is a suitable treatment option. It is underlined because there is a definition for this in the 'terms used in this guideline' section to which it is hyperlinked.
Medtronic Ltd	Short	48	26	The guidance states that "DBS is expensive". We suggest that this statement be removed as there is no reference to what it is being compared to. The most relevant factor is cost effectiveness as the guidance goes on to discuss.	Thank you for your comment. This sentence has been removed.
NHS England	General	General	General	The draft guideline is comprehensive around the needs of adults with cerebral palsy and it is easy to read too. There are numerous references to assessments, reviews and referrals. Some are clearly in the domain of primary care	Thank you for your comment. The committee agreed that there is variation in practice in access to assessments, reviews and referral. It was decided that they needed to promote equality in access to services for adults with

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				and some clearly in the domain of specialist care. However, I am concerned that it is not clear in all the guidance where or to whom the responsibility ideally lies to either carry out the assessment, review or referral. Adults could get lost between services. There may be a need for commissioners to consider an integrated care pathway. (RP)	cerebral palsy. It was therefore recommended that 'commissioners and service providers should develop pathways that allow adults with cerebral palsy access to a local network of care' (recommendation 1.1.4) so that care can be tailored to each person. The committee could not be prescriptive about who should carry out the assessment, review or referral because people with cerebral palsy have a wide range of needs and therefore the individual health or social care professional would vary. The committee further noted that transitions to adult services are managed in line with other NICE guidelines which should ensure that young adults would not get lost between services. The committee agreed that this was sufficiently covered in the current version of the guideline.
NHS England	General	General	General	Overall this guideline is welcomed however the availability of sufficient suitably trained AHPs with specialist Skills in the management of adults with cerebral palsy may make adherence to the guideline a challenge (SC)	Thank you for your comment. The committee acknowledged that a number of these recommendations would increase demand on Allied Health Professionals and this has been acknowledged in the rationale and impact section where appropriate. The committee wanted to emphasise that the recommendations refer individuals to services which are already established (with skills in general management of neurodisabilities) and that a major component of the rationale for these recommendations is establishing equality in access to these services in line with the Human Rights Act 1998 and the Equality Act 2010. Both of these have been extensively referenced throughout the rationale and impact sections.

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
NHS England	General	General	General	The provision of appropriate communication aids for this client group is an issue, commissioners may struggle to meet the financial burden this places on resources and should be assessed (SC)	Thank you for your comment. The committee recognised that this recommendation is likely to lead to additional costs as highlighted in the rationale and impact section. The committee appreciated that there was a paucity of clinical and economic evidence for this recommendation and made a relatively weak 'explore' recommendation. The committee also made a research recommendation to investigate both the clinical and cost effectiveness of augmentative and alternative communication systems reflecting both the uncertainty and importance around this recommendation.
NHS England	Short	4	17	1.1.4 We would welcome acknowledgement of Speech and Language Therapy and Dietetics within this section due to the challenges that are associated with adults gaining such support for both their associated communication issues and management of dysphagia, these issues with access are often greatest for adults without an associated learning disability (SC)	Thank you for your comment. We have added a 'speech and language therapy and dietetics' as further examples to recommendation 1.1.4. Dietitians and speech and language therapists are also noted in recommendation 1.4.21 as relevant clinical specialists to refer to if assessment suggests adults with cerebral palsy have difficulties with eating or malnutrition.
NHS England	Short	6	6	1.1.8 Staff should be aware of any communication strategies being used by the adult with CP, and ensure these are used to enable effective communication to take place (SC)	Thank you for your comment. The section on communication specifically highlights how some of the difficulties with speech intelligibility and communication can be addressed. General advice on how to provide information and communicate with adults receiving care, including those with disabilities, is provided in the NICE guideline on patient experience in adult NHS services, which is signposted in the guideline (see recommendation 1.2.7).
NHS England	Short	8	9	1.2.5 is particularly welcomed however the challenges associated with access to funding to supply equipment as	Thank you for your comment. The committee identified that there was likely to be additional costs, at least in the short term, from this recommendation. The committee

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Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				prescribed/recommended as a resultant outcome of these needs assessments need to be addressed (SC)	recognised there was a paucity of evidence comparing intensive speech and language therapy to augmentative and alternative communication aids. The committee therefore made a relatively weak 'explore' recommendation. The committee also made a research recommendation to investigate both the clinical and cost effectiveness of augmentative and alternative communication systems possibly compared to or in addition to intensive speech and language therapy reflecting both the uncertainty and importance around this recommendation. The alternative to either approach was essentially 'no treatment' which was not identified as clinically acceptable. We have added that the recommendations support compliance with the fundamental rights of people with disabilities to freedom of expression and opinion, and access to information as set out in Article 21 of the UN Convention on the rights of persons with disabilities to the rationale and impact section. We have also added to the 'how the recommendations might affect practice' section that, the benefits of being able to communicate would outweigh the additional costs of increased use of augmentative and alternative communication systems. Further information about this can be found in the related evidence review which also includes the characteristics of the research that is proposed.
NHS England	Short	9	13	1.2.11 This vague global statement will be difficult to monitor and may lead to issues for commissioners in meeting the resultant demand for services. (SC)	Thank you for your comment. The committee noted that finding out what adults with cerebral palsy would like to do as a 'chosen' activity is not routinely done in current practice. They recommended that if possible any factors

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					that could be addressed should be. We have re-ordered this section to move this recommendation to the beginning of the section to emphasise that this should be done before any referral is made (recommendation 1.2.9). Referral could then be monitored and audited.
NHS England	Short	10	8	1.2.14 – what are these services, and who should be providing them (SC)	Thank you for your comment. These services and commissioning for these services is described in an NHS England document on service specification for 'Environmental Control Equipment for Patients with Complex Disability (All Ages)'. A reference to this is made in the 'rationale and impact' section.
RCGP	General	General	General	An impressive document (short form) looking at best practice for a group in society who are living longer with complex and multiple needs. There may be handicapping conditions involving sight, hearing, movement, and behaviour. There may be associated learning disability The best practice here is wide ranging and thoughtful in considering the person, family and care team where services struggle and are limited.	Thank you for your comment.
RCGP	General	General	General	Attention should be drawn to the possibilities of and keeping in employment and of access to continued education	Thank you for your comment. The committee agreed that this is important and therefore covered this in recommendations 1.2.13 to which we have now also added 'continued education'.
RCGP	General	General	General	There is also the difficult area of sexual needs, masturbation, intercourse, contraception, pregnancy and care for a young child	Thank you for your comment. The committee agreed that the topic of sexual needs is important. This was outside the scope of the guideline because including it would imply that sexual needs of people with cerebral palsy would always be a clinical issue. However, the committee agreed that 'pregnancy and parenting' is a topic that requires clinical

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					consideration and have now added this to recommendation 1.1.3 as examples of a changing need that can lead to re-assessment by a multidisciplinary team. It has now been acknowledged as an important topic in the 'context' section of the guideline where the following text was added: Adults with cerebral palsy and associated comorbidities may have difficulties with all aspects of health and daily living. However, this guideline has not been able to look at the evidence and develop recommendations for all areas of care. Areas that are not covered include bowel and bladder continence, sexual health and dental health. The principles of access to services, providing information and appropriate referral, discussed in the guideline, apply not only to areas directly addressed but also equally to other areas of care.' NICE is also currently developing a Quality Standard on sexual health which does not exclude any group with protected characteristics. The standards in this will therefore also be relevant to people with cerebral palsy.
RCGP	General	General	General	Dental care is important and oral hygiene, controlled sweet eating, oral hygiene regular checks and conservative care are part of the spectrum of holistic care.	Thank you for your comment. The committee agreed that dental health is an important area but it was outside the scope of the guideline. However, the committee believes that this would fall into the remit of other guidelines that are specifically focused on dental care which mention 'physical and sensory impairments' and 'protected characteristics' and do not exclude people with cerebral palsy (such as the NICE guidelines oral health promotion: general dental practice, dental checks: intervals between oral health

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					reviews and oral health for adults in care homes). Dental care is also mentioned in a NICE guideline on learning disabilities – see care and support of people growing older with learning disabilities (however, since dental care was not one of the topics in the scope we could not directly cross refer to this or the other guidelines).
RCGP	General	General	General	The epidemiology of this CP population detailing demography, handicap and disability is essential to planning and resourcing services	Thank you for your comment. The planning and resourcing related to this guideline's recommendations is the responsibility of local commissioners. It is therefore outside the scope of this guideline.
RCGP	Short	6	13	It is important to consider advanced care planning and emergency treatment plans as well as holidays and respite care. The person should be encouraged to consent to enhanced summary care records to allow fuller information to available to out of hours care providers in the care. This allows • improve the flow of information across the health and care system • increase safety and efficiency • improve care • respond to particular challenges such as winter pressures https://digital.nhs.uk/services/summary-care-records-scr/additional-information-in-scr	Thank you for your comment. The committee agreed that this is an important aspect of care. General care, advance care or emergency planning were outside the scope of this guideline because they are not specific to people with cerebral palsy. The committee did include a reference to advance care planning and a definition of it in the guideline in relation to respiratory failure which is a life limiting / threatening condition. They agreed that in this context it would be important to highlight that this would be a necessary component of care.
RCGP	Short	7	16	1.1.16	Thank you for your comment. Whilst the committee generally agree with this comment, the specific content and

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				During the annual health checks there needs to specific emphasis in the history taking and examination on certain clinical systems as this systematic review highlights the increased prevalence of certain long term conditions https://academic.oup.com/fampra/advance-article-abstract/doi/10.1093/fampra/cmy027/4989145?redirectedFrom=fulltext Compared to the general population, adults with CP had higher rates of seizure disorder, obesity and asthma across all ages. Adults with CP under 30 years of age had higher rates of hypertension (16.7 versus 5.6%; *P* = 0.04), urinary incontinence (41.7 versus 10.5%; *P* < 0.001) and depression (16.7 versus 6.9%; *P*= 0.07). Conversely, there were lower rates of alcohol misuse, tobacco/nicotine and sexually transmitted illnesses. Independence with all activities of daily living decreased from 37.5% at 18–29 years of age to 22.5% in those 60 and over. Seizure disorders, urinary incontinence and gastroesophageal reflux disease were all independently associated with lower functional status Adults with CP should be monitored for conditions occurring at higher prevalence in CP, as well as common conditions occurring with advancing age. Age-related functional decline should be anticipated, especially with coexisting seizure disorders and urinary incontinence.	information was outside of the scope of the guideline. The committee agree that this should be included in local protocols. The included reference did not feature as part of the evidence since it did not directly relate to any of the review protocols. However, the rates provided in this report are now used by NICE to estimate the resource impact of some of the recommendations that are made.
RCGP	Short	8	22	It is important to ask adults with CP what they enjoy doing and consider ways to minimise boredom to help with	Thank you for your comment. We have re-ordered the recommendations in 'vocational skills and independent

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				person centred care. This allows us helps to recognise the quality of someone life. When we look are ill people, we can make biased assumptions based on someone's appearance and not recognise the quality of their life and that they are someone's brother, sister, cousin etc.	living' and have revised recommendation 1.2.9 to 'Ask adults with cerebral palsy what they enjoy doing and if they find it difficult to participate in a chosen activity, assess their physical and mental health and address any factors identified that may be affecting participation, if possible' to put more emphasis on the person's choice in this. Some topics around assumptions and family life are covered in the 'access to services' section. We have revised this section to include possible solutions to potential barriers, such as 'staff training to overcome communication difficulties' and 'providing support to help with social and emotional factors such as fear of stigma, lack of motivation and exhaustion' (see recommendation 1.1.8). Reasons for these recommendations are described in the rationale and impact sections in the short version of the guideline and the committee discussion of the related evidence reviews provides a further summary of the discussion that led to these recommendations (see evidence report D1 and F2).
RCGP	Short	10	1	Electronic assistive technology section needs expanding to include the range of technologies available including wireless phones chargers, intelligent wheelchairs https://upcommons.upc.edu/bitstream/handle/2117/7102/getPDF.pdf;sequence=1 and robotics legs https://zyrobotics.com/tag/cerebral-palsy/	Thank you for your comment. We looked for evidence for the effectiveness of any electronic assistive technology but did not identify any. The two references that are highlighted are not specifically designed to address the effectiveness of these electronic assistive technologies because they are descriptive studies. The committee therefore could not make specific recommendations related to these. However, they have recommended in 1.2.15 that 'If adults with

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
				Artificial intelligence has huge potential with people with CP https://onlinelibrary.wiley.com/doi/full/10.1111/dmcn.13942 Alexa or Google Home Someone who has a very bad speech impediment or who is difficult to understand might find these frustrating. These devices can control most lights, television, music and even lock and unlock doors by using Alexa. Every day new actions are available for Alexa to do.	cerebral palsy have complex physical, cognitive, language or sensory needs, consider referring them to services providing information, assessment and provision of electronic assistive technology'. Newer technologies could feature in such considerations.
RCN	General	General	General	The RCN would like to confirm that we do not have any comments to submit for the above consultation on this occasion. Thank you for the opportunity to participate.	Thank you for your comment.
RCOT	Short	General	General	The RCOTSS_NP welcomes the introduction of a guideline to support people living with cerebral palsy. While the document is easy to read there are some concerns about the lack of evidence to inform this guideline and the reliance on good practice definitions by the Guideline Development Group.	Thank you for your comment. It is true that little evidence was uncovered for many topics in the guideline. Therefore it was difficult to make strong recommendations for particular treatments and assessment tools. However, the committee noted that there was wide variation in practice and in particular in access to services for people with cerebral palsy. The guideline aimed to standardise care and to promote equality of access. The committee acknowledged that there were gaps in the evidence and therefore made research recommendations to encourage the collection of further data to inform future guidance. Reasons for why the committee has or has not made

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					research recommendations are described in the 'rationale and impact' sections in the short guideline and in the 'committee discussion sections' in the evidence reviews.
RCOT	Short	4	14	1.1.3 While there is reference to adults with cerebral palsy the emphasis is undoubtedly on those transitioning to adult services. There is a lack of acknowledgement of the needs of adults ageing with cerebral palsy, a relatively new and poorly understood group at this stage.	Thank you for your comment. Although we have made a specific recommendation related to transitioning from children's to adult services (see recommendation 1.1.1), we have acknowledged the potential issues related to cerebral palsy and the aging process throughout the guideline. We have revised recommendation 1.1.3 to address more clearly when re-assessment should take place 'at different points in their lives to ensure that their changing needs are met (for example decreased mobility due to hip arthritis, pregnancy and parenting, loss of care support from an elderly parent).' The committee did not want to be too prescriptive about 're-assessment' because there are many changing needs that would lead to this. However, the guideline has sections on assessment and monitoring of a number of common conditions that adults with cerebral palsy can experience (see section 1.4 and its subsections) during their life and into old age. These subsections then include recommendations on referral for these conditions which would lead to re-assessment by specialists. The committee therefore decided that no additional change was required.
RCOT	Short	9	13	The RCOT would like to include specific reference to referral to "an occupational therapist" to assess physical and mental health and address key factors identified that may be affecting participation.	Thank you for your comment. We have now added to recommendations 1.2.12 and 1.2.13 an occupational therapist as an example of 'a professional with expertise in vocational and independent living skills'. However, this can be delivered by other professionals and there was

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					insufficient evidence to justify the cost of restricting this to 'specialist occupational therapy services'.
RCOT	Short	9	16	1.2.12 Some areas of the UK has adopted Universal Credit and it is being rolled out further. We would welcome inclusion of work coaches in job centres to support with vocation.	Thank you for your comment. We have now revised the first bullet point in recommendation 1.2.12 to 'Job-seeking or access to work schemes' to address your point.
RCOT	Short	9	17	While reference is made to "a professional with expertise in vocational and independent living skills" the RCOT would welcome the specific inclusion of occupational therapy within this context.	Thank you for your comment. We have now added to recommendations 1.2.12 and 1.2.13 an occupational therapist as an example of 'a professional with expertise in vocational and independent living skills'. However, this can be delivered by other professionals and there was insufficient evidence to justify the cost of restricting this to 'specialist occupational therapy services'.
RCOT	Short	9	20	1.2.12 'Access to work' is a specific government scheme to support people with disability in employment. Is the guideline referencing this scheme specifically or talking about schemes to support people with job seeking? We would suggest that this is clarified and that both are mentioned. Job seeking support for people with disability may be via the job centre, charity providers or vocational rehabilitation services.	Thank you for your comment. We have now revised the first bullet point in recommendation 1.2.12 to 'Job-seeking or access to work schemes' to address your point.
RCOT	Short	10	21	We would like to suggest reference to "health and wellbeing" instead of "physical and mental health".	The committee wanted to emphasise that physical activity not only improves physical but also mental health. They decided to keep the wording as it is because 'wellbeing' is part of 'health' and therefore it would be difficult to delineate the two whereas physical and mental health is conceptually clearer and would be more readily understood.

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
RCOT	Short	20	24	1.4.12 We would suggest the inclusion of anxiety, sleep and fatigue in the bullet point examples	Thank you for your comment. Anxiety is already covered in recommendation 1.4.10 which cross references other NICE guidance. However, we have added 'sleep' to the list of examples in recommendation 1.4.12. It is not an exhaustive list and therefore fatigue could feature in discussions if the person has particular concerns related to this.
RCOT	Short	29	1	Review of 24-hours postural needs, please consider adding the additional text "considering postures to allow for participation in daily activities."	Thank you for your comment. We have amended this definition accordingly.
RCSLT	Short	4	11	While these listed factors are important, we believe it may be better phrased to change the following to capture that MDT management may be required as a lifestyle is changing therefore we propose amendment of this line to the following: - their ability to carry out their daily activities changes as a result of deterioration or change in lifestyle	Thank you for your comment. In this specific section the committee's aim was to set out some general principles for service organisation and access to services. The two bullets in the recommendations highlight when referral to a multidisciplinary team experienced in the management of neurological impairments should take place. The committee intentionally stated 'their ability to carry out their usual daily activities deteriorates' because it would be deterioration that would need assessment rather than 'changes in abilities that are caused by lifestyle changes'. The committee believed that the term 'lifestyle changes' could be open to misinterpretation since potentially any change (such as buying a car) could be a lifestyle change and impact on abilities but not all such lifestyle changes would require assessment by a multidisciplinary team. They therefore kept the recommendation as it is.
RCSLT	Short	5	8	Include suggestion of speech and language therapy	Thank you for your comment. We have added speech and language therapy services to one of the bullet points.

Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
RCSLT	Short	8	Sep-13	This list of reasons for referral to speech therapy appears quite restrictive. Other reasons to assess their need include: - voice therapy - communication partner training - Language therapy (Binger & Light, 2008).	Thank you for your comment. The committee already recommend intensive speech therapy to improve speech intelligibility (see recommendation 1.2.6) and training of communication partners is addressed in relation to alternative and augmentative communication systems in recommendation 1.2.4. The reference that is highlighted was not included as evidence because it is not specifically related to the effectiveness of interventions to improve speech and language of adults with cerebral palsy.
RCSLT	Short	9	2	Add - communication barriers	Thank you for your comment. In this section the committee wanted to specifically highlight factors that may affect vocational and independent living skills. The committee agreed that communication is a particularly important factor and possible barrier to accessing services. They therefore highlighted this specifically in the more general recommendation related to barriers in the first section of the guideline (see recommendation 1.1.8) and there is also a specific section of the guideline dedicated to communication (recommendations 1.2.1 to 1.2.7). The committee did not want to repeat this in every subsection of the guideline because they thought that this could be confusing to the reader.
RCSLT	Short	10	5	Suggestion to add caveat that smart/ high-tech assistive technology is likely to need reviewing/updating on a much more regular basis than an annual review- therefore service should be available to assist at these times.	Thank you for your comment. Recommendation 1.2.14 referred to discussion about the equipment and potential changes in need at 'every review'. The minimum is an 'annual review' for people with cerebral palsy and complex needs. However, the committee also recommended that a referral can be made anytime as long as 'their ability to carry out their usual daily activities deteriorates' which

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
					would be the case if their technology no longer functions correctly (see recommendation 1.1.2). The committee decided that they could not be more specific in relation to smart / high-tech assistive technology because no evidence was identified that was applicable to the related review question.
RCSLT	Short	22	25	We recommend inclusion of referral to particular professionals in this guideline e.g. - speech and language therapy for difficulties with eating related to swallow (dysphagia) - dieticians for difficulties with nutrition - Occupational therapist for sensory difficulties	Thank you for your comment. We have revised recommendation 1.4.21 by adding two examples of 'relevant clinical specialist'. It now reads 'Refer adults with cerebral palsy to a relevant clinical specialist, such as dietitians and speech and language therapists, if assessment suggests they have difficulties with eating or malnutrition'. These specialists would then be able to assess oromotor and swallowing skills as well as nutritional factors. The occupational therapist is now mentioned as an example in the section on vocational and independent living skills and the committee decided that examples of the main specialist in the section on 'difficulties with eating and nutritional problems' would be speech and language therapists and dietitians. However, these are only examples and not an exhaustive list. If an occupational therapist is needed by a particular person with cerebral palsy in relation to eating and nutrition, then this recommendation does not preclude this.
RCSLT	Evidence Review D4 - Interventions that	General	General	In this document related to communication, more could be said with regard to adaptations/modifications/-- ongoing assessment related to communication aids.	Thank you for your comment. The committee recognised the changing nature of communication needs in adults with cerebral palsy. They recommended awareness of the possibility of changing communication needs, and that people with cerebral palsy and their families and carers

Cerebral Palsy in Adults

Consultation on draft guideline - Stakeholder comments table
16/07/18 to 28/08/18

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	improve function and participation: communication				should be asked at each clinical review about any changes in hearing, speech or communication. Our searches found no evidence about adaptations or modifications to communication aids, however the committee recommended referral to speech and language therapy services to assess the need for intervention, which might include such adapted or modified communication aids.
RCSLT	Evidence Review B3 - Assessing and monitoring complications and comorbidities: feeding and nutritional problems	General	General	The document relating to feeding could be strengthened in the area of dysphagia---(Perhaps that should be in the title of that document as well) and referral to speech and language therapy particularly if there are chest infections or the individual is having more difficulty with swallowing and choking.	Thank you for your comment. The guideline committee discussed this and have changed recommendation 1.4.21 to "Refer adults with cerebral palsy to a relevant clinical specialist, such as dietitians and speech and language therapists, if assessment suggests they have difficulties with eating or malnutrition".