Cerebral palsy in under 25s: assessment and management

Consultation on draft guideline - Stakeholder comments table
8 August – 20 September 2016

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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
Action Cerebral Palsy	Full	General	General	There are two principal concerns that we wish to raise in this response: 1. A fundamental consideration of the guideline should be on the importance of an accurate understanding of the nature and site of the brain injury sustained and its implication on developmental prognosis, intervention and education. 2. While Action Cerebral Palsy (ACP) are aware that NICE has previously issued guidance on spasticity in under 19s, we do not believe these cerebral palsy guidelines adequately take into account "optimising movement and posture for optimal activity and participation" for non-spastic presentations of cerebral palsy (CP), which make up 20-30% of CP diagnoses. A concern across the document is that too little attention is paid to therapeutic inputs, (e.g. physiotherapy, conductive education and postural management), in relation to motor skills for children with non spastic presentations in two respects. First, from the perspective of improving immediate functionality and mobility; and second, in avoiding potentially unnecessary surgery or other interventions in future. Also, there is scant mention of upper limb functional difficulties for this group. We believe that this consultation is a missed opportunity to examine the efficacy of diverse therapeutic inputs and develop recommendations accordingly. ACP's 2014 Parliamentary inquiry *Enabling Potential: Achieving a New Deal for Children with Cerebral Palsy*[1] found that 94% of children with CP aged three or under had accessed physiotherapy services through the NHS. The report also found that, on average, children aged six or under received just 12 hours of physiotherapy care per annum. By way of comparison, children with CP in Canada received an average of 6.5 hours per month. Action Cerebral Palsy, *Enabling Potential – Achieving a New Deal for Children with Cerebral Palsy* (2014), available at http://www.cplondon.org.uk/wp-content/uploads/2015/07/ACP-Report-21st-Jan-2015.pdf The disparity in international standards described above, and the levels with which children with CP undergo physiotherapy treatment, suggest that wider-reaching analysis and discussion is required. Moreover, while aspects of CP care such as managing saliva control and sleep disturbances are important on an individual/localised level, we believe that the near-universality of matters pertaining to gross and fine motor skills necessitates closer scrutiny.	Thank you for your comment. 1. The guideline does consider risks and causes in detail. The Committee were guided by clear stakeholder input to inform the scope of the guideline. 2. Posture, therapeutic and motor management, in both spastic and and dyskinetic populations, were excluded from the scope of this guideline. The NICE spasticity guideline did cover physiotherapy in great detail and many of these issues are relevant to children and young people with cerebral palsy and minimal spasticity. Please refer to NICE for any comments related to the Spasticity in under 19s guideline https://www.nice.org.uk/Guidance/CG145
Action Cerebral Palsy	Full	20; General	5; 13-17	Comments received by ACP from Mike Davies (Clinical Neuro Psychologist) have drawn attention to an omission in the draft guidelines. The introduction refers to formal definitions of CP such as the ICF- that brain damage leads "primarily to disorders of movement and posture, causing 'activity limitation' and 'functional impact'", and that "as well as outlining the intrinsic	Thank you for your comment. We have used the international definition of cerebral palsy in the guideline as outlined in Developmental Medicine Child Neurology (DMCN). Although this is a valid point, the guideline is not intended to be a

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				neurologically derived movement disorder, the formal definition of cerebral palsy also recognises the fact that there are often a variety of other associated clinical and developmental comorbidities. These include disturbances of sensation, perception, cognition, communication and behaviour, epilepsy and secondary musculoskeletal problems'". The wording of this definition suggests that these are less significant, but in fact it can be argued that the reverse is true and ignorance about the specific learning difficulties associated with the spastic type of CP and the absence of cognitive impairment in non spastic types of CP, despite dysarthric speech, blights the identification, assessment and education of very many children with CP. The clinical guidance should consequently recognise the fundamental distinction between children with CP who are likely to be affected with learning difficulties (spastic type) from those unlikely to be as affected with preserved cognitive function (now called non-spastic type/dyskenetic, and previously referred to as 'athetoid' and 'ataxic'). We would therefore recommend that a section is added to the guidance which clearly sets out the distinction between sites of neurological injury (e.g. pyramidal tract or extra pyramidal tract) and the subsequent impact on the intellectual implications for the child. The universally used medical rating of CP, the GMFCS, as it is currently used, only makes reference to the severity of the physical presentation and thus can describe two individuals as having the same level of physical disability when in fact there will be a huge disparity in their cognitive abilities due to different areas of brain damage. This cannot be right and the GMFCS therefore requires a radical redesign although this is acknowledged to be well beyond the remit of these guidelines.	comprehensive medical text book on the aetiology of cerebral palsy but is intended to provide recommendations for support for clinical practice. We have also added further detail to the evidence to recommendations section (27.19.2) of the full guideline.
Action Cerebral Palsy	Full	23	5	With reference to figure 1 (Cerebral palsy algorithm – identification), ACP would like to question the nature of the "increased surveillance" described. We would question: what is the nature of the surveillance; who is doing the routine surveillance (whether a health visitor, family doctor, nursery, school or parent); what is the trigger during surveillance for referral to child development (CD) services, by whom and in what timescale; and what does "increased surveillance" mean and look like. ACP believes further detail of these factors is required in the pathway/algorithm.	Thank you for your comment. We have revised the colour coding for the section relevant to the high risk population to specialist services and for the child presenting with cerebral palsy to all services. For a statement about which children should be referred to child development service and at what timepoints, see recommendations in section 1.3 in the short guideline. Further, it is outside the scope of the guideline to provide detail on specific surveillance programmes.
Action Cerebral Palsy	Full	23	5	With reference to figure 1, line 1.5 (referral to child development services for Early MDT assessment), we question what timescale this would operate to, and what the make-up of the MDT assessment would be.	Thank you for your comment. The specific details on timescales and make-up of the MDT assessment are outside of the scope of the guideline.
Action Cerebral Palsy	Full	23	5	With reference to figure 2 (Cerebral palsy algorithm – management), we wish to highlight there is no mention of assessing and management of (non spastic) sensory motor (fine and gross) disturbances and disorders, although the use of the General Movement Assessment is referenced in section 6.5.1. ACP is pleased to see this included in the recommendations, as also identified in *Enabling Potential.*	Thank you for your comment. The management of movement disorders including was outside the scope of this guideline. We have covered the point you make as we refer to the NICE spasticity guideline

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					https://www.nice.org.uk/Guidance/CG145 in the management algorithm.
Action Cerebral Palsy	Full	25	12	ACP feel that the list of signs of CP given in the document is substantive, however, a number of gaps exist. The document should more clearly highlight risk factors that could lead to cerebral palsies. These include: maternal drug use; maternal disease and infection; multiple births; maternal history of miscarriage or still birth; genetic predisposition and post-natal infection, stroke, or injury.	Thank you for your comment. The risk factors that the Committee prioritised for review in this guideline were: Antenatal factors • Infections (for example rubella, toxoplasmosis, cytomegalovirus [CMV], herpes simples) • Multiple pregnancy • Intrauterine growth restriction • Haemorrhagic events Perinatal • Hypoxic ischaemic events at term/post term • neonatal encephalopathy • Apgar score at 10 min (Low/very low below 4/3) • Neonatal sepsis Postnatal • Extremely preterm 24 – 27 +6 weeks gestational age • Preterm 28 - 31 +6 weeks gestational age • Late preterm (32-37 weeks gestational age) • Infections: meningitis and encephalitis • Clotting disorders /hyper coagulation in mother • Trauma/non-accidental injury The risk factors included in the recommendations were thosewhere the Committee was satisfied that the evidence did indeed show an association.
Action Cerebral Palsy	Full	27	1	ACP welcomes the use of General Movement Assessment during routine neonatal follow up assessment at 0-6 months, and recommended this in *Enabling Potential.*	Thank you for your comment.
Action Cerebral Palsy	Full	27	26-28	We are particularly supportive of early referral to a MDT and that the said MDT is effective and fit for purpose.	Thank you for your comment.
Action Cerebral Palsy	Full	27	5-12	When recognising abnormal motor development, we would question who will identify delayed motor milestones and refer this to a MDT? There are implications for parents and pre-nursery training, and it should be required to red flag concerns to primary care professionals. ACP welcomes a focus on MD assessment, diagnosis and intervention at the earliest possible stage, but is doubtful whether practitioners working with CYP with CP have the relevant skills to identify symptoms. If a child's symptoms are mild they may not concern parents and so may not be flagged up to the relevant professionals or a MDT.	Thank you for your comment. We have revised the recommendations in the section you mention in light of stakeholder comments. High risk infants are reviewed in post neonatal follow-up clinics for at least 24 months. Child developmental screening for low risk children is undertaken in primary care. These are the 2 predominant sources of referral to the MDT. We have made this clearer in the recommendations in section 1.3 of the short guideline and the evidence to recommendations section (6.6.2) of the full guideline.

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Action Cerebral Palsy	Full	28	32-41	We generally agree with the information provided on prognosis, however, it fails to fully recognise the importance of gross motor skills in the broadest sense. Though these are touched upon, they are not analysed in any depth and no reference is made to, for example, steps that can be taken by parents, practitioners or medical professionals to support children with CP in this regard. When considering the prognosis for walking, talking and life expectancy, information to parents should also include the importance of harnessing neuroplasticity: the earlier and more intensive the intervention, the better prognosis for developmental skills and outcomes. ACP are also aware of the NICE guidelines previously published on spasticity in under 19s; but as presentation of spasticity only affects 60-70% of CP diagnoses, we feel there are still some significant gaps in the motor and sensory aspects of this guidance.	Thank you for your comment. The Committee prioritised the clinical and developmental prognostic indicators in relation to walking, talking and life expectancy as it was agreed during scoping that these were the areas of greatest concern for parents and carers. Please note that neuroplasticity is outside of the scope for this guideline. Movement and posture disorders are covered by the spasticity in under 19s guideline: https://www.nice.org.uk/Guidance/CG145 Your comment has been passed to the NICE surveillance team.
Action Cerebral Palsy	Full	29	32	On educational placements, advice should also include information on specialist Early Years/Preschool settings and providers for CP/motor disorders, due to the importance of intensive early intervention.	Thank you for your comment. We have added the following on the educational placements advice: (including information on specialist Early Years/Preschool settings)
Action Cerebral Palsy	Full	29	34-38	In 2016 ACP published *Variations in Care: An analysis of cerebral palsy provision*[2], which found that 91.9% (192) of CCGs were unable to provide details of their pathway for children and young people (CYP) with CP and just 6.7% (14) had specific, tailored pathways of care. Furthermore, ACP research found that just "10 CCGs were able to provide service frameworks for children and young people with cerebral palsy." [2] Action Cerebral Palsy, *Variations in Care: An analysis of cerebral palsy provision* (2016), available at http://media.wix.com/ugd/fe7f3c_cca38ba263d243b0a92c34541841f468.pdf We are therefore strongly in agreement with the emphasis placed on providing clarity of information on the options available to children with CP and their families. We would like to stress the importance of access to information in ensuring that children with CP can access the best and most appropriate care available to them, so that their development can be effectively supported, monitored and understood.	Thank you for your comment.
Action Cerebral Palsy	Full	29	39	ACP welcomes the recommendation to provide information about local support and advocacy groups to the CYP and parents/carers.	Thank you for your comment.
Action Cerebral Palsy	Full	30	3-6	A personal 'folder' should be a supplementary tool to complement information on patient pathways, with routine update meetings between health professionals and families to ensure their alignment.	Thank you for your comment. We have now revised the evidence to recommendations section (11.5.2) of the full guideline on information and support to note the point you make.
Action Cerebral Palsy	Full	30	41-43	We would question who would refer the CYP to a local specialist MDT if their issues have not been reported to their GP or health visitor.	Thank you for your comment. Any clinician in primary, secondary or tertiary care can refer to a local specialist

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					MDT. We have clarified this in section 6.6.2 of the full guideline.
Action Cerebral Palsy	Full	31	10-28	We would question why there is only mention of enteral feeding criteria for nutritional rather than respiratory reasons. The section considers the use of videofluoroscopy, but isn't clear on the treatment pathways following this.	Thank you for your comment. The Committee considered that enteral feeding criteria was not relevant to the recommendation you mention and it was outside the scope of the guideline
Action Cerebral Palsy	Full	31	7-9	One response that ACP received from contacted stakeholders expressed concern over the tone of the section on the assessment of eating, drinking and swallowing difficulties, which seemed to advocate initial low-cost options for assessment before MRI and videofluoroscopy are used.	Thank you for your comment. The Committee stated that most problems with eating, drinking and swallowing can be diagnosed and managed from clinical assessment alone, avoiding the need for more costly and invasive options. The Committee outlined the scenarios where the benefits from a VF could outweigh the cost, anxiety and complications of the procedure. The Committee also wanted to reduce the number of unnecessary or failed videoflururoscopy investigations by including a recommendation to refer children and young people with eating, drinking and swallowing difficulties to a local specialist multidisciplinary team with training in assessing and treating dysphagia before VF is considered.
Action Cerebral Palsy	Full	31	General	As discussed previously, we agree that individual care plans for CYP with CP are a vital means of ensuring that they can enjoy the best possible standards of care. However, a crucial factor in the management of CP has not been discussed in this document, namely: support and development for healthcare and educational professionals in understanding and responding to CP. *Enabling Potential* found that awareness of CP was too low among both medical generalists (GPs and health visitors) and those working in schools (teachers, TAs, school-based therapists etc.) and that improved training was required to bridge the ongoing knowledge gap. We believe that the management of CP is best served holistically with collaboration taking place wherever possible.	Thank you for your comment. The Committee agree that the support and development of healthcare and educational professionals, including improvements in the awareness of CP, are important considerations for this population. However, making recommendations about issues such as training were considered outside the scope of the guideline.
Action Cerebral Palsy	Full	32	43-46	Augmentative and alternative communication (AAC) provision should be a priority for children with delayed communication/language, and the earliest intervention possible from the intentional stage is vital in order to maximise cognitive development, social, and emotional skills long before the emergence of first words.	Thank you for your comment. The Committee agree.
Action Cerebral Palsy	Full	33	1-3	We would question how "regularly" reviewing CYP using AAC systems would be quantified; but believe this will also support safeguarding. Provision of appropriate AAC/SLT should be made on diagnosis, or earlier if possible.	Thank you for your comment. Given the limited evidence, the Committee did not think it would be appropriate to be overly prescriptive.
Action Cerebral Palsy	Full	33	4-6	ACP believes that provision of AAC and individualised training should be made available at preschool/nursery.	Thank you for your comment. The Committee have revised the recommendation to say: *Provide individualised training in communication techniques for families, carers, preschool and school staff and other people involved in the care of a child or young person with cerebral palsy.*

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Action Cerebral Palsy	Full	33	8-10	ACP argues that before starting drug therapy, SLT oro-motor training on lip closure should also be considered.	Thank you for your comment. The evidence to recommendations section (17.6.2) of the full guideline has been revised to cover the point that you raise.
Action Cerebral Palsy	Full	35	19-25	ACP would recommend adding immobility/postural issues and sensory processing difficulties as further common condition-specific causes of pain in CYP with CP.	Thank you for your comment. The Committee have added 'muscle fatigue and immobility' to the recommendation you mention.
Action Cerebral Palsy	Full	35	27-31	We would suggest adding "and may be caused by difficulties with self-regulation" to the bullet points on explaining sleep disturbances to parents/carers.	Thank you for your comment. The Committee consider that this is already covered in the recommendation you mention.
Action Cerebral Palsy	Full	35	7-9	It is also important to note that due to possible sensory registration and processing disorders, a child with CP may not register pain in the same way that other children do, and therefore increased careful monitoring of possible causes of pain is required.	Thank you for your comment. The Committee have revised the recommendation to say: *Explain to children and young people with cerebral palsy and their parents or carers that pain is common in people with cerebral palsy, especially those with more severe motor impairment, and this should be recognised and addressed.*
Action Cerebral Palsy	Full	37	18	The use of sensory strategies to calm and regulate could also be considered to optimise sleep hygiene.	Thank you for your comment. The Committee prioritised and agreed the interventions to manage sleep disturbances early on. Please see final evidence protocol in appendix D.20. This is also covered in the linking evidence to recommendation section which discusses sleep hygiene and simple strategies.
Action Cerebral Palsy	Full	39	12-18	The second bullet point should be expanded to read "Complex disorders of sensory processing and perception, such as planning movement, regulation and sensitivity."	Thank you for your comment. The Committee have revised the recommendation you mention in light of stakeholder comments which now says: *Explain to children and young people with cerebral palsy and their parents or carers that difficulties with learning and movement may be exacerbated by difficulties with registering or processing sensory information, and so affect function and participation. These difficulties may include:* • *primary sensory disorders in any of the sensory systems, such as processing of visual or auditory information (for example, difficulties with depth perception may affect the ability to walk on stairs) (see recommendations 1.17.3 to 1.17.8)* • *disorders of sensory processing and perception, such as planning movements or being able to concentrate and pay attention.*
Action Cerebral Palsy	Full	39	15	We would highlight that it is not just visual or hearing information that can be difficult to process due to primary sensory disorders. This also includes tactile, vestibular, proprioception, olfactory, gustatory and interoception information.	Thank you for your comment. The recommendations give a few examples and the rest of the terms are described in sections 26.1 and 26.6 of the full guideline.

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Action Cerebral Palsy	Full	39	17	We would recommend amending this bullet point to read "complex disorders of sensory processing and perception, such as reactivity, regulation and attention, posture and movement planning responses."	Thank you for your comment. The Committee have revised the recommendation you mention in light of stakeholder comments which now says: *Explain to children and young people with cerebral palsy and their parents or carers that difficulties with learning and movement may be exacerbated by difficulties with registering or processing sensory information, and so affect function and participation. These difficulties may include:* • *primary sensory disorders in any of the sensory systems, such as processing of visual or auditory information (for example, difficulties with depth perception may affect the ability to walk on stairs) (see recommendations 1.17.3 to 1.17.8)* • *disorders of sensory processing and perception, such as planning movements or being able to concentrate and pay attention.*
Action Cerebral Palsy	Full	39	19	There appears to be a lack of technical understanding in this area – perception is the outcome of sensory processing.	Thank you for your comment. The Committee has revised the recommendation in order to clarify that sensory processing and perception refer to separate concepts: *Explain to children and young people with cerebral palsy and their parents or carers that difficulties with learning and movement may be exacerbated by difficulties with registering or processing sensory information, and so affect function and participation. These difficulties may include:* • *primary sensory disorders in any of the sensory systems, such as processing of visual or auditory information (for example, difficulties with depth perception may affect the ability to walk on stairs) (see recommendations 1.17.3 to 1.17.8)* • *disorders of sensory processing and perception, such as planning movements or being able to concentrate and pay attention.*
Action Cerebral Palsy	Full	39	23	The wording of this suggests that there is no evidence of the efficacy of any intervention. This is misleading because therapists do provide interventions as part of their role. For example, occupational therapists routinely provide specific interventions for children's sensory processing challenges where they have the time to provide it. Occupational therapy is an intervention, and the guidelines do not appear to recognise this.	Thank you for your comment. The Committee provided further rationale and context of the recommendations in section 26 of the full guideline and the Committee discussed the role of the occupational therapist specifically in the evidence to recommendations section (26.6.3) of the full guideline.
Action Cerebral Palsy	Full	39	31-42	ACP would recommend adding to this list: • Sensory VI/HI intervention • Specialist teaching support and intervention at pre-school and school age. • Provide training and support to parents and carers.	Thank you for your comment. The Committee has included the first two points you suggest, but consider that the third is already covered in the recommendations included in section 1.6 of the short guideline.

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Action Cerebral Palsy	Full	39	37	By not listing physiotherapy and occupational therapy separately on this list, it implies that the Committee views the two professions as the same, when they have distinctly different knowledge bases and specialisms.	Thank you for your comment. This has now been revised in the recommendation you mention.
Action Cerebral Palsy	Full	40	1-2	ACP believes it is excellent that routes to access specialist teams on a regional basis are highlighted.	Thank you for your comment.
Action Cerebral Palsy	Full	40	32-42	The guidance should include an additional paragraph on information to parents about additional sensory impairments associated with CP, i.e. vestibular, tactile and proprioceptive impairments. This should also state that ongoing assessment and intervention may be required for these.	Thank you for your comment. The Committee consider that this is covered in sections 26.1 and 26.6 of the full guideline.
Action Cerebral Palsy	Full	40	32-42	On the bullet point on learning disabilities, this should be expanded to say "However, physical impairment and expressive language difficulties may mask intellectual ability and will make accurate cognitive assessment more difficult."	Thank you for your comment. This has now been added to the evidence to recommendations section (27.19.2) of the full guideline.
Action Cerebral Palsy	Full	41	15-23	The following bullet point should be added on behavioural difficulties associated with CP: "Difficulty with sensory processing, registration and regulation may present as behavioural difficulties."	Thank you for your comment. The Committee have added the following recommendation: *Recognise that difficulties with registering or processing sensory information (see section 1.16) may present as behavioural difficulties.*
Action Cerebral Palsy	Full	42	18-21; 37-40	We believe that a care pathway should be developed for children with CP from birth with monitoring at key intervals. Early intervention should remain the goal, particularly in the crucial 0-2 age range. We do not believe that the recommendations fully reflect the importance of identifying children with CP as early as possible and establishing plans to help them reach their potential. We recommend that the integration of health and education support is made more explicit and that a whole child approach to care is recommended. Though changes to the Children and Families Act marked a start in this process, these reforms fell short of what is needed to ensure integration is achieved.	Thank you for your comment. The Committee consider that they have covered this in the 'looking for signs of cerebral palsy' section of the short guideline and the 'clinical and developmental manifestations of cerebral palsy' chapter in the full guideline.
Action Cerebral Palsy	Full	42	8-11	We concur with the conclusions made in points 136 and 137 on social care needs, and believe that they point to an important area of cooperation in raising standards of care generally.	Thank you for your comment.
Action Cerebral Palsy	Full	43	32-44	ACP would like the following key research recommendation to be included: "What is the clinical and cost effectiveness of interventions using sensory integration strategies for children with CP?"	Thank you for your comment. The Committee discussed the areas for further research extensively and prioritised the main areas across the different topics reviewed in this guideline.
Action Cerebral Palsy	Full	119	14-18	We welcome the consideration of early detection and identification of children at high risk of CP and the recommendation that they should have neonatal follow up for the first few months of infancy.	Thank you for your comment.
Action Cerebral Palsy	Full	119	24-26	ACP also welcomes the recommendation that there is a need for continuous records of developmental changes to be kept. Screening is important to ensure that children who present with symptoms later than the first years of life do not fall through the net and subsequently do not receive essential early intervention.	Thank you for your comment.

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Action Cerebral Palsy	Full	119	41-44	ACP remains concerned that low risk infants and children may be at risk of not being identified through routine screening assessments, which do not include sufficient focus or detail on motor skill development. The ability of routine assessment screening to identify developmental/motor delays and act on it is dependent on the knowledge and skill of the clinicians carrying them out. There are also concerning issues relating to the availability of healthcare professionals, e.g. specialist Health Visitors, across the country required for an effective level of screening and referral both routine and specialist (as discussed in *Variations in Care).*	We agree. The Committee aimed to minimise variations in the identification of infants and children in the UK who should be referred to child development services and have highlighted the priorities in the recommendations. The scope of the guideline on developmental follow-up of pre-term babies guideline (in development) also covers identification of children who are considered at risk of cerebral palsy.
Action Cerebral Palsy	Full	119	45-48	It is noted that the Committee agreed that healthcare professionals "should" be able to recognise clinical features which may suggest CP – but ACP would question how consideration of these features will be routinely incorporated into all observations and assessments of high risk infants, or through developmental surveillance programmes?	We agree. High risk infants should have increased surveillance performed by neonatal and developmental services, not just by standard surveillance programmes. We have made this clearer in the recommendations in section 1.3 of the short guideline and the evidence to recommendations section (6.6.2) of the full guideline.
Action Cerebral Palsy	Full	120	19-20	ACP welcome the principle that therapy can be started based on the child's developmental problems whilst waiting for a diagnosis to be made.	Thank you for your comment.
Action Cerebral Palsy	Full	120	21-24	We appreciate the importance placed on communication between all tiers of service, but would like to note that parents should be at the centre of all communications and the requirement to continually repeat information to different services should be avoided.	Thank you for your comment. The Committee have noted the point you make in evidence to recommendations section (11.6.2) of the full guideline.
Action Cerebral Palsy	Full	120	26-34	ACP welcomes the Committee's wish to identify recommended levels of surveillance that infants and children with CP should receive to prevent regional variations in care. However, we would add that regional variation of the resources available in CCGs, NHS Trusts and LAs for specialist support for CP remains a concern – as highlighted in ACP's *Variations in Care* report – and therefore delivery of NICE's recommendations will be challenging given current variations in local resources. Nonetheless, the guidelines for surveillance will provide a welcome standard which will inform commissioning and enable provision to be measured in the future. ACP would also question whether it is current clinical practice to provide enhanced surveillance for those at high risk, as this is not evidenced through our experience.	Thank you for your comment. The Committee agreed that enhanced surveillance for those at risk may not be common practice throughout the UK. High risk infants should have increased surveillance performed by neonatal and developmental services, not just by standard surveillance programmes. We have made this clearer in the recommendations in section 1.3 of the short guideline and the evidence to recommendations section (6.6.2) of the full guideline.

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Action Cerebral Palsy	Full	121	33-39	ACP welcomes the recommendations that the GMA should be used to screen/identify high risk infants who may require further assessment and follow up. Also highly welcome is the recommendation that high risk infants continue to receive MD assessment by specialists for the first two years of life, but further detail on what the MD assessment would involve, what intervention would be put in place, how and with what level of intensity is required.	Thank you for your comment. Further detail on the MDT assessment and subsequent interventions are outside of the scope of this guideline.
Action Cerebral Palsy	Full	121	33-39	On providing enhanced clinical and developmental follow-up for children at increased risk of developing CP, we recommend that the guideline on the use of the General Movement Assessment is changed from “up to 6 months” to no later than 3-4 months, as after this time general movements are not present and purposeful movements take over. After 3 months the best instrument to use is the Hammersmith “HINE”.[3] [3] This comment was informed by a response from Dr Sarah McIntyre, Senior Research Fellow at the Cerebral Palsy Alliance Research Institute, University of Sydney	Thank you for your comment. We have revised the recommendation on the use of GMA to 3-4 months. With regard to the Hammersmith ‘HINE’, this tool was not prioritised by the Committee as one of the tools to identify clinical and developmental manifestations in the protocol. Please see the relevant protocol in section D3 in appendix D.
Action Cerebral Palsy	Full	126	7	On the first research recommendation, ‘Can epidemiological recording in the UK of the burden of care of CP improve equity of access to care’, ACP warmly welcomes the recommendation for a national CP register which has been and continues to be a key focus of our agenda. We agree that such a register will have a significant impact on the identification of patterns and trends in the prevalence of CP and in supporting further research into the effectiveness of interventions.	Thank you for your comment.
Action Cerebral Palsy	Full	240	45-46	ACP welcomes the recommendation to consider the use of AAC systems for children with CP and to provide individualised training for families and all those involved in the education and care of children with CP.	Thank you for your comment.
Action Cerebral Palsy	Full	241	14-15	ACP welcomes the recommendation for continued research into best practice in the use of AAC.	Thank you for your comment.
Action Cerebral Palsy	Full	317	1	We were disappointed to see that the section on mental health makes no reference to the impact on a child with CP’s mental health resulting from a lack of recognition throughout their education, including university, of whether their type of cerebral palsy is associated with learning difficulties. Many CYP with spastic type CP have learning difficulties but are treated as if they do not; while those with non-spastic type CP are treated as though they have severe learning difficulties when in fact they do not.[4] [4] This comment was informed by a response from Mike Davies. It should also be noted that many mental health issues can be socially caused, and so to some extent could be prevented. Children with CP are often seen to have their level of learning disability linked with their level of physical disability; and these learning disabilities with neurological causes can also be exacerbated by a lack of specialist educational input.	Thank you for your comment. We have added further detail to the evidence to recommendations section (27.19.2) of the full guideline on intellectual (learning) difficulties, specifically “Though intellectual disability can be seen in any form of cerebral palsy, the Committee recognised that certain types of cerebral palsy were associated with greater risk. Cortical impairment, i.e. spastic cerebral palsy is associated with greater risk than basal ganglial impairment i.e. dystonic cerebral palsy. The Committee noted that physical impairment and expressive language difficulties may mask intellectual ability and will make accurate cognitive assessment more difficult.”
Action Cerebral Palsy	Full	339	10-11	Although the document claims there is “little understanding of how impairment in the motor system directly or indirectly affects sensory and perceptual processing”, there is evidence that these difficulties are a result of CNS	Thank you for your comment. Section 26.1 of the full guideline has now been revised to cover the point that you raise.

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				damage/abnormalities and challenges to sensory receptors and neurology, rather than just because of impairment in the motor system.	
Action Cerebral Palsy	Full	339	18	We would argue these difficulties may remain unrecognised if they are not looked for. There is a lack of recognition of the work undertaken by therapists in the field, and therefore a lack of research support.	Thank you for your comment. This has been added to the evidence to recommendations section (26.6.2) of the full guideline.
Action Cerebral Palsy	Full	339	28-29	As well as these sensory domains, interoception should be included. We would also question why, after listing these sensory areas, vision and hearing are then dealt with separately.	Thank you for your comment. The clinical areas to look at for this evidence review were prioritised with the Committee during the agreement of the evidence review protocol. For further details, please see the protocol in section D23 of appendix D.
Action Cerebral Palsy	Full	349	11-13	ACP acknowledge that there is too little research on interventions for sensory processing difficulties, but this body of research is increasing.	Thank you for your comment.
Action Cerebral Palsy	Full	349	27	ACP are pleased that the guidance acknowledges that CYP with CP *do* have sensory and perceptual issues, rather than simply saying they *may* have these issues.	Thank you for your comment.
Action Cerebral Palsy	Full	349	28-29	We would agree that it often is difficult to separate the signs of sensory and motor impairment, but this wouldn't be the case if we had good assessment tools and well-trained staff.	Thank you for your comment. The evidence to recommendations section (26.6.2) of the full guideline has now been revised to include "how clinical research should be supported along with improved sensory processing assessment and training of staff."
Action Cerebral Palsy	Full	349	34-36	ACP applauds the Committee's note of the importance of regular assessment of children with motor disorders, and in particular, the need for considering and looking for potential sensory processing problems, as in our experience sensory processing problems are a very common feature in children with CP and motor disorders.	Thank you for your comment.
Action Cerebral Palsy	Full	349	General	ACP agree that it is a problem that there is a lack of clinical research in this area, and this should be supported along with improved sensory processing assessment and training of staff.	Thank you for your comment. This has been added to the evidence to recommendations section (26.6.2) of the full guideline.
Action Cerebral Palsy	Full	350	13-16	We would question whether it is correct that parents and carers focus on "low quality evidence" when requesting interventions, and think this is an unlikely assumption. The subsequent recommendation to "explain to parents and carers that there is a lack of evidence to support specific interventions" also does not offer a solution to this.	Thank you for your comment. On balance, the Committee consider that the recommendations in the section you mention are a fair reflection of the evidence reviewed and the Committee's views. For further detail on the Committee's deliberations, please see the evidence to recommendations section (26.6) of the full guideline.
Action Cerebral Palsy	Full	350	20-22	The guidelines make an important point on improving a patient's health-related quality of life, but there is no comment on the tools necessary to correctly target the sensory and perceptual problems. Unless this report defines the appropriate tools and recommends training in them, therapists will not have the skills to "target" the sensory and perceptual problems noted by the Committee.	Thank you for your comment. The Committee noted that the evidence was of too low quality and non-specific to allow them to recommend any particular therapeutic approach. However, the Committee noted some key principles that could be applied to rehabilitation or treatment plans and agreed to incorporate these in the recommendations. Please see the evidence to recommendations section (26.6.2) of the full guideline.
Action Cerebral Palsy	Full	350	23	There appears to be a narrow focus on this single aspect of treatment (web-based interventions), which fails to recognise the broader behaviour and	Thank you for your comment. The protocol for this systematic review sought evidence for other

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				functional challenges that are part of sensory processing difficulties, and which would only be marginally addressed by web-based approaches.	approached to treatment (for example, goal-directed therapy and task-orientated therapy, see Section D.23 in Appendix D for the full list). The linking evidence to recommendation section of the guideline has been amended to reflect this.
Action Cerebral Palsy	Full	350	29	We would question what is meant by this "functional approach".	Thank you for your comment. The Committee consider that this is sufficiently clear.
Action Cerebral Palsy	Full	350	30-33	In saying "The Committee were unable to describe the resource use these sessions would incur", the guidelines are arguably avoiding the central problem of substantial underfunding in this area.	Thank you for your comment. The Committee stated that those sessions aimed to manage sensory and perceptual problems would be individualised as problems differ in their cause and severity. For these reasons, the frequency and content of the sessions will vary; hence, the Committee considered it was inappropriate to report a mean or range of costs. Given that sensory and perceptual problems are correctly identified, the Committee agreed that the benefits of an individualised approach outweigh the costs of that approach.
Action Cerebral Palsy	Full	350	34-35	While we agree with taking an individualised approach, we believe that to avoid the meaning of this being lost, the sentence should be reworded to say "the value of an individualised approach outweighs the cost of that approach".	Thank you for your comment. The sentence has been amended as suggested.
Action Cerebral Palsy	Full	350	7-11	ACP wholeheartedly welcome this research recommendation, and believe in the need to encourage use and development of appropriate assessment tools so interventions for children with CP are founded on a sound evidence base.	Thank you for your comment.
Action Cerebral Palsy	Full	351	31	ACP welcome the research recommendation to investigate the clinical and cost effectiveness of interventions to manage specific sensory and perceptual difficulties. However, sensory difficulties won't present as standalone "specific" difficulties.	Thank you for your comment The Committee agree, but as you state this is an important area to highlight for further research.
Alder Hey Children's NHS Foundation Trust	General	general	general	I cannot find any reference in the document to managing urinary dysfunction, which occurs in one third of children with cerebral palsy. Morbidity and mortality may occur due to urinary tract infection and renal damage The cost implication of faecal and urinary incontinence are huge. Combined with the impact on quality of life for the individual and carers, this issue should be covered by the guidance. There is just one sentence that mentions possible constipation.	Thank you for your comment. Bladder dysfunction was excluded from the scope of the guideline (4.3.2e) , which was agreed following feedback from stakeholders and review of existing guidance.
Association of British Neurologists (ABN)	Full	General	General	Overall the guideline is comprehensive in its nature addressing the needs of children and young adults with Cerebral palsy. The scope is to cover people with CP to age 25 however many have transitioned / begin transition from the age of 16. It has been identified that there is a lack of evidence on many areas and some research needs have been identified. A statement of the roles of individual health professionals and the structure of the multidisciplinary team would be beneficial. There is an omission of the role of the Neurologist in transition to adult services and management of epilepsy, spasticity, movement disorders frequently lies in their remit at this stage.	Thank you for your comment. The Committee consider that it would be overly prescriptive to state the roles of the individual health professionals and the structure of the multidisciplinary team and this would be up to local arrangements. We have now revised the recommendation you mention to say:

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				Services for people with CP are fragmented after transition following an episode of care model and MDT expertise to continue management of complex patients is lacking. This unmet need requires addressing within adult services. The recommendation of a registry is commendable however this should include all people with CP inform long term outcomes.	*Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:* • *is able to meet their individual needs within agreed care pathways* • *can provide the following expertise, as appropriate, through a local network of care:* – *paediatric or adult medicine* – *nursing care* – *physiotherapy* – *occupational therapy* – *speech and language therapy* – *dietetics* – *psychology* • *can enable access to other services within their local or regional network as appropriate, including:* – *paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and/or surgical specialist care* – *orthopaedics* – *orthotics and rehabilitation services* – *social care* – *visual and hearing specialist services* – *teaching support for preschool and school-age children, including portage (home teaching services for preschool children).*
Association of British Neurologists (ABN)	Full	7	6.2	Line 30 – assessment by a trained health professional. The guideline should include details of the role of people in diagnosing and managing CP and structure of MDT	Thank you for your comment. The Committee reviewed the recommendation you mention and include professionals have skills in diagnosing and management CP as well as clearly outlining the structure of the local integrated core multidisciplinary team: *Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:* • *is able to meet their individual needs within agreed care pathways* • *can provide the following expertise, as appropriate, through a local network of care:* – *paediatric or adult medicine* – *nursing care* – *physiotherapy* – *occupational therapy* – *speech and language therapy* – *dietetics*

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					– psychology *• can enable access to other services within their local or regional network as appropriate, including:* *– paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and/or surgical specialist care* *– orthopaedics* *– orthotics and rehabilitation services* *– social care* *– visual and hearing specialist services* *– teaching support for preschool and school-age children, including portage (home teaching services for preschool children).*
Association of British Neurologists (ABN)	Full	7	8	Research recommendations: Establishing a UK wide register of children with CP is warranted; however it would also be informative to include adults with CP as (less frequently) new diagnoses are also made in those in adult services. Inclusion of those may help identify those with other neurological syndromes in childhood.	Thank you for your comment and support of the research recommendation about needing UK-wide prevalence data. However, the scope for this guideline is only for children and young people with cerebral palsy therefore we are unable to make a research recommendation about adults as we did not look for evidence in this population. Please note that NICE has commissioned the development of a guideline on cerebral palsy in adults. For further details please see: **https://www.nice.org.uk/guidance/indevelopment/gid-ng10031**.
Association of British Neurologists (ABN)	Full	8	General	The recommendation is to not offer routine MRI for young infants with CP unless atypical features. There is a lack of robust evidence of its utility, which does not indicate it would not be useful. The views of parents today need to be addressed as many parents may express a preference to proceed with a scan before the age of 2. The cost of the scan may be offset by the desire for multiple clinical opinions. In line with a registry – routine MRI could be optional for those entering the registry and be a valuable bio-resource.	Thank you for your comment. If clinical and developmental history and examination in the presence of clear risk factors can sufficiently determine the aetiology of cerebral palsy the Committee agreed an MRI should not routinely be used to confirm diagnosis as the costs cannot justify the information obtained from an MRI in those cases and parents should accept this. The Committee also added that because of the developmental and maturational processes of the brain, the aetiology of cerebral palsy may not be fully apparent until 2 years of age. For this reason, a recommendation that says age should be taken into account was made; hence, MRIs could be performed under the age of 2 years when necessary. The Committee stated that a routine MRI in line with the registry is idealistic as it would require substantial resources to undertake - those resources have a high opportunity cost and should be used elsewhere in the NHS where they can generate greater benefits.

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Association of British Neurologists (ABN)	Full	9	General	As with the role in diagnosis, there is a lack of evidence with regards to prognosis. No research recommendations made however incorporation with the registry may help provide evidence.	Thank you for your comment. The Committee agree that this will be a useful factor within the development of a national registry.
Association of British Neurologists (ABN)	Full	17.7	68	We are concerned that this recommendation may imply that Botulinum toxin injections can be done only under ultrasound guidance.	Thank you for your comment. The Committee consider that in paediatrics botulinium toxin injections should only be administered using ultrasound guidance, and that this is the international consensus (Reddihough 2010, Botulinum toxin assessment, intervention and aftercare for paediatric and adult drooling: international consensus statement)**.**
Association of British Neurologists (ABN)	Full	17.7	70	This recommendation will be a challenging change in practice because it does not define what constitutes insufficient response. The recommendation also does not mention the combination of transdermal hyoscine patch, oral glycopyrrolate and botulinum toxin injection Should combination treatment be tried before surgical intervention?	Thank you for your comment. The Committee agree that it is a challenging change but is appropriate and agree a combination of treatments is frequently used in clinical practice, bearing in mind potential implications from side-effects.
Association of British Neurologists (ABN)	Full	17.7	General	The recommendations do not include role of Speech and Language therapy for control of salivation. They also do not address the use of other medications for symptom management of spasticity, epilepsy etc and reduction of salivation as a result e.g. tizanidine, gabapentin. The anticholinergic load can have an adverse effect on arousal and cognition and it is important to minimise the number of medications being used.	Thank you for your comment. The evidence to recommendations section (17.6.2) of the full guideline has been revised following your comment. Movement and posture disorders are covered by the spasticity in under 19s guideline: https://www.nice.org.uk/Guidance/CG145 In addition, the management of epilepsy is covered by the Epilepsy diagnosis and management guideline: https://www.nice.org.uk/guidance/cg137 Your comment has been passed to the NICE surveillance team. **A comment about side-effects has been added to the full guideline as requested.**
Association of British Neurologists (ABN)	Full	18.6	71	We are concerned that this recommendation may imply that children and young adults with cerebral palsy who receive steroids for other conditions need not be considered as having high risk for low bone mineral density	Thank you for your comment. The Committee have noted in the evidence to recommendations section (18.5.2) of the full guideline the prolonged use of oral or intramuscular steroids as a risk factor for low bone mineral density.
Association of British Neurologists (ABN)	Full	20.6	83	We are concerned that this recommendation may result in missing some of common causes for new onset pain in children and young adults with cerebral palsy such as chest infection, urinary tract infections and renal and uretric colic.	Thank you for your comment. The Committee agreed that the following recommendation in the management of pain, discomfort and distress section of the short guideline addresses your concern: *For reversible causes of pain, discomfort and distress identified in children and young people with cerebral palsy, treat the cause as appropriate using targeted interventions in line with the following NICE guidelines:*

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					○ *spasticity in under 19s* ○ *constipation in children and young people* ○ *gastro-oesophageal reflux disease in children and young people and gastro-oesophageal reflux disease and dyspepsia in adults* ○ *headaches in over 12s* ○ *low back pain in adults* ○ *urinary incontinence in neurological disease* ○ *urinary tract infection in under 16s.*
Association of British Neurologists (ABN)	Full	22.6	93	We are concerned that this recommendation may imply that young adults above the age of 16 need not be screened for Urinary tract infections as a cause of pain and distress.	Thank you for your comment. This recommendation provides cross-reference to relevant NICE guidelines that address the management of areas that may a source of reversible pain, discomfort and distress. The breadth of the populations is a direct reflection of the guidance, which in this case, covers the under 16s only. ○
Association of British Neurologists (ABN)	Full	25.7	General	We are concerned that this recommendation does not mention the role of drugs in the treatment of mental health issues in young adults people with cerebral palsy. We are concerned that this recommendation does not highlight the excessive risk of cognitive and extrapyramidal side effects of antipsychotic medications in this population.	Thank you for your comment. The Committee agree and have revised the recommendation you mention to say: *Recognise that there are specific challenges in managing and minimising the impact of mental health problems in children and young people with cerebral palsy. These include:* • *communication difficulties* • *comorbidities, particularly epilepsy and pain* • *side effects and drug interactions of multiple medicines (polypharmacy)* • *adverse effects of medicines used for managing mental health problems on motor function* • *adverse effects of medicines used for managing motor function on mental health* • *specific social care needs.*
Association of British Neurologists (ABN)	Full	27.2	118	We are concerned that this recommendation does not mention the role of the Neurologist in the multidisciplinary team. Neurologist have a key role in the management of co-morbidities especially epilepsy, movement disorders and spasticity.	Thank you for your comment. We have now revised the recommendation you mention to say: *Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:* • *is able to meet their individual needs within agreed care pathways* • *can provide the following expertise, as appropriate, through a local network of care:* – *paediatric or adult medicine* – *nursing care* – *physiotherapy* – *occupational therapy* – *speech and language therapy*

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					– *dietetics* – *psychology* • *can enable access to other services within their local or regional network as appropriate, including:* – *paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and/or surgical specialist care* – *orthopaedics* – *orthotics and rehabilitation services* – *social care* – *visual and hearing specialist services* – *teaching support for preschool and school-age children, including portage (home teaching services for preschool children).* The Committee recognises that there is variation in the expertise available across various regions with regards to adult specialist in the management of cerebral palsy, and that it may not be possible to have access to a neurologist as part of the core multidisciplinary team.
Association of British Neurologists (ABN)	Full	29.6	General	This recommendation will be a challenging change in practice because of lack of resources in the adult services. The adult rehabilitation services follow an episode of care model and there is no continuous support and review as in children's neurodisability services.	Thank you for your comment. From their experience, the Committee believed that there were not enough resources devoted to the transition from paediatric to adult services in children and young people with cerebral palsy. Consequently they wanted to make recommendations that identified the minimum level of support children and young people with cerebral palsy, their families and carers should expect to receive to prevent geographical variation. Adult rehabilitation services are beyond the remit of this guideline.
Association of Paediatric Chartered Physiotherapists (APCP)	Draft	15	16-19	This recommendation for VF to be carried out only at a specialist national centre will be a challenging in practice because there are few national centres available to serve the geographical spread of clients. Any referral to locally based services may not necessarily result in VF. Depending upon local access and availability - for example, barium swallow or endoscopy may be offered. In some cases VF is available locally but cannot be accessed by wheelchair users. Significant service development and costs would be necessary to nationally provide the recommendations set out in this paper. We wonder if this is realistic and attainable for a small population of clients?	Thank you for your comment. The Committee is not saying that this needs to happen at a specialist national centre, only that there is the need for a team that has expertise to understand the necessary assessment.
Association of Paediatric Chartered Physiotherapists (APCP)	Draft	15	23-35	The recommendation for children to be seen at a regional tertiary centre will be a challenging, because there are very limited resources and access to such provision from community based services.	Thank you for your comment. The Committee agree this will be challenging and have decided to remove 'regional' from the recommendation to allow for greater flexibility. It is appropriate that children with severe dysphagia have access to specialist teams.

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Association of Paediatric Chartered Physiotherapists (APCP)	Full	General Section 20.6	General	The APCP acknowledges the decision not to include musculoskeletal (MSK) in this document and the reference to the previous NICE guidelines Spasticity in under 19's: Management. It recognises the link to previous NICE guidelines (Spasticity in under 19's: Management) but does not feel the information contained within the Spasticity guidelines is as comprehensive as other aspects examined within this document such as Mental Health, Communication, Eating/drinking/swallowing, Saliva control, Nutrition, Pain/discomfort/sleep issues, Bone Mineral Density, Sensory and Perceptual Difficulties, Social Care, Communication/Support/Information, Multidisciplinary team, Transition. The NICE guidelines on Spasticity do note the need for monitoring of the secondary consequences such as pain or contracture but do not fully investigate the evidence surrounding regular, standardised, objective assessment of range of movement measures in the lower limb and the impact in terms of preventing/lessening the consequences. The focus is limited to managing risk of hip displacement rather than managing the risk of any evolving contracture/deformity. It also does not explore the impact of these secondary consequences on the child or young person's activity and participation The APCP feel there were several missed opportunities throughout this document to highlight, examine and suggest management strategies regarding MSK complications and the adverse impact they may potentially have on other areas covered in this document such as prognosis for walking (section 10), Information and support (section 11) and Pain, discomfort, distress and sleep disturbances (sections 20-22) The MSK consequences are of equal importance to all other issues examined within this document and are integral to the overall well-being of the child/young person with Cerebral Palsy. This lack of inclusion of the impact of MSK complications, combined with the recent decision not to update the Guideline on Spasticity, raises concerns that future care and management decisions in terms of provision of services for prevention/management of MSK complications will be adversely affected. MSK complications are noted in the document to be the primary cause of pain. Management in terms of assessment, prevention as well as provision of information to parents should have been further explored. No research recommendations are made regarding further investigating the link between pain and MSK problems. The addition of more comprehensive guidance building on existing documents does appear to have occurred in regards to the section on Transition where previous NICE guidelines were acknowledged but then expanded upon to give more thorough recommendations.	Thank you for your comment. The Committee recognises the points made, but it was decided early on that movement and posture disorders were strictly covered by the guideline on spasticity in under 19s: management. Your comment has been passed to the NICE surveillance team. Please however note that the effects of musculoskeletal system on pain etc. are discussed in both guidelines. Please see chapters 20 to 22 of the full guideline.

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Association of Paediatric Chartered Physiotherapists (APCP)	Full	General	General	The APCP would have liked to have seen more recognition of the respiratory problems faced by children as a significant comorbidity which is often ultimately the cause of mortality as well as significant morbidity. We realise respiratory symptoms have been mentioned in relation to concerns about oromotor dysfunction and this may be felt to be enough but in our experience we often meet these children late when they have lung damage and bronchiectasis which may have been prevented by earlier review of feeding/GORD and timely management of chest infections. If we are trying to 'prevent people dying prematurely' as in the NHS outcomes framework asking about chest infections and number of courses of antibiotics/hospital admissions is an easy way of identifying children with underlying causes which may be able to be addressed. It has been our experience that this is an area of care which parents are very worried about and keen to be empowered to know what to do to try and prevent hospital admission if possible.	Thank you for your comment. The Committee have now revised the evidence to recommendations section (10.6.2) of the full guideline to reflect the significance of respiratory problems as a cause of mortality and morbidity in children and young people with cerebral palsy.
Association of Paediatric Chartered Physiotherapists (APCP)	Full	Section 10 – 10.1, 10.6.2 and 10.7.29		The introduction to this section on prognosis for walking, talking and life expectancy notes the problem of muscle tightness, contracture formation and weakness but does not further examine the impact of this. The prognosis for walking does note 'the more severe physical abnormalities in function/more severe the child's physical impairment' is associated with increased odds of being unable to walk' and but then does not explore strategies to prevent or manage this.	Thank you for your comment. The Committee prioritised the prognosis of walking, talking and life expectancy as a clinical area to be covered in the guideline and the systematic reviews were in line with what was agreed in the final scope, as informed by stakeholders. In chapter 13 this guideline has covered strategies to manage difficulties with eating, drinking and swallowing and in chapters 15 and 16, the guideline has also covered strategies to improve speech, language and communication. Please refer to NICE for any comments related to the Spasticity in under 19s guideline https://www.nice.org.uk/Guidance/CG145.
Association of Paediatric Chartered Physiotherapists (APCP)	General			Neuromuscular electrical stimulation therapy has recently been approved by NICE for treatment of swallowing under certain conditions. The use of neuromuscular electrical stimulation treatment of swallowing has not been addressed for treatment of swallowing in CP. We would welcome comments on this.	Thank you for your comment. Neuromuscular electrical stimulation therapy was not prioritised by the Committee as an intervention to be looked at as part of the evidence review. Please also note that the NICE IPG 490 was not supportive of this technique as an approach even in adults. The evidence was limited in quantity and quality and it should only be done after informing local governance teams. There was no comment at all about its applicability in children: https://www.nice.org.uk/guidance/ipg490/chapter/1-Recommendations

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Association of Paediatric Chartered Physiotherapists (APCP)	Short	General	General	The APCP feel there is a section missing detailing about respiratory management. This is equally as important as speech and language, etc and links in closely with saliva control, feeding difficulties and pain, distress and discomfort. This must be one of the most important factors for those at the more severe physical and functional impairments, as respiratory pathology is a significant cause of morbidity and mortality in these patients. The section could mention sleep studies, management of retained mucus/secretions, training of family and carers, use of prophylactic antibiotics, oxygen etc.	Thank you for your comment. The Committee have now revised section 10.6.2 in the chapter on prognosis of walking, talking and life expectancy of the full guideline to reflect the significance of respiratory problems as a cause of mortality and morbidity in children and young people with cerebral palsy.
Association of Paediatric Chartered Physiotherapists (APCP)	Short	General	General	On the whole the document focuses on overview of services and medical management rather than therapeutic.	Thank you for your comment. Movement and posture disorders are covered by the spasticity in under 19s guideline: **https://www.nice.org.uk/Guidance/CG145**
Association of Paediatric Chartered Physiotherapists (APCP)	Short	General	General	Useful ideas/guidance for streamlining services particularly assessment, early support and Transition	Thank you for your comment.
Association of Paediatric Chartered Physiotherapists (APCP)	Short	11	24	Who will hold the personal folder and be responsible for maintaining it, keeping it updated, etc. It would be best held electronically potentially on a device – where would funding come from for this type of provision. This will be challenging in practice	Thank you for your comment. The evidence to recommendations section (11.5.2) of the full guideline on information and support has been revised to note the point you make.
Association of Paediatric Chartered Physiotherapists (APCP)	Short	12	18-23	Will there be a regional database for professionals to access with details of local/regional services? It will be difficult for professionals and families to keep up to date with what is available	Thank you for your comment. The Committee consider that this will be up to local/regional services to decide.
Association of Paediatric Chartered Physiotherapists (APCP)	Short	24	13-15	Concern that there aren't enough specialist MDT pain teams for children with CP to be referred to nationally – will there be specialist SLT with skills in communication/AAC etc	Thank you for your comment. The Committee agreed not to be overly prescriptive as it would depends on local resources.
Association of Paediatric Chartered Physiotherapists (APCP)	Short	35	16-18	Will there be a regional database for professionals to access with details of local/regional Transition services? ? It will be difficult for professionals and families to keep up to date with what is available	Thank you for your comment. The Committee consider that this will be up to local arrangements.
British Academy of Childhood Disability (BACD)	Full		1.8.7	Re 'Ensure that children and young people with ongoing eating, drinking and swallowing difficulties have access to regional tertiary specialist assessment.' Regional tertiary specialist assessment needs qualification - this should not necessarily be to a Regional Tertiary Feeding Team (it is unlikely that such services would have capacity) but to other specialist tertiary services such as Paediatric Surgery, Respiratory, etc. to add to the information and overall risk management carried out by local specialist feeding / nutrition multidisciplinary team	Thank you for your comment. The Committee agree this will be challenging and have decided to remove 'regional' from the recommendation to allow for greater flexibility. It is appropriate that children with severe dysphagia have access to specialist teams. The Committee have revised the recommendation to say: *Ensure that children and young people with ongoing eating, drinking and swallowing difficulties have access*

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					to tertiary specialist assessment, including advice from other services (such as paediatric surgery and respiratory paediatrics).
British Academy of Childhood Disability (BACD)	Full	General	General	The guideline has been well received and is a comprehensive summary of clinical practise and available evidence in the management of children with CP. This is a diverse clinical group – with a range of clinical severity and co-morbidities; with multiple potential complex interventions for care; and a significant paucity of evidence. The draft guideline is well structured and highlights the need for future research in many areas. Some members of the BACD have raised specific questions and queries outlined below.	Thank you for your comment. We have addressed the specific comments as they appear.
British Academy of Childhood Disability (BACD)	Full	General	General	Other areas where omissions were highlighted: What about gaining and maintaining bladder control? Link to palliative care guideline? Prognosis is covered; but identification of causes of death could be helpful.	Thank you for your comment. We have now cross-referenced the NICE guidelines on neurological incontinence and end of life care in children and young people. Please note that the main causes of death have been clarified in the evidence to recommendations section (10.6.2.3) of the full guideline. Further, the management of bladder dysfunction was excluded from the scope (4.3.2e).
British Academy of Childhood Disability (BACD)	Full	General	General	As above, concern has been raised regarding the emphasis on motor impairment and management; further discussion (amongst members) has highlighted that the rationale for this was on the basis that the therapy and surveillance of motor impairments would be incorporated into the NICE guidance on spasticity management; pending imminent update in Autumn 2016. The recent information that the NICE guidance for Spasticity in under 19's will not be reviewed is therefore a significant concern; and we would be grateful if NICE could re-consider this decision.	Thank you for your comment. Movement and posture disorders are covered by the spasticity in under 19s guideline: https://www.nice.org.uk/Guidance/CG145 Your comment has been passed to the NICE surveillance team.
British Academy of Childhood Disability (BACD)	Full	30	36	The recommendation of a personal folder to include clinical information and carer support information relevant to the individual young person; is welcome. Implementation in electronic form (e.g. an app/ tablet/ weblinks); rather than paper based may be more appropriate; although confidentiality and data protection issues would need careful consideration.	Thank you for your comment. The evidence to recommendations section (11.5.2) of the full guideline has been revised to include your point on confidentiality and data protection as we have already discussed options for individual use.
British Academy of Childhood Disability (BACD)	Full	127	Table 27	The recommendation of a national registry of children with CP is very welcome. This recommendation is also now timely with respect to the imminent implementation of the CPIPS register - there is a working group, led by NHS England, putting together a business case for funding for the CPIP across England. Based on Swedish and Australian epidemiological evidence (Hagglund and Kerr Graham) there is clear evidence that hip surveillance reduces hip dislocation and associated morbidity in children and young people with CP. If this is to be implemented universally, the recommendation needs to be endorsed in NICE guidance. We recognise that implementation of such a registry may be challenging (experience of maintenance of a CP database in the North of England – NECCPS highlighted difficulties of achieving full capture; after the requirement for written parental consent was introduced. However most of the data previously reported to the North of England Cerebral Palsy Survey has been included in the Disabilities Terminologies Set, that in turn has been embraced within the Children and Young People's Health Services dataset	Thank you for your comment. The Committee agree.

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				(the CYPHS). As of 15 Oct 2015, NHS providers have been mandated to report data to the CYPHS, which flows thought to NHS Digital (previously the Health and Social Care Information Centre). There is thus a mechanism in place for clinicians to collect data at the point of care and for this to flow to NHS Digital, for monthly reports to go to CCGs and Trusts. This will cover all disabling conditions and a range of other common paediatric diagnoses, but very importantly captures a lot of information about those with cerebral palsies.	
British Academy of Childhood Disability (BACD)	Full	128	8.7	Many BACD members had comments regarding imaging – and felt very strongly regarding the importance of MRI imaging. The full guidance does give a clear and comprehensive review of the current research and a pragmatic approach to imaging; within the clinical context of the child's presentation. Highlighting red flags for other progressive conditions; and the importance of recognising when the clinical presentation is not consistent with imaging. The value of timing of imaging is also highlighted (after 2 years, where possible.) In view of the comments received in collating this response on behalf of BACD (included below - italics) – members are of the strong view that this recommendation requires review. *"It is surprising that the committee's view is that MRI need only be undertaken when aetiology of cerebral palsy is 'not clear'* *This risks missing the significant proportion of those with developmental brain anomalies (~10%) that may co-exist with other factors, are much less likely to be correctly identified on cranial ultrasound and may have significant implications for clinical management as well as for genetic counselling."* *"Developmental brain anomalies may have other implications for the child or young person e.g. endocrinopathies (as in e.g. septo-optic dysplasia), vision impairment (again as in e.g. septo-optic dysplasia), increased risk of epilepsies or as a red flag for chromosomal conditions (cortical dysplasias as in e.g. 22q11 deletion syndromes)"* *"There is increasing evidence of correlation between MRI findings and function (see Himmelmann K, Uvebrant P. Function and neuroimaging in cerebral palsy: a population-based study. Dev Med Child Neurol. 2011;53(6):516-521"* *"Those with 'apparent' cerebral palsies may have other conditions. For example, a child born at 32 weeks gestation with clinical evidence of bilateral lower limb spasticity was assumed to have bilateral cerebral palsy. MRI revealed bilateral very symmetrical periventricular white matter changes not typical of periventricular leukomalacia that prompted further investigation,that led to a diagnosis of metachromatic leukodystrophy. The management of this condition is completely different to the management of cerebral palsy and the*	Many thanks for your comment. The Committee spent a considerable period of time reflecting on your points, reviewing the evidence provided and discussing all aspects with our clinical expert neuroradiologist. A number of other stakeholders welcomed the recommendation as stated. The Committee clarified recommendation 1.2.10 to "Offer MRI to investigate aetiology in a child or young person with suspected or known cerebral palsy if this is not clear from:…" but maintained the importance of clinical decision-making when considering the use of MRI for aetiology, by listing a number of considerations that should be assessed before an MRI is offered that would also assist in the interpretation of an MRI With regard to consideration of any abnormal clinical or developmental trajectory, the Committee consider that the recommendation as outlined in the short guideline for an urgent MRI would stand.

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				family had a right to know the actual diagnosis and to consider the genetic implications for their family". *"It is very surprising that the committee are not making a stronger recommendation on this, encouraging MRI in ALL children and young people with suspected cerebral palsies. This is a missed opportunity to improve the quality of information available to share with people with cerebral palsies and their families. It is NOT true that MRI findings do not change management, as they absolutely do if a developmental brain anomaly is identified that may be associated with endocrinopathy, vision impairment or if a progressive condition with genetic implications is identified.* *Please can the committee carefully and seriously reconsider this important area."*	
British Academy of Childhood Disability (BACD)	Full	243	17.2	The very recent head-to-head study comparing glycopyronium bromide with hyoscine hydrobromide was acknowledged pg 244, line 11 and referenced unpublished. We would be grateful if the results of this study could be reported. Although this showed the drugs to be equally effective, it showed that hyoscine is associated with more problematic side effects and is less likely to be tolerated. The guidance mentions constipation and glycopyrronium - this was found in the trial but most parents found this manageable and this did not lead to treatment cessation - most parents continued glycopyrronium treatment during the trial. However, for hyoscine, there was a high rate of treatment cessation related to side effects - 50% of parents stopped this treatment. We think this is a key point that the guidance should mention. We are interested that in this context, hyoscine is recommended strongly as first line treatment, as this wasn't our conclusion. Parr JR, Todhunter E, Pennington L, Cole M, Morrison J, Stocken D, Colver A. The Drooling Reduction Intervention (DRI) trial: Is hyoscine or glycopyrronium more effective and acceptable for the treatment of drooling in children with neurodisability? *Arch Dis Child* 2016;101:A55-A56	Thank you for your comments. Each of the points has been addressed separately. 1. Study by Parr 2016 The results of this study cannot be reported as we can only include peer-reviewed published studies. 2. Recommendation of Hyoscine hydrobromide as a first line treatment The Committee agreed that transdermal hyoscine hydro bromide and glycopyrronium bromide were equally effective at reducing drooling in children and young people with cerebral palsy, however, given that hyoscine hydro bromide is substantially cheaper, it was recommended as a first line treatment. The Committee acknowledged the tolerability and side effects of transdermal hyoscine hydro bromide over time (such as skin irritation and deterioration of seizure control). Furthermore, they noted that the studies included in the clinical evidence review were too short to demonstrate the risk of adverse events sometimes seen in the clinical practice, particularly for transdermal hyoscine hydro bromide. Consequently, the Committee made a recommendation to consider glycopyrronium bromide if transdermal hyoscine hydro bromide was not tolerated. A recommendation was also prioritised to ensure monitoring for tolerance and side effects was in place for all treatments, especially when used in children with severe communication difficulties who could not easily report adverse effects. For further details regarding the economic model in which the decision was made see 'consideration of economic benefits and harms' section in the 'managing saliva control' chapter; full guideline.

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British Academy of Childhood Disability (BACD)	Full	299	21.6 Rec 92	This recommendation is VERY welcome, encouraging enquiry about pain, sleep and distress as part of all clinical encounters	Thank you for your comment.
British Academy of Childhood Disability (BACD)	Full	398	29	Inclusion of transition to adult is hugely important; and the recognition of the need for clinicians to have expertise in management of young adults with CP. At present ensuring effective handover to adult services is unlikely to be achievable as these services/ clinicians are very limited. The pending NICE guidance on Adults with CP will be immensely valuable to identify the deficit here and should include practical guidance on how this can be resourced and achieved.	Thank you for your comment. The Committee agree it is important that you are involved in the scoping process for the guideline on Adults with CP.
British Academy of Childhood Disability (BACD)	Full/Short	General	General	Concern has been raised regarding the integration of managing the motor impairment together with all the other areas in this guideline which would lend itself to a 'what to think about at different ages' approach to care of the child/young person with CP for those involved with disability care. As it is, we are referred to spasticity guideline with the danger of perpetuating division of care.	Thank you for your comment. Although they are separate guidelines the recommendations were made taking account of the Spasticity guideline and that we have made cross references where appropriate. The 2 guidelines should be considered together and this will be reflected in the NICE pathway for this guideline. Movement and posture disorders are covered by the spasticity in under 19s guideline: **https://www.nice.org.uk/Guidance/CG145** Your comment has been passed to the NICE surveillance team.
British Academy of Childhood Disability (BACD)	Short version	4	19	Other post natal risk factors could include a) Head trauma b) Encephalopathy / encephalitis (it is acknowledged that these are included in the full guidance.	Thank you for your comment. The risk factors that the Committee prioritised for review in this guideline were: Antenatal factors • Infections (for example rubella, toxoplasmosis, cytomegalovirus [CMV], herpes simples) • Multiple pregnancy • Intrauterine growth restriction • Haemorrhagic events Perinatal • Hypoxic ischaemic events at term/post term • neonatal encephalopathy • Apgar score at 10 min (Low/very low below 4/3) • Neonatal sepsis Postnatal • Extremely preterm 24 – 27 +6 weeks gestational age • Preterm 28 - 31 +6 weeks gestational age • Late preterm (32-37 weeks gestational age) • Infections: meningitis and encephalitis • Clotting disorders /hyper coagulation in mother • Trauma/non-accidental injury The risk factors included in the recommendations were those were the Committee was satisfied that the evidence did indeed show an association.

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British Academy of Childhood Disability (BACD)	Short version	6	21	One BACD member asked if it 'Other infections' –could be more specific: i.e. does this mean 'serious infections / sepsis / encephalitis' or just 'any other infection'?	Thank you for your comment. The Committee understands your viewpoint but the evidence did not provide details about specific infections so are unable to be any more specific in the recommendation. However, yhe Committee agreed that for antenatal infections, examples could be rubella, toxoplasmosis, cytomegalovirus (CMV), herpes simples. For postnatal infections, the Committee agreed that examples could be meningitis and encephalitis.
British Academy of Childhood Disability (BACD)	Short version	7	17	Many hospitals use oral sedation rather than general anaesthesia for MRI in very young children. Again – it is noted that this is included in the full guidance; but many clinicians may only read short version!	Thank you for your comment. The recommendation has now been revised to say 'or sedation'.
British Academy of Childhood Disability (BACD)	Short version	9	Para 1.5.2.	In the multidisciplinary team – Orthopaedics could be added	**Thank you for your comment.** We have now revised the recommendation you mention to say: *Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:* • *is able to meet their individual needs within agreed care pathways* • *can provide the following expertise, as appropriate, through a local network of care:* – *paediatric or adult medicine* – *nursing care* – *physiotherapy* – *occupational therapy* – *speech and language therapy* – *dietetics* – *psychology* • *can enable access to other services within their local or regional network as appropriate, including:* – *paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and/or surgical specialist care* – *orthopaedics* – *orthotics and rehabilitation services* – *social care* – *visual and hearing specialist services* – *teaching support for preschool and school-age children, including portage (home teaching services for preschool children).*
British Academy of Childhood Disability (BACD)	Short version	22	23	There was concern raised that the language used here is not very sensitive considering that the guideline is also meant for use by parents of children with CP – perhaps it would be important to state that by acknowledging the prevalence of pain - professionals and carers should ensure they identify this in young people if present. (implied but not stated)	Thank you for your comment. The Committee think this is covered in recommendation you mention.

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British and Irish Orthoptic Society	Full	17.6.2	23-34	Use of hyoscine can impair accommodative response. This reduction in accommodation can be cumulative. Children using hyoscine should have their visual acuity checked and a dynamic retinoscopy performed to determine if bifocal glasses are required to help with near vision to maximise their learning and aid with the viewing of their augmented communication devices.	Thank you for your comment. The Committee consider that this would be covered under the following recommendation: *Regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control.* The evidence to recommendations section (17.6.2) of the full guideline has also been revised.
British and Irish Orthoptic Society	Full	27.19.2		There should be inclusion of strategies to improve visual function . As identified, there is an increased prevalence of CVI in this population. Therefore it is important that this is incorporated into the ophthalmic assessment and documented and shared with relevant parties such as involved professionals and involved staff from education. It may be appropriate to refer to specialist teams of teachers for the visually impaired for additional support. It may be appropriate to consider registration of children with CVI as being sight impaired / severely sight impaired.	Thank you for your comment. The Committee agree but standard screening protocols are outside of the remit of this guideline. However, a recommendation has been added to section 1.17 of the short guideline to say: *Refer all children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis.*
British and Irish Orthoptic Society	Full/Short	General	General	All children should have a vision test at age 4-5 years as recommended by the National Screening Committee.	Thank you for your comment. The Committee agree but standard screening protocols are outside of the remit of this guideline. However, a recommendation has been added to section 1.17 of the short guideline to say: *Refer all children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis.*
British and Irish Orthoptic Society	Full/Short	General	General	It is recommended that children with cerebral palsy should be referred to an eye clinic for assessment. This should include an assessment by an orthoptist, including a visual acuity test and eye motor control and a cycloplegic refraction and fundus check as a baseline to detect any underlying refractive errors which may hinder development or hinder the use of augmented communication devices. A detailed case history should be taken and additional tests, such as visual field testing and dynamic retinoscopy, should be considered. Once it has been established that there is no significant refractive error and there is good vision the care of these children should follow the same guidance as provided for all children.	Thank you for your comment. The Committee agree but standard screening protocols are outside of the remit of this guideline. However, a recommendation has been added to section 1.17 of the short guideline to say: *Refer all children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis.*
British and Irish Orthoptic Society	Full/Short	General	General	In addition to impaired accommodation as a result of medication, children with CP demonstrate significantly reduced accommodative responses. It is important for children with CP to have a dynamic retinoscopy to determine if they require bifocal glasses to help with near vision to maximise their learning and aid with the viewing of their augmented communication devices.	Thank you for your comment. The Committee agree but standard screening protocols are outside of the remit of this guideline. However, a recommendation has been added to section 1.17 of the short guideline to say: *Refer all children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis*
British and Irish Orthoptic Society	Short	1.17.3		It states that "regular ongoing visual assessment is necessary". This statement is not informative eg what ages does this cover, what sort of assessment is required and who completes it? Therefore clinical application of this guideline would be very variable. Given the lack of evidence on the natural history of the ophthalmic conditions that occur in these children, a	Thank you for your comment. The Committee agree but standard screening protocols are outside of the remit of this guideline. However, a recommendation has been added to section 1.17 of the short guideline to say: *Refer all*

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				definitive guide is not currently possible. The National Screening Committee guidelines on vision screening should be a minimum standard but further test should be included to detect the conditions with a high prevalence and due to potential difficulties with standard visual acuity test, a refraction is also recommended. See point 2 for further details.	*children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis.*
British Society of Bobath Trained Therapists	Full	General	General	It would be useful to have a section on Selective Dorsal Rhizotomy Surgery if possible.	Thank you for your comment. For further detail on Selective Dorsal Rhizotomy Surgery please refer to the Spasticity in under 19s guideline https://www.nice.org.uk/Guidance/CG145.
British Society of Bobath Trained Therapists	Full	291-292	29	We have identified that there is an additional recommendation in the short version of this guideline that is omitted. On page 24, lines 27-29 "for common interventions used in the management of cerebral palsy (such as physical therapies, botulinum toxin A injections and surgery) that can cause acute pain: - advise the child or young person and their parents or carers that these interventions may reduce discomfort in the long term - minimise discomfort during these procedures".	Thank you for your comment. The recommendation you refer is included in section 22.6 of the full guideline.
British Society of Bobath Trained Therapists	Full	148	26	Is the word "only" necessary at the end of this sentence?	Thank you for your comment. The word "only" has been removed as suggested.
British Society of Bobath Trained Therapists	Full	178	24-27	We would suggest that an additional limitation of the VF procedure is that the VF assessment is not necessarily undertaken when children are in their specialised equipment. This may not be a true reflection of function of their typical eating/ drinking in their normal environment.	Thank you for your comment. The Committee agree and have stated that VF in children and young people with cerebral palsy should only be performed in centres that are used to doing this.
British Society of Bobath Trained Therapists	Full	293	28	This paragraph is difficult to follow. We suggest there needs to be an additional word after "cerebral palsy" on line 28 or is this a separate bullet point starting at "assist"?	Thank you for your comment. The word "assist" has been removed from the section you mentionto improve the wording.
British Society of Bobath Trained Therapists	Full	294	Table 92	Limitations of the study: "scares" should be "scarce"?	Thank you for your comment. This has now been amended from "scares" to "scarce"
British Society of Bobath Trained Therapists	Full	337	25	In addition to making a referral for specialist psychological assessment, we would like to suggest that specialist clinical psychologists should be permanent members of multidisciplinary teams caring for children with cerebral palsy.	Thank you for your comment. The Committee agree but consider that depends on local resources and they cannot be prescriptive.
British Society of Bobath Trained Therapists	Full	354	19	Repetition of 'as'.	Thank you for your comment. We have revised the section you mention.
British Society of Bobath Trained Therapists	Full	370	38	In addition to regular, standard visual assessments, we suggest that more specialist functional visual testing should be recommended, particularly for children with CVI.	Thank you for your comment. A recommendation has been added to section 1.17 of the short guideline to say: *Refer all children with cerebral palsy for an initial baseline ophthalmalogical and orthoptic assessment at the time of diagnosis*
British Society of Bobath Trained Therapists	Full	373	General	Drooling and management of drooling is not mentioned.	Thank you for your comment. For further information on saliva control please see chapter 17 of the full guideline.

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British Society of Bobath Trained Therapists	Full	384	Table 129	'Use of public transport' in Description of Theme or Finding column needs to be bold.	Thank you for your comment. The text you refer to has now been amended as you suggested.
British Society of Bobath Trained Therapists	Full	385	Table 129	Lack of 'lists' should be 'lifts'?	Thank you for your comment. The word "lists" in the table you refer to has been amended to "lifts".
British Society of Bobath Trained Therapists	Full	387	Table 129	Extra bullet point, then no bullet points for some subheadings.	Thank you for your comment. The table you refer to now includes bullets for each relevant point.
British Society of Bobath Trained Therapists	Full	403	Table 133 and 134	Would be useful to bold the subheadings under Description on Theme or Finding column.	Thank you for your comment. The subheadings in Table 134 and Table 134 have been made bold as you suggested.
British Society of Bobath Trained Therapists	Full version	376	31-33	Whilst the NICE guideline for spasticity is relevant for children with sustained hypertonus, this guideline does not give guidance on managing movement and posture in children with other subtypes of cerebral palsy, such as dyskinesia, ataxia and hypotonia. We feel that a section dealing with movement and posture in these subtypes of cerebral palsy would be an essential addition to this guideline.	Thank you for your comment. Movement and posture disorders are covered by the spasticity in under 19s guideline: **https://www.nice.org.uk/Guidance/CG145** Your comment has been passed to the NICE surveillance team.
British Society of Bobath Trained Therapists	Short	19-20	11-19	We suggest that this section should include recommending eye tests for children on hyoscine patches.	Thank you for your comment. This has been added to the evidence to recommendations section (17.6.2) of the full guideline.
British Society of Bobath Trained Therapists	Short	5	9-12	The percentages for the causes of cerebral palsy only add up to 75%. We suggest that it should be expanded to include other abnormalities and be closer to 100%.	Thank you for your comment. The numbers are not intended to add up to 100% as results focus on the main causes only.
British Society of Bobath Trained Therapists	Short	6	11-16	We have identified that the causal pathways for ataxic cerebral palsy are not mentioned - should this be included?	Thank you for your comment. The Committee noted in the evidence to recommendations section (5.5.2) of the full guideline that the ataxic form of cerebral palsy was the most difficult to identify for clinicians, and it was considerably rarer, hence it was a problem to be represented by the data. In addition, they thought that if a child presented with it then specialist review by a Consultant in Paediatric Neurosciences would be warranted.
British Society of Bobath Trained Therapists	Short	8	26	1.3.5 – Persistent toe walking: this needs further clarification. Is this related to the age of the child? What is the definition of persistent?	Thank you for your comment. The Committee considered that this would be up to clinical judgment.
British Society of Bobath Trained Therapists	Short	10	3	We suggest that the words "physiotherapy" and "occupational therapy" should be split onto different lines, as we feel that both are essential for children who have cerebral palsy and meet different although overlapping needs.	Thank you for your comment. The recommendation has been revised as you suggested.
British Society of Bobath Trained Therapists	Short	22	23-25	Would "many" rather than the word "most" be a fairer reflection of the literature?	Thank you for your comment. The recommendation has now been revised to say: *Explain to parents and carers and children and young people with cerebral palsy that pain is common, especially with more severe motor impairment; this should be recognised and addressed.*

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British Society of Neuroradiologists	Full	General	General	The British Society of Neuroradiologists supports the recommendation for the selective application of MRI. In this context, we would recommend a stronger emphasis on providing the reporting specialist Neuroradiologists with as clear and comprehensive clinical information as possible. This is mentioned in passing on Page 133, line 4, but would benefit from inclusion in the Guideline Summary.	Thank you for your comment. The Committee agree and have added to the evidence to recommendations section (8.6.2) of the full guideline.
British Society of Neuroradiologists	Full	General	General	1. Taking economic and medical (change in management) arguments into account – they are NOT recommending routine brain MRI for identification of causes of CP (Section 8). 2. They are also NOT recommending routine brain MRI for prognosis of CP (Section 9). This appears to be against recommendations in the USA and there is recognition of that this might generate similar expectations in the UK (Section 9.3 – Page 137, line 21). Instead, the decisions for MRI are to be judged on an individual basis. 3. Cleverly, there is also no specific mention of the training or experience required of the reporting Radiologist/Specialist (however, 'Paediatric Neuroradiologist' is mentioned once, see below) I have a lot of sympathy for this position and the evidence based arguments are well set out in this draft document. I did think there might be some benefit from emphasising somewhere in the Guideline Summary part of the document the importance of providing the reporting Neuroradiologist with as much clinical information as possible. It is only mentioned in passing in Section 8.6.3 (page 133, line 4): The expert opinion and Committee advised that a Paediatric Neuroradiologist would be well equipped to assess the aetiology of cerebral palsy from an MRI when provided with a clear clinical history and examination.	Thank you for your comment. The Committee agree and have added to the evidence to recommendations section (8.6.2) of the full guideline.
British Society of Rehabilitation Medicine	Full	357-377		I was very pleased with the focus on mental health and thought it was very valuable. I was particularly interested in the section on learning disabilities, which gave some useful information about prevalence. However, I felt that the issuer specific learning disabilities was somewhat glossed over and I think more could have been made of the incidence of difficulties with executive function, dyspraxia et cetera, which may be contributing to problems in individuals with "largely normal intelligence". Such individuals sometimes struggle in mainstream with planning, problem solving organisation which has a greater impact as they get older and move on into further end, possibly higher education. There are individuals who have been in mainstream education, but have not necessarily had an enjoyable or supported time and I think there could have been some comment on awareness that these difficulties are not uncommon, and are not always picked up. Such individual children are not always picked up by statementing unless they have significant physical problems. This can also have an important effect on employability. This can also impact on relationships, friendships, mental health, et cetera.	Thank you for your comment. The Committee agree but the points you raise in terms of support provided to those with intellectual disabilities are outside of the scope of this guideline. It may be useful to discuss this during the scoping process for the upcoming cerebral palsy in adults guideline. For further details please see: https://www.nice.org.uk/guidance/indevelopment/gid-ng10031.

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				I would like to see more understanding of neuropsychological deficits in CP Secondly, I think there is a controversy regarding EHP's, although these are mandated up to the age of 25. There are significant number of people regarding learning disabilities who are considered that there needs can be met better in social care, then educational parent therefore they are effectively being removed from the educational system to either save money or to "use the money over 52 weeks rather than simply the educational term.". I would have liked to have seen some comment or recommendation on the importance or otherwise of continuing education to the age of 25 in terms of well-being.	
British Society of Rehabilitation Medicine	Full	394		Section on social care. I think could have been expanded to employment and occupation in the broadest sense. I think it could have covered transition to independent/shared supported living, and also looked at day occupation provision. In particular I would like to see some recommendations as to the role of occupational therapy/psychology in preparation for vocational and independent living. The section on social, cultural and spiritual and religious networks is important, however, I think specific mention should have been made of the challenges of providing care in areas with large ethnic minority groups where there may be 2 or more disabled children within the family. I think that delivering effective services to this group of people, particularly models of care that are culturally appropriate, but meet the needs of the individuals is an area which should have been highlighted among the research recommendations.	Thank you for your comment. The Committee agree but the points you raise in terms of social care support with regard to vocational practice and independent living that is provided to young people with cerebral palsy are outside of the scope of this guideline. This information has been passed to the developer for CP in adults for the upcoming cerebral palsy in adults guideline. For further details please see: https://www.nice.org.uk/guidance/indevelopment/gid-ng10031.
British Society of Rehabilitation Medicine	Full	398		Transition is a very important area for many of us working in Rehabilitation Medicine and we would have liked to have seen a specific mention of ourselves as being suitable physicians to refer individuals onto. In my trust I receive direct referrals from paediatricians for people in transitional phases in an area over around 500,000 population in West Yorkshire. I also provide inreach clinics into special schools/young adult residential services so I can see transitional children with their parents, with the school nurse/physiotherapist, rather than having two doctors in the same clinic, which is not always economic. I would have liked to have seen some reference made to some of the international work on transition programs run out of the University of Rotterdam in terms of supporting and educating young people and training them in the life skills that they are likely to need. I would like to have seen some mention of the work of learning disability liaison nurses within hospitals to try and make sure that anybody admitted beyond the age of paediatrics has an appropriate care plan in place and can have arrangements such as carers/parents staying with them. I would like to think that the adult CP guidelines would be able to pick some of this up as well.	Thank you for your comment. The Committee recognise the importance of considering transition and referral between services and have made many recommendations about the need to refer children and young people with cerebral palsy onto other services and specialities. The section of multidisciplinary team on the appropriate members of the team recognises and reflects the key importance of specialists in adult rehabilitation medicine in ongoing care of individuals with cerebral palsy. However, specific recommendations on transition programmes were outside the remit of this guideline. Please see existing NICE guidance on Transition from children's to adults' services for young people using health or social care services. The Committee consider that it may be useful to discuss this during the scoping process for the upcoming cerebral palsy in adults guideline. For further details please see: https://www.nice.org.uk/guidance/indevelopment/gid-ng10031.

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				I think the reference to GPs as a name, contact and that there would not be additional need for training, I think is highly erroneous, I think that a lot of practitioners find it very difficult to diagnose and treat health problems in young adults with disabilities, particularly those who cannot communicate. I think there is a massive need for GP training and support in this area. Another omission is specific reference to the link between learning disabilities, psychiatry services and paediatrics in terms of transition. There are direct problems with referrals having to go through social services in many areas, so clinicians cannot refer directly to clinicians.	
College of Occupational Therapists	Full	General	General	We are concerned about the omission of participation and function as a means of therapy intervention given the evidence. Although goal based therapy is mentioned it is worthy of a specific section reviewing evidence and the means of delivery. Enabling function and participation is in line with the ICF and the increasing body of evidence that demonstrates that communication, gross motor and fine motor improvements are more likely to be achieved when put in the context of Goal Directed Training. For example, please see: Novak, I., Mcintyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., Stumbles, E., Wilson, S.-A. and Goldsmith, S. (2013), A systematic review of interventions for children with cerebral palsy: state of the evidence. Dev Med Child Neurol, 55: 885–910. doi:10.1111/dmcn.12246	Thank you for your comment. The Committee prioritised participation and function throughout the guideline as reflected in the selection of outcomes to assess interventions to manage sensory and perceptual difficulties, some of which cover aspects of participation and function: • Improvement in processing sensory and perceptual information (for example, improvement in learning, cognitive function, emotional well-being, physical function, socialising and making friends) • Health related quality of life • Improvement in psychological wellbeing (anxiety and depression) (for example, HADS, Becks Depression Inventory) • Wellbeing of parents and carers (for example, Becks Depression inventory) We have retrieved the suggested systematic review (Novak 2013) and individually assessed the included studies that were related with goal directed training approaches. See details below: • Ketelaar M, Vermeer A, Hart H, van Petegem-van Beek E, Helders PJM. Effects of a functional therapy programme on motor abilities of children with cerebral palsy. Phys Ther 2001; 81: 1534–45. Response: This study cannot be included because it aimed at improving motor abilities (i.e. standing, walking, running and jumping), which were not considered in the protocol (See Appendix D) • Lowing K, Bexelius A, Brogren Carlberg E. Activity focused and goal directed therapy for children with cerebral palsy-Do goals make a difference? Disabil Rehabil 2009; 31: 1808–16. Response: The objectives of the intervention of this study (self-care, mobility or self-care) do not match

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					with the ones listed in the protocol of this section (See Appendix D) • Novak I, Cusick A, Lannin N. Occupational therapy home programmes for cerebral palsy: double-blind, randomized, controlled trial. Pediatrics 2009; 124: e606–14 Response: The objectives of the intervention of this study (function and parent satisfaction, child function, participation, goal attainment, and quality of upper limb skill) do not match with the ones listed in the protocol of this specific review question (See Appendix D) • Sakzewski L, Ziviani J, Abbott DF, et al. Randomized trial of constraint-induced movement therapy and bimanual training on activity outcomes for children with congenital hemiplegia. Dev Med Child Neurol 2011; 53: 313–20. Response: The objectives of the intervention of this study (upper limb activity) do not match with the ones listed in the protocol of this specific review question (See Appendix D) • Wallen M, Ziviani J, Naylor O, et al. Modified constraint-induced therapy for children with hemiplegic cerebral palsy: a randomized trial. Dev Med Child Neurol 2011; 53: 1091–9. Response: The objectives of the intervention of this study (activities of daily living and upper limb outcomes) do not match with the ones listed in the protocol of this specific review question (See Appendix D).
College of Occupational Therapists	Full	General	General	The document is clear that we do not know why individuals with cerebral palsy experience sensory and perceptual problems. We also do not know that we can effect change in these areas. We do know that despite these difficulties individuals with cerebral palsy can develop functional skills and participate in chosen activities as part of Goal Directed Training. The document dedicates a section to an area that we have no proof we can change and cannot accurately assess and does not give equal weight to an aspect we can assess and we know we can effect change, namely participation.	Thank you for your comment. The Committee prioritised the following outcomes to assess interventions to manage sensory and perceptual difficulties, some of which cover aspects of participation and function: • Improvement in processing sensory and perceptual information (for example, improvement in learning, cognitive function,

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					emotional well-being, physical function, socialising and making friends) • Health related quality of life • Improvement in psychological wellbeing (anxiety and depression) (for example, HADS, Becks Depression Inventory) • Wellbeing of parents and carers (for example, Becks Depression inventory) Evidence was sought on goal-directed training (see protocol D23 in appendix D), but was not found and this is discussed in the linking evidence to recommendation section of the full guideline.
College of Occupational Therapists	Full	348	17	We should be asking if work on perceptual and sensory skills improves function or participation. Sensory or perceptual skills are not a goal in their own right.	Thank you for your comment. The Committee prioritised the following outcomes to assess interventions to manage sensory and perceptual difficulties, some of which cover aspects of participation and function: • Improvement in processing sensory and perceptual information (for example, improvement in learning, cognitive function, emotional well-being, physical function, socialising and making friends) • Health related quality of life (Child health questionnaire, CPQOL) • Improvement in psychological wellbeing (anxiety and depression) (for example, HADS, Becks Depression Inventory) • Wellbeing of parents and carers (for example, Becks Depression inventory) • Goal attainment scales
College of Occupational Therapists	Full	350	10	A more appropriate recommendation given the shift in clinical practice in line with evidence would be to consider if sensory and perceptual issues affect the function and participation of individuals with cerebral palsy after functional, goal directed therapy (or if the functional needs are met then are these deficits requiring intervention?). Research and intervention is moving away from the fixing of component skills.	Thank you for your comment. The Committee agrees with your suggestion and have added a focus on function and participation to the existing research recommendation. The Committee prioritised the following outcomes to assess interventions to manage sensory and perceptual difficulties, some of which cover aspects of participation and function: • Improvement in processing sensory and perceptual information (for example, improvement in learning, cognitive function,

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College of Occupational Therapists	Full	350	30	There is clinical literature to support Goal Directed Training approaches and this should be reviewed and appraised. Please see Novak reference above.	Thank you for your comment. The Committee prioritised the following outcomes to assess interventions to manage sensory and perceptual difficulties, some of which cover aspects of participation and function: • Improvement in processing sensory and perceptual information (for example, improvement in learning, cognitive function, emotional well-being, physical function, socialising and making friends) • Health related quality of life • Improvement in psychological wellbeing (anxiety and depression) (for example, HADS, Becks Depression Inventory) • Wellbeing of parents and carers (for example, Becks Depression inventory) We have retrieved the suggested systematic review (Novak 2013) and individually assessed the included studies that were related with goal directed training approaches. See details below: • Ketelaar M, Vermeer A, Hart H, van Petegem-van Beek E, Helders PJM. Effects of a functional therapy programme on motor abilities of children with cerebral palsy. Phys Ther 2001; 81: 1534–45. Response: This study cannot be included because it aimed at improving motor abilities (i.e. standing, walking, running and jumping), which were not considered in the protocol (See Appendix D) • Lowing K, Bexelius A, Brogren Carlberg E. Activity focused and goal directed therapy for children with cerebral palsy-Do goals make a difference? Disabil Rehabil 2009; 31: 1808–16. Response: The objectives of the intervention of this study (self-care, mobility or self-care) do not match

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College of Occupational Therapists	Full	351	7,8,9	The recommendation of a functional approach is welcome. A fuller section on the evidence-supporting Goal Directed Training to achieve functional skills and participation is required.	Thank you for your comment. The Committee prioritised the following outcomes to assess interventions to manage sensory and perceptual difficulties, some of which cover aspects of participation and function: • Improvement in processing sensory and perceptual information (for example, improvement in learning, cognitive function,

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					emotional well-being, physical function, socialising and making friends) • Health related quality of life • Improvement in psychological wellbeing (anxiety and depression) (for example, HADS, Becks Depression Inventory) • Wellbeing of parents and carers (for example, Becks Depression inventory) The Committee sought evidence on the intervention of goal-directed training (see Section D.23 in Appendix D), but no evidence was identified. The linking evidence to recommendation section of the guideline has been amended to reflect this.
Department of Health	Full/Short	General	General	Thank you for the opportunity to comment on the draft for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment. .
Guy's and St Thomas' NHS Foundation Trust	Full	Overall	General	Overall we were unable to see a reference to maternal mental health and impact on a child with cerebral palsy. We also felt it is important to address how the topic/issue initiating tube feeding is addressed as this can significantly impact on the acceptance by the child and family. The work of Dr Gillian Craig could be referenced. Comments from Paediatric Dietitians: Mary-Anne Leung, Julia Hopkins and Kate O'Leary	Thank you for your comment. Maternal mental health was outside of the scope of this guideline. Further detail on when to initiate tube feeding has been added to the evidence to recommendations section (14.6.2) of the full guideline. Please also see existing NICE guidance on Antenatal and postnatal mental health: clinical management and service guidance.
Guy's and St Thomas' NHS Foundation Trust	Full	185	15/16	Mealtimes may be lengthy, distressing, emotional and unproductive in terms of achieving adequate or perceived adequate intake.	Thank you for your comment.. The Committee agreed with your comment and added the following text to the section you refer to "Mealtimes may be lengthy, distressing, emotional and unproductive in terms of achieving adequate or perceived adequate intake."
Guy's and St Thomas' NHS Foundation Trust	Full	186	27	Adams 2011: Unclear of the relevance of this study to the population group for the UK for which this guidelines are aimed at. Clawson 2007: Very small study in 8 children. Unfamiliar environment to the child and carer would likely have an impact on feeding. Gisel 2001: ISMAR appliance this needs to written in full before an abbreviation is used. Reference 2 is not indicated at point of documentation. Ottenacher 1981: Short time frame and no follow up. Quite an old reference	Thank you for your comment. The protocol for this review (See Appendix D.9) was agreed by the Committee. The protocol was kept intentionally broad, as the Committee anticipated little evidence. Please see comments to each highlighted reference: Adams 2011: it was the only study identified in the search including a training programme. The Committee agreed to include the study, but when assessing the quality of the evidence it was noted that the study

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					included indirect population (See GRADE evidence profile in Appendix H.9, Table 9). Clawson 2007: we agree the sample size is very small. This was taken into account when assessing the quality of the study. Gisel 2001: ISMAR appliance has now been written in full before abbreviation is used. There are 3 studies by the same author (Gisel 1995, 1996, 2001). The 3 references are in the reference list. Ottenacher 1981: as indicated above, the protocol was kept broad in order to be more inclusive. We acknowledge the study is old, and follow-up is short to expect changes in anthropometric measures (9 weeks), but the Committee agreed it was useful to include it. The quality of the evidence was rated as very low (see GRADE evidence profile in Appendix H.10, Table 10), and this was taken into consideration when making recommendations.
Guy's and St Thomas' NHS Foundation Trust	Full	190	3	As professionals reading this document we found it very difficult to interpret the data and the relevance of the studies when such small numbers of patient groups are being looked at over a short period of time. Perhaps it could be summarised in a more concise manner. The choice of studies is poor for including in this guideline	Thank you for your comment. We understand that the usual format of the clinical evidence profile can result in it being difficult to follow, especially in the presence of multiple studies. However, due to the necessity of assessing each of the outcomes retrieved for each study, this means that in certain cases clinical evidence profile tables may be long. For a more summarised synthesis of the evidence, please see the description of the 'clinical evidence profile' section and the 'evidence statements' ('Management of eating, drinking and swallowing' chapter 13; full guideline). The studies selected meet the inclusion criteria of the protocol signed by the Committee (Appendix D.9).
Guy's and St Thomas' NHS Foundation Trust	Full	197	17-22	10 weeks and 9 weeks follow up are relatively short periods of time to expect a change in weight for a child with Cerebral Palsy. For cohesiveness, outcomes should use the same measurements, even if the study outcomes are in pounds this should be converted to kg for use or discussion in this guideline.	Thank you for your comment. The protocol for this review (see Appendix D.9) was agreed by the Committee. The protocol was kept intentionally broad, as the Committee anticipated little evidence. We agree that 9 and 10 weeks are short periods for follow-up, Measurements have now been changed to Kgs for consistency, but this was the only available evidence and the Committee agreed it was useful to report it. This was taken into account when assessing the quality of the study, and it is noted in the 'summary of studies table' ('Management of eating, drinking and swallowing' chapter 13; full guideline).

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Guy's and St Thomas' NHS Foundation Trust	Full	198	11-30	again short period of time to expect change to take place. The studies do not compare the same outcomes, time frames are too short. Due to the age of the studies most are irrelevant to current practice. Overall this section seems to be quite extensive but we query how necessary it is to include all the information. Simply summarising e.g. a literature search has revealed the following studies provide unsatisfactory conclusions on the benefits of interventions.	Thank you for your comment. The protocol for this review (See Appendix D.9) was agreed by the Committee. The protocol was kept intentionally broad, as the Committee anticipated little evidence. We agree follow-up should be longer, but this was the only available evidence and the Committee agreed it was useful to report it. This was taken into account when assessing the quality of the study, and it is noted in the summary of studies table (see GRADE evidence profile in Appendix H.10, Table 9).
Guy's and St Thomas' NHS Foundation Trust	Full	198	2-8	short period of time to expect change	Thank you for your comment. The protocol for this review (See Appendix D.9) was agreed by the Committee. The protocol was kept intentionally broad, as the Committee anticipated little evidence. We agree follow-up should be longer, but this was the only available evidence and the Committee agreed it was useful to report it. This was taken into account when assessing the quality of the study, and it is noted in the summary of studies table (see GRADE evidence profile in Appendix H.10, Table 9).
Guy's and St Thomas' NHS Foundation Trust	Full	204	42	Format of recommendations much easier to read and in a more comprehensive format. This is what people are looking for from a guideline.	Thank you for your comment.
Guy's and St Thomas' NHS Foundation Trust	Full	208	24	PEJ feeding should also be included	Thank you for your comment. Percutaneous endoscopic jejunostomy (PEJ) feeding has now been added as an intervention in the section you refer to (introduction). Please note that both PEJ and percutaneous endoscopic gastrostomies (PEG) were included in the protocol for this review question.
Guy's and St Thomas' NHS Foundation Trust	Full	209	25	Tables could be put in appendix as opposed to main text for ease of reading. Patrick (1986): We query whether this study should be included given the age of the study and low numbers in the study.	Thank you for your comment. Tables presented in the main text are part of the description of clinical evidence and are placed in the main text following NICE standards. In the Appendices section there is other information that complements the main text, such as GRADE tables (Appendix H.11) or Forest plots (Appendix I.11). Patrick 1986 has been included as it met the inclusion criteria stated in the protocol (See Appendix D.11), in which no year limits were described. With regards to its small sample size, we agree that is lower than 30 participants (which is the minimum number stated in the protocol); however is the only study that compared high energy tube feeding versus control. Nonetheless, this study was rated as very low quality (See Appendix J.11 full evidence tables) and this was taken into consideration when developing the recommendations.

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Guy's and St Thomas' NHS Foundation Trust	Full	213	32	Change to "can be common" to "are common" Whole section is very well written and very comprehensive	Thank you for your comment. The section you mention has been revised from "can be common" to "are common"
Guy's and St Thomas' NHS Foundation Trust	Full	214	22-23	add in "if oral intake is insufficient or unsafe to provide adequate nutrition…"	Thank you for your comment. The section you mention has been revised to include the text in your comment
Guy's and St Thomas' NHS Foundation Trust	Full	214	25	We feel this should specify "access to **paediatric** dietitians"	Thank you for your comment. Our preference is to refer to 'dieticians' rather than 'paediatric dieticians' as the guideline includes young people up to the age of 25 years.
Guy's and St Thomas' NHS Foundation Trust	Full	214	38-44	Appears in the wrong section of the guideline as it relates to administration of medications	Thank you for your comment. We disagree as the section you mention also refers to cost considerations.
Guy's and St Thomas' NHS Foundation Trust	Full	215	29	paediatric dietitian	Thank you for your comment. Our preference is to refer to 'dieticians' rather than 'paediatric dieticians' as the guideline includes young people up to the age of 25 years.
Guy's and St Thomas' NHS Foundation Trust	Full	216	2	This is a very specific piece of research on a defined group. ? where this fits with the general population of children with cerebral palsy and thus relevance to the wider guidelines Overall very clear and well written chapter	Thank you for your comment. The population specified in this research recommendation is intended to be in line with the population detected by any screening programme of high-risk infants in this guideline.
Guy's and St Thomas' NHS Foundation Trust	Full	275	41	dietary assessment by a **paediatric dietitian**	Thank you for your comment. Our preference is to refer to 'dietitians' rather than 'paediatric dietitians' as the guideline includes young people up to the age of 25 years so it should be just 'dietitian'.
Guy's and St Thomas' NHS Foundation Trust	Full	278	1	Format makes it easy to read/interpret	Thank you for your comment.
Medtronic Limited	Full	23	Fig 2	Fig 2: "Cerebral palsy algorithm – management" refers to C145 as "CG145 Spasticity in Children and Young People". This is not the correct title of the guideline and suggests that CG145 covers children and young people up to the age of 25 as per in this cerebral palsy guideline.	Thank you for your comment. The algorithm in the full guideline has been amended to reflect the correct population.
Medtronic Limited	Short	10	16	This draft guideline covers the diagnosis, assessment and management of cerebral palsy in children and young people from birth up to their 25th birthday. "Young person" means a person over compulsory school age but under 25 as defined in the Children and Families Act 2014. This scope of this guideline does not include management of spasticity and states ***"For guidance on managing problems with movement and posture in children and young people with cerebral palsy, see the NICE guideline on spasticity in under 19s".*** CG145 "Spasticity in the under 19s: management "does not cover "young people" between 19 and 25 years.	Thank you for your comment. Movement and posture disorders are covered by the spasticity in under 19s guideline: **https://www.nice.org.uk/Guidance/CG145** Your comment has been passed to the NICE surveillance team.

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				CG145 "Spasticity in under 19s: management" is currently under review and NICE has provisionally decided not to update this guideline. The surveillance review proposal is that the CG145 guideline scope should not be extended to include ages 19 to 25 years. Cerebral palsy is the most common condition associated with spasticity in children and young people therefore we are concerned that the inconsistency in the ages covered by the two related guidelines leaves a gap in guidance on the management of spasticity in young adults with cerebral palsy, aged between 19 and 25 years. We suggest that one or the other of these guidelines should be updated to include this age group.	
Nutricia Advanced Medical Nutrition	Full	31	1	We would feel that weight loss or no weight gain in the last 6 months should also be an indication for referral to specialist services. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee agree but think that this should be in the first instance investigated by a paediatrician.
Nutricia Advanced Medical Nutrition	Full	31	1	We feel that mealtimes being stressful or distressing for parent or child/young person should also be an indication for referral to specialist services. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee have added 'mealtimes regularly being stressful or distressing' to the recommendation you mention.
Nutricia Advanced Medical Nutrition	Full	31	6	Guidance on what constitutes prolonged mealtimes should be included – Some authors suggest more than 30 mins, on a regular basis. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee have noted your point on guidance on prolonged mealtimes in the evidence to recommendations section (12.4.2) of the full guideline.
Nutricia Advanced Medical Nutrition	Full	32	14	We feel guidance on appropriate anthropometric measurements should be included here	Thank you for your comment. Further examples have been added to the evidence to recommendations section (14.6.2) of the full guideline.
Nutricia Advanced Medical Nutrition	Full	32	18-20	We feel that more guidance is needed on how long after oral intake fails to provide adequate nutrition that tube feeding should be considered. Some authors suggest 1–3 months depending on the child's age and nutritional status. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The evidence to recommendations section (14.6.2) of the full guideline has been revised.
Nutricia Advanced Medical Nutrition	Full	32	23-37	Should this be listed under the 'Optimising nutritional status' section? Seems to relate to language and communication?	Thank you for your comment. The headings within the full list of recommendations in the full guideline has been revised so that the recommendations fall under the appropriate sections.
Nutricia Advanced Medical Nutrition	Full	184	11	We would feel that weight loss or no weight gain in the last 6 months should also be an indication for referral to specialist services. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee agree but think that this should be in the first instance investigated by a paediatrician.
Nutricia Advanced Medical Nutrition	Full	184	11	We feel that mealtimes being stressful or distressing for parent or child/young person should also be an indication for referral to specialist services. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee have added 'mealtimes regularly being stressful or distressing' to the recommendation you mention.

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Nutricia Advanced Medical Nutrition	Full	184	16	Guidance on what constitutes prolonged mealtimes should be included – Some authors suggest more than 30 mins, on a regular basis. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee have noted your point on guidance on prolonged mealtimes in the evidence to recommendations section (12.4.2) of the full guideline.
Nutricia Advanced Medical Nutrition	Full	215	26	We feel guidance on appropriate anthropometric measurements should be included here	Thank you for your comment. Further examples have been added to the evidence to recommendations section (14.6.2) of the full guideline.
Nutricia Advanced Medical Nutrition	Full	215	30	We feel that more guidance is needed on how long after oral intake fails to provide adequate nutrition that tube feeding should be considered. Some authors suggest 1–3 months depending on the child's age and nutritional status. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The evidence to recommendations section (14.6.2) of the full guideline has been revised to include the Committee's view that "tube feeding is indicated in cases of unsafe or inefficient oral feeding, preferably before the development of undernutrition."
Nutricia Advanced Medical Nutrition	Short	14	23	We would feel that weight loss or no weight gain in the last 6 months should also be an indication for referral to specialist services. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee agree but think that this should be in the first instance investigated by a paediatrician.
Nutricia Advanced Medical Nutrition	Short	14	23	We feel that mealtimes being stressful or distressing for parent or child/young person should also be an indication for referral to specialist services. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The developers have added 'mealtimes regularly being stressful or distressing' to the recommendation you mention.
Nutricia Advanced Medical Nutrition	Short	14	28	Guidance on what constitutes prolonged mealtimes should be included – Some authors suggest more than 30 mins, on a regular basis. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee have noted your point on guidance on prolonged mealtimes in the evidence to recommendations section (12.4.2) of the full guideline.
Nutricia Advanced Medical Nutrition	Short	18	26	We feel guidance on appropriate anthropometric measurements should be included here	Thank you for your comment. Further examples have been added to the evidence to recommendations section (14.6.2) of the full guideline.
Nutricia Advanced Medical Nutrition	Short	19	4	We feel that more guidance is needed on how long after oral intake fails to provide adequate nutrition that tube feeding should be considered. Some authors suggest 1–3 months depending on the child's age and nutritional status. Please refer to A Practical Approach to the Nutritional Management of Children with Cerebral Palsy European Journal of Clinical Nutrition 2013	Thank you for your comment. The Committee agreed that tube feeding is indicated in cases of unsafe or inefficient oral feeding, preferably before the development of undernutrition. This has been reflected accordingly in the evidence to recommendations section (14.6.2) of the full guideline.
Oxford University Hospitals	Full	299	2	Could the specialist MDTs considered for assessment / treatment of pain (and other distressing symptoms) include paediatric palliative care services? Maybe there could be a link to the NICE guidance on end of life care for children?	Thank you for your comment. The Committee agree and have referred to palliative care services in recommendation 1.13.12 of the short guideline and have also noted the NICE guidance on end of life care in the evidence to recommendations section (22.5.2) of the full guideline.
Oxford University Hospitals	Full	305	1	Could treatments for pain (and other distressing symptoms) include more non-pharmacological approaches? This would tie in nicely with the guidance for children with palliative care needs. Such treatments would be available to many CP patients via children's hospices.	Thank you for your comment. The Committee have revised the recommendation you mention to add the

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					following: *take into account the impact of anxiety, depression or other possible mental health problems* They have also referred to palliative care services in recommendation 1.13.12 of the short guideline and have also noted the NICE guidance on end of life care in the evidence to recommendations section (22.5.2) of the full guideline. Non-pharmacological approaches were not prioritised for inclusion in the scope. However, the Committee have commented about the importance of managing anxiety in terms of a pain intervention in the linking evidence to recommendation section of the guideline.
Oxford University Hospitals	Full	397	1-4	Could the list of support services available include paediatric palliative care and children's hospice services?	Thank you for your comment. The Committee have revised the recommendation to say: •support groups (including psychological and emotional support for the child or young person and their families and carers, and siblings, and hospice services).
Oxford University Hospitals	General			Congratulations on a truly holistic and detailed piece of guidance, which ought to make a real difference to current inequities in care. I wonder if there may merit in mentioning the support services available from Paediatric Palliative care and Children's Hospices to children with the more severe forms of cerebral palsy? (around 20% would meet the criteria for most services). They constitute a significant, complex and vulnerable proportion of our patient population.	Thank you for your comment. The Committee have revised the recommendation to say: *Provide information on the following topics, and direct families to where they can find further information, at diagnosis of cerebral palsy and as appropriate thereafter:* • *social care services* • *financial support, welfare rights and voluntary organisations* • *support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings)* • *respite and hospice services.*
Proveca Limited	Full	General	General	On 16th September 2016 Proveca Ltd were awarded a Paediatric Use Marketing Authorisation (PUMA) for its product Sialanar (glycopyrronium bromide oral liquid 2mg/5ml) for the treatment of severe chronic pathological drooling in children aged 3 years and older. This is the only product licenced for the treatment of this condition in Europe. Neither hyoscine nor botulinum toxin have any licence for this indication. The Sialanar product licence was granted during the consultation period for this procedure and its inclusion in these guidelines (as first line pharmacological intervention, following conservative measures) follows best practice.	Thank you for your comment. The Committee agreed that glycopyrronium bromide should be recommended as an option to treat drooling problems. However, use of a medicine outside its licensed indication (off-label use) may be considered in some circumstances; for example, if this use is common practice in the UK, if there is good evidence for this use, or there is no other medicine licensed for the indication. As a result, the Committee also agreed that hyoscine should be recommended given that it was cheaper to acquire than gylcopyrronium bromide, currently used to treat drooling in clinical practice, and there was evidence that showed it was as effective as glycopyrronium bromide to treat drooling problems. The Committee have also revised the licensing indications footnote for glycopyrronium.

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					In addition to clinical effectiveness, the Committee also considered cost-effectiveness when making their recommendations. Glycopyrronium bromide is an expensive ongoing pharmacological treatment that would be dominated by botulinium toxin when long-term treatment is needed as botulinum toxin would be cheaper and at least as effective. Combined with their clinical expertise, the Committee concluded that botulinum toxin should be considered if anticholinergic drugs provide insufficient benefit or are not tolerated.
Proveca Limited	Full	General	General	The licence for Sialanar (glycopyrronium bromide oral liquid 2mg/5ml) includes comprehensive prescriber and carer information in the form of the standard documents (Summary of product characteristics, and Patient information leaflet). In addition healthcare professional and parent/carer educational materials have been developed in conjunction with the European Medicines Agency (EMA) to help with dose titration and maintenance as well as the recognition and management of adverse events, particularly since the communication skill of the patient may not allow for them to indicate the presence of specific adverse events. Sialanar has been formulated specifically for children with minimal excipients, a mild raspberry flavour and a concentration of the liquid (2mg/5ml) to ensure an suitably low volume is given per dose, since the reason for the prescription is difficulty in swallowing. The product comes with an oral dosing syringe and a clear dosing table, based on the weight of the child and the dose titration schedule.	Thank you for your comment. The Committee agreed that glycopyrronium bromide should be recommended as an option to treat drooling problems. The Committee have also revised the licensing indications footnote for glycopyrronium. The guideline also includes a recommendation to regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control. The guideline will assume that prescribers will use a medicine's summary of product characteristics to inform decisions made with individual patients.
Proveca Limited	Full	General	General	The management guidelines for the treatment of chronic drooling do not give guidance on the issues with the numerous different concentrations of glycopyrronium liquid available on the UK specials market. The different concentrations regularly result in dosing errors for the child (both under and overdosing) since a product with a different concentration may be dispensed from that which the patient had previously. Proveca have correspondence from clinicians indicating that this has happened to their patients. Prescribing of a licensed product should negate this issue over time but it seems prudent to advise within these guidelines that the pharmacist dispenses the product with the paediatric licence to ensure consistency of dosing and availability of the approved documentation leading to consistently safe and effective use of the product.	Thank you for your comment. The guideline includes a recommendation to regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control which would reduce the downstream costs associated with dosing errors. Please note that NICE use the generic name and not the branded name in recommendations relating to medicines. The guideline will assume that prescribers will use a medicine's summary of product characteristics to inform decisions made with individual patients.
Proveca Limited	Full	General	General	*The areas that will have the biggest impact on practice and be challenging to implement.* The availability of Sialanar, the first paediatric licensed product for the treatment of chronic drooling in children with cerebral palsy will improve the treatment of children in the longer term. The challenge to implementation will be a change from the most common first line treatment hyoscine to the licensed product glycopyrronium (Sialanar). More importantly perhaps is the challenge to ensure that the same (licensed) product is always dispensed to	Thank you for your comment. The Committee agreed that glycopyrronium bromide should be recommended as an option to treat drooling problems. Please note that NICE use the generic name and not the branded name in recommendations relating to

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				remove the risk of under or overdosing which occurs when different strengths are dispensed..	medicines, therefore the guideline would not refer to Sialanar explicitly. The guideline will assume that prescribers will use a medicine's summary of product characteristics to inform decisions made with individual patients.
Proveca Limited	Full	General	General	*How to help users overcome challenges.* It is envisaged that the work conducted by Proveca to gain a Paediatric Use Marketing Authorisation for Sialanar (2mg/5ml glycopyrronium bromide oral liquid) throughout EU will greatly enhance the safety of children with chronic drooling associated with cerebral palsy. The standard, paediatric specific formulation, with low volume, oral dosing syringe, clear dosing and safety information, educational materials and enhanced safety monitoring, will result in more consistent dosing, ready availability of product and improved efficacy and safety of the management of drooling in this vulnerable population.	Thank you for your comment. The Committee agreed that glycopyrronium bromide should be recommended as an option to treat drooling problems. The guideline will assume that prescribers will use a medicine's summary of product characteristics to inform decisions made with individual patients.
Proveca Limited	Full	33	15 (and associated note 'c')	Given the licenced status of Sialanar (glycopyrronium bromide oral liquid 2mg/5ml), which was granted during the consultation period, it is not appropriate to make the first line drug of choice an unlicensed product. (Further rationale is given below). Note 'c' should be amended to acknowledge the licensed status of Sialanar. The logic of proposing unlicensed hyoscine as first line product be reconsidered.	Thank you for your comment. The Committee have revised the licensing indications footnote for glycopyrronium. If hyoscine and glycopyrronium bromide were equally effective at reducing drooling in children and young people with cerebral palsy, hyoscine should be recommended as a first line treatment as it is substantially cheaper. However, when the Committee considered the potential side effects of hyoscine they concluded that the expected decrements in quality of life and expected costs to manage those events would outweigh the lower acquisition cost of hyoscine, leading to similar estimates of cost-effectiveness. As a result, the Committee recommended glycopyrronium bromide or hyoscine once other factors such as positioning, medication history, reflux and dental issues have been assessed.
Proveca Limited	Full	251	11	Table 78 includes details of the Parr 2016 comparative study. The measure of tolerability by means of withdrawal due to an adverse event is not referenced (although this is mentioned later in the document). Short/mid term tolerability is highly relevant to the treatment of this vulnerable population. 45% of children in the hyoscine group compared to 18% in the glycopyrronium group withdrew from treatment due to adverse events over the 12 week study period. It is considered appropriate to include this outcome in Table 78.	Thank you for your comment. Tolerability was not included as an outcome of interest in the protocol (See Appendix D.14), and it was therefore not included in table 78. However, in the light of the results of this study, the Committee discussed the issue of tolerability when drafting the recommendations, and this was captured in the evidence to recommendations section (17.6.2) in the full guideline.
Proveca Limited	Full	255	23	Whilst the committee noted the 'comparative lack of clinical evidence with hyoscine', we feel that to be transparent it should be stated that no placebo-controlled studies with transdermal hyoscine in the treatment of chronic drooling in children have been conducted.	Thank you for your comment. This has now been changed to 'comparative lack of evidence in comparison to either placebo or alternative treatment on the use of transdermal hyoscine hydrobromide'.
Proveca Limited	Full	255	27-28	Despite the lower price of transdermal hyoscine compared with oral glycopyrronium, the licensed status of Sialanar ((glycopyrronium bromide oral liquid 2mg/5ml)) compared to the unlicensed status of hyoscine requires	Thank you for your comment. The Committee agreed that the recommendation should acknowledge the importance of considering the license status of a

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				glycopyrronium to be the recommended first line drug for purposes of this guideline.	treatment and has revised the recommendation to: to say: 1.11.2 To reduce the severity and frequency of drooling in children and young people with cerebral palsy, consider the use of anticholinergic medication: • Glycopyrronium bromidelate (oral or by enteral tube) or • transdermal hyoscine hydrobromide or • trihexyphenidyl hydrochloride for children with dyskinetic cerebral palsy, but only with input from specialist services. When choosing which medicine to use, take into account the preferences of the child or young person and their parents or carers, and the age range and indication covered by the marketing authorisation. The Committee have also revised the licensing indications footnote for glycopyrronium.
Proveca Limited	Full	255	29-30	The median treatment duration in a cohort of 426 children treated with oral glycopyrronium for chronic drooling was 6 months (range 1-92 months)(Proveca study of data from CPRD 2016). Parr 2016 shows hyoscine is less well tolerated over a 3 month period compared to glycopyrronium (hyoscine 45% withdrawal due to adverse event compared to glycopyrronium 18%). Given the data (on file) shows a medium treatment duration of 6 months it does not seem prudent to recommend hyoscine as first line treatment over glycopyrronium bromide. In addition, glycopyrronium is now the only licensed product in EU for treating chronic drooling in children.	Thank you for your comment. The Committee revised the recommendation in light of stakeholder feedback to: 1.11.2 To reduce the severity and frequency of drooling in children and young people with cerebral palsy, consider the use of anticholinergic medication: • Glycopyrronium bromidelate (oral or by enteral tube) or • transdermal hyoscine hydrobromide or • trihexyphenidyl hydrochloride for children with dyskinetic cerebral palsy, but only with input from specialist services. When choosing which medicine to use, take into account the preferences of the child or young person and their parents or carers, and the age range and indication covered by the marketing authorisation. . The guideline also includes a recommendation to regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control. The Committee have also revised the licensing indications footnote for glycopyrronium.
Proveca Limited	Full	255	32-34	The committee highlighted 'the importance of not cutting transdermal hyoscine hydrobromide patches as the active ingredient is maintained in a matrix between 2 membranes, and if the integrity of the patch is altered so will its effectiveness'. Cutting the patch is the practice for the majority of prescribers/carers since there is no other way to titrate the dose of hyoscine. Nevertheless cutting the patch results in too high an initial dose and minimal/no dose on the second and third day of treatment. This results in very unstable and erratic drooling control. Not cutting the patch means there	Thank you for your comment. Please note that the evidence to recommendations in section (17.6.2) of the full guideline states the following: *They considered important to highlight the importance of not cutting transdermal hyoscine hydrobromide patches as the active ingredient is maintained in a matrix between 2 membranes, and if the integrity of the patch is altered so will its effectiveness*. Following your comment the

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				is no ability to titrate the dose for any given child, resulting in a high potential for overdose for the required body weight. On the other hand, oral liquid glycopyrronium is highly adapted to specific up and down dose titration as required by the child, resulting in a low level of side effects easily managed through dose moderation. This is reflected in the Parr 2016 study where despite a small increase in adverse events with glycopyrronium, only 18% of children withdrew treatment as a consequence of the adverse events compared to 45% on hyoscine. The ability to titrate the dose accurately is critical to optimise symptom management and should be reflected in the discussions about drug choice.	Committee have now also added: *they also noted that to obtain half a patch in contact with the skin then a slip of tegaderm occlusive dressing can be placed between half the patch and the skin.* The guideline includes a recommendation to regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control. The Committee agrees it is easier to titrate oral glycopyrronium than transdermal **hyoscine** hydrobromide and this is reflected in the linking evidence to recommendation section of the guideline.
Proveca Limited	Full	255	41-46	The committee discussed the low level of data on the side effect profile of glycopyrronium. Whilst the glycopyrronium data is not comprehensive it is more extensive than the data on hyoscine given that, unlike glycopyrronium, there are no placebo controlled trials with hyoscine. In addition hyoscine crosses the blood brain barrier, which glycopyrronium does not. This fact is not referred to in the document but results in an increase in neurological adverse events with hyoscine. The low affinity for glycopyrronium to cross the blood brain barrier, compared to other anticholinergic drugs such as hyoscine, is seen in the Parr 2016 study, in which unpredicted side effects leading to withdrawal showed hyoscine to be associated with; ataxia (3), hyperactivity (2), hypotonia/floppiness (1) and increased seizure activity (1); while glycopyrronium was associated with 1 episode of hyperactivity. Constipation and urinary retention are seen with glycopyrronium, although evidence for visual disturbances was not found by Proveca in its review of the data for the licence application for Sialanar. Anticholinergic adverse events can be managed by stopping the drug for the duration of the event or titrating the dose down. The licensed product Sialanar contains clear instructions on what to do in the event of specific adverse events such as constipation or urinary retention.	Thank you for your comment. The guideline includes a recommendation to regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control. The Committee have also revised the licensing indications footnote for glycopyrronium. The Committee agree that in practice side-effects are seen more frequently with transdermal hyoscine hydrobromide than glycopyrrlate and this is reflected in the linking evidence to recommendation section of the full guideline. The guideline will assume that prescribers will use a medicine's summary of product characteristics to inform decisions made with individual patients.
Proveca Limited	Full	256	20-21	The labelling for the licensed product Sialanar includes comprehensive details for the prescriber and the carer on how to manage adverse events and recommends the need for regular follow up (3 monthly maximum intervals). The information package and the post licence risk minimisation measures required with the Sialanar licence will significantly improve the ongoing patient management and safety of children with chronic drooling who would benefit from pharmacological treatment.	Thank you for your comment. The guideline includes a recommendation to regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control. The Committee have also revised the licensing indications footnote for glycopyrronium. The guideline will assume that prescribers will use a medicine's summary of product characteristics to inform decisions made with individual patients.
Royal College of General Practitioners	Short	General	General	The RCGP welcomes such a good quality document. This could be consider the ideal model of what such a document should be: clear, comprehensive, and trying to remind users of the range of things they should consider rather than direct them to do anything in particular. (DJ)	Thank you for your comment. Although this is a valid point, the guideline is not intended to be a comprehensive text book on cerebral palsy and is intended for use in clinical practice. Please note that NICE will be issuing a pathway for this guideline. .

<table>
<tr><th>Stakeholder</th><th>Document</th><th>Page No</th><th>Line No</th><th>Comments
Please insert each new comment in a new row</th><th>Developer’s response
Please respond to each comment</th></tr>
<tr><td></td><td></td><td></td><td></td><td>However, we feel that this guideline could be enhanced infographics such as a summary table showing follow up management and the emphasis of care of each age group such as (Care Pathways for Children and Young people with cerebral palsy 2012 by Dr. Bidisha Lahoti Dr Charlie Fairhurst and Dr Karen Horridge). See below:
<table>
<tr><th>Age Group</th><th>Emphasis of care</th></tr>
<tr><td>Birth through 2 years</td><td>Global development, vision, hearing, cognitive and motor development, hip stability, nutrition, dental, language and psycho-social concerns.
Referral for appropriate early intervention community programs and services.
Anticipatory notification to SEN in Education.
Routine screening hip X-Ray GMFCS 1 – 5
Support parents to come to terms and develop positive outlook.</td></tr>
<tr><td>3 through 5 years</td><td>Evaluation of needs for preschool and early primary school.
Encouragement of optimal development by promoting educational, social, and recreational interaction in the least restrictive environment.
Attainment of ability to perform appropriate activities of daily living.
Continuing screening of hip and spinal development. Need for X-rays dependent on clinical examination and level of walking ability</td></tr>
<tr><td>6 through 12 years</td><td>Ongoing therapeutic input to build on and maintain optimal function.
Urological evaluation, if indicated.
Help with child’s understanding of the condition.
Continued screening of musculo-skeletal integrity, especially hip and spine, throughout growth.</td></tr>
<tr><td>13 through 21 years</td><td>Ongoing therapeutic input to build on and maintain function. Review of bone health in</td></tr>
</table></td><td>Movement and posture disorders are covered by the spasticity in under 19s guideline: https://www.nice.org.uk/Guidance/CG145
Your comment has been passed to the NICE surveillance team.</td></tr>
</table>

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				non-ambulant children, especially if on anticonvulsant therapy. Transition to adult services Vocational counseling. Transition to independent living, or at least optimise choices. (MH) The RCGP also feels that the guidelines addresses some important areas but does not appear other areas such as postural care (apart from a brief mention in regards to swallowing) and hip surveillance. It would useful to reference specialist guidelines such as http://www.bacdis.org.uk/policy/documents/CPpathway.pdf. There does not appear to any mention of annual health checks DES for people with learning disabilities by their GP practice from the age of 14 years or annual influenza vaccination. (MH)	
Royal College of General Practitioners	Short	1.1	General	Risk factors included 'low birth weight', but not defined. It would be advisable to provide some evidence to confirm if the risk of cerebral palsy increases as birth weight goes down. But the writers presumably have in mind a threshold at which the enhanced follow up should be offered and it would help to define it. The same might apply to maternal infections. 'Treated in hospital' is presumably being used as a proxy for severity. It does not sound very robust – is there anything better? (DJ)	Thank you for your comment. We have now defined in the glossary of the full guideline what the Committee meant by 'low birth weight'. The Committee discussed maternal infections at length and they agreed the term 'treated in hospital' was reflected in the evidence reviewed and was in their view an appropriate way to convey more severe infections.
Royal College of General Practitioners	Short	1.11	General	Saliva control. This section looked slightly out of place. All the others concern areas that are of obvious functional and health importance. As far as we know, drooling is a matter of annoyance and embarrassment. It would be welcomed an explanation in this matter please. (DJ)	Thank you for your comment. The Committee consider that drooling has a major impact on quality of life for young people and their families. It was highlighted early on as a key clinical area to be looked at by stakeholders.
Royal College of General Practitioners	Short	1.2	General	There is no reason given why doctors should try to find the cause. It would be ideal to have further explanation please. (DJ)	Thank you for your comment. The Committee noted that it was a major concern from parents and carers to establish the cause of cerebral palsy.
Royal College of General Practitioners	Short	1.18.3	General	National support organisations should be named included SCOPE www.scope.org.uk (MH)	Thank you for your comment. Your point has been added to the evidence to recommendations section (11.5.5) of the full guideline.
Royal College of General Practitioners	Short	1.12.8	General	Is referral really necessary for this? Bisphosphonate therapy for older patients not affected by cerebral palsy is something that GPs are familiar with. Why is this not a matter for GPs? Also is there evidence that can guide	Thank you for your comment. The Committee consider that Bisphosphonate therapy in paediatrics is not something recommended outside specialist centre

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				clinicians in deciding how long to continue bisphosphonate therapy in this group? (DJ)	supervision by an paediatric endocrinologist or expert in bone health in Neurodisability.
Royal College of General Practitioners	Short	Page 39	Context	The RCGP would recommend to move this section at the beginning of the document. Is there any reason it has been decided to include it at the end? (DJ)	Thank you for your comment. We are unable to move this section as this is the standard NICE template for short guidelines.
Royal College of Nursing	Full/Short	General		This is to inform you that the Royal College of Nursing have no comments to submit to inform on the above consultation.	Thank you for your comment.
Royal College of Ophthalmologists	Short	30	20	The RCOphth Paediatric sub-Committee agrees that measurement of visual acuity is important - using a range of testing modalities as appropriate to the child. However, assessment should be of the whole visual system, to include acuity as well as examination of the front and back of the eye, assessment of eye movements/strabismus and refraction is important. This is particularly important at key points of transition in the life of the child with CP i.e. school entry, transition from primary to secondary education and the move to higher education. The frequency of reviews will be determined by the clinical findings and the presence of refractive error.	Thank you for your comment. In light of stakeholder comments, the Committee has reviewed the recommendations on visual impairment and the corresponding evidence to recommendations section (27.19.2) in the full guideline. The entire section on vision was revised, taking into account stakeholder feedback.
Royal College of Ophthalmologists	Short	30	9-28	Children with CP are at increased risk of not only poor visual acuity but also refractive error, strabismus, nystagmus and visual field deficits. The statement should acknowledge the broad range of specific deficits within "visual impairment". Cerebral visual impairment is a broad term which refers to a range of difficulties in the processing of visual information in the brain. It is as acknowledged a common feature of Cerebral Palsy.	Thank you for your comment. In light of stakeholder comments, the Committee has reviewed the recommendations on visual impairment and the corresponding evidence to recommendations section (27.19.2) in the full guideline. The entire section on vision in the full guideline was revised, and outlines the breadth of deficits that may be classified as a 'visual impairment'.
Royal College of Paediatrics and Child Health	Full		1.8.7	Re 'Ensure that children and young people with ongoing eating, drinking and swallowing difficulties have access to regional tertiary specialist assessment.' Regional tertiary specialist assessment needs qualification - this should not necessarily be to a Regional Tertiary Feeding Team (it is unlikely that such services would have capacity) but to other specialist tertiary services such as Paediatric Surgery, Respiratory, etc. to add to the information and overall risk management carried out by local specialist feeding / nutrition multidisciplinary team	Thank you for your comment. The Committee agree this will be challenging and have decided to remove 'regional' from the recommendation to allow for greater flexibility. It is appropriate that children with severe dysphagia have access to specialist teams. The Committee have revised the recommendation to say: *Ensure that children and young people with ongoing eating, drinking and swallowing difficulties have access to tertiary specialist assessment, including advice from other services (such as paediatric surgery and respiratory paediatrics).*
Royal College of Paediatrics and Child Health	Full	General	General	The guideline has been well received and is a comprehensive summary of clinical practise and available evidence in the management of children with CP. This is a diverse clinical group – with a range of clinical severity and co-morbidities; with multiple potential complex interventions for care; and a significant paucity of evidence. The draft guideline is well structured and	Thank you for your comment. We have addressed the specific comments as they appear.

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				highlights the need for future research in many areas. Some members of the BACD have raised specific questions and queries outlined below.	
Royal College of Paediatrics and Child Health	Full	General	General	Other areas where omissions were highlighted: What about gaining and maintaining bladder control? Link to palliative care guideline? Prognosis is covered; but identification of causes of death could be helpful.	Thank you for your comment. We have now cross-referenced the NICE guidelines on neurological incontinence and end of life care in children and young people. Please note that the main causes of death have been clarified in the evidence to recommendations section (10.6.2.3) of the full guideline. Further, the management of bladder dysfunction was excluded in the scope (4.3.2e).
Royal College of Paediatrics and Child Health	Full	General	General	As above, concern has been raised regarding the emphasis on motor impairment and management; further discussion (amongst members) has highlighted that the rationale for this was on the basis that the therapy and surveillance of motor impairments would be incorporated into the NICE guidance on spasticity management; pending imminent update in Autumn 2016. The recent information that the NICE guidance for Spasticity in under 19's will not be reviewed is therefore a significant concern; and we would be grateful if NICE could re-consider this decision.	Thank you for your comment. Movement and posture disorders are covered by the spasticity in under 19s guideline: https://www.nice.org.uk/Guidance/CG145 Your comment has been passed to the NICE surveillance team.
Royal College of Paediatrics and Child Health	Full	30	36	The recommendation of a personal folder to include clinical information and carer support information relevant to the individual young person; is welcome. Implementation in electronic form (e.g. an app/ tablet/ weblinks); rather than paper based may be more appropriate; although confidentiality and data protection issues would need careful consideration.	Thank you for your comment. The evidence to recommendations section (11.5.2) of the full guideline has been revised to include your point on confidentiality and data protection as we have already discussed options for individual use.
Royal College of Paediatrics and Child Health	Full	32	23-55	Bullet points are in inappropriate section. Refers to assessment of children with communication problems under Nutritional status.	Thank you for your comment. The headings within the full list of recommendations in the full guideline has been revised so that the recommendations fall under the appropriate sections.
Royal College of Paediatrics and Child Health	Full	41	5	Paragraph needs rewriting as word order is incorrect.	Thank you for your comment. This section of the guideline has been updated.
Royal College of Paediatrics and Child Health	Full	127	Table 27	The recommendation of a national registry of children with CP is very welcome. Implementation of such a registry may be challenging (experience of maintenance of a CP database in the North of England – NECCPS highlighted difficulties of achieving full capture; after the requirement for written parental consent was introduced.) However this recommendation is now timely with respect to the imminent implementation of the CPIPS register. Maintenance and review of the registry will need to be carefully considered and resourced appropriately.	Thank you for your comment. The Committee agree.
Royal College of Paediatrics and Child Health	Full	128	**8.7**	Many BACD members had comments regarding imaging – and felt very strongly regarding the importance of MRI imaging. The full guidance does give a clear and comprehensive review of the current research and a pragmatic approach to imaging; within the clinical context of the child's presentation. Highlighting red flags for other progressive conditions; and the importance of recognising when the clinical presentation is not consistent with imaging. The value of timing of imaging is also highlighted (after 2 years, where possible.)	Thank you for your comment. The Committee spent a considerable period of time reflecting on them, reviewing the evidence provided and discussing all aspects with the Committee and the clinical expert neuroradiologist. A number of other stakeholders welcomed the recommendation as stated. The Committee clarified recommendation 1.2.10 to "Offer MRI to investigate aetiology in a child or young person with suspected or known cerebral palsy if this is

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				However – in view of the comments received in collating this response on behalf of BACD (included below - italics)– perhaps the emphasis of the recommendations particularly in the short version may need review. *"It is surprising that the committee's view is that MRI need only be undertaken when aetiology of cerebral palsy is 'not clear'* *This risks missing the significant proportion of those with developmental brain anomalies (~10%) that may co-exist with other factors, are much less likely to be correctly identified on cranial ultrasound and may have significant implications for clinical management as well as for genetic counselling."* *"Developmental brain anomalies may have other implications for the child or young person e.g. endocrinopathies (as in e.g. septo-optic dysplasia), vision impairment (again as in e.g. septo-optic dysplasia), increased risk of epilepsies or as a red flag for chromosomal conditions (cortical dysplasias as in e.g. 22q11 deletion syndromes)"* *"There is increasing evidence of correlation between MRI findings and function (see Himmelmann K, Uvebrant P. Function and neuroimaging in cerebral palsy: a population-based study. Dev Med Child Neurol. 2011;53(6):516-521"* *"Those with 'apparent' cerebral palsies may have other conditions. For example, a child born at 32 weeks gestation with clinical evidence of bilateral lower limb spasticity was assumed to have bilateral cerebral palsy. MRI revealed bilateral very symmetrical periventricular white matter changes not typical of periventricular leukomalacia that prompted further investigation,that led to a diagnosis of metachromatic leukodystrophy. The management of this condition is completely different to the management of cerebral palsy and the family had a right to know the actual diagnosis and to consider the genetic implications for their family".* *"It is very surprising that the committee are not making a stronger recommendation on this, encouraging MRI in ALL children and young people with suspected cerebral palsies. This is a missed opportunity to improve the quality of information available to share with people with cerebral palsies and their families. It is NOT true that MRI findings do not change management, as they absolutely do if a developmental brain anomaly is identified that may be associated with endocrinopathy, vision impairment or if a progressive condition with genetic implications is identified.* *Please can the committee carefully and seriously reconsider this important area."*	not clear from:…" , but maintained the importance of clinical decision-making when considering the use of MRI for aetiology, by listing a number of considerations that should be assessed before an MRI is offered that would also assist in the interpretation of an MRI. With regard to consideration of any abnormal clinical or developmental trajectory, the Committee consider that the recommendation as outlined in the short guideline for an urgent MRI would stand.
Royal College of Paediatrics and Child Health	Full	175		Table 44. Abbreviation VS does not correspond to Glossary.	Thank you for your comment. This has now been revised.

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Royal College of Paediatrics and Child Health	Full	185	14	Unsure of the term 'immature food texture'	Thank you for your comment. The Committee have added (single texture/puree) to the section you mention.
Royal College of Paediatrics and Child Health	**Full**	243	**17.2**	The very recent head-to-head study comparing glycopyronium bromide with hyoscine hydrobromide was acknowledged pg 244, line 11 and referenced unpublished. We would be grateful if the results of this study could be reported. Although this showed the drugs to be equally effective, it showed that hyoscine is associated with more problematic side effects and is less likely to be tolerated. The guidance mentions constipation and glycopyrronium - this was found in the trial but most parents found this manageable and this did not lead to treatment cessation - most parents continued glycopyrronium treatment during the trial. However, for hyoscine, there was a high rate of treatment cessation related to side effects - 50% of parents stopped this treatment. We think this is a key point that the guidance should mention. We are interested that in this context, hyoscine is recommended strongly as first line treatment, as this wasn't our conclusion. Parr JR, Todhunter E, Pennington L, Cole M, Morrison J, Stocken D, Colver A. The Drooling Reduction Intervention (DRI) trial: Is hyoscine or glycopyrronium more effective and acceptable for the treatment of drooling in children with neurodisability? *Arch Dis Child* 2016;101:A55-A56	Thank you for your comments. Each of the points has been addressed separately. 1. Study by Parr 2016 The results of this study cannot be reported as we can only include peer-reviewed published studies. 2. Recommendation of Hyoscine hydrobromide as a first line treatment The Committee agreed that transdermal hyoscine hydro bromide and glycopyrronium bromide were equally effective at reducing drooling in children and young people with cerebral palsy, however, given that hyoscine hydro bromide is substantially cheaper, it was recommended as a first line treatment. The Committee acknowledged the tolerability and side effects of transdermal hyoscine hydro bromide over time (such as skin irritation and deterioration of seizure control). Furthermore, they noted that the studies included in the clinical evidence review were too short to demonstrate the risk of adverse events sometimes seen in the clinical practice, particularly for transdermal hyoscine hydro bromide. Consequently, the Committee made a recommendation to consider glycopyrronium bromide if transdermal hyoscine hydro bromide was not tolerated. A recommendation was also prioritised to ensure monitoring for tolerance and side effects was in place for all treatments, especially when used in children with severe communication difficulties who could not easily report adverse effects. For further details regarding the economic model in which the decision was made see 'consideration of economic benefits and harms' section in the 'managing saliva control' chapter; full guideline.
Royal College of Paediatrics and Child Health	Full	254	general	No reference to electro-stimulation efficacy using NMES or TES which some parents have asked for in management of drooling.	Thank you for your comment. The Committee did not prioritise electro-stimulation as one of the interventions to look at as part of the management of drooling. Please see relevant protocol D14 in appendix D.
Royal College of Paediatrics and Child Health	Full	264	Section 18.5.3	The details around DEXA are addressed in terms of cost. We feel there should be some recognition in the document as to how difficult it can be to undertake a bone density scan in children with severe CP due to scoliosis and contractures. These can mean the DEXA images are then of poor quality to not be clinically useful. Also a DEXA scan of lying still for 5-10 minutes is often not practical in children with a significant level of disability.	Thank you for your comment. The Committee agree. The evidence to recommendations section (19.6.2) has been revised to recognise the point you make.

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				This would in turn translate in the Recommendations section to the fact that there should be consideration given as to how practical it is to undertake a DEXA in an individual child.	
Royal College of Paediatrics and Child Health	Full	278	Rec 77 & 78	At present the guideline recommends a bone density scan in children with CP who have sustained a low impact fracture prior to referral to a specialist centre. It would be more appropriate would suggest that bone density scans are only undertaken in these individuals after referral to a specialist centre. In addition, the specialist centre has knowledge of the practicalities of what is involved in a child undergoing a DEXA scan, often erroneously thought to be similar to having a quick Xray. For the reasons explained above in item 1, there should be consideration as to whether to do it. Also the specialist centre can then evaluate if the DEXA is likely to change management in that child. It would be sensible to consider whether 77 can be subsumed into 78 which would therefore read as: a. Refer children and young people with cerebral palsy with reduced bone density and a history of low-impact fracture to a specialist centre for consideration of DEXA scan and consideration of bisphosphonate therapy.	Thank you for your comment. Under specialist guidance allows for regional flexibility as to what works best in the area. The Committee agreed that it can be difficult to obtain a good quality image in children with severe CP and concluded that the practicality of performing and reporting of the DEXA needs to be under specialist guidance.
Royal College of Paediatrics and Child Health	Full	299	21.6 Rec 92	This recommendation is VERY welcome, encouraging enquiry about pain, sleep and distress as part of all clinical encounters	Thank you for your comment.
Royal College of Paediatrics and Child Health	Full	398	29	Inclusion of transition to adult is hugely important; and the recognition of the need for clinicians to have expertise in management of young adults with CP. At present ensuring effective handover to adult services is unlikely to be achievable as these services/ clinicians are very limited. The pending NICE guidance on Adults with CP will be immensely valuable to identify the deficit here and should include practical guidance on how this can be resourced and achieved.	Thank you for your comment. The Committee agree it is important that you are involved in the scoping process for the guideline on Adults with CP.
Royal College of Paediatrics and Child Health	Full/Short	General	General	Concern has been raised regarding the integration of managing the motor impairment together with all the other areas in this guideline which would lend itself to a 'what to think about at different ages' approach to care of the child/young person with CP for those involved with disability care. As it is, we are referred to spasticity guideline with the danger of perpetuating division of care.	Thank you for your comment. Although they are separate guidelines the recommendations were made taking account of the Spasticity guideline and that we have made cross references where appropriate. The 2 guidelines should be considered together and this will be reflected in the NICE pathway for this guideline. Movement and posture disorders are covered by the spasticity guideline. Please refer to NICE for any comments related to the Spasticity in under 19s guideline https://www.nice.org.uk/Guidance/CG145.
Royal College of Paediatrics and Child Health	General	-		Value of promoting posture and movement is discussed but what about participation in sport- timely for para-Olympics?!	Thank you for your comment. We have now revised recommendation 1.6.7 to say: *Provide information to the child or young person and their parents or carers, and to all relevant teams around them, about the local and regional services available (for example, sporting clubs, respite care and specialist schools) for children*

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					and young people with cerebral palsy, and how to access them.
Royal College of Paediatrics and Child Health	Short			We felt that this seemed to read well, but were surprised there doesn't seem to be a definition of CP in the shortened version- had to long version to find it.	Thank you for your comment. The glossary contained in the short version are for terms that are only specific to the guideline. All other general terms are contained in the full guideline glossary.
Royal College of Paediatrics and Child Health	Short		1.31	For at risk babies recommendation for "enhanced developmental follow-up". This needs further advice on timings for referral and levels of expertise and explanation of "GMA"- is this performed by a health visitor or doctor or physiotherapist? Please could you explain "multidisciplinary neurological assessment"	Thank you for your comment. We have revised the recommendations you mention to say: *Provide an enhanced clinical and developmental follow-up programme provided by a multidisciplinary team for children up to 2 years (corrected for gestational age) who are at increased risk of developing cerebral palsy (see recommendation 1.1.1).* *Consider using the General Movement Assessment (GMA) during routine neonatal follow-up assessments for children between 0 and 3 months who are at increased risk of developing cerebral palsy.* The Committee consider that further advice on timings and levels of expertise would be overly prescriptive based on the evidence reviewed. The GMA is normally conducted by a clinician with specific training in this tool.
Royal College of Paediatrics and Child Health	Short	-	1.5	Advice to refer "immediately" to multidisciplinary service needs further explanation of recommended waiting time and suggested members of multidisciplinary service which will depend on available and accessible services, and have cost implications.	Thank you for your comment. The Committee agreed not to be prescriptive as this will like you say depend on available resources.
Royal College of Paediatrics and Child Health	Short	General		Impressive document but no stated indication for recommended time frames for referrals or involvement of multidisciplinary teams or level of expertise required – which may have significant cost implications	Thank you for your comment. Given the limited evidence, the Committee did not consider it was appropriate to specify timeframes for referrals or involvement or levels of expertise required.
Royal College of Paediatrics and Child Health	short	General	-	Reviewed Section 1.8, 1.9, 1.95 and 1.11. Following recommendations would have little impact on practice as already implementing in dept.	Thank you for your comment.
Royal College of Paediatrics and Child Health	Short	General	general	A definition of Cerebral palsy at the outset of the document would be useful, particularly in understanding the post neonatal causes listed.	Thank you for your comment. Both the introduction to the full guideline and context section of the short guideline include definitions of cerebral palsy.
Royal College of Paediatrics and Child Health	Short	General	General	We are disappointed that the management of respiratory problems, apart from those associated with aspiration, seems to have been neglected. Should children and YP have regular influenza vaccination, and pneumococcal vaccination beyond the routine conjugated vaccine? Might there be a role for prophylactic antibiotics? What role might suction play in protecting the airway, and are forms of protection recommended?	Thank you for your comment. The Committee have now revised section 10.6.2 in the chapter on prognosis of walking, talking and life expectancy of the full guideline to reflect the significance of respiratory problems as a cause of mortality and morbidity in children and young people with cerebral palsy.

Cerebral palsy in under 25s: assessment and management

Consultation on draft guideline - Stakeholder comments table
8 August – 20 September 2016

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				Considering that respiratory complications are the major cause of death in this population we do feel this is a serious omission by this otherwise excellent guideline.	
Royal College of Paediatrics and Child Health	Short	4	11 - 19	Perinatal and postnatal factor list very limited, i.e. other important factor groups not mentioned: Perinatal stroke (separate from neonatal encephalopathy) Intracranial haemorrhage (Vit K deficiency) Metabolic disorders (e.g. congenital hyperinsulinism, kernicterus) Maternal medication (including illicit drugs) Trauma (non-accidental and accidental) Reference: UpToDate: • Epidemiology, etiology, and prevention of cerebral palsy • Etiology and pathogenesis of neonatal encephalopathy	Thank you for your comment. The risk factors that the Committee prioritised for review in this guideline were: Antenatal factors • Infections (for example rubella, toxoplasmosis, cytomegalovirus [CMV], herpes simples) • Multiple pregnancy • Intrauterine growth restriction • Haemorrhagic events Perinatal • Hypoxic ischaemic events at term/post term • neonatal encephalopathy • Apgar score at 10 min (Low/very low below 4/3) • Neonatal sepsis Postnatal • Extremely preterm 24 – 27 +6 weeks gestational age • Preterm 28 - 31 +6 weeks gestational age • Late preterm (32-37 weeks gestational age) • Infections: meningitis and encephalitis • Clotting disorders /hyper coagulation in mother • Trauma/non-accidental injury The risk factors included in the recommendations were those were the Committee was satisfied that the evidence did indeed show an association.
Royal College of Paediatrics and Child Health	Short	5	9 - 12	Percentages total up to 75 % - incomplete presentation of distribution potentially skewing the message	Thank you for your comment. The numbers are not intended to add up to 100% as results focus on the main causes only.
Royal College of Paediatrics and Child Health	Short	6	9 - 22	Percentages total up to 94 % if taken together – incomplete/misleading presentation of distribution potentially skewing the message	Thank you for your comment. The numbers are not intended to add up to 100% as results focus on the main causes only.
Royal College of Paediatrics and Child Health	Short	7	17	…not generally required in babies in the first year of life – common practice	Thank you for your comment. The Committee discussed the use of sedation and anaesthetic in very young children and this was taken into account when formulating the recommendation. This is discussed in the linking evidence to recommendation section of the guideline.
Royal College of Paediatrics and Child Health	Short	7	2	We welcome recognition that MRI is not essential in every case	Thank you for your comment.
Royal College of Paediatrics and Child Health	Short	8	20	According to WHO <u>not</u> sitting without support can stil be normal up to the age of 9 months	Thank you for your comment. The Committee consider that as part of the UK developmental screening programme the threshold set for further assessment if

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				Adobe Acrobat Document	sitting has not been obtained is 8 months corrected age.
Royal College of Paediatrics and Child Health	short	16	1.8.9 general	Section refers to modifying fluids. No other reference made in Short or Long Doc to evidence base for this, best type of thickener or prescription guidance for licenced meds for young people under 18	Thank you for your comment. Specific thickeners and prescription guidance was not prioritised by the Committee as part of the evidence review. In addition, limited evidence was found in management of these difficulties.
Royal College of Paediatrics and Child Health	short	35	16-18	Whilst the comments about transition are welcome, in practice this may be difficult to apply. There is no adult medicine equivalent of the community paediatrician, neurologists will often limit their interest to managing the epilepsy, it may be difficult to get good holistic care	Thank you for your comment. The Committee recognise your point and have revised the following recommendation in light of stakeholder comments: *Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:* • *is able to meet their individual needs within agreed care pathways* • *can provide the following expertise, as appropriate, through a local network of care:* – *paediatric or adult medicine* – *nursing care* – *physiotherapy* – *occupational therapy* – *speech and language therapy* – *dietetics* – *psychology* • *can enable access to other services within their local or regional network as appropriate, including:* – *paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and/or surgical specialist care* – *orthopaedics* – *orthotics and rehabilitation services* – *social care* – *visual and hearing specialist services* – *teaching support for preschool and school-age children, including portage (home teaching services for preschool children).*
Royal College of Paediatrics and Child Health	Short version	4	19	Other post natal risk factors could include a) Head trauma b) Encephalopathy / encephalitis (it is acknowledged that these are included in the full guidance.	Thank you for your comment. The risk factors that the Committee prioritised for review in this guideline were: Antenatal factors • Infections (for example rubella, toxoplasmosis, cytomegalovirus [CMV], herpes simples) • Multiple pregnancy • Intrauterine growth restriction

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					• Haemorrhagic events Perinatal • Hypoxic ischaemic events at term/post term • neonatal encephalopathy • Apgar score at 10 min (Low/very low below 4/3) • Neonatal sepsis Postnatal • Extremely preterm 24 – 27 +6 weeks gestational age • Preterm 28 - 31 +6 weeks gestational age • Late preterm (32-37 weeks gestational age) • Infections: meningitis and encephalitis • Clotting disorders /hyper coagulation in mother • Trauma/non-accidental injury The risk factors included in the recommendations were those were the Committee was satisfied that the evidence did indeed show an association.
Royal College of Paediatrics and Child Health	Short version	6	21	One BACD member asked if it 'Other infections' –could be more specific: i.e. does this mean 'serious infections / sepsis / encephalitis' or just 'any other infection'?	Thank you for your comment. The Committee understands your viewpoint but the evidence did not provide details about specific infections so are unable to be any more specific in the recommendation. However, yhe Committee agreed that for antenatal infections, examples could be rubella, toxoplasmosis, cytomegalovirus (CMV), herpes simples. For postnatal infections, the Committee agreed that examples could be meningitis and encephalitis.
Royal College of Paediatrics and Child Health	Short version	7	17	Many hospitals use oral sedation rather than general anaesthesia for MRI in very young children. Again – it is noted that this is included in the full guidance; but many clinicians may only read short version!	Thank you for your comment. The have now recommendation has now been revised to say 'or sedation'.
Royal College of Paediatrics and Child Health	Short version	9	1.5.2.	In the multidisciplinary team – Orthopaedics could be added	Thank you for your comment. We have now revised the recommendation you mention to say: *Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:* • *is able to meet their individual needs within agreed care pathways* • *can provide the following expertise, as appropriate, through a local network of care:* – *paediatric or adult medicine* – *nursing care* – *physiotherapy* – *occupational therapy* – *speech and language therapy* – *dietetics* – *psychology*

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					• *can enable access to other services within their local or regional network as appropriate, including:* – *paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and/or surgical specialist care* – *orthopaedics* – *orthotics and rehabilitation services* – *social care* – *visual and hearing specialist services* – *teaching support for preschool and school-age children, including portage (home teaching services for preschool children).*
Royal College of Paediatrics and Child Health	Short version	22	23	There was concern raised that the language used here is not very sensitive considering that the guideline is also meant for use by parents of children with CP – perhaps it would be important to state that by acknowledging the prevalence of pain - professionals and carers should ensure they identify this in young people if present. (implied but not stated)	Thank you for your comment. The Committee think this is covered in recommendation you mention.
SeeAbility	Full and short	General comment – location of section on visual impairment needs to move towards the start of guideline	Eg. short guideline on speech language and communication features 1.9 (prior to visual assessment in 1.17)	SeeAbility welcomes the recognition that visual impairment can be strongly associated with cerebral palsy and that the guidance contains information on its prevalence, as well as an emphasis on regular visual assessment (although see below as we believe there are improvements which are needed to the guideline). Vision is the most important sense underpinning child development, with development of the visual pathways taking place up to the age of 8 so it is important there are regular checks on a child's sight. Children with cerebral palsy (particularly those affected more severely by speech and language issues) will be highly dependent on active use of vision to support their communication and learning. **For these reasons we consider that vision needs more prominence and early discussion than is given in the current guideline.** For example, in the guideline information on sensory and perceptual difficulties and interventions, and the use of interventions such as assistive and augmentative communication come **before** the section on visual impairment. It would be more intuitive to ensure visual impairment is highlighted and a child's vision is assessed **prior** to providing strategies on AAC and sensory difficulties.	Thank you for your comment. In light of stakeholder comments, the Committee reviewed the recommendations on visual impairment and the corresponding evidence to recommendations section (27.19.2) in the full guideline. Visual impairment was reviewed as part of a systematic review about common comorbidities with a view to early identification and as such the Committee believe the order of the reviews is appropriate.
SeeAbility	Full and short	General comment – section on	1.17.3 (short guideline) and paragraph	While it is helpful to note that *visual impairment associated with CP may include "control of eye movements, ocular function and cerebral visual processing"* ocular function is not a term that is well understood in optometric	Thank you for your comment. In light of stakeholder comments, the Committee has reviewed the recommendations and added more commonly used

Stakeholder	Document	Page No	Line No	**Comments** Please insert each new comment in a new row	**Developer's response** Please respond to each comment
		visual impairment needs more explanation and discussion of common visual needs of children with CP	120 (long guideline)	or ophthalmological care, and it is not a term that we regularly come across in our clinical work. **It would be more helpful if the guideline contains more commonly used terms and the full breadth of visual difficulties experienced.** For example, there is certainly evidence that a child with cerebral palsy is more likely to experience: - Refractive errors, particularly hyperopia (long sightedness) - Strabismus (squint) and/ or other ocular movement anomalies such as nystagmus or limitations in eye movement control - Hypoaccomodation – problems focusing on near objects/ shifting focus between different distances - Reduced visual acuity and contrast sensitivity (ability to pick out detail, shapes and objects) - Visual field deficits such as only being able to see to one side or only above or below their eyes. References: Nielsen, Jensen, Skov,Risk factors of ophthalmic disorders in children with developmental delay. Acta Ophthalmologica http://dx.doi.org/10.1111/j.1755-3768.2007.01158.x Salt, A, & Sargent, J. (2014). Common visual problems in children with disability. Archives of Disease in Childhood. doi:10.1136/archdischild-2013-305267. Little et al (2013) Low contrast acuity measurement: does it add value to the visual assessment of Down Syndrome and Cerebral Palsy populations? Invest.Ophthalm. and Visual Science.	terms, such as 'problems with controlling eye movements; strabismus; refractive errors; problems of eye function , including retinopathy or prematurity; impaired cerebral visual information processing or visual field defects' (see 'recommendations' in section 27.20; full guideline). This broad range of visual impairments has also been reflected in the corresponding evidence to recommendations section (27.19.2) in the full guideline.
SeeAbility	Full/Short	General – section on sensory and perceptual difficulties, and vision impairment – lack of mention of interventions, support or management that is possible	1.16.2 and 1.17.3 (short guideline) and paragraphs 115 and 120 (long guideline)	**SeeAbility is concerned that ophthalmological management and treatment for visual impairment (and sensory processing that is related to vision) is omitted from the guideline. Presently it reads as if there is "nothing that can be done" for a child who has visual impairment including cortical visual impairment. Elsewhere in the document there is advice on management and treatment of other difficulties associated with cerebral palsy, or signposting to associated NICE guidelines, so this appears to be a major omission.** Some visual problems (such as strabismus, or amblyopia) can be treated and corrected if identified early, and refractive errors such as astigmatism, longsightedness, shortsightedness and hypo accommodation can be treated with glasses. We feel it is important that parents are given information that a child's vision may improve with appropriate treatment or it may mature in different ways,	Thank you for your comments. Each point has been addressed separately. 1. Lack of evidence to support interventions for visual problems: Thank you for your comment. The Committee members discussed that a wide variety of interventions without clear evidence based showing any benefits was being used in clinical practice. Furthermore, the Committee agreed not to recommend any particular interventions or associated resources used in current UK clinical practice as these would be individualised to the patient. This is because sensory and perceptual problems vary considerably in their complexity and presentation (see evidence to recommendations section (26.6.2) of the full guideline).

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				and it is possible to help a child sustain the use of glasses through the right information and support. SeeAbility and other clinicians have experience providing support to children in special schools, some of whom will have cerebral palsy. Even where a child has uncorrectable visual problems, we can commonly use adaptive strategies to support a child with visual field loss or reduced visual acuity (such as better lighting, or appropriately sized or contrasting educational material) In the case of sensory processing and perceptual information, the guideline also wrongly states that clinicians should *explain to parents or carers that there is a lack of evidence to support specific interventions.* **It should be made clear that there is *some* evidence to support interventions that can help a child with their visual processing.** Most straightforwardly the benefits of refractive correction for children with neurodevelopmental impairments were recently acknowledged in a scoping review of the evidence. The same review also discusses the evidence for interventions to improve control or pursuit of saccadic eye movements and adaptation of the visual environment. (Reference: Wiliams, C et al. How to help children with neurodevelopmental and visual problems: a scoping review. Wiliams, C. Br J Ophthalmol. 2014 Jan;98(1):6-12. doi: 10.1136/bjophthalmol-2013-304225.) In addition under 1.17.4 there is rightly inclusion of the need to ensure children are regularly assessed for signs of cortical visual impairment. We suggest that there is a need for parents and carers to be signposted to sources of support and advice on CVI which is often little understood. For example, in our work in special schools we are aware that parents can be told by clinicians that their child's eyes are healthy but they should be registered blind, which is very confusing. Parents can be given very little information on what CVI is, what it means and what their child can actually "see".	Furthermore, the Committee acknowledged the importance of providing children and young people with cerebral palsy with the correct support and adequate interventions to tackle visual problems, which is why the Committee agreed to develop a research recommendation to assess the clinical and cost effectiveness of interventions to manage specific sensory and perceptual difficulties". (See 'research recommendations' table in 'management of sensory and perceptual difficulties' chapter; full guideline). 2. The suggested additional reference has been retrieved and assessed for inclusion Wiliams, C et al. How to help children with neurodevelopmental and visual problems: a scoping review. Wiliams, C. Br J Ophthalmol. 2014 Jan; 98 (1):6-12. doi: 10.1136/bjophthalmol-2013-304225. Response: This scoping review included 13 studies, of which 10 included population other population than cerebral palsy (i.e. Down syndrome, intellectual disability or severe learning difficulties). Indirect population studies were not considered for this specific section/review question (See Appendix D). Of the 3 included studies with participants with cerebral palsy, all of them presented with small sample size. Furthermore, for this specific section/review question, RCTs were prioritised. Only when limited RCT evidence of cerebral palsy population was found, observational studies above 30 participants were considered (See Appendix D). See details of the 3 studies including participants with cerebral palsy below: • Saeed M, Henderson G, Dutton GN. Hyoscine skin patches for drooling dilate pupils and impair accommodation: spectacle correction for photophobia and blurred vision may be warranted. Dev Med Child Neurol 2007;49:426–8 – Response: this is a before-after study with 5 participants • Horinek D, Hoza D, Cerny R, et al. Two cases of improvement of smooth pursuit eye movements after selective posterior rhizotomy. Childs Nerv Syst 2008; 24:1283–8. –

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					Response: this is a before/after study with 2 participants • Poland DJ, Doebler LK. Effects of a blacklight visual field on eye-contact training of spastic cerebral palsied children. Percept Motor Skills 1980; 51:335–8. – Response: this is a controlled cross over trial with 4 participants 3. Parents and carers to be signposted to sources of support and advice on CVI Thank you for your comment. Proving information about resources in a timely and clear manner is an overarching principle of this guideline and we acknowledge that this type of information is of special value for parents and carers. Informed by the evidence, the Committee developed recommendations about providing clear, timely and up-to-date information. Furthermore, it was stated that information regarding advocacy groups and local support should be provided; as well as information about local and regional services available for the children and young person and how to access them. In this way, the Committee wanted to ensure that all patients had access to a minimum level of support (see section 11.6 in the full guideline).
SeeAbility	Full/Short	General comment – clearer guidance is needed to ensure a child's vision is assessed, what visual assessment is, and how often.	1.17.3 in short guideline, paragraph 120 in fuller guideline and 1.7.4.	**While we welcome the inclusion of visual assessment this reads currently reads is if it "*may be useful*" and in discussion with parent carers.** **We would prefer the recommendation to read that childrena and young people with CP "should be regularly assessed for visual impairment, including signs of cortical visual impairment, from diagnosis onwards"** **We would like to see this section also contain more information on what "visual assessment" is and how often it should be.** We note in one major study it was stated that referral for ophthalmological examination should take place early on and even prior to diagnosis…. *In the case of CP….- or where there is the suspicion these conditions – the ophthalmological examination should be mandatory and a high priority.* (Reference: Nielsen, Jensen, Skov,Risk factors of ophthalmic disorders in children with developmental delay. Acta Ophthalmologica http://dx.doi.org/10.1111/j.1755-3768.2007.01158.x)	Thank you for your comments. Each point has been addressed separately. 1. Recommendations about the content of an assessment would require a new evidence review which is not possible to add at this stage. Areas for inclusion were prioritised with stakeholder input and discussion by the Committee at the outset of development. 2. Additional references. The suggested references have been retrieved and assessed for inclusion. • Nielsen, Jensen, Skov, Risk factors of ophthalmic disorders in children with developmental delay. Acta Ophthalmologica http://dx.doi.org/10.1111/j.1755-3768.2007.01158.x

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				There is compelling evidence that visual difficulties occurring in children with neurodevelopmental impairments are not always being identified, in cases of more severe cerebral palsy this may often be due to diagnostic overshadowing or a child's inability to self report they have a sight problem. Barriers also exist in accessing routine eye care, such as through optometric practices, despite a child's right to a free NHS sight test each year or more frequently if clinically justified. There is also evidence that parents may be under the wrong impression that school vision screening programmes offer a child a full sight test. The reasons and evidence to support these statements are set out in SeeAbility's research report "An equal right to sight" see. https://www.seeability.org/who-we-are/media-centre/research/an-equal-right-to-sight This is why SeeAbility and others are operating to provide specialist sight tests in special schools to children with profound and complex needs, including those with cerebral palsy. Over half of children we test in special schools have a vision problem. The importance of testing runs from the early years, when visual pathways are developing, to teenage years. For example we tested one young lady with cerebral palsy at 18 whose last sight test was at 12, in the interim she had developed a high level of longsightedness. She was reliant on eye gaze technology which she can now use properly with the right glasses. Recently we have worked with the Royal College of Opthalmologists, British and Irish Orthoptic Society and College of Optometrists, amongst others, to set out a clinical framework of the recommended vision testing protocols for children in special schools. This can be found here with the full range of suggested tests www.rcophth.ac.uk/2016/07/seeability-provides-framewok-for-provision-of-eye-care-in-special-schools-in-england/ . It can be seen as a minimum we recommend this should be performed annually (or more frequently if clinically justified) given the level of visual need seen in special schools and that every child is entitled to a free annual sight test on the NHS. This framework builds on the clinical recommendations on children's health set out in the Hall Report 'Health for all Children'. This recommends that children of any age with suspected visual deficits, a significant family history or any neurological or disabling condition, should be routinely referred for a visual assessment.	Response: this is a mixed population study. Mixed population studies or indirect populations have not been considered for inclusion (See Appendix D). Furthermore, the total number of participants with cerebral palsy is 147 and only studies above 250 participants were considered (See Appendix D). • https://www.seeability.org/who-we-are/media-centre/research/an-equal-right-to-sight Response: this is not a peer-reviewed publication, and therefore does not meet NICE inclusion criteria. • www.rcophth.ac.uk/2016/07/seeability-provides-framewok-for-provision-of-eye-care-in-special-schools-in-england/ Response: this is not a peer-reviewed publication, and therefore does not meet NICE inclusion criteria. • Sargent (2014) Identifying visual difficulty in children with special educational needs: where should we look? Arch Dis Child. 2014 Jun;99(6):491-2. doi: 10.1136/archdischild-2013-305256. Response: This is a narrative review thus cannot be included in a prevalence review question (See Appendix D). 3. Visual difficulties not being identified: Thank you for your comment. The Committee acknowledged the difficulty of recognising visual impairment during the early stages, particularly if there are problems with communication or learning present in the child. They also noted that recognition will sometimes only occur when children are at school age, as the impairment becomes more apparent in the learning process. As a result of this, they concluded that it was important to regularly assess children and young people with cerebral palsy (see section 27.9.2 of the full guideline). Furthermore, this aspect has been reflected in the recommendations, where it is recognised that visual

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				Please also see Sargent's discussion paper: Sargent (2014) Identifying visual difficulty in children with special educational needs: where should we look? Arch Dis Child. 2014 Jun;99(6):491-2. doi: 10.1136/archdischild-2013-305256.	impairment is very common in cerebral palsy, and that cortical visual impairment "may be difficult to recognise at an early stage", (see recommendations in section 27.20 of full guideline).
Sexual Health and Disability Alliance (SHADA)	Full	398	general	It is illegal **not** to support disabled adults to enjoy the same pleasures as others enjoy in the privacy of the their own homes (Equality Act 2010, Human Rights Act 1998).	Thank you for your comment. The Committee consider that the guideline is supportive of disabled adults.
The Bobath Centre	Full	27	36	No reference has been made to the Gross Motor function classification system	Thank you for your comment. Most of the evidence included in this guideline is based on the GMFCS, and the Committee agreed that it was not required to mention it specifically in the recommendations.
The Bobath Centre	Full	39	37	Consider the separation of bullet point for physiotherapy and occupational therapy as these are autonomous professions	Thank you for your comment. We have revised the recommendation in light of your comment and separated the bullet points to reflect that these are autonomous professions
The Bobath Centre	Short	general	general	The short version has a section dedicated to early multidisciplinary care that does not appear in the long version	Thank you for your comment. The recommendations that are contained in the early multidisciplinary care section it the short guideline are included in sections 6.7 and 27.20 of the full guideline.
The Bobath Centre	Short	10	16	We are concerned that, although this was not included within the Scope document about the guideline, it is insufficient to think that all physical therapy and other therapy interventions for the motor aspects of cerebral palsy would be covered by the Spasticity guidelines (up to 19yr), as many children with CP have dyskinesia, hypotonia or ataxia not spasticity. In addition, the physical therapy recommendations in the spasticity guideline are primarily about managing that aspect of the motor difficulty only.	Thank you for your comment. Movement and posture disorders are covered by the spasticity in under 19s guideline: https://www.nice.org.uk/Guidance/CG145 Your comment has been passed to the NICE surveillance team.
The Bobath Centre	Short	10	3	Consider the separation of bullet point for physiotherapy and occupational therapy as these are autonomous professions	Thank you for your comment. We have revised recommendation 1.5.3 to include separate bullet points for physiotherapy and occupational therapy as suggested..
The Bobath Centre	Short	14	25	Consider additional symptom of 'changes in pattern of breathing' before changes in colour.	Thank you for your comment. The recommendation has been revised to say: 'altered breathing pattern or colour change while eating or drinking'.
The Bobath Centre	Short	16	6	Consider eating, drinking and swallowing difficulties in relation to the child / young person being fully dependent, with assistance or independent feeding.	Thank you for your comment. This was considered by the Committee as part of the individualised plan.
The Bobath Centre	Short	25	1-2	These statements are very general	Thank you for your comment. The Committee agree that the statements are general in nature, but consider them clinically important and therefore important to include in a recommendation.
The Bobath Centre	Short	29	20	Consider referencing this sensory-perceptual management with the management of comorbidities section – vision	Thank you for your comment. This has been considered by the Committee in recommendation 1.17.4 of the short guideline.
The Bobath Centre	Short	29	28	We are concerned that his statement would discourage referral for therapies which address sensory-perceptual difficulties	Thank you for your comment. The Committee disagree that would be the intention of the recommendation.

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					Please note that the recommendations have been revised in light of stakeholders to say: *For children and young people with cerebral palsy who have difficulties with registering and processing sensory information:* • *agree a functional, goal-orientated, individualised programme in partnership with parents or carers* • *explain to parents or carers that there is a lack of evidence to support specific interventions.*
The Bobath Centre	Short	42	18	To participate it would be important to include 'communication'	Thank you for your comment but we are not sure which section of the short guideline you are referring to.
The Bobath Centre	Short & Full	general	general	Prechtl general movements assessment is not designed for infants after three months of age	Thank you for your comment. We have now revised the recommendations on use of GMA to say: *Consider using the General Movement Assessment (GMA) during routine neonatal follow-up assessments. From 0- 3 months in children who at increased risk of cerebral palsy*
The Bobath Centre	Short & Full	general	general	Our Centre has successfully implemented an Early Intervention program covering at-risk infants aged 0-18 months. We are expanding our service and would be willing to share our learning and the experiences of families within the program to the NICE database	Thank you for your comment. We will forward your comment onto NICE.
The Bobath Centre	Short (Full)	8 (27)	5 (1-4)	This implies that multidisciplinary assessment will not commence until after 6months – however it is known that neuroplasticity carries the potential to make changes before that time. High-risk infants often present with feeding difficulties therefore early SLT/MDT referral would be instrumental in their management. This is an area not covered by the Prechtl assessment There could be a cost implication of delaying MDT referral in infants who are at very high risk of hip subluxation and contracture development.	Thank you for your comment. We have revised the recommendation you mention in light of stakeholder comments to say: *Provide an enhanced clinical and developmental follow-up programme provided by a multidisciplinary team for children up to 2 years (corrected for gestational age) who are at increased risk of developing cerebral palsy (see recommendation 1.1.1).*

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The Bobath Centre	Short (Full)	9 (27)	21(26)	This paragraph would appear to contradict your previous statements regarding referral of at-risk children	Thank you for your comment. Recommendation 1.3.3 has been amended so there is no longer a contradiction in the urgency of referral and now reads: 1.3.3 Recognise the following as possible early motor features in the presentation of cerebral palsy: • unusual fidgety movements or other abnormalities of movement, including asymmetry or paucity of movement • abnormalities of tone, including hypotonia (floppiness), spasticity (stiffness) or dystonia (fluctuating tone) • abnormal motor development, including late head control, rolling and crawling • late sitting, crawling or walking • feeding difficulties.
The British Association of Prosthetists and Orthotists (BAPO)	Full	39	31	Recommendation 118 BAPO are pleased to see access to orthotics listed here. BAPO would however prefer the Orthotist to be listed as the key clinician in assessment, prescription, fitting and review of orthoses. At current this is not stated and leaves guidance free to interpretation by the reader. The orthotist is the only AHP qualified as standard to assess, prescribe, fit and review orthoses so clearer signposting should be made here.	Thank you for your comment. We have revised the recommendation you mention in light of stakeholder comments to say: *Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:* • *is able to meet their individual needs within agreed care pathways* • *can provide the following expertise, as appropriate, through a local network of care:* – *paediatric or adult medicine* – *nursing care* – *physiotherapy* – *occupational therapy* – *speech and language therapy* – *dietetics* – *psychology* • *can enable access to other services within their local or regional network as appropriate, including:* – *paediatric or adult neurodisability, neurology, neurorehabilitation, respiratory, gastroenterology and/or surgical specialist care* – *orthopaedics* – *orthotics and rehabilitation services* – *social care* – *visual and hearing specialist services* – *teaching support for preschool and school-age children, including portage (home teaching services for preschool children).*

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The British Association of Prosthetists and Orthotists (BAPO)	Full	290	34	Sections 20.5.2 BAPO are concerned that orthoses are described as a potentially painful intervention that will disturb sleep. This is unsubstantiated. BAPO contest this statement and advocate that a well fitting orthosis should not cause pain or harm. Orthotists provide regular review to ensure orthotic prescriptions achieve biomechanical goals whilst allowing comfort for the user.	Thank you for your comment. The Committee were aware of the Parkinson 2013 study (Table 2) which showed that physical therapy and use of "splints or restraints" did indeed cause pain and discomfort. Please see evidence review in chapter 20 and the evidence statements in section 20.4.1.5.
The British Association of Prosthetists and Orthotists (BAPO)	Full	303	26	Section 22.5.2 BAPO are concerned by the use of the phrase 'ill-fitting or inappropriate orthoses'. This phrase sits within a list of interventions that may cause acute pain. BAPO would not consider the use of an 'ill-fitting or inappropriate orthosis' to be a treatment intervention, rather BAPO would consider the use of 'orthoses' (well fitting and appropriately prescribed) to be a treatment intervention. Orthotists do not prescribe ill-fitting or inappropriate orthoses. Orthotists provide regular review to ensure orthotic prescriptions achieve biomechanical goals whilst allowing comfort for the user. This is of importance to keep on top of factors that will determine the ongoing suitability of an orthosis such as of growth and/or dynamic change in presentation. The general statement that orthoses cause pain is also unsubstantiated. BAPO contest this statement and advocate that a well fitting orthosis should not cause pain or harm. In many cases orthoses are prescribed with the goal of pain relief. Examples include using orthoses to fine tune biomechanics through reduction in painful excessive peak pressures acting on the body or improved control of painfully unstable body joints by motion restriction. Furthermore, BAPO oppose the negative tone surrounding orthotics within this paragraph. It is understandable that an ill fitting or inappropriate orthosis will be a cause of pain. Each of the other listed interventions could viewed in a similar light. For example 'physiotherapy stretches' are listed but these are not described as 'inappropriate stretches' which would also clearly be painful.	Thank you for your comment. The Committee were aware of the Parkinson 2013 study which showed that physical therapy did indeed cause pain and discomfort. The list of causes in the recommendation is not exhaustive and as such it is prefaced by the word "includes". Please see evidence review in chapter 20 and the evidence statements in section 20.4.1.5.
The British Psychological Society	Full	General	General	We welcome the clear guidance for multidisciplinary working for this population.	Thank you for your comment.
The British Psychological Society	Full	20	17	Although Cerebral Palsy is not curable it would be helpful for there to be some reference here to the importance of rehabilitation for maintenance of function and potential.	Thank you for your comment. We accept this is an important point and the vital role of multidisciplinary rehabilitation to improve function is highlighted later in the introduction.
The British Psychological Society	Full	20	General	The Society welcomes the description of the interaction of primary and secondary factors and the breadth of difficulties faced by individuals with Cerebral Palsy.	Thank you for your comment.
The British Psychological Society	Full	27	29	The Society welcomes ongoing communication between all levels of care professionals for people with Cerebral Palsy both at diagnosis and afterwards but stress that ongoing and open communication with families at these times is also vital in supporting them and helping with their coping and adjustment. This is particularly important where cerebral palsy is the result of birth	Thank you for your comment. We agree.

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				complications as parents may already have developed a mistrusting relationship with the health service.	
The British Psychological Society	Full	29	29	Within the support services provided to parents and families, it would be good to include 'psychological services if available' also.	Thank you for your comment. The Committee have revised the recommendation to say: • *support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings, and hospice services).*
The British Psychological Society	Full	29	39	The Society welcomes providing information to children and families based on their understanding but it is important to stress that a child's developmental level will change over time and therefore this information needs to be provided according to their stage of development and reviewed at important transitions, i.e. starting school, adolescence, transition to adult services.	Thank you for your comment. We have clarified the point you make in section 11.5.2 of the full guideline.
Visual Impairment Paediatric Special Interest Group	Appendices A-D F H-I, K	General	general	As the reviewers have included Register studies only, apparently on the grounds of sample size and geography, **other informative studies have been excluded such as Fazzi 2012 DMCN Neuroophthalmological disorders in CP: ophthalmological, oculomotor and visual aspects** (n=129 children consecutively enrolled) **and Woo 2011 Optom and Vis Sci Ocular Findings in Cerebal Palsy patients undergoing orthopedic surgery** (n=88, consecutive enrolments from children attending for surgical procedures). **Da Cunha Matta 2008 Dev Neurorehab. Outpatient evaluation of vision and ocular motricity in 123 children with cerebral palsy.** All of these authors achieved comprehensive ocular examination and visual assessment the advantage of which is referred to as above. Fazzi concluded that different clinical types of CP are characterised by a different neuro-ophthalmological profile. Reduced visual acuity, refractive error and oculomotor abnormality are all demonstrated by both Fazzi and Woo. These types of study are important in providing further detail of the range of abnormalities that may be found and the frequency according to severity of motor impairment. **Critical appraisal: Fazzi**: sample is representative of target population. Study recruited consecutively from children attending a child neuro-ophthalmology clinic. It is not clear whether children attending this clinic were those with pre-existing concerns about vision or whether all children with CP are routinely referred to the clinic. Sample size is adequate. Study subjects described according to distribution of CP, age, gender, cognitive ability. Mobility and hand skills not described in detail using GMFCS/MACS. Assessment procedures were described in detail. **Critical appraisal: Woo:** Sample included children in all 5 GMFCS categories and is thus representative of whole CP population however there may be bias in that all children were undergoing orthopaedic surgery. However sample was consecutive. Sample size is adequate. Study subjects described according to age, gender and distribution of CP, and GMFCS level.	Thank you for your comment. The exclusion of studies with less than 250 participants was specified a priori for the prevalence review of 'other' comorbidities in cerebral palsy (See Appendix D, protocol D24). The sample size threshold was used to restrict the inclusion of studies that were likely to provide an imprecise estimate of the true prevalence. We retrieved and assessed the suggested publications for assessment. As indicated, we found these types of studies provided further detail about the neuro-ophthalmological profile that the patient presents with and its frequency according to the level of functional ability. However, the Committee did not believe that the inclusion of these data would have changed the conclusions of the review. The studies have been added to the excluded studies list (Appendix K).

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				Assessment procedures were described in detail. Appropriate statistical methods used. **Critical appraisal: Da Cunha Matta.** Sample is representative of target population and recruited from a suitable population however it is not clear whether recruitment was from consecutive children referre to/seen in the rehab programme or whether there was any selection. Total sample size was 123 though not all aspects of assessment achieved in whole group. Assessment procedures were described in detail. Subjects described according to age, gender, distribution of CP, GMFCS level.	
Visual Impairment Paediatric Special Interest Group	appendices A-D F H-I, K	329	General	The reviewers have excluded Dufresne 2014 on the basis of the paper's small sample size and that it reports non UK data. However it is important to note that this study reports on the *same* initial cohort of children from the REPACQ register based study used in Shevell 2009, which the reviewers *have* included. A total of 301 children with CP were identified in this REPACQ cohort from 1999-2002. The Dufresne paper reports on 213 children, which represents those for whom imaging data was available and parental consent available. The Shevell paper reports on 243 of the original 301, which is the number for which info on CP subtype was available. **The Dufresne paper is relevant** because, despite its smaller sample size, there is a wider range of anomalies of the visual system described. This is useful in illustrating the range of ocular and visual outcomes that ophthalmological and orthoptic assessment should address in any individual child. These outcomes include reduced visual acuity, refractive errors, oculomotor impairment, squint. Dufresne does not address in detail the various degrees of reduced acuity that may occur and describes only the most severe degree of reduced acuity, terming this cortical blindness, without specifying any particular acuity cut-off. Dufresne comments that information available to Register based studies reflects 'usual ophthalmological care' and acknowledged that findings may be an underestimate of the full range or degree of difficulty, because visual assessment in children with limited response methods can be challenging. However the Dufresne paper has limitations (as do other Register based studies) precisely because they usually report the findings of 'usual ophthalmological care'. Studies which are cross sectional or case series in design, which administer a full ophthalmological, orthoptic and visual assessment, may be more informative as evaluation is often more comprehensive than that achieved in 'usual care'	Thank you for your comment. We have retrieved the publications mentioned for assessment. The suggested study was not initially included because of its reduced sample size and because there was already evidence in visual impairment from 3 other studies (Shevell, Delacy and Surman), one of them a large cohort. Given that Dufresne 2014 provides additional information regarding the neuro-ophthalmological profile and its frequency by motor type, it has been now been included.
Visual Impairment Paediatric Special Interest Group	Appendices A-D F H-I, K	330	General	Ghasia 2008 has been excluded on the basis of small sample size. In the absence of other studies with larger sample sizes **this exclusion may be premature** since participants were selected according to reasonable criteria and underwent more comprehensive assessment than those reported on in Shevell, Delacy and Surman. Ghasia reports on the findings of comprehensive ophthalmological and orthoptic assessment in a cross sectional study design. Over a 6 year period all children referred to the St Louis CP centre were enrolled and subsequently	Thank you for your comment. The study was indeed excluded due to its small sample size (See protocol in Appendix D). As indicated, this study concluded that the severity of visual impairment is linked to the severity of cerebral palsy. This is already addressed in the recommendations (see recommendations 1.17.3 to 1.17.7 in the short guideline).

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				10 children in each GMFCS level were selected to achieve a **representative cohort of 50 children**. The benefit of this type of study is that full evaluation is intended and usually achieved. Evaluation included ocular examination, acuity, refraction, eye movements, field, assessment of fixation, saccades and pursuit movements. A distinction was made between sensory deficits (limitations of visual system input) and visuo-motor deficits (eye movements, fixation) which is highly useful given the crucial role that vision plays in supporting learning, interacting and responding in children with the most severely restricted movements. This paper usefully reports on the range of refractive errors found (higher than in the non CP population), strabismus, increased risk of reduced visual acuity (though again no distinction was made between different levels of reduced acuity) and range of eye movement difficulties. It should be noted however that acuity measurement methods included sweep VEPs and there are no details given as to which children were tested in this way. It may be presumed that this method was only used in children who could not perform optotype matching. This is important since some specialists do not consider that a VEP response can be taken as an equivalent of a behavioural acuity measure. The findings may therefore be an underestimate of true rates of behavioural acuity reduction. Nevertheless the paper clearly indicates that children with CP are at risk of reduced visual acuity and that the risk increases with increasing motor impairment. **The paper also importantly documents the increased risk of squint, refractive error and eye movement difficulties that occur in children with CP.**	
Visual Impairment Paediatric Special Interest Group	Appendix J (evidence tables)	362-363	General	Shevell 2009: this paper reports on 'severe visual impairment' but does not give a more precise definition. 'Cortical blindness' is defined only as having required diagnosis by an Ophthalmologist. It is not clear on what basis either diagnosis was made and is likely to reflect 'usual care' only which can be challenging and therefore incomplete. Without a better definition of what is included within 'visual impairment' the clinician receives little guidance as to what the examination consisted of and the criteria for 'diagnosis' of VI/severe VI. As commented above, this does not provide specific guidance to the referring or assessing clinician as to what aspects of ocular and visual function should be assessed	Thank you for your comment. We agree that more precise definitions and further guidance on how 'severe visual impairment' and 'cortical blindness' were diagnosed in Shevell 2009 are needed. This was fully taken into consideration when assessing the study (rated as low quality evidence) and when doing the recommendations. For consistency purposes, the lack of clarity in the diagnoses has been specified in the summary of included studies (see 'Table 124' in the 'other comorbidities in cerebral palsy' chapter 27; full guideline), in the evidence statements (see 'visual impairment' section in the 'other comorbidities in cerebral palsy' chapter 27; full guideline) and evidence table (Appendix J.24). While the recommendations about vision and hearing were reorganised following stakeholder consultation but the Committee felt it was not the place of this guideline to go into any greater degree of detail as to what aspect of ocular and visual function should be assessment.

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Visual Impairment Paediatric Special Interest Group	Appendix J (evidence tables)	382	General	The Delacy paper uses a similar cut off of 6/60 or worse to Surman and uses the term 'functional blindness'. The only other visual category used was 'some visual impairment' which effectively describes children with a refractive error sufficient to require corrective spectacle wear to achieve normal acuity at age 5. This therefore describes refractive errors, an important outcome, but the use of the term 'some visual impairment' is misleading since correction of the refractive error led to normal acuity. No other aspect of ocular dysfunction is mentioned. **Thus while the paper includes a large number of subjects, the information available is limited.**	Thank you for your comment. We agree that the use of 'some visual impairment' for describing children who at age 5 required normal lenses to achieve normal visual acuity may be misleading. For transparency purposes, we have specified this it in the included studies (see 'Table 124' in the 'other comorbidities in cerebral palsy' chapter 27; full guideline) and in the evidence table (Appendix J.24).
Visual Impairment Paediatric Special Interest Group	Appendix J (evidence tables)	360-1, 377	General	Surman reports on a cohort of 4492 children reported to local CP registers; 43% are said to have 'visual impairment' and 10% had 'severe visual impairment', defined as 6/60 or worse or clinical judgement. However 'visual impairment' is not defined in the paper and it is therefore not known whether this refers only to reduction of visual acuity, or whether other abnormalities have been subsumed under a generic heading of visual impairment, which, though arguably inappropriate, does happen (see comment 13 on Delacy below). This therefore does not provide specific guidance to the referring or assessing clinician as to what aspects of ocular and visual function should be assessed, which is currently much needed.	Thank you for your comment. The Committee agree that the definition for visual impairment should have been provided in the study by Surman 2009. For this reason, this study, initially rated as moderate quality evidence, has now been rated as low quality evidence. Furthermore, the absence of a definition for visual impairment has been reflected in the summary of included studies (see 'Table 124' in the 'other comorbidities in cerebral palsy' chapter 27; full guideline), in the evidence statements (See 'visual impairment' section in the 'other comorbidities in cerebral palsy' chapter 27; full guideline) and evidence table (Appendix J.24). The recommendation about vision and hearing were reorganised following stakeholder consultation but the Committee felt it was not the place of this guideline to go into any greater degree of detail as to what aspect of ocular and visual function should be assessment. .
Visual Impairment Paediatric Special Interest Group	Full draft	339	general	This section links together 'sensory and perceptual difficulties' and states that the Review question is to establish what interventions are effective for managing 'difficulties in registering and processing of sensory and perceptual information'. This whole section is extremely problematic as although the stated aim is to identify interventions, there is no coherent definition of 'sensory and perceptual difficulties'. Without clarity on what an intervention is intended to address, an intervention cannot be evaluated. It is surprising that a whole section is devoted to review of interventions for this poorly defined group of conditions, and yet identification (and not management of) vision and hearing impairment are subsumed as two of several 'other comorbidities in CP' (from p354). *A vital aspect of management of visual impairment is that visual acuity should be accurately assessed so that adaptation of visual materials for learning and play can be provided – eg enlargement, positioning, and so on.* With particular regard to vision, a 'difficulty in registering and visual information' could more straightforwardly be defined as reduced visual input	**Thank you for your comment.** See protocol D.23 in appendix D for a description of the types of sensory and perceptual difficulties that were included in the review. Although the **entire** section on vision impairment was revised in light of stakeholder feedback, it is not exhaustive and areas were prioritised for inclusion by the Committee at the time of protocol development. Each of the included studies in the suggested review (Ego 2015) has been retrieved and assessed. See details below: • Fazzi E, Bova SM, Uggetti C, et al. Visual-perceptual impairment in children with periventricular leukomalacia. Brain Dev 2004; 26: 506–12. Respose: This is not an intervention study, this study is set to define visuo-perceptual impairment related to periventricular leukomalacia (PVL) using

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				or reduced visual acuity. The term 'visual processing' is often used in a rather loose and undefined way by different professionals and an attempt to specify what is meant in more detail is required. A straightforward attempt to explain 'visual processing' might begin by stating that it can refer to a number of different aspects of cognitive function such as recognition, sustained attention, coordination with controlled movement, underpinned by the visual skills of looking and seeing**. 'Visual processing' not otherwise defined is too vague a term to have any meaning.** The second paragraph of this section (lines 14-23) risks implying that emerging reading and writing skills may be due to ill defined 'sensory and perceptual' difficulties, rather than due to other difficulties such as cognitive impairment, dyslexia, movement limitations. The authors may however wish to refer to the occurrence of visual perceptual problems as the group of skills that are assessed using formal visual perceptual tests. Reference to such identifiable difficulties may be valid, but if this is the intention it should be described much more coherently. A useful paper in this regard is **Ego, A., Lidzba, K., Brovedani, P., Belmonti, V., Gonzalez-Monge, S., Boudia, B., Ritz, A. and Cans, C. (2015), Visual–perceptual impairment in children with cerebral palsy: a systematic review. Dev Med Child Neurol, 57: 46–51.** The conclusion from this review is that visual perceptual impairment should be considered a core disorder within CP and that its presence can be identified using standardised tools. *Whilst the purpose of this aspect of the review is to identify interventions which can address perceptual difficulties, the omission of visual perceptual difficulties from the list of 'Other Comorbidities' is surprising.* (As regards hearing, difficulties with 'registering and processing auditory information' could refer both to a hearing impairment (unable to register the sound), receptive language impairment (cannot understand the words) and 'auditory processing', which requires further explicit definition.)	the Developmental Test of Visual Perception (DTVP) • Pagliano E, Fedrizzi E, Erbetta A, et al. Cognitive profiles and visuoperceptual abilities in preterm and term spastic diplegic children with periventricular leukomalacia. J Child Neurol 2007; 22: 282–8. Response: Not an intervention study. The study aimed at comparing the cognitive abilities and visuoperceptual abilities of a group of children and its relation to periventricular leukomalacia severity. • Burtner P, Dukeminier A, Ben L, Qualls C, Scott K. Visual perceptual skills and related school functions in children with hemiplegic cerebral palsy. N Z J Occup Ther 2006; 53: 24–9. Response: This is not an intervention study. This study investigated differences in visual perception and visual-motor based school functions in children with and without congenital hemiplegia. • Ito J, Saijo H, Araki A, et al. Neuroradiological assessment of visuoperceptual disturbance in children with spina bifida and hydrocephalus. Dev Med Child Neurol 1997; 39: 385–92. Response: This is not an intervention study, only included indirect population. • Koeda T, Inoue M, Takeshita K. Constructional dyspraxia in preterm diplegia: isolation from visual and visual perceptual impairments. Acta Paediatr 1997; 86: 1068–73. Response: This is not an intervention study, its main aim was to evaluated ophthalmological profiles. • Ito J, Araki A, Tanaka H, Tasaki T, Cho K. Intellectual status of children with cerebral palsy after elementary education. Pediatr Rehabil 1997; 1: 199–206. Respose: This is not an intervention study. It aimed to compare the IQ of children with spastic

					diplegia and spastic quadriplegia after 2 years of education • Darlow BA, Horwood LJ, Mogridge N, Clemett RS. Prospective study of New Zealand very low birthweight infants: outcome at 7–8 years. J Paediatr Child Health 1997; 33: 47–51. Response: This is not an intervention study • Tsai LT, Lin KC, Liao HF, Hsieh CL. Reliability of two visual-perceptual tests for children with cerebral palsy. Am J Occup Ther 2009; 63: 473–80. Response: This is not an intervention study • Menken C, Cermak SA, Fisher A. Evaluating the visualperceptual skills of children with cerebral palsy. Am J Occup Ther 1987; 41: 646–51. Developmental Medicine & Child Neurology 2015, 57 (Suppl. 2): 46–51 Response: This is not an intervention study. In this study the Test of Visual-Perceptual Skills was used to determine if children with cerebral pals demonstrated problems in visual perception. • Hard AL, Aring E, Hellstrom A. Subnormal visual perception in school-aged ex-preterm patients in a paediatric eye clinic. Eye 2004; 18: 628–34. Response: This is not an intervention study. The aim of this study was to assess visual perception at school age of children born preterm with known lesions to the posterior visual pathways or with ophthalmologic signs that might indicate such lesions. • Hard AL, Niklasson A, Svensson E, Hellstrom A. Visual function in school-aged children born before 29 weeks of gestation: a population-based study. Dev Med Child Neurol 2000; 42: 100–5. Response: This is not an intervention study. The aim of this study was to assess visual function, including visual perception, in a geographically-based population of school-aged children, with a median age of 7.2 years (range 5.1 to 9.3 years), born before 29 weeks of gestation. • Reid D, Drake S. A comparative study of visual perceptual skills in normal children and children

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					with diplegic cerebral palsy. Can J Occup Ther 1990; 57:141–6. Response: This is not an intervention study • Stiers P, Vanderkelen R, Vanneste G, Coene S, De Rammelaere M, Vandenbussche E. Visual-perceptual impairment in a random sample of children with cerebral palsy. Dev Med Child Neurol 2002; 44: 370–82. Response: This is not an intervention study • Ortibus E, Lagae L, Casteels I, Demaerel P, Stiers P. Assessment of cerebral visual impairment with the L94 visual perceptual battery: clinical value and correlation with MRI findings. Dev Med Child Neurol 2009; 51:209–17. Response: This is not an intervention study • Smits DW, Ketelaar M, Gorter JW, et al. Development of daily activities in school-age children with cerebral palsy. Res Dev Disabil 2011; 32: 222–34. Response: This is not an intervention study
Visual Impairment Paediatric Special Interest Group	Full draft	351		This recommendation appears to be circular: As 'problems with registering or processing sensory information' have not been defined clearly, learning and movement problems cannot be exacerbated by something that has not been defined. 'Primary sensory disorders' relating to vision and hearing should be redefined as visual and hearing impairment. The reference (lines 20-21) to 'complex disorders of planning movement' may also be misleading since movement difficulties are themselves influenced by the presence of abnormalities of tone ie the cerebral palsy itself. To imply that movement planning difficulties may be influenced by poorly defined 'complex disorders of sensory processing and perception ' again ascribes causation to something that has not been defined.	Thank you for your comment. The Committee consider that the points you raise are already covered in section 26.1 of the full guideline.
Visual Impairment Paediatric Special Interest Group	Full draft	351		There is however some published evidence that use of standardised visual perceptual testing, including visuo-motor integration, can be useful alongside cognitive assessment when assessing children who have difficulties with reading and writing. A specific reference to the use of these tools may be useful. Use of the word 'complex' can be unhelpful as it can imply that the problem is too challenging to be understood, when in fact use of standardised assessments can be very informative in illustrating the basis of a child's difficulties. The guideline may be strengthened by including a section on the availability of tools to assess visual perception with attention to when these tools should be used.	Thank you for your comment. Evidence of standardised visual perceptual testing was not included in the evidence reviewand this was outside the scope of the guideline.
Visual Impairment Paediatric	Full draft	367	4-15	Description of clinical evidence: Visual Impairment. This summarises the evidence from the three papers included and refers only to 'visual impairment' without clarifying that this is intended to refer to reduced visual acuity. The summary is brief and does not reference the cut offs used to define severe	Thank you for your comment. The definition for visual impairments used by the studies has been added to

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Special Interest Group				visual impairment nor comment on what met the definition of 'visual impairment'. As stated elsewhere, Delacy included children with refractive errors in the 'visual impairment' group. There is no reference to the wider range of ocular problems that can occur in children with CP, because this was not the focus of the papers included.	Table 124 and the evidence statements in section 27.15.1.
Visual Impairment Paediatric Special Interest Group	Full draft guideline	370	29-34	This section is muddled: the definition given of visual impairment is confused (for example 'visual loss' does not generally result from a problem with eye muscles; astigmatism is listed rather than refractive errors as a whole; astigmatism is linked with 'eye muscles' which is inaccurate) and an outdated definition of cortical visual impairment is used. Rather than distinguishing between 'visual impairment' and 'cortical visual impairment' the guideline will be strengthened by clarifying that visual impairment, ie reduction of visual acuity, should be sought in any child with CP, irrespective of the underlying cause. Reduced visual acuity may occur in the absence of signs or symptoms and may necessitate adaptations to play and learning materials. If it is not identified, necessary adjustments may not be put in place, and developmental progress may be constrained. Reduced visual acuity will result in image degradation irrespective of whether this is due to abnormalities in the eye, nerve or brain, though the underlying cause should of course be clarified. In the absence of ocular or nerve abnormality and refractive error, reduced visual acuity may be presumed to be due to cerebral damage (which could be in the optic tract or cortex or other areas) and can be termed cerebral visual impairment. Cerebral visual impairment is now generally preferred over cortical visual impairment as it is recognised that damage resulting in visual difficulty may not be confined to the cortex. The papers included in the review did not contain sufficient detail of the underlying cause of reduced visual acuity to allow a distinction between cerebral and non-cerebral causes of VI.	Thank you for your comment. In light of stakeholder comments, the Committee has reviewed the recommendations on visual impairment and the corresponding evidence to recommendations section (27.19.2) in the full guideline. The definition of cortical visual impairment in section 27.19.2 has been amended to cerebral visual impairment as you suggested**.** The definition for visual impairments used by the studies has been added to Table 124 and the evidence statements in section 27.15.1.
Visual Impairment Paediatric Special Interest Group	Full draft guideline	370	35-39	Consideration of clinical benefits and harms: **this section is awkwardly worded**. It is misleading to refer to the 'early stages' of visual impairment. The committee may be attempting to draw a parallel with the gradual manifestation of movement disorders as an evolving consequence of an earlier brain insult, but this is not helpful. Reduction of visual acuity, if present, will be present early on, but visual acuity may actually improve as general maturation occurs (this is also the case for normally developing children). It is true that some ocular abnormalities are not present from birth, but may develop when the child is older, for example squint and refractive error. It is important that this is recognised as a normal evaluation at a young age does not preclude later abnormality. The Committee may wish to refer to the possibility that abnormal visual responses may be overlooked when a child is young, when other concerns such as feeding and abnormal movements predominate. Ocular abnormality and visual impairment can be identified in the pre-school child if a thorough evaluation is conducted. Measurement of visual acuity can be challenging in a child of any age if speech and movement is limited, but assessment can be achieved by skilled professionals. Children may be seen in an Eye clinic and	Thank you for your comment. In light of stakeholder comments, the Committee has reviewed the recommendations on visual impairment and the corresponding evidence to recommendations section (27.19.2) in the full guideline. The entire linking evidence to recommendation section was also revised.

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				yet not undergo vision assessment, leading to a false belief that visual impairment is not present. It is crucial that visual impairment be recognised early on to allow for adaptations to learning and play materials, and so that the child's responses are accurately understood. Multiple assessment episodes may be required until a full evaluation of the ocular and visual system has been achieved, with a full account of what has and has not been evaluated. When ocular or visual difficulties are identified, the reason for follow up should be made explicit, so that children are not undergoing 'routine review' with no clear purpose. On the basis of the evidence considered by the committee, it is also not accurate to state that 'recognition often only occurs [at] school age, as the impairment becomes more apparent in the learning process'. **Visual impairment is often poorly identified during school age children with 'complex needs'**. (See Das 2010 Evidence that all children with special needs require visual assessment, and Woodhouse 2013 Ocular and visual status among children in special schools in Wales: the burden of unrecognised visual impairment. Although the characteristics of children with severe VI in these papers are not described in full, it is reasonable to presume that they were those with the most severe movement limitations). It is the clinical experience of VIP-SIG members that within specialist school settings, children may show poor visual responses for a variety of reasons not restricted to the presence of visual impairment. The child with a visual impairment may manifest visual responses that are little different to peers with cognitive impairment, attentional difficulties or reduced social interest. *This similarity can make it less likely that educational staff may suspect a visual impairment*. Some children with significant visual impairment have been seen in Eye clinics when younger but visual assessment may not have taken place, the significance of assessment responses may not have been appreciated or reported, and qualitative comments on the child's visual performance may not have been made. Furthermore, if reduced acuity is not actively identified early on, a belief that there is none present becomes established and this also presents a major obstacle to later identification. VIP-SIG members would therefore encourage the committee to rework this final paragraph. In particular, it is insufficient to produce a bland recommendation for 'regular assessment'. A failure to specify exactly what should be assessed, leaves open the possibility that assessment may remain incomplete, leading to false assumptions that problems are absent. VIP-SIG members agree that a failure to identify visual impairment that is significant enough to warrant adaptations of environment and materials represents clinical harm.	
Visual Impairment	Short and full	general	general	A comprehensive guideline which summarises the main *ocular and visual abnormalities* which occur in children with CP will be helpful to parents,	Thank you for your comment. In light of stakeholder comments, the Committee agreed that it is important

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Paediatric Special Interest Group				children and professionals. Currently these problems, particularly visual impairment ie visual acuity reduction, as opposed to identification of squint and refractive error, may remain undiagnosed. A guideline which emphasises the need to achieve comprehensive ocular and vision assessment for this group of children is very welcome. Sufficient capacity is required within secondary level Eye care services to provide ocular and visual assessment. In theory, refraction and acuity assessment can be provided by a High St optician under the General Optical Services contract as for all children, but in practice the required clinical skill within High St services for this patient group may be lacking. The charity Seeability through their Children in Focus Campaign (www.seeability.org/children-in-focus) has demonstrated the feasibility of providing a within school sight testing programme for children attending specialist schools; this would include any CYP with CP attending specialist schooling. Children with CP attending mainstream schooling would not be reached. This model of service provision is valued by parents and teachers as children are assessed within school. Seeability have produced (in collaboration with the Royal College of Ophthalmologists Paediatric subcommittee and other eye care professional bodies) a recommended framework for an eye care service for all special schools regarding extension of such a service to all special schools in England, which, if implemented, would require provision of appropriate funding. An emphasis on the need for visual as well as ocular assessment could avoid some unproductive monitoring of squint and refractive error if significant visual acuity is identified.	that visual impairment is recognised early on to allow for the corresponding adaptions in children and young people with cerebral palsy (see evidence to recommendations in section 27.19 in the full guideline). For this reason, the Committee has reviewed the recommendations on visual impairment to say: *Refer all children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis.*
Visual Impairment Paediatric Special Interest Group	Short draft	30	18-19	Lines 11-12 make reference to 'impairments of control of eye movements, ocular function and cerebral visual processing'. This statement fails to clarify what types of ocular function may occur (for example, refractive errors and squint, which occur more commonly in children with CP than without), and does not define 'cerebral visual processing'. Moreover, the studies used as evidence do not explicitly report on oculomotor problems, nor on 'cerebral visual processing' and so the guideline cannot justify these statements on the basis of evidence considered. However, these problems do occur in children with cerebral palsy and should be highlighted, though separately from 'visual impairment' as per the comment above. In later comments (see comments 10 and 14) other papers which provide information on ocular abnormalities are given.	Thank you for your comment. In light of stakeholder comments, the Committee has reviewed the recommendations on visual impairment to say: Talk to children and young people and their parents or carers about the different types of visual impairment

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					that can be associated with cerebral palsy. Explain that these could include one or more of the following: • problems with controlling eye movements • strabismus (squint) • refractive errors (short or long sighted or distorted image) • problems of eye function, including retinopathy of prematurity • impaired cerebral visual information processing (problems with seeing objects caused by damage to the parts of the brain that control vision) • visual field defects (loss of the part of usual field of vision). The corresponding evidence to recommendations section (27.19.2) has been updated accordingly to reflect the broad range of visual impairments seen in children and young people with cerebral palsy.
Visual Impairment Paediatric Special Interest Group	Short draft	30	20	VIP-SIG agrees that an emphasis on visual (acuity) assessment is important, since this vital aspect of the visual system is often overlooked in children with CP, despite assumptions made by families and professionals that an Eye clinic visit inevitably includes this. Acuity assessment can be incomplete or not attempted if movement or cognitive difficulties preclude the use of recognition acuity tests. However, the emphasis here should also be on the need for evaluation of the whole visual system, to include ocular health, eye movements, refraction, squint **and** visual acuity. Assessment of the ocular and visual system should not be considered complete until a full understanding of all these factors is achieved. Thereafter, the need for further review will be determined by assessment findings, and the child's age. Continued assessment of confirmed refractive errors, or for the emergence of refractive error over time, is important but assessment should not be restricted to this.	Thank you for your comment. In light of stakeholder comments, the recommendations on visual impairment have been revised to say: If concerns about visual impairment are raised by parents, carers or members of the care team, consider referring the child or young person with cerebral palsy to a specialist team for evaluation of the whole visual system (including eye health, eye movements, refraction, squint and visual acuity), especially if there are communication difficulties. The corresponding evidence to recommendations section (27.19.2) in the full guideline has been updated to reflect the necessity of regularly assessing the ocular and visual system of children and young people with cerebral palsy.
Visual Impairment Paediatric Special Interest Group	Short draft	30	21-22	VIP-SIG acknowledges the relevance of highlighting the importance of brain related visual problems in children with CP. However this statement is unhelpful as it implies that cortical visual impairment may be entirely different from visual impairment and does not guide as to what 'signs' are being sought. The statement thus results in some degree of mystification about cortical visual impairment particularly for the family and non-specialist, which is undesirable particularly given current controversies about the definition of cerebral visual impairment, the spectrum of possible consequences and the potential for overlap with other aspects of a child's developmental or movement difficulties. (See Boot et al 2010 Res	Thank you for your comment. In light of stakeholder comments, the Committee has reviewed the recommendations on visual impairment to say:

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				Dev Dis: Cerebral Visual Impairment: which perceptive visual dysfunctions can be expected in children with brain damage? A systematic review) As stated elsewhere, the term cortical visual impairment is no longer used by many experts, and has been superceded by 'cerebral visual impairment'. There is much continuing professional discussion about a precise definition and diagnostic criteria for this condition, with a wide range of potential consequences reported, including reduced visual acuity. Given the potential for overlap with other aspects of development, there is an established need for developmental assessment to inform concerns about possible manifestations of CVI. However the guideline can very usefully emphasise the need for identification of visual impairment, defined as reduced visual acuity, irrespective of the anatomical site of the underlying abnormality, and for assessment of other potential manifestations of CVI to occur alongside cognitive and neuropsychological assessment, using a multidisciplinary approach. The guideline should also usefully acknowledge that some children with CP may have ocular abnormalities that arise from a common underlying aetiology such as prematurity. Retinopathy of prematurity may result in retinal damage causing acuity reduction and this may therefore co-occur with CP. As stated in comments on line 28, the emphasis does not need to be on provision of regular assessment, but on sufficient assessment until all abnormalities are identified.	Regularly assess children and young people with cerebral palsy for signs of cerebral visual impairment, bearing in mind that this: • occurs in around 1 in 5 children and young people with cerebral palsy • may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment • may be difficult to recognise in the early stages. The corresponding evidence to recommendations section (27.19.2) in the full guideline has been updated to reflect the differences between visual and cerebral visual impairment. Furthermore, this section includes a discussion about the necessity of carrying out multiple visual assessments in children and young people with cerebral palsy until a full evaluation of the whole ocular and visual system has been achieved.
Visual Impairment Paediatric Special Interest Group	Short draft	30	23-24	This appears to reference the prevalence of 'severe visual impairment' or 'cortical blindness' in the included papers. To reference 'cortical visual impairment' only as regards its most severe consequences may be unhelpful in implying that lesser degrees are of no relevance. As stated above, the guideline would be strengthened by referring to VI as reduction of visual acuity, irrespective of underlying cause.	Thank you for your comment. In light of stakeholder comments, the evidence to recommendations section (27.19.2) has been updated to reflect that visual impairment is considered a reduction in the clarity of vision. The recommendation 102 in the full guideline is based on the evidence, which showed that the prevalence of cortical visual impairment (reported as cortical blindness alone) varied between cerebral palsy type (see Shevell 2009 in table 124 in Chapter 27). This information has also been reflected in the evidence to recommendations section (27.19.2).
Visual Impairment Paediatric Special Interest Group	Short draft	30	25-27	These lines become redundant as a specific reference to 'cortical' VI	Thank you for your comment. In light of a number of stakeholder comments, the Committee has reviewed the entire series of recommendations on visual impairment and the corresponding evidence to recommendations section (27.19.2) in the full guideline.

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Visual Impairment Paediatric Special Interest Group	Short draft	30	28	This statement is misleading despite its intention to be helpful in highlighting the real possibility that ocular abnormalities and visual impairment may be poorly identified in children with CP. The statement would be more powerful if it highlighted the likelihood that abnormalities of visual response can be overlooked in young children if other concerns (feeding, movement) predominate, that acuity assessment is incomplete or omitted in children who are 'difficult to assess' by virtue of their movement difficulties, but that visual assessment can be achieved. The Dufresne (paper disregarded by the Committee, see comment 9) commented on this with reference to Fazzi 2012, a paper not considered by the Committee (see comment 14)	Thank you for your comment. In light of stakeholder comments, the Committee has reviewed the corresponding evidence to recommendations section (27.19.2) in the full guideline, where the Committee provided rationale for this statement. It was specified that visual impairment may be more difficult to recognise at an early stage, particularly if there are problems with movement, communication or learning.
Visual Impairment Paediatric Special Interest Group	Short draft	30	9-28	The first statement, 'VI occurs in around 1 in 2 CYP with CP' should be re-examined and amended. Whilst this statement is simple and powerful, and should alert families and professionals to the important issue of VI, and is presumed to be a rounding up from the prevalence data presented, namely that up to 40% of children are found to have VI, it is arguable as to whether the prevalence data used supports this broad conclusion about 'visual impairment'. VIP-SIG suggests that the statement would be improved by qualifying what is meant by visual impairment, (principally acuity reduction), acknowledging also that this may occur to varying degrees. The statement could make a specific reference to severe visual impairment with a more accurate figure given for this in all groups of CP, bearing in mind the limitations from the evidence used. It is also very important to highlight the increased risk of ocular abnormalities such as refractive error, squint and oculomotor impairment, but it is **not** helpful to subsume these abnormalities under the term 'visual impairment'. Therefore, the statement should be expanded to refer to an increased risk of visual impairment (defined as reduced acuity) AND ocular disorder. The committee may wish to consider an alternative statement such as: Talk to children and young people and their parents or carers about ocular abnormalities and visual impairment that can be associated with cerebral palsy. These problems are very common in children with cerebral palsy. • Visual impairment means reduced clarity of vision (visual acuity). This can vary in degree from mild, to moderate to severe. It can occur because of the underlying brain damage, or be due to eye damage that arises from a common underlying cause • Reduced visual acuity may occur in CYP with all degrees of functional motor ability or subtype, but prevalence and severity increase with increasing severity of motor impairment • Reduced visual acuity can sometimes but not always be suspected from a child's visual responses and general behaviour, and	Thank you for your comment. The Committee discussed the prevalence data and it was felt appropriate to make an initial overarching statement of around 1 in 2 to cover all problems in visual processing. In light of stakeholder comments, the evidence to recommendations section (27.19.2) has been updated to reflect that visual impairment has been referred to as results from problems in processing information at any level of the brain, but especially the visual cortex. Squint and refractive errors were recognised as ocular abnormalities. In this same section, it has also been specified that the likelihood of visual impairment increases by GMFCS level, although it can occur in all severities. The Committee agreed that recognition of visual impairment often only occurs when children are of school age, as the impairment becomes more apparent in the learning process. Therefore, the Committee agreed that it was important to regularly assess children and young people with cerebral palsy.

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				assessment of acuity using appropriate materials should be performed in all children with CP • Other concerns may predominate when a child is young and along with challenges in assessment methods this can mean that reduced visual acuity or other problems are not identified or fully characterised • Visual field defects may also result from structural brain damage • Ocular abnormalities which can also affect everyday use of vision include refractive errors, squint, and eye movement difficulties • Refractive errors refer to a failure of the focussing action within the eye and include myopia (short sight), hypermetropia (long sight) and astigmatism. Refractive errors can be corrected by spectacle wear. However correction of a refractive error does not guarantee normal visual acuity, if there is an additional cause for this. It is important that the role of glasses is fully explained to CYP and their parents and carers • These abnormalities also occur more frequently in CYP with the most severe degrees of functional motor impairment Cerebral visual impairment is a general term that may be used to describe a wide range of identifiable abnormalities of visual function. It can be thought of as a spectrum condition with a range of potential consequences, not all of which will occur in all children. Brain processing of visual images captured by the eye overlaps with cognitive skills which underpin, for example, the ability to 'look' at, to 'know' what and to 'remember' what is seen. • Consideration of possible cerebral visual impairment will be informed by consideration of other developmental or cognitive difficulties • Some aspects of cerebral visual impairment may be suspected from observation of child's visual responses, or enquiry about behaviour and general progress, however multidisciplinary assessment which takes account of cognitive and motor skills is recommended, in a setting which ensures the child's best performance. • Comprehensive assessment of ocular health and function, visual acuity, and any other aspects of visual function identified as requiring further exploration, should continue until complete. Monitoring and follow up should include though not be restricted to assessment and correction of refractive error • Comprehensive assessment of vision including visual acuity can be challenging particularly in children with limited movements and speech but it can be achieved • The difference between examination of the eye and ocular functions such as refraction and eye movements, and vision assessment which establishes how clearly a child can see should be understood by parents and carers and non-specialists.	For this reason, they reviewed the recommendations to say: *Regularly assess children and young people with cerebral palsy for signs of cerebral visual impairment, bearing in mind that this:* • *occurs in around 1 in 5 children and young people with cerebral palsy* • *may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment* • *may be difficult to recognise in the early stages.*

[Registered stakeholders](#)

The Bobath Centre has declared that they have 'Past funding from the Tobacco Pipe Sellers and Tobacco Blenders Benevolent Fund'.