National Institute for Health and Clinical Excellence

Spasticity in children and young people
Guideline Consultation Comments Table
19 October -14 December 2011

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
1.	SH	Allergan Ltd	1	Full	General		In terms of the different licenses that different brands of Botulinum Toxin Type A possess, there is evidence of different clinical properties between the toxins in terms of migration and potential side effects as well as a lack of dose interchangeability. This is not clearly communicated within this clinical guidance, and Allergan feels that this clinically relevant information needs to resonate throughout the guidance. The available presentations of botulinum toxin type A in the UK are distinct in terms of their formulation and clinical development, licensed indications and licensed doses. This is recognised in the SPCs for each product, and in guidance issued by the CHMP in 2007 which states that: "To promote interchangeability of BOTOX® , Dysport™ and Xeomin™ is to ignore the advice explicitly given by the regulatory authorities in all three product licences" [EMEA, 2007].Within this same document, the EMEA requests that	The NICE guideline development process and editorial style together determine the level of detail about the characteristics of pharmacuetical products that can be included in guideline recommendations. The footnotes to the guideline recommendations follow a prescribed style that is intended to indicate whether drugs are being recommended outside licensed indications. NICE does not normally allow other characteristics (such as dosages) to be included in guideline recommendations. The recommendations are not allowed to refer to pharmaceutical products by their trade names, and in the case of botulinum toxin type A the developers are aware that there are several drugs with different properties and different licensed indications, some of which are suitable for use in children and young people with spasticity and some of which are not. The footnotes to the recommendations are intended to reflect this and to help healthcare professionals identify the relevant products for use in clinical practice

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							manufacturers submit a risk management plan, including detailed strategies for educating physicians regarding lack of interchangeability between BoNT-As.	
2.	SH	Allergan Ltd	2	Full	6 11,13,14,15,81,124,125,126	Foot note	Most of the clinical studies analyzed in the document were with BOTOX. There is no recognition of different product characteristics, e.g. – different dosages, AE profile, toxin spread (this can be very important in the paediatric population) and non interchangeability. Through the document you can find this paragraph: "At the time of publication (October 2011), some botulinum toxin type A products were licensed for use in focal spasticity in children and adults, including the treatment of dynamic equinus foot deformity due to spasticity in ambulant paediatric cerebral palsy patients, two years of age or older. Other products were licensed only for use on the face in adults or for post-stroke spasticity of the upper limb in adults." We recommend increased clarity regarding which products are currently licensed for use in children and which are not. We suggest this could be achieved via an additional column in tables showing	The NICE guideline development process and editorial style together determine the level of detail about the characteristics of pharmacuetical products that can be included in guideline recommendations. The footnotes to the guideline recommendations follow a prescribed style that is intended to indicate whether drugs are being recommended outside licensed indications. NICE does not normally allow other characteristics (such as dosages) to be included in guideline recommendations. The recommendations are not allowed to refer to pharmaceutical products by their trade names, and in the case of botulinum toxin type A the developers are aware that there are several drugs with different properties and different licensed indications, some of which are suitable for use in children and young people with spasticity and some of which are not. The footnotes to the recommendations are intended to reflect this and to help healthcare professionals identify the relevant products for use in clinical practice

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							which product has been used in each study. This will enable greater transparency regarding the different product characteristics, and their implications for patient safety.	
3.	SH	Allergan Ltd	3	Full	5	11	We recommend that instead of line 11 stating 'to offer BoNT-A as an adjunct to physical therapy', that there should be a standalone point to describe the value of BoNT-A on its own merits. The guideline rightly acknowledges throughout the need for there to be 'functional gain' in justifying BoNT-A in which case, physical therapies would be concurrent, but there are other reasons to give BoNT-A in these patients besides functional gain. For example this includes recognised improvements in terms of pain management, hygiene with injecting, body image and so forth. The publication by Lundy et al [Lundy CT, Doherty GM and Fairhurst CB. Botulinum toxin type A injections can be an effective treatment for pain in children with hip spasms and cerebral palsy. Dev Med Child Neurol 2009;51(9):705-10] discusses some of these additional key reasons to consider using BoNT-A	The recommendation referred to here has been revised and therefore the comment is no longer directly relevant to it. However, the developers acknowledge that in the draft recommendations there were some inconsistencies about the use of botulinum toxin A in relation to pain management and have made revisions where necessary to correct this
4.	SH	Allergan Ltd	4	Full	13	65	We agree with the recommendations laid out in Recommendation number 65,	The NICE guideline development process and editorial style together determine the level of detail

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							however it is important to make very clear that not all toxins are licensed for use in paediatric patients, that there are clinical differences between the toxins and the doses are not interchangeable. The available presentations of botulinum toxin type A in the UK are distinct in terms of their formulation and clinical development, licensed indications and licensed doses. This is recognised in the SPCs for each product, and in guidance issued by the CHMP in 2007 which states that: "To promote interchangeability of BOTOX® , Dysport™ and Xeomin™ is to ignore the advice explicitly given by the regulatory authorities in all three product licences" [EMEA, 2007].Within this same document, the EMEA requests that manufacturers submit a risk management plan, including detailed strategies for educating physicians regarding lack of interchangeability between BoNT-As.	about the characteristics of pharmacuetical products that can be included in guideline recommendations. The footnotes to the guideline recommendations follow a prescribed style that is intended to indicate whether drugs are being recommended outside licensed indications. NICE does not normally allow other characteristics (such as dosages) to be included in guideline recommendations. The recommendations are not allowed to refer to pharmaceutical products by their trade names, and in the case of botulinum toxin type A the developers are aware that there are several drugs with different properties and different licensed indications, some of which are suitable for use in children and young people with spasticity and some of which are not. The footnotes to the recommendations are intended to reflect this and to help healthcare professionals identify the relevant products for use in clinical practice
5.	SH	Allergan Ltd	5	Full	14	73	We agree with recommendation 73, namely *"Consider using ultrasound-guided injection or electrical muscular stimulation when injecting botulinum toxin type A into muscles".* This appears to be best practice in most Paediatric Services although this is not always employed with Orthopaedic Injectors. We note that Electrical	Thank you for your comment indicating agreement with the recommendation

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							Stimulation is invasive but used by fewer specialists now.	
6.	SH	Allergan Ltd	6	Full	23	14	With regard to the statement "Further research is needed to evaluate the effectiveness of botulinum toxin type A, particularly when used over long time periods (for example, 10 years)", we wanted to bring to the reviewers attention that there are some published long term data for Botox® in paediatric populations, ranging from a mean approximately 1.5 through 4.5 years treatment. In brief: In the paediatric population the long-term safety and efficacy of repeated intramuscular injection of BOTOX in juvenile cerebral palsy per licence was reported in 175 children receiving at least one year of therapy (a mean duration of exposure of 1.46 years per patient) [Koman LA, Brashear A, Rosenfeld S et al. Botulinum toxin type A neuromuscular blockade in the treatment of equines foot deformity in cerebral palsy: a multicenter, open-label clinical trial. Pediatrics 2001;108(5):1062-71]. Two additional reports using off label multiple dosing of BOTOX have described longer term safe and stable treatment follow-up in the paediatric	Thank you for your comment. The studies cited in the comment have been considered by the guideline developers. They are not randomised controlled trials and so they do not meet the inclusion criteria for the guideline review. As noted in the comment the studies present longer-term data with the use of botulinum toxin. They do not, however, extend to the 10 years considered important by the guideline developers and do not evaluate the effectiveness of botulinum toxin in comparison with other treatment options. The 'why this is important' section of this research recommendation has been revised to clarify that long-term comparative data are required

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							population of 4 years 6 months (range 1 year 8 months to 8 years 9 months) [Molenaers G, Schorkhuber V, Fagard K et al. Long-term use of botulinum toxin type A in children with cerebral palsy: treatment consistency. Eur J Paed Neurol 2009;13(5):421-9] and a mean period of 3.7 years [Tedroff K, Granath, F, Forssberg, H et al. Long-term effects of botulinum toxin A in children with cerebral palsy. Developmental Medicine & Child Neurology 2009, 51: 120–127].	
7.	SH	Allergan Ltd	7	Full	23	14	The recommendation 14 that there is limited evidence in terms of improving function suggests that only functional gain justify offering BoNT-A. This runs counter to elsewhere in the guidance (page 13 line 65 and 66) which stipulates that BoNT-A treatment should be considered where focal spasticity is: • impeding fine motor function • compromising care and hygiene • causing pain • impeding tolerance of other treatments, such as orthoses • causing concerns about appearance to the child or young person. The overall broader-ranging merits of BoNT-A should be reflected throughout the guidance.	This research recommendation has been reworded to clarify that goals other than those relating to function are important in evaluating the potential benefits of botulinum toxin type A
8.	SH	Allergan	8	Full	125	78	Stating that 'a clear functional goal is	This recommendation has been broadened to

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		Ltd					identified' is too limiting as previously stated; the reason for offering toxin may be to achieve functional gain, but also to improve hygiene, pain, tolerance of other therapies, and cosmetic appearance concerns of the child or young person.	cover any intended goal (not just a functional goal)
9.	SH	British Pain Society	1	Full	16	83	Informing patients or parents that test result might predict response to treatment is misleading as no literature supports this statement. Testing is a difficult issue and it should be explained more clearly that the role of ITB testing is a guide but may not adequately predict response.	Thank you for your comment. The developers have revised the wording of the recommendation to clarify how the test might help to indicate the response to treatment
10.	SH	British Pain Society	2	Full	18	96	We query the value of informing the patients' carers about correct pump settings as the patients' carers are unable to change the settings and as patients / carers receive a large amount of information related to pump implants this seems to be a case of too much information. We agree entirely that patients carers should be informed of the signs and symptoms of overdose / under dose, but information regarding pump settings and safe and effective pump management seem unnecessary.	Thank you for your comment. The developers agree with this concern in principle and considered carefully whether the volume of information suggested in the recommendation was appropriate. They concluded that providing information about pump settings should not be included in the recommendation but that information about safe and effective management of continuous pump-administered intrathecal baclofen should be included in case the family moved to another area and needed to communicate this information to other healthcare professionals
11.	SH	British Pain Society	3	Full	18	97	If the response from intrathecal baclofen is unsatisfactory is it not reasonable to investigate the catheter position locally, before referring on to the specialist centres, to establish urgency of referral?	The recommendation has been revised to make clear that continuous intrathecal baclofen is provided by the specialist neurosurgical centre working in collaboration with other members of the network team. The focus of the recommendation is now about removing the pump and alternative management options rather than the vague reference to specialist support

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12.	SH	British Pain Society	4	Full	18	101	We would prefer substituting: and delivery of baclofen at the desired dose to the intrathecal space has been confirmed rather than the infusion pump system has been confirmed to be working as the 2 are not always equivalent.	Thank you for your comment. This suggestion has been reflected in the revised recommendation
13.	SH	British Society of Rehabilitation Medicine	1	Full	9 52 56	31 31 21	There is not enough detail on how transition can be practically implemented, nor on the breadth of transition. We would like to see a recommendation for a phased and multidisciplinary transition to adult rehabilitation services. We would be happy to provide evidence for this approach.	The revised guideline includes a recommendation that highlights the central role of network teams in transition to prepare young people and their parents or carers for transfer to adult services
14.	SH	British Society of Rehabilitation Medicine	2	Full	General		It would be helpful to highlight the difference in organisation of services between children's and adult care – i.e. once transferred over to adult care, the equivalent of the multidisciplinary, coordinated approach as recommended for children's services in page 7 point 5, would be provided by an adult rehabilitation medicine or transition or spasticity service.	The revised guideline includes a recommendation that highlights the central role of network teams in transition to prepare young people and their parents or carers for transfer to adult services
15.	SH	Chartered Society of Physiotherapy	1	Full	27	7	This section would be strengthened by a reference for the definition used of spasticity. This paragraph does not mention hypertonia, nor give a definition of hypertonia, which is essential in any discussion about spasticity. It does not indicate that spasticity is just one contribution to hypertonia.	Thank you for your comment. The definitions of hypertonia and spasticity from Sanger 2003 have been added to the introduction to the full guideline

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							An eminent group from the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) recently spent a considerable amount of time defining, hypertonia, spasticity, dystonia, etc. There definitions are published and well accepted internationally. The group was lead by Terence Sanger. References: Sanger TD (2003) et al ' Classification and definition of disorders causing hypertonia in childhood', Pediatrics 111: E89-E97 Sanger TD (2006) et al ' Definition and Classification of negative motor signs in childhood', Pediatrics 118: 2159-2167 Sanger TD (2010) et al ' Definition and classification of hyperkinetic movements in childhood', Movement Disorders 25 (11) :1538-1549 There definitions are Hypertonia -'abnormally increased resistance to externally imposed movement about a joint' (Sanger et al 2003) Spasticity- hypertonia in which one or both of the following signs are present 1) Resistance to externally imposed movement increases with increasing speed of stretch and varies with the direction of joint movement And/or 2) Resistance to externally imposed movement rises rapidly above a	

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							threshold speed or joint angle.	
16.	SH	Chartered Society of Physiotherapy	2	Full	10	32	There are many other goals for lower limb orthotics that have been omitted. Many are written in International Standards Organisation (ISO) documents. These would include: Improve and normalise the kinematics and kinetics of standing, stepping, gait and transfers. Obtain normal order of the development of segment kinematics. Facilitate motor learning (there is some evidence for this). Obtain, maintain, as near normal muscle strength as possible Maximise use of muscle strength during gait cycle. Prevent, reduce, and improve bony alignment, bony structure, and bony growth. Add length to a segment or improve the length of a segment Cosmetics Pain reduction Reduce or redistribute the load on tissues to protect tissues or promote healing. I can send a large grid of possible goals based on World Health Organisation International Classification of Functioning and Disability if this would be useful.	Thank you for your comment. The developers acknowledge that there may be other goals for lower limb orthoses but did not think it was appropriate to add this level of detail to the recommendations. Instead they have sought to highlight the more common instances where specific types of othoses are or are not appropriate. They have also expanded other recommendations to emphasise that the network team should include an orthotist and that other professionals should seek expert advice from them if necessary to ensure that orthoses are appropriately designed for the individual child or young person and are sized and fitted correctly

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17.	SH	Chartered Society of Physiotherapy	3	Full	11	49	This is the wrong way round It should read: - a solid AFO if they have poor control of knee or hip extension - a hinged AFO if they have good control of knee or hip extension. Also there are other contraindications to hinged AFOs such that even if child had good hip and knee control a hinged should not be used. They are: - an unstable mid-foot, - short gastrocnemius: need 10 dorsiflexion with knee extended, - weak soleus and gastrocnemius, - sufficiently high tone that the child does not open the hinge.	Thank you for your comment. This error had been corrected The developers acknowledge that there may be other contraindications but do not think it is appropriate to add this level of detail to the recommendations. Instead they have sought to highlight the more common instances where specific types of othoses are or are not appropriate. They have also expanded other recommendations to emphasise that the network team should include an orthotist and that other professionals should seek expert advice from them if necessary to ensure that orthoses are appropriately designed for the individual child or young person and are sized and fitted correctly
18.	SH	Chartered Society of Physiotherapy	4	Full	12	52	Can this statement be re-worded? The amount of time that a child would need to wear any orthosis will depend on the short and long term goals for the intervention. Some children do not need to wear them this long to achieve the set goals. Some will need a lot more than 6 hours. I couldn't see where the evidence for this statement is derived; it is a commonly held belief based on one study of 8 CP children measuring soleus only (Tardieu C et al 1988 'For how long must soleus be stretched each day to prevent contracture' Dev Med Child	Thank you for your comment. The developers have revised the recommendation to clarify that orthoses designed to maintain stretch to prevent contractures are likely to be more effective if worn for longer periods of time (for example, at least 6 hours a day), whereas orthoses designed to support a specific function should be worn only when needed. The study cited in the comment could not be included because it is about sustained stretch preventing contracture rather than how sustained stretch is achieved and therefore does not meet the inclusion criteria for the review question. Because of the lack of direct evidence, the developers used their expertise and experience to form a consensus recommendation

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							Neurol 30: 3-10.)	
19.	SH	Chartered Society of Physiotherapy	5	Full	76	22	Disagree with this statement. A child can be fitted with an orthosis at any age.	This sentence has been deleted
20.	SH	College of Occupational Therapists	1	FULL	36	6	Whilst the full guidelines provide explanation of the summary term 'physical therapists', the College of Occupational Therapists (COT) do not support this terminology and are concerned that the term does not recognise the unique contribution made by occupational therapists and physiotherapists to the lives of children with spasticity. It undermines the 'non physical' elements of care provided by occupational therapists, who would also address the daily activities in which children should be participating, sensory factors, cognitive skills, social skills, visual perceptual abilities. COT calls for physiotherapy and occupational therapy to be described in full throughout the guidelines and NICE version.	The guideline developers acknowledged that most children and young people included in the research studies reviewed for the guideline would have received physiotherapy and/or occupational therapy. In publications reviewed for the guideline, it was not always clear exactly what form of therapy had been delivered, or what sort of healthcare professional had prescribed or administered the therapy. The developers agreed to use the term 'physical therapy' to encompass all those interventions that would normally be prescribed or performed by a physiotherapist or an occupational therapist. This is reflected in Section 3 of the full guideline and in all the guideline recommendations relating to physical therapy, which have been revised to emphasise the important role of occupational therapists within network teams
21.	SH	College of Occupational Therapists	2	Full	52	30	'...*have access to an occupational therapists'* implies that the Occupational Therapy is an adjunct service and not a core team member. Occupational Therapy should be listed on equal terms with the physiotherapist and the paediatrician. Children should 'have access to 'a speech and language therapist.	The developers acknowledge that the recommendation referred to in the comment was easily misunderstood and have deleted it. The evidence to recommendations has been updated accordingly

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22.	SH	College of Occupational Therapists	3	Full	54	KPI 2	Intervention from Occupational Therapists for those with upper limb spasticity is supported by evidence and welcomed by COT. However, this could be misconstrued that upper limb therapy is the predominant role and it would be useful to clarify that occupational therapists have a very active role with all children with spasticity including those with specifically upper limb spasticity. This recommendation does not acknowledge the holistic role of Occupational Therapists who would never treat a body part in isolation.	The developers acknowledge that the recommendation referred to in the comment was easily misunderstood and have deleted it. They have clarified the role of the occupational therapist throughout the guideline, for example, by specifying that an occupational therapist should be included in the network team
23.	SH	College of Occupational Therapists	4	FULL	52	28	COT disagrees with the premise that occupational therapists do not have a role with babies and young with spasticity and those younger children should always be referred to a physiotherapist first. Feeding, play sensory needs, postural management and ease of care fall into the domain and expertise of Occupational Therapists and there is always a risk with the 'refer on as necessary' approach implied here that these problems may be overlooked by other professionals or not prioritised in early therapy. The statement also overlooks the key role of occupational therapists in NICU and SCBU who will carry out neurological assessments and offer advice and intervention. It inevitably downgrades the occupational therapy role and contribution.	The developers acknowledge that the recommendations in this section lacked clarity. The developers have clarified the role of the occupational therapist throughout the guideline, for example, by specifying that an occupational therapist should be included in the network team, and have amended the key priority for implementation in the physical therapy section to make it clear that an occupational therapist should be involved in the assessment if necessary

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24.	SH	College of Occupational Therapists	5	NICE	13	1.2.8	COT believes that 'consider' is too loose a recommendation in relation to postural management which is an essential element of assessment and provision. 'Ensure inclusion' would be an alternative.	The term 'consider' is used in this context to reflect the strength of the evidence. The developers could not be sure that all children would benefit from postural management therefore they concluded that consider was the most appropriate term
25.	SH	College of Occupational Therapists	6	NICE	14	1.2.13	All children with spasticity are likely to have an element of functional difficulty and this should be stressed. The reference to maintenance activities is not very clear – is this referring to a school or home programme put in place by occupational therapists that train school staff and parents accordingly, monitor success and any problems as well as goals achievement? This programme could also address skill deficit areas such as sensory, cognitive perceptual, ocular motor.	This comment is no longer relevant as the recommendation has been reworded to emphasise its primary purpose, which is to incorporate physical therapy into daily activities
26.	SH	College of Occupational Therapists	7	FULL			COT welcomes the use of the ICF and the emphasis throughout the guideline on goal setting and functional improvement	Thank you for your comment
27.	SH	College of Occupational Therapists	8	FULL	36	6	Children with spasticity should receive physiotherapy *and* occupational therapy.	The guideline developers acknowledged that most children and young people included in the research studies reviewed for the guideline would have received physiotherapy and/or occupational therapy. In publications reviewed for the guideline, it was not always clear exactly what form of therapy had been delivered, or what sort of healthcare professional had prescribed or administered the therapy. The developers agreed to use the term 'physical therapy' to encompass

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								all those interventions that would normally be prescribed or performed by a physiotherapist or an occupational therapist. This is reflected in Section 3 of the full guideline and in all the guideline recommendations relating to physical therapy, which have been revised to emphasise the important role of occupational therapists within network teams
28.	SH	College of Occupational Therapists	9	FULL	50	5	Passive stretching evidence not found that this is effective, given the time spent on passive stretching by physiotherapists, occupational therapists and particularly parents. COT feels this requires greater prominence and emphasis in the final document.	The guideline developers did not recommend the use of short-term passive stretching and the evidence to recommendations section reflects the lack of evidence to support this intervention. It also emphasises that sustained passive stretching is effective, and this is reflected in the recommendations
29.	SH	College of Occupational Therapists	10	Full	55	KPI 17	The analysis of the typical components of physical therapy is welcome. However for many therapists, occupational and physio alike, the treatment includes Neuro Developmental Treatment. This approach is not directly referred to throughout the guideline, yet is very widely applied in practice. Given the prominence of the technique and the high cost of training in terms of time and money, it would be useful to have the efficacy considered. If the exclusion is due to a lack of good quality research it would be useful to say so explicitly.	Neurodevelopmental treatment was covered by the systematic searches undertaken for the review question on physical therapy but no relevant studies were identified for inclusion for that question. This has been clarified in the evidence statements in the full guideline
30.	SH	College of Occupational Therapists	11	Full	55	KPI 13	Children with spasticity access a number of specialist centres, some within NHS provision some outside it. For example Bobath regional centres do	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care

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							receive referrals for children with spasticity, requesting assessment or intervention. It would be useful to specify and clarify the differences.	by defining the network of care. In particular the recommendations in the principles of care section have been revised to make it explicit what expertise would be needed in the network team at a local or regional level. The recommendation referred to in the comment has been replaced with one that states that if a child or young person receives treatment for spasticity from healthcare professionals outside the network team, this should be planned and undertaken in discussion with the network team to ensure integrated care and effective subsequent management
31.	SH	College of Occupational Therapists	12	Full	49	8	There is a significant cost implication of delivering CIMT and bi manual therapy in context rather than in a clinic setting which could be acknowledged – travelling to settings significantly reduces the amount of children therapists can see in a day. COT appreciates that a cost benefit analysis may be difficult with lack of evidence and data but it would be useful if this was acknowledged.	Thank you for your comment. The view of the guideline developers was that delivering constraint-induced movement therapy and bimanual therapy in context is more effective than in a clinic setting. It would be difficult to develop a cost-benefit analysis without quantifying these benefits. The developers have added more consideration of cost effectiveness in the evidence to recommendations section
32.	SH	College of Occupational Therapists	13	Full	166	111	COT supports the need for specialist teams to confer with community therapy teams including occupational therapists, regarding surgery. However COT feels that it should be made clear that this communication should include a discussion regarding the goals of surgery or Botox and not solely relate to the therapy required afterwards. Community occupational therapists and physiotherapists may disagree with the proposed interventions based on their	Thank you for your comment. The developers share your desire to ensure joint decision making regarding appropriate management strategies and have revised the recommendations to encourage effective communication and integrated team working across the network of care supported by agreed care pathways

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							knowledge of the child in context have no or little contribution to the decision making process. The understanding of the child's functional abilities in context can inform the decision making process regarding such major interventions.	
33.	SH	D.M.Orthotics Ltd		Full	General		I had long discussions with the team before the group were setup on the options of orthotic intervention. I mentioned the effects on spasticity of dynamic Lycra orthoses otherwise known as Dynamic Elastomeric Fabric Orthoses. I know that they are widely used in the children's hospitals in the UK including Great Ormond street, Edinburgh and Birmingham Children's Hospital, however, there is no mention of them in the draft document despite published evidence. I have done my M.Phil on the use of DEFOs on children with diplegia and have a fairly full list of evidence. I enclose the list run on the BMJ hierarchy for your team to discuss. This method of orthotic intervention is also being used on children with dystonia and botox at Great Ormond Street.  Appendix A. Table 1 (Hierarchy of Evidenc	Thank you for your comment and for sending in your literature list. The guideline developers have examined the citations therein. The recent randomised controlled trial (Elliot 2011) is now included in the guideline. Whilst there were no other parallel randomised controlled trials to include in the review for orthoses, the developers agreed that included studies should be prospective, should include randomisation to the order of treatment received and should present data allowing comparison of different treatment groups or treatment periods. None of the other studies on your literature list would be included in this review for reasons of methodological quality and relevance (for example, the population, interventions or outcomes were not relevant to the guideline review as specified in the review protocol). Further, some of the references have been published only as conference abstracts and these reports are excluded from NCC-WCH guidelines

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34.	SH	Department of Health	1	Full	General		Overall this looks good, but there was discussion about the need to include management of associated dyskinesia (dystonia, athetosis and chorea). The final scope includes this statement : "Oral medications specifically baclofen, benzodiazepines (diazepam, nitrazepam, clonazepam), levodopa, tizanidine and dantrolene Levodopa can be used in dyskinetic patients. but I can't find it in the NICE guideline and am very concerned if management of dyskinesia has been omitted as my understanding is medicines are used to manage such movement disorders in cerebral palsy". I enclose what Baroness Thornton said in the House of Lords debate on cerebral palsy 4/11/09 5.40pm : *"My noble friend Lord MacDonald referred dystonia and medication. I want to put it o record that NICE has been commissioned produce guidance on the management of in children with cerebral palsy. That will in medicines effective in dystonia"*. Sorry if I missed a key section somewhere but if this is really missing from the guideline, it needs to be addressed in some way.	Thank you for your comment. The revised guideline includes a number of recommendations relating to drug treatment in children and young people with dystonia. Specifically, there is a recommendation to consider a trial of oral drug treatment (for example, with trihexyphenidyl, levodopa or baclofen) in children and young people in whom dystonia is considered to contribute significantly to problems with posture, function and pain. There is also a recommendation to consider a trial of botulinum toxin type A treatment in children and young people where focal dystonia is causing serious problems, such as postural or functional difficulties or pain

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35.	SH	HemiHelp	1	Nice	General		There is continuous reference to "multidisciplinary child development team" however parents have reported that in some areas there is no such thing. One parent reported the following "The OTs and physios worked in different NHS trusts until July last year. Orthotics do not have a paediatric strand and will be moving to a hospital away from Orthopaedic surgeons. The Child Development Centre isn't really what it says as it is mainly used by paediatricians and audiology, so there isn't really a multi-disciplinary team as such"	Thank you for your comment. The developers acknowledge that delivery of care varies from area to area and have revised the recommendations by replacing the local multidisciplinary child development team with a more flexible structure called the network team. Within this the recommendations continue to emphasise what expertise should be available to all children and young people at a local or regional level and the importance of this being implemented has been indicated by identifying it as a key priority for implementation
36.	SH	HemiHelp	2	Nice	10		Recommendation 1.1.1 This assumes that there is a multi-disciplinary team working together in every location. Our experience is that this is not always the case. Suggest you add another section saying that a multi-disciplinary team should exist. One parent commented "there needs to be greater coordination with physios and OT"	Thank you for your comment. The developers acknowledge that delivery of care varies from area to area and revised the recommendations by replacing the local multidisciplinary child development team with a more flexible structure called the network team. The revised guideline now also includes a recommendation that the network should exist as suggested in the comment. The importance of this being implemented with a view to increasing consistency and continuity of care across England and Wales has been indicated by identifying it as a key priority for implementation. The recommendations continue to emphasise what expertise should be available to all children and young people at a local or regional level, and the need for healthcare professionals in the network team to be experienced in the management of spasticity in this group. The recommendations also continue to emphasise the need for good communication between healthcare professionals

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								in the network
37.	SH	HemiHelp	3	Nice	10		Recommendation 1.1.2 Our experience is that the multidisciplinary centres do not exist in all areas. One parent commented "doesn't actually mean anything in my area. You need separate referrals to each and every healthcare professional required"	Thank you for your comment. The developers acknowledge that delivery of care varies from area to area and have revised the recommendations by replacing the local multidisciplinary child development team with a more flexible structure called the network team. Within this the recommendations continue to emphasise what expertise should be available to all children and young people at a local or regional level and the need for professionals in the network team to be experienced in the management of spasticity in this group. The importance of this being implemented with a view to increasing consistency and continuity of care across England and Wales has been indicated by identifying it as a key priority for implementation. The recommendations continue to emphasise the need for good communication between professionals in the network
38.	SH	HemiHelp	4	Nice	10		Recommendation 1.1.3 This is too vague, there is no mention of when or how frequently they will have access. One parent with a child with hemiplegia aged 8 commented "we haven't seen the OT for over 2 years"	The developers acknowledge that the recommendation referred to in the comment was easily misunderstood and have deleted it. They have clarified the role of the occupational therapist throughout the guideline, for example, by specifying that an occupational therapist should be included in the network team
39.	SH	HemiHelp	5	Nice	10		Recommendation 1.1.4 When asked about this one child (aged 7) commented "When doing football club my physio came to see my coach and gave him special exercises for me" Another (aged 9) commented "I feel that it's special to me. My goals are special to me such as trying to tie up my hair, use a knife and fork and open a packet	Thank you very much for your comment which the developers considered to support the recommendation that the management programme should be individualised, goal focused and developed and implemented in partnership with the child or young person and their parents or carers

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							of crisps"	
40.	SH	HemiHelp	6	Nice	10		Recommendation 1.1.5 When asked about this one child (aged 7) commented "There was no chance to talk about treatment choices or different results. There was nothing to read" Another (aged 11) said "No this did not happen". Another child (aged 9) commented "they speak to my mom about this and give her the information, because it is adult information. My mom finds it useful and they discuss what's best for me"	Thank you for your comment which the developers considered highlighted the fact that information is sometimes not shared with children and young people. The developers have now specified that the information and education materials should be age and developmentally appropriate
41.	SH	HemiHelp	7	Nice	12		Recommendation 1.2 Despite the title including Occupational Therapy, the text in 1.2 doesn't refer to OT. Maybe references in this section which currently say "physiotherapist" should say "therapist" or "physiotherapist and occupational therapist" to avoid confusion of the roles of the two professionals.	The developers acknowledge that the recommendations in this section lacked clarity. They have clarified the role of the occupational therapist throughout the guideline, for example, by specifying that an occupational therapist should be included in the network team, and have amended the key priority for implementation in the physical therapy section to make it clear that an occupational therapist should be involved in the assessment if necessary
42.	SH	HemiHelp	8	Nice	12		Recommendation 1.2 This whole section doesn't adequately reflect the holistic role of therapists. One parent commented "I personally take issue with referring to an OT as a 'physical therapist' as we certainly are not focused on the physical as we look holistically at the social, psychological, emotional, environmental, spiritual needs of the child which are all important in their development"	The guideline was limited by the scope which excluded the holistic management of spasticity and therefore has focussed on the role of physical therapists in relation to the specific interventions covered by the scope. The terminology physical therapist reflects the guideline developers' view and experience that the roles of the occupational therapist and physical therapist sometimes overlap. The developers have clarified the role of the occupational therapist throughout the guideline, for example, by specifying that an occupational therapist should be included in the network team, and have amended the key priority

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								for implementation in the physical therapy section to make it clear that an occupational therapist should be involved in the assessment if necessary
43.	SH	HemiHelp	9	Nice	12		Recommendation 1.2.3 When asked one child (aged 7) commented "They explain how it will help me build muscle in my leg" and another (aged 9) said "They talk about the exercises that are going on in school and how I am getting on with my assistant at school. They don't know if I am going to reach my goal, but they ask me often if I am trying to do the tasks at home. Yes, my physiotherapist has a program that I am supposed to follow at home and school which gives times per exercise. She does not mention that it may get in the way of other things."	Thank you for your comment which the developers considered to be supportive of the recommendation to take account of the child or young persons views
44.	SH	HemiHelp	10	Nice	15		Recommendation 1.2.17 When asked about this, one child (aged 7) said "physio is done at school with the teaching assistant as I have a 'Statement'. I don't want to do physio at home but I do lots of sports". Another child (aged 11) said "Yes, we talked about how my family can help, but they haven't asked what I think about the physio" Another child (aged 9) said "Yes. I have a program she has given me that outlines the things and exercises I am supposed to do at home and school. Yes she has asked me what I think and I think it is good for me to do at home, though I'd rather do the exercises with my physiotherapist in a session."	Thank you very much for these comments. The guideline developers think the recommendation emphasises the need to consider the abilities and wishes of the individual children and young people in relation to physical therapy

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45.	SH	HemiHelp	11	Nice	16		Recommendation 1.3.2 When asked about this, one child (aged 7) said "We kind of discussed this – about things getting better – but not the other stuff" Another child (aged 9) commented "yes they talk to my mom about that. There is a lot of talk about how I am getting on and what can be done to improve my hand and leg"	Thank you very much for your comment which the developers considered supported the recommendation that, when considering an orthosis, healthcare professionals should discuss with the child or young person and their parents or carers the balance of possible benefits against risks (such as cosmetic appearance, the possibility of discomfort or pressure sores, or of muscle wasting through lack of muscle use). The developers recognise the importance of discussing the benefits and risks of any treatment and have aimed to emphasise this throughout the recommendations
46.	SH	HemiHelp	12	Nice	16		Recommendation 1.3.6 This is vague - we would like to see firm timeframes. One parent commented "Orthosis appointments currently take 8 weeks and the orthosis itself is taking up to 3 months to arrive so 5 months from wanting an orthosis to getting it is too long". Suggested new wording: "A child with spasticity who requires an orthosis should have continuity of access to a suitable appliance. When continuity is not possible a child should wait no longer than 4 weeks without a device"	Thank you for your comment. The developers considered this issue carefully, but as it is to do with service delivery, were limited by the remit of the clinical guideline. The commissioners of the guideline (NICE) require that recommendations giving specific timings for treatments should be supported by strong evidence because they can have significant resource implications. The developers were aware that variation in waiting times exists in England and Wales but thought that it was unlikely that there would be direct evidence to support a specific recommendation. For this reason it was decided during the guideline scoping phase to prioritise questions about the effectiveness of treatments as these would be more likely to be answered by a systematic review of research evidence. Consequently the developers did not have sufficient information from the body of evidence that was considered for the guideline to make detailed recommendations on this topic
47.	SH	HemiHelp	13	Nice	16		Recommendation 1.3.7 There is no specific responsibility with	Thank you for your comment. The recommendations have been revised throughout

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							one profession for ensuring the orthosis fits well. One parent commented "clear responsibility as to who is responsible for the fit of the orthosis in my opinion it should be the physio"	to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
48.	SH	HemiHelp	14	Nice	21		Recommendation 1.5.8 These two treatments should be delivered as one interlinked package, so that when booking the slot for Botox, the hospital also books an orthotist slot at the correct post op interval. This would avoid the child waiting an unreasonable time and the Botox wearing off before the new splint can do its work. One parent commented "my son had serial casting then waited 17 weeks for an orthotic assessment, by which point his foot was worse than it had started as he had been so long without orthotic support"	The developers acknowledge that the draft recommendations about using botulinum toxin together with orthoses or serial casting lacked clarity and have made several changes throughout the guideline to resolve this. They have also emphasised that children and young people who receive treatment with botulinum toxin type A should be offered timely access to orthotic services and they have included a new recommendation stating that agreed care pathways within the network should aim to minimise delays in supplying an orthosis
49.	SH	HemiHelp	15	Nice	21		Recommendation 1.5.8 There is no mention of serial casting as a treatment option. One parent commented "my son had serial casting without Botox (due to severe allergies and a previous allergic reaction to anaesthetic). I understand that this is the old fashioned way of doing it however there is no mention of this treatment in the guidelines so I'm concerned in case this potentially useful treatment is eliminated from practice. I don't know	Thank you for your comment which highlighted an omission in the recommendations. The developers agree that serial casting without botulinum toxin can be helpful for some children and young people with spasticity in the context of postural management and have amended the recommendations to reflect this

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							what the research says – perhaps its ineffective – but I cant say as the lack of an orthosis compromised the outcome for D. I personally am dubious about putting a toxin into my child and I think families would like to know that serial casting is a treatment in its own right. Having the guidelines say something on the comparable effectiveness of Botox plus casting vs casting alone would be useful. Or even something like "serial casting without Botox is ineffective – do not use" would at least clear up the situation"	
50.	SH	HemiHelp	16	Nice	24		Recommendation 1.5.13 Agree that it is important that these things are happening but feedback shows that it is not always at the moment. When asked about this, one child (aged 9) said "They have told me that I may not be able to swim backstroke after the Botox, but that this would wear off in a few months. There was nothing 'serious' that was mentioned."	Thank you very much for your comment which the developers consider to be supportive of the guidance as it highlights the need for a specific recommendation to discuss the rare but serious complications of botulinum toxin type A treatment so that children and young people and their parents or carers can make informed decisions about this treatment and recognise the complications should they occur
51.	SH	HemiHelp	17	Nice	32		Recommendation 1.7.8 Although these things may be discussed, there isn't always an element of choice. One child (aged 7) commented "Yes he explained what would happen, I would have a cast and have it taken off at London. I always had to go to London to check my leg was ok, they repaired my cast at London. It's a long way to go (from Dover)"	Thank you for your comment which the developers considered to support the recommendation that the network team should discuss and agree with the child or young person and their parents or carers a rehabilitation programme and how and where it will be delivered
52.	SH	HemiHelp	18	Nice	32		Recommendation 1.7.8	Thank you for your comment. The developers

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							This principle is right, but the programme needs to ALSO be agreed and planned with rehab professionals so the child's needs can be met in a timely and planned way. It may be agreed that a new orthosis and physiotherapy is needed immediately post-operation but this is no help if the child goes onto a 12-week waiting list for these services.	have changed the terminology around delivery of care to define a network of care that incorporates local and regional services. They also state that the network should use agreed care pathways and these would include agreed pathways for rehabilitation. In recommending the use of such care pathways, the developers recognised that this would not only identify key team members and their roles, but would make clear key links and lines of communication and this would facilitate timely delivery of care
53.	SH	HemiHelp	19	Nice	General		There are no references to specific waiting times in these guidelines. The wait for physiotherapy and OT appointments, orthoses and for diagnosis can be 6 months or longer. We would like to see some guidance on this so that the experience is less varied and that shorter waiting times are aimed for. One parent commented "we are currently waiting 6 months for a physio appointment and we haven't seen the OT for over 2 years… there is a real necessity for early diagnosis and intervention (it was a battle to get our child diagnosed as the GP said he was just lazy!!)" and "Initial waiting lists need to be reduced (it was 4 months to get to see the consultant, which we then pestered down to 4 weeks and I believe that those early months are critical to open new pathways)"	Thank you for your comment. The developers considered this issue carefully, but as it is to do with service delivery, were limited by the remit of the clinical guideline. The commissioners of the guideline (NICE) require that recommendations giving specific timings for treatments should be supported by strong evidence because they can have significant resource implications. The developers were aware that variation in waiting times exists in England and Wales but thought that it was unlikely that there would be direct evidence to support a specific recommendation. For this reason it was decided during the guideline scoping phase to prioritise questions about the effectiveness of treatments as these would be more likely to be answered by a systematic review of research evidence. Consequently the developers did not have sufficient information from the body of evidence that was considered for the guideline to make detailed recommendations on this topic. However, in acknowledgement of their clinical consensus that beneficial treatments should be accessible to all children and young people, and that delay in treatments can result in unnecessary harm, the developers have

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								emphasised in the first recommendation (a key priority for implementation) that children and young people with spasticity should have access to a network of care that uses agreed care pathways supported by effective communication and integrated team working. Furthermore, in specific circumstances where the developers recognised timing to be a particular issue (for example, in the provision of orthoses) they have provided guidance stating that agreed care pathways within the network should aim to minimise delays. Throughout the recommendations the developers have also emphasised the need to consider timing through the use of words and phrases such as 'promptly' and 'timely'
54.	SH	HemiHelp	20	Nice	General		One ongoing theme in the feedback we received from parents about these guidelines was the inconsistency of service integration. There seem to be some areas of very good practice and other areas where this is not happening at all. We feel that resolving this is key but as the guidelines are written currently you are assuming that coordination of professionals is happening smoothly already. Our experience shows that it is not.	Thank you for your comment. The developers acknowledge that delivery of care varies from area to area and have revised the recommendations by replacing the local multidisciplinary child development team with a more flexible structure called the network team. Within this the recommendations continue to emphasise what expertise should be available to all children and young people at a local or regional level and the need for professionals in the network team to be experienced in the management of spasticity in this group. The importance of this being implemented with a view to increasing consistency and continuity of care across England and Wales has been indicated by identifying it as a key priority for implementation
55.	SH	International Society for Prosthetics and	1	Full	6	13	Add Orthotist as a member of the multidisciplinary team who should be involved	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care

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		Orthotics National Members Society UK (ISPO UKNMS)						by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
56.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	2	Full	6		Recommendation 2. The multidisciplinary team should include an experienced paediatric orthotist	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
57.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	3	Full	5	10	There are several definitions of spasticity with Potentially differing implications. May I suggest the intended definition is stated at the outset of the document	Thank you for your comment. The definitions of hypertonia and spasticity from Sanger 2003 have been added to the introduction to the full guideline
58.	SH	International Society for Prosthetics and Orthotics National Members Society UK	3	Full	8	14	Add orthotist	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also

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		(ISPO UKNMS)						revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
59.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	4	Full	8	16	Consult with the orthotist to advise on use of orthoses to compliment programmes	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
60.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	5	Full	9	27	…Use of serial casting or suitable orthoses….	The developers acknowledge that the draft recommendations about using botulinum toxin together with orthoses or serial casting lacked clarity and have made several changes throughout the guideline to resolve this. The recommendation referred to in the comment has been merged with other recommendations on this topic in the botulinum toxin section to make it clearer when either an orthosis or serial casting should be considered
61.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	6	Full	9	29	Involve the orthotist to reassess fit, function and appropriateness of any orthoses	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
62.	SH	Internationa	7	Full	10	32	The orthotist shall as part of the	Thank you for your comment. The

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		l Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)					multidisciplinary team consider…..	recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
63.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	8	Full	10	36	An orthotist should be involved in advising and providing the most appropriate orthosis used.	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
64.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	9	Full	10	38	Are optimised for gait and function	The developers considered that this would be covered by the bullet that states that orthoses should be appropriate to intended treatment goals
65.	SH	International Society for Prosthetics and Orthotics	10	Full	11	42	But be aware that some orthoses may optimise appropriate muscle recruitment in gait and function	The developers agree that some orthoses may be helpful for the circumstances described in the comment but the recommendation cannot cover every eventuality. The examples given are of common concerns, but are not a comprehensive

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		National Members Society UK (ISPO UKNMS)						list of risks and benefits
66.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	11	Full	11	43	Orthoses used in managing spasticity need to be sufficiently rigid to maintain a correction which may result in high corrective forces. It is important this is done and well managed by a paediatric orthotist	Thank you for your comment. The developers agree with this point which highlighted a lack of clarity in the draft recommendation. The recommendation has been reworded to make it clearer that it is about monitoring whether the rigid orthosis is causing difficulties, rather than suggesting that rigid orthoses should not be used in this group. The recommendations now also state that the network team should include an orthotist and that other professionals should seek expert advice from them if necessary
67.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	12	Full	11	46	Prior to using an orthosis overnight it is important that it has been established that the orthosis can be tolerated and skin integrity is not compromised by use over that period	Thank you for your comment. The developers agree with this and have expanded the recommendation to make clear the need to check that the orthosis can be tolerated and does not cause injury. The developers have also now created a separate recommendation to clarify the use of orthoses to control two adjacent joints
68.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	13	Full	11	49	Many factors influence optimum prescription between a hinged or fixed ankle foot orthosis. It is essential the orthotist is involved as part of the multi-disciplinary team in making this decision	Thank you for your comment. The developers agree with this point and have expanded the recommendations to emphasise that the network team should include an orthotist and that other professionals should seek expert advice from them if necessary to ensure that orthoses are appropriately designed for the individual child or young person and are sized and fitted correctly

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69.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	14	Full	11	50	However be aware that supra-malleoli orthoses do not maintain range at the ankle if loss of dorsiflexion range is likely	This recommendation has been deleted
70.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	15	Full	12	56	For those with difficulty in sitting. Sitting braces as well as spinal orthoses may be appropriate	In this guideline, the available evidence for hip and trunk orthoses, including spinal braces, was reviewed. No specific evidence relating to 'sitting braces' was identified for inclusion
71.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	16	Full	14	74	Ensure ther is good co-ordination between appropriate orthotic provision to optimise the opportunity botulinum therapy offers	The developers acknowledge that the draft recommendations about using botulinum toxin and orthoses together lacked clarity and have made several changes throughout the guideline to resolve this. In particular the they have recommended that orthoses should be considered after treatment with botulinum toxin to enhance stretching of the temporarily weakened muscle and enable the child or young person to practice functional skills. They have also emphasised that children and young people who receive treatment with botulinum toxin type A are offered timely access to orthotic services and they have included a new recommendation which states that agreed care pathways within the network should aim to minimise delays in supplying an orthosis

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72.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	17	Full	29	39	And orthotic management	The importance of orthoses has been emphasised in the revised guideline
73.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	1	Full				No response required from the guideline developers
74.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	19	Full	58	11	An orthotist is an allied health professional specifically trained in the understanding and provision of orthoses and should be an integral part of the multi-disciplinary team	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
75.	SH	International Society for Prosthetics and Orthotics	20	Full	58	14	Provision of any orthosis should involve the expertise of the orthotist to fully understand the options and consequences of intervention	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of

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		National Members Society UK (ISPO UKNMS)						having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
76.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	21	Full	58	16	Orthoses may also maintain or improve joint range, function and may help with the presentation of spasticity but may have some disadvantages	Thank you for this comment. The developers agree and the introduction highlights the potential value of orthoses in improving function (which could include improvement in joint range) and acknowledges the possible disadvantages
77.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	22	Full	58	31	Solid ankle foot orthoses help with swing phase but are more specifically used to control stance phase by aligning the tibia over the foot to control excessive knee flexion or hyper-extension	The guideline developers have reordered the sequence here to further emphasise the role in controlling stance
78.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	23	Full	53	15	And orthotist with paediatric experience	The developers have revised the recommendations to make it clear that an orthotist would be part of the network team and that all members of the network team will have experience in the care of children and young people with spasticity

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79.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	24	Full	54	2	And orthotist	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
80.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	25	Full	58	35	A posterior leaf spring AFO does not prevent knee extension	Thank you for your comment. The reference to preventing knee extension has been removed
81.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	26	Full	59	8	Remove hold the hip in a neutral position and replace with limit movement to a more functional range	This change has been made
82.	SH	International Society for Prosthetics and Orthotics	27	Full	78	26	In very young children learning to stand, careful assessment is essential. Whilst rigid AFOs may in some cases make it more difficult. In some children, in others, lack of control may severely limit	This comment is no longer relevant as the associated recommendation has been deleted

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		National Members Society UK (ISPO UKNMS)					there ability to stand and develop function and appropriate use of rigid AFOs can be of considerable benefit	
83.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	28	Full	78	24	However an initial period of close monitoring short period use is essential to get the child accustomed to the orthosis and check skin and pressure tolerance for long term use	Thank you for your comment. This has been reflected in the evidence to recommendations section as suggested to support the recommendations that orthoses should be reviewed for adverse effects at every contact and checked that they are tolerated and do not cause injury before they are used overnight
84.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	29	Full	78	32	Replace weakness with tone	This change has been made
85.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	30	Full	79	26	Replace custom made with any orthosis	The recommendations no longer refer to custom-made orthoses, and the corresponding reference to custom-made orthoses in the evidence to recommendations section has been deleted
86.	SH	Internationa	31	Full	80	32	Improve quality of gait to prevent longer	The developers considered that the existing

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		l Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)					term problems	bullets about walking efficiency and preventing or slowing specific consequences already covered this point
87.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	32	Full	80	32	An orthotist should take the lead in advising most appropriate intervention and applying that intervention in the most appropriate manner considering function, comfort, compliance and cosmesis to meet the agreed goals of treatment and management in the most acceptable way for the child and carers	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
88.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	33	Full	81	49	Wrong way around. A solid AFO is indicated for poor knee control and a hinged one when knee control is greater however several other factors require consideration and this judgement should be made with the orthotist	Thank you for your comment. This error had been corrected. The recommendations now also state that the network team should include an orthotist and that other professionals should seek expert advice from them if necessary
89.	SH	International Society for Prosthetics and Orthotics National	34	Full	81	50	Spra malleolar AFOs and rigid AFOs do completely different things. If range needs to be maintained then rigid AFOs will be required	This recommendation has been deleted

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
		Members Society UK (ISPO UKNMS)						
90.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	35	Full	81	51	Orthoses are important for the non ambulant to prevent further contracture and deformity	The comment is true but the recommendation already covers this by stating that a goal would be to improve foot position. The recommendation does not attempt to list the causes of poor foot position
91.	SH	International Society for Prosthetics and Orthotics National Members Society UK (ISPO UKNMS)	36	Full	80	33	Hinged or solid AFOs must be appropriately tuned by the orthotists and physiotherapist to optimise alignment at the knees and hips and parents and carers must be advised on the impact of heel height and footwear design on the effect of these orthoses	Thank you for your comment. The importance of having an orthotist within the network team has been emphasised in the revised recommendations. The guideline developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought The developers agree that the specific point raised in the comment is important and it should be communicated to parents and carers. The developers would expect healthcare professionals to address such matters as advised in the recommendation about how to apply and wear orthoses
92.	SH	International Society for Prosthetics and Orthotics National Members	37	Full	81	51	Orthoses are important for the non ambulant to prevent further contracture and deformity	The comment is true, but the recommendation covers this by stating that a goal would be to improve foot position. The recommendation does not attempt to list the causes of poor foot position

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		Society UK (ISPO UKNMS)						
93.	SH	Medtronic Ltd	1	Full	General		Medtronic thanks NICE for the opportunity to comment, and we welcome the recommendations as put forward in this Guideline and have no further comments to add.	Thank you for your comment
94.	SH	Neonatal and Paediatric Pharmacists Group (NPPG)	1	Full	General		NPPG supports the recommendations in this Guideline.	Thank you for your comment
95.	SH	Neonatal and Paediatric Pharmacists Group (NPPG)	2	Full	91	36	In view of the lack of studies identified for a number of the oral drugs referred to, in particular clonidine, NPPG considers that these could have been identified as potential areas for further research.	The guideline developers agreed not to make an additional research recommendation relating to oral drugs in general, or clonidine in particular, because such a recommendation would be of relatively low priority and would dilute the impact of the existing research recommendations relating to oral baclofen
96.	SH	NETSCC – Referee 1	1	Full	General		1.1 Are there any important ways in which the work has not fulfilled the declared intentions of the NICE guideline (compared to its scope – attached) There has been a clear attempt to identify all the relevant evidence in order to answer the identified questions – albeit for much of the scope, there is little published evidence.	Thank you for your comment
97.	SH	NETSCC – Referee 1	2	Full	General		2.1 Please comment on the validity of the work i.e. the quality of the methods and their application (the methods should comply with NICE's Guidelines Manual available at	Thank you for your comment. We have addressed your specific points below

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							http://www.nice.org.uk/page.aspx?o=guidelinesmanual). The general methods seem to have followed the guidance. Some specific points are listed below.	
98.	SH	NETSCC – Referee 1	3	Full	32	42-43	It is perhaps a little surprising that given the lack of identified evidence, attempts were not made to look for unpublished studies, etc, nor any handsearching of key journals undertaken.	The guideline developers followed the established NICE guideline development process, which does not include searching the grey literature or handsearching of key journals
99.	SH	NETSCC – Referee 1	4	Full	127	24-	In text, states there were 9 publications relevant to the question, but in Appendix G (p292) says there were 10 papers included?	This typo has been corrected
100.	SH	NETSCC – Referee 1	5	Full	General		2.2 Please comment on the health economics and/or statistical issues depending on your area of expertise. Blinding – this should be clarified briefly perhaps in description of each included study.	Blinding was one of the issues addressed systematically as part of the quality assessment conducted for each included study. Where lack of blinding was thought likely to have influenced the results reported in a particular study (or where the extent to which study participants, investigators, etc were blinded) this is noted in the quality assessment under limitations (see Appendix K)
101.	SH	NETSCC – Referee 1	6	Full	General		Care needs to be taken with the interpretation of directions of effects, as this is sometimes unclear. In particular, care needs to be taken when between-group comparisons have been made in terms of change scores, as currently some of the statements are not correct.	Thank you for your comment. In response to this general comment and other specific comments the guideline developers have reviewed the style of the evidence statements. Relevant evidence statements have been amended to indicate the direction of treatment effects and to clarify where final score comparisons and change score comparisons were reported in the included studies
102.	SH	NETSCC – Referee 1	7	Full	General		p-values of 0.0000 should be replaced with p<0.0001, etc, throughout.	This change has been made
103.	SH	NETSCC – Referee 1	8	Full	General		Need consistency of use of terminology when describing study designs.	The description of study designs is now consistent throughout the guideline. The studies in Chapter 5

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
								that were described as randomised comparative studies in the draft guideline have been re-classified as cross-over randomised controlled trials
104.	SH	NETSCC – Referee 1	9	Full	34	19	When using meta-analyses, were fixed or random effects models used? I could not identify this anywhere.	The meta-analyses presented in Tables 7.1, 7.3 and 7.5 were reported in a Cochrane review (Hoare 2010). Some of these meta-analyses were conducted using a fixed effect model and others were conducted using a random effects model. The guideline developers reported the results from the Hoare 2010 meta-analyses based on the fixed or random effects models used in that review, and where statistically significant heterogeneity was identified, the guideline evidence statements reported findings from the individual studies that contributed to the meta-analysis The meta-analyses presented in Tables 7.5 and 10.2 were conducted specifically for the guideline. By default, a fixed effect model was used, and where statistically significant heterogeneity was identified a random effects model was used This has now been clarified in Section 3.1 of the full guideline
105.	SH	NETSCC – Referee 1	10	Full	34	19	Unfortunately no forest plots were included in this draft.	The revised guideline includes forest plots for meta-analyses conducted specifically for the guideline (Appendix J)
106.	SH	NETSCC – Referee 1	11	Full	38		In the evidence tables, need to explain what "MD" is.	The abbreviations used in the tables were not included in the draft guideline but they are included in the revised guideline, and thus MD is now defined In response to general and specific comments

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							Also need to state somewhere clearly the DIRECTION of the differences given (presumably for Active vs Control, but this is not clear), throughout the report. It would be helpful to bolden the statistically significant results/confidence intervals.	made by stakeholders, the guideline developers reviewed the style of the evidence statements. Evidence statements have been amended to indicate the direction of treatment effect and to clarify where final score comparisons and change score comparisons were reported. This has been performed as part of an accuracy check in response to specific comments made regarding evidence statements Statistically significant findings have not been formatted in bold type because this would not conform to the full guideline template used by the NCC-WCH. This comment has, however, been noted for further development of the full guideline template
107.	SH	NETSCC – Referee 1	12	Full	39 46		No or incomplete 'results' are given for 39 of the comparisons in the main report and so it is difficult to establish whether the resulting evidence statements are valid or not. Some further comments are given as footnotes in Appendix K but this has made it difficult to try and pull the evidence together. It is particularly surprising that where the outcome measure is binary, no attempt has been made to provide the appropriate confidence intervals, which are after all easily calculated from summary data.	The footnotes containing effect sizes etc were omitted from the draft guideline in error and they have been reinstated in the revised guideline

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
108.	SH	NETSCC – Referee 1	13	Full	43	Dodd 2003, AEs	Repetition of 3/11.	This typo has been corrected
109.	SH	NETSCC – Referee 1	14	Full	43 44		Is the walking speed outcome table duplicated on p44? The headers are slightly different "optimisation of movement" vs "optimisation of function" but the outcome measures labels and data are the same?	Thank you for your comment. Walking outcomes are considered to be an aspect of function, rather than movement (around the joint). The previous duplication of data in relation to this has been corrected in the revised guideline
110.	SH	NETSCC – Referee 1	15	Full	45		Evidence Statements – see comment above.	Thank you for your comments. The guideline developers appreciate that presentational issues are important and all the stakeholder comments will help to improve readability of future guidelines. Given the timescale for responding to the stakeholder comments, the developers prioritised issues of accuracy in relation to the clinical and cost effectiveness evidence alongside issues that directly affect interpretation of evidence to inform recommendations. Where possible the developers have also improved the general clarity and presentation of the text. Thus the accuracy of all the evidence statements has been reviewed and corrections for accuracy have been made where appropriate, particularly in relation to specific comments made by stakeholders. Restyling the evidence statements has, however, been deprioritised because it would not change the recommendations. The comments regarding use of the 'linking evidence to recommendations' format and for reporting effect sizes will inform development of future guidelines
111.	SH	NETSCC – Referee 1	16	Full	45	20	This outcome is rated as MODERATE in summary tables	Thank you for your comment, A correction to the evidence statement has been made, as suggested, for accuracy and to Footnote 1 of

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
								Table K 4.2 for clarity
112.	SH	NETSCC – Referee 1	17	Full	45	23-30	Statement on Aarts study on Goal assessment t-scores and COPM outcomes do not tie in with p-values given in footnotes in Appendix K. At 8 weeks, the 4-wk and 8-wk groups did better than control (HIGH) in terms of GAS T score, but only the 8-wk group did better than control in terms of COPM at 8 weeks.	Thank you for your comment which we believe relates to outcomes from Novak 2009. The following amendments for accuracy have been made in response to the concern expressed in the comment. • Footnotes 6-13 in Appendix K, Table K.4.2 relating to the outcomes GAS-T and COPM-P and footnotes 1-5 in Table K.4.3 for COPM–S outcomes have been amended. • Footnotes in corresponding full guideline tables have also been amended. • Evidence statements for corresponding study outcomes have been amended
113.	SH	NETSCC – Referee 1	18	Full	46	16-19	The first statement seems incorrect – according to the Appendix, the p-value for comparing groups at 6 weeks for GMFM88 goal dimension was 0.02, i.e. statistically significant. The authors may also want to make comment somewhere on the use of 1-tailed hypothesis tests. With this outcome and many others, the authors need to consider that the comparison has been made in terms of the CHANGE from baseline, and the statements need to reflect this (throughout the document).	Thank you for your comment. The publication (Liao 2007) states that the calculations were based on a 1-tailed significance level of 0.05 but did not state the expected treatment effect direction. They did not state for which outcome their study was powered. The developers agree with the specific concern expressed in the comment that this may be a weaker use of hypothesis testing (especially with such small numbers of participants recruited to the study) in order to generate significant findings which might not remain significant with 2-tailed testing. The p-value in the footnote to which the comment refers pertains to analysis of covariance on the post-strengthening training scores and not to the change score estimated by the guideline developers from the data reported. There was an additional error (from dropped superscript footnotes) in the presentation of the treatment

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								group sizes for this outcome in Table 4.5. The developers hope that amendments to footnotes 5 and 32 in Table K.4.5 (for the outcome walking speed (m/minute) at 6 weeks (change from baseline), and the corresponding evidence statements for these outcomes have addressed the concern regarding clarity of the presentation of these mean change results
114.	SH	NETSCC – Referee 1	19	Full	46	19-21	This study (Lee?) is marked as MODERATE in the summary table.	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile as suggested
115.	SH	NETSCC – Referee 1	20	Full	46	21-24	This study (Dodd?) is marked as MODERATE in the summary table.	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile from low to moderate as suggested
116.	SH	NETSCC – Referee 1	21	Full	46	24-26	No evidence in summary table or appendix to support "no statistically significant difference" in function/GMFM E-walking, running and jumping) at 18 weeks and unsure which of Lee or Dodd this refers to. Both Lee and Dodd are marked as MODERATE in the summary table for this outcome.	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile as suggested
117.	SH	NETSCC – Referee 1	22	Full	46	26-29	This study (Dodd?) is marked as MODERATE in the summary table.	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile as suggested
118.	SH	NETSCC – Referee 1	23	Full	46	29-31	This study (Dodd?) is marked as MODERATE in the summary table.	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile as suggested
119.	SH	NETSCC – Referee 1	24	Full	46	32-34	No evidence in summary table or appendix to support "no statistically significant difference" in GMFM total at 6 weeks. This outcome (Lee?) is marked	Thank you for your comment. The evidence statement has been amended for clarity to address this concern and for the evidence statement to correspond with the evidence profile

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
							as MODERATE in the summary table.	as suggested
120.	SH	NETSCC – Referee 1	25	Full	46	34-36	No evidence in summary table or appendix to support "no statistically significant difference" in GMFM total at 6 weeks. This outcome (Dodd?) is marked as MODERATE in the summary table.	Thank you for your comment. The evidence statement has been amended for clarity to address this concern and for the evidence statement to correspond with the evidence profile as suggested
121.	SH	NETSCC – Referee 1	26	Full	46	42-44	No evidence in summary table or appendix to support "no statistically significant difference" in walking speed at 6 weeks (?Dodd).	Thank you for your comment. The evidence statement has been amended for clarity to address this concern
122.	SH	NETSCC – Referee 1	27	Full	46	44-47	No evidence in summary table or appendix to support "no statistically significant difference" in walking speed at 8 weeks (?Unger).	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile as suggested
123.	SH	NETSCC – Referee 1	28	Full	46	49-52	No evidence in summary table or appendix to support "no statistically significant difference" in walking speed at 18 weeks (?Dodd).	Thank you for your comment. The evidence statement has been amended to address this concern
124.	SH	NETSCC – Referee 1	29	Full	46	52-54	No evidence in summary table or appendix to support "no statistically significant difference" in timed stair test at 18 weeks (?Dodd).	Thank you for your comment. The evidence statement has been amended for clarity to address this concern and for the evidence statement to correspond with the evidence profile as suggested
125.	SH	NETSCC – Referee 1	30	Full	47	4	This outcome is marked as LOW in the summary table.	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile as suggested
126.	SH	NETSCC – Referee 1	31	Full	47	7	This outcome is marked as LOW in the summary table.	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile as suggested
127.	SH	NETSCC – Referee 1	32	Full	47	10-17	Surprising that the AE data on falls (20.6%) is not mentioned here?	Thank you for your comment. The evidence statement has been amended to correspond with

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								this outcome, as suggested, and for others in the evidence profile
128.	SH	NETSCC – Referee 1	33	Full	47	47-49	Data on AE of need for changed cast within 48 hours is not in table; what was the rate in the delayed group?	Thank you for your comment. The evidence statement has been amended to address this concern
129.	SH	NETSCC – Referee 1	34	Full	59	22-34	Lack of details given about the studies. It looks from the tables as if a number of the studies were of a "matched-pair" design, but this is not detailed. If this is the case, were the statistical analyses undertaken appropriate to the study design?	Further detail has been added to the description of included studies section. The publications included in this chapter provided few details regarding the statistical analyses undertaken in the six cross-over randomised controlled trials that examined different types of ankle-foot orthosis. Children and young people were randomised to order of treatment and group (ensemble) means were calculated. This has been made clearer in the evidence statements
130.	SH	NETSCC – Referee 1	35	Full	73	33	This outcome is marked as LOW in the summary table.	Thank you for your comment. The evidence statement has been amended from moderate to low to correspond with the evidence profile
131.	SH	NETSCC – Referee 1	36	Full	74	48-50	The subgroup analysis is not included in the summary table so unable to interpret this.	Thank you for your comment. This was an error of presentation and has been removed. No subgroup analysis for participants with diplegia was reported
132.	SH	NETSCC – Referee 1	37	Full	77	49	Do the authors mean "The order of treatment was randomly allocated to children"?	Thank you for your comment. The suggested amendment has been made
133.	SH	NETSCC – Referee 1	38	Full	83	32-39	Lack of details given about the studies. Seems from later text that at least one included study was of cross-over design. It would also be helpful to know which studies used no treatment and which used a placebo.	The description of included studies sections in Chapters 4 to 10 have been standardised to provide an outline of the study design, intervention, comparator (where applicable) and population (including the participants' age ranges and medical conditions) for each included study. A more detailed description of each included study is provided in the evidence tables (Appendix I)

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134.	SH	NETSCC – Referee 1	39	Full	84 89	Tables	Previous chapters included e.g. (5.4 higher to 6.5 higher) for clarity of interpreting CIs and I would suggest this should be adopted and made consistent throughout all the chapters.	Where possible these data have already been inserted, but they are reported only where the study results were suitable for processing in RevMan 5 software. The comment has been noted for the development of future guidelines
135.	SH	NETSCC – Referee 1	40	Full	89	9-11	I suspect from the Appendix that a three way comparisons between placebo, half-dose and full-dose diazepam might have been made using 1-way ANOVA – were any follow-up comparisons given to actually show statistically significant differences between half-dose and placebo and full-dose and placebo?	Thank you for your comment. These results are from two reports (Mathew 2005a; Mathew 2005b) relating to a single randomised controlled trial. Mathew 2005b reports only that 1-way analysis of variance was used in statistical analysis. Mathew 2005a does not report any statistical methods. Therefore the results have been presented in the guideline just as they were reported in the publications from which they were extracted, and no further information is available
136.	SH	NETSCC – Referee 1	41	Full	89 91		Statements should also refer to the time points at which the outcomes were measured.	Thank you for your comment. The outcome assessment time points have been added to the evidence statements where available
137.	SH	NETSCC – Referee 1	42	Full	86	2	Should this read "No studies reported outcomes relevant to pain OR QUALITY OF LIFE"?	Thank you for your comment. The suggested amendment has been made
138.	SH	NETSCC – Referee 1	43	Full	90	34-36	The summary table shows no evidence of a significant difference in rates of Drowsiness (CI 0.53 to 4.26 for RR). This outcome is marked as MODERATE in the summary table.	Thank you for your comment. This was an error of presentation in the evidence profile of the full guideline. This has been amended to correspond with the evidence profile in the appendices document. This evidence statement has not been amended, but now corresponds to the data presented
139.	SH	NETSCC – Referee 1	44	Full	90	36-39	The summary table does not seem to include the data referred to here.	Thank you for your comment. This was an error of presentation and the summary evidence profile in the full guideline has been amended to correspond with the evidence profile in the appendices document

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140.	SH	NETSCC – Referee 1	45	Full	90	40-45	Either the data in the summary table is wrong or the rates given in the text are wrong, for both Sheinberg parental reports.	Thank you for your comment. This was an error of presentation (dropped superscript footnotes) and has been amended in the evidence profiles of the appendices and full guideline document
141.	SH	NETSCC – Referee 1	46	Full	91	16	This outcome is marked as MODERATE in the summary table.	Thank you for your comment. The evidence statement has been amended to correspond with the evidence profile
142.	SH	NETSCC – Referee 1	47	Full	91	28-31	Are the corresponding numbers (16/163 and 6/164) in the summary table wrong?	Thank you for your comment. The amendment has been made to correct the presentational error of the treatment group sizes in the evidence profiles both in the appendices and full guideline document
143.	SH	NETSCC – Referee 1	48	Full	92	17	Evidence also identified for oral trihexyphenidyl?	Thank you for your comment. The developers' consideration of the evidence for trihexyphenidyl has been added to the evidence to recommendations section
144.	SH	NETSCC – Referee 1	49	Full	92	42-43	Assuming that the table should read 6/15 and 4/15 (i.e. 40% vs 27%), whilst technically the statement is correct, there was not a statistically significant difference in the proportions of patients willing to continue with the medication.	Thank you for your comment. Amendments to the evidence statement and the evidence to recommendations section have been made to clarify that there was no statistically significant difference
145.	SH	NETSCC – Referee 1	50	Full	97	8-16	Lack of details given about the studies. Last comparison might read better as "Delivery of BoNT A with ….."	The description of included studies sections in Chapters 4 to 10 have been standardised to provide an outline of the study design, intervention, comparator (where applicable) and population (including the participants' age ranges and medical conditions) for each included study. A more detailed description of each included study is provided in the evidence tables (Appendix I). The specific suggestion made in this comment has also been made
146.	SH	NETSCC – Referee 1	51	Full	98	Tables	Previous chapters included eg (5.4 higher to 6.5 higher) for clarity of	Where possible these data have already been inserted, but they are reported only where the study results were suitable for processing in

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
					111		interpreting Cis and I would suggest this should be adopted and made consistent throughout all the chapters.	RevMan 5 software. The comment has been noted for the development of future guidelines
147.	SH	NETSCC – Referee 1	52	Full	107	3-4	Text says "One RCT reported outcomes relevant to acceptability and tolerability" but the following table has data from 4 other studies as well?	This typo has been corrected
148.	SH	NETSCC – Referee 1	53	Full	113	50-51	Data in the summary table do not support a statistically significant improvement in right ankle dorsiflexion (knee flexion) PROM at 6 months (CI 0.27 lower to 17.33 higher).	Thank you for your comment. A correction to the evidence statement has been made to address this concern
149.	SH	NETSCC – Referee 1	54	Full	113	53-55	There is no data in the summary table to support a statistically significant improvement for MAS right adductor change at 6 months. NB there are also question marks beside the sample sizes under 6 months. The MAS right adductor outcome is marked as MODERATE in the summary table.	Thank you for your comment. The data have been reviewed against Reddihough 2002 Amendments have been made to the quality for the Modified Ashworth Scale right adductor results. Amendments have also been made to remove the question marks and to the evidence statements which now correctly state that there was very low quality evidence that compared to the botulinum toxin and physical therapy group, the group that received physical therapy alone showed significant improvement of tone in right and left adductors at 6 months compared to baseline
150.	SH	NETSCC – Referee 1	55	Full	113 114	55-2	The confidence interval in the summary table does not support the statement that "there were no significant differences in total reduction of (MAS) at three months" (CI 3.22 lower to 1.8 lower).	Thank you for your comment. A correction has been made to the evidence statement to address this concern

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151.	SH	NETSCC – Referee 1	56	Full	114	24	The pooled outcome from the three outcomes is marked as LOW in the summary table. Similarly for the two RCTs at 6 months.	Thank you for your comment. An amendment has been made to the evidence statement in both places to change moderate to low as suggested
152.	SH	NETSCC – Referee 1	57	Full	114	26	There is no evidence summary given for the QUEST outcomes shown in the summary table for optimisation of function in the upper limb (shown on p104-405).	Thank you for your comment. Evidence statements for the Quality of Upper Extremity Skills Test scores have now been added to the full guideline
153.	SH	NETSCC – Referee 1	58	Full	114	33-34	Add in that the statistically significant improvement in GMFM Total Score was AT 6 MONTHS.	Thank you for your comment. A correction has been made to the evidence statement to indicate the result was observed at 6 months
154.	SH	NETSCC – Referee 1	59	Full	114	39-40	Need to describe direction of effect for CHQ emotional role.	Thank you for your comment. An amendment has been made to the evidence statement to describe the direction of effect for the Child Health Questionnaire emotional role at 3 months
155.	SH	NETSCC – Referee 1	60	Full	114	43-44	Need to insert "(Moderate)".	Thank you for your comment. This insertion has been made as suggested
156.	SH	NETSCC – Referee 1	61	Full	114	51-53	Unsure why data that is in the text was not included in the corresponding summary table?	Thank you for your comment. Footnotes have now been added to the summary table in the full guideline to correspond to the evidence statement
157.	SH	NETSCC – Referee 1	62	Full	115	3-10	In text on p108 states "none of the included studies reported outcomes relevant to adverse effects pertaining to upper limb" but p115 reports SAEs?	Thank you for your comment. This sentence has been removed
158.	SH	NETSCC – Referee 1	63	Full	115	11-17	Similarly, no data given in summary tables for AEs for lower limbs, but text on p115 refers to 10 AEs?	Thank you for your comment. Footnotes have now been added to the summary table in the full guideline to correspond to the evidence statement which has been amended for greater clarity
159.	SH	NETSCC – Referee 1	64	Full	115	21-26	Unsure where the evidence is to support statements regarding "no statistically	Thank you for your comment. An amendment has been made to these evidence statements to

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
							significant differences", as no CIs given in summary tables or in Appendix?	address this concern
160.	SH	NETSCC – Referee 1	65	Full	115	30	CI for convulsions at 28 months includes zero, so would be a little cautious about interpreting this as "significantly more" without a little qualification.	Thank you for your comment. As per footnote 4 in Table K.7.12, the study authors noted the statistical significance of their finding, but consider this to be unrelated to the treatment regimens. The evidence statement has been amended to make this clearer
161.	SH	NETSCC – Referee 1	66	Full	115	39-50	Need to clarify in text that the outcomes were at 3 months.	Thank you for your comment. Clarification has been inserted in these evidence statements
162.	SH	NETSCC – Referee 1	67	Full	116	6-15	? No data is given in summary table or Appendix to support or otherwise a significant difference for any of the three outcomes on reduction of spasticity or optimisation of movement and function.	Thank you for your comment. Amendments have been made to the evidence profiles and evidence statements for accuracy and clarity to address the comment
163.	SH	NETSCC – Referee 1	68	Full	127	23-28	Lack of details given about the studies. From later text, at least some of the studies were of a cross-over design, but little details. If this is the case, were the statistical analyses undertaken appropriate to the study design?	The description of included studies sections in Chapters 4 to 10 have been standardised to provide an outline of the study design, intervention, comparator (where applicable) and population (including the participants' age ranges and medical conditions) for each included study. A more detailed description of each included study is provided in the evidence tables (Appendix I). The specific issue relating to analysis of cross-over studies is addressed in the quality assessment for each included study which is reported in Appendix K
164.	SH	NETSCC – Referee 1	69	Full	127 140		No data is given in virtually all of the summary tables, making it difficult to assess the evidence statements. Some details are given as footnotes to tables in Appendix K only.	The footnotes containing effect sizes etc were omitted from the draft guideline in error and they have been reinstated in the revised guideline
165.	SH	NETSCC – Referee 1	70	Full	140		The 'style' has changed in this chapter in the evidence statements – previously	Thank you for your comment. In response to this specific comment and comments regarding

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					144		the actual outcomes and timing of outcome measurements has always been given. This should be consistent.	evidence statements, the evidence statements in this chapter have been amended for consistency, accuracy and clarity
166.	SH	NETSCC – Referee 1	71	Full	140	12-22	No evidence is given in summary tables to support the statements. Footnotes are given in Appendix K only.	The footnotes containing effect sizes etc were omitted from the draft guideline in error and they have been reinstated in the revised guideline
167.	SH	NETSCC – Referee 1	72	Full	141	7-9	There is no evidence to support this statement. Footnote in Appendix K suggests that there was no comparison made between ITB-T and placebo – only changes from baseline for each of ITB-T and placebo are given.	Thank you for your comment. The evidence statement has been amended for greater clarity to address the comment
168.	SH	NETSCC – Referee 1	73	Full	141	21-30	It is again difficult (impossible?) to determine the appropriateness of the statements as the comments are made at a general level rather than on each outcome at each time point as per previous chapters.	Thank you for your comment. In response to this specific comment and comments regarding evidence statements in general, the evidence statements in this chapter have been amended for consistency, accuracy and clarity
169.	SH	NETSCC – Referee 1	74	Full	141	33-36	Quality = LOW.	Thank you for your comment. An insertion has been made to indicate low quality evidence
170.	SH	NETSCC – Referee 1	75	Full	141	45-48	Quality = VERY LOW.	Thank you for your comment. An insertion has been made to indicate very low quality evidence
171.	SH	NETSCC – Referee 1	76	Full	142	20-23	No evidence is given to support this statement. In the footnotes in Appendix K, a significant difference is indicated for CITB but no comparison was made between CITB and usual care.	Thank you for your comment. The evidence statement has been amended for greater clarity to address the comment
172.	SH	NETSCC – Referee 1	77	Full	142	24-25	Unsure what is meant by "both assessment points at 12 months".	Thank you for your comment. An amendment has been made to the evidence statement to clarify that outcomes were assessed at 12 months only
173.	SH	NETSCC – Referee 1	78	Full	142	26-29	AT 6 MONTHS, No evidence is given to support this statement. In the footnotes	Thank you for your comment.This evidence statement has been amended to reflect the

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
							in Appendix K, a significant difference is indicated for usual care only but no comparison was made between CITB and usual care.	concern expressed in the comment and confirms that there was no across-group comparison available
174.	SH	NETSCC – Referee 1	79	Full	142	38-41	Statement refers to AT 6 MONTHS.	Thank you for your comment. An insertion has been made to the evidence statement to clarify that the outcome was assessed at 6 months
175.	SH	NETSCC – Referee 1	80	Full	142	51-54	Statement refers to AT 6 MONTHS.	Thank you for your comment. An insertion has been made to the evidence statement to clarify that the outcome was assessed at 6 months
176.	SH	NETSCC – Referee 1	81	Full	143	9	"20 months" should be replaced by "18 months".	Thank you for your comment. An amendment has been made as suggested
177.	SH	NETSCC – Referee 1	82	Full	143	10-13	Statement refers to AT 6 MONTHS.	Thank you for your comment. The evidence statement has been amended for greater clarity to address the comment
178.	SH	NETSCC – Referee 1	83	Full	143	13-15	Table states that higher values are better, so unsure that "significant decrease" indicates "improvement"?	Thank you for your comment. The evidence statement has been amended for greater clarity to address the comment
179.	SH	NETSCC – Referee 1	84	Full	143	16-20	Are high values in Pain VAS really indicating "better" as in table headers? The text suggests that lower values are better.	Thank you for your comment. The evidence statement has been amended for greater clarity to address the comment
180.	SH	NETSCC – Referee 1	85	Full	143	24	"18 months" should be "12 months".	Thank you for your comment. An amendment has been made as suggested
181.	SH	NETSCC – Referee 1	86	Full	143	32-34	From footnote to table in Appendix K, only evidence for a significant difference between groups for CHQ psychosocial summary at 6 months.	Thank you for your comment. The error in this evidence statement has been corrected and further amendments have been made to improve clarity
182.	SH	NETSCC – Referee 1	87	Full	144		No health economics section is included.	A health economics section has been added to this chapter
183.	SH	NETSCC – Referee 1	88	Full	160	2-5	In footnote to table in Appendix K, evidence is only given to support no	Thank you for your comment. The evidence statement and footnotes within the corresponding

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							significant difference for Velocity, not for the other three outcomes.	evidence profiles (in the full guideline and appendices documents) have been corrected and amended for greater clarity to address the concern expressed in the comment
184.	SH	NETSCC – Referee 1	89	Full	160	30-32	There is no evidence to support this statement either in the summary table or in Appendix K.	Thank you for your comment. The evidence statement has been amended for greater clarity to address the concern expressed in the comment
185.	SH	NETSCC – Referee 1	90	Full	160	35-38	There is no evidence to support this statement either in the summary table or in Appendix K.	Thank you for your comment. The evidence statement has been corrected and amended for greater clarity to address the concern expressed in the comment
186.	SH	NETSCC – Referee 1	91	Full	160	45-48	Statement needs to be clear that the statements refer to "within group" comparisons, with no comparison made between groups.	Thank you for your comment. The evidence statement has been amended for greater clarity to address the concern expressed in the comment
187.	SH	NETSCC – Referee 1	92	Full	168	44-	The descriptions of the included studies are very much more detailed in this chapter compared to previous chapters. This needs consistency.	The description of included studies sections in Chapters 4 to 10 have been standardised to provide an outline of the study design, intervention, comparator (where applicable) and population (including the participants' age ranges and medical conditions) for each included study. A more detailed description of each included study is provided in the evidence tables (Appendix I)
188.	SH	NETSCC – Referee 1	93	Full	170 177		Very little information given in summary tables.	Thank you for your comment. Footnotes have been added to provide more information to the tables (these had been omitted in error in the draft guideline)
189.	SH	NETSCC – Referee 1	94	Full	182	14-16	There is no evidence to support this statement either in the summary table or in Appendix K.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately

	Type	Stakeholder	Order No	Document	Page No	Line No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
190.	SH	NETSCC – Referee 1	95	Full	183	1-4	There is no evidence to support this statement, including "significant reduction in the SDR group… compared to therapy alone", either in the summary table or in Appendix K.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
191.	SH	NETSCC – Referee 1	96	Full	183	7-9	There is no evidence to support this statement either in the summary table or in Appendix K.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
192.	SH	NETSCC – Referee 1	97	Full	183	7	Assuming that there was evidence (which has not been included), wording needs to be along the lines of "no evidence to support a difference" and not "evidence of no difference" (unless an equivalence study design was used).	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
193.	SH	NETSCC – Referee 1	98	Full	183	10-13	There is no evidence to support this statement either in the summary table or in Appendix K.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
194.	SH	NETSCC – Referee 1	99	Full	183	13-14	There is no evidence to support this statement either in the summary table or in Appendix K.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
195.	SH	NETSCC – Referee 1	100	Full	183	15-18	There is no evidence to support most of these statements, either in the summary table or in Appendix K. There is only evidence shown to support a significant difference in Ashworth at knee at 9 months in the Steinbok study.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
196.	SH	NETSCC – Referee 1	101	Full	183	18-21	There is no evidence to support this statement either in the summary table or	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus

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							in Appendix K.	physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
197.	SH	NETSCC – Referee 1	102	Full	183	22-25	There is no evidence to support this statement either in the summary table or in Appendix K.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
198.	SH	NETSCC – Referee 1	103	Full	183	26-39	There is no evidence to support most of these statements, either in the summary table or in Appendix K. Only evidence given is for Steinbok study for Ashworth at ankle at 9 months, for which evidence is given to support a significant difference between groups. No other evidence is given to support or otherwise significant differences between groups.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
199.	SH	NETSCC – Referee 1	104	Full	183	40-43	There is no evidence to support these statements either in the summary table or in Appendix K.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
200.	SH	NETSCC – Referee 1	105	Full	183	45-54	No CIs or p-values are given in the summary table or appendix for the outcomes from Wright or Steinbok studies, to support or refute significant between-group differences and so there is no evidence to support a number of these statements.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
201.	SH	NETSCC – Referee 1	106	Full	184	2-5	Again, no CIs or p-values are given in the summary table or appendix for the outcomes from Wright study and so there is no evidence to support this part	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately

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							of the statement.	
202.	SH	NETSCC – Referee 1	107	Full	184	5-7	There is no evidence to support these statements either in the summary table or in the appendix. The only evidence (footnote in appendix) is for significant within-group changes in GMFM at 20 months.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
203.	SH	NETSCC – Referee 1	108	Full	184	8-15	There is no evidence to support this statement either in the summary table or in Appendix K.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
204.	SH	NETSCC – Referee 1	109	Full	178	6-39	Unsure why there is no summary table for these results; although text reads well, it is essentially duplicated in the Evidence Statement section on page 184.	Thank you for your comment. The resources for guideline development, including responding to stakeholder comments, are limited. The developers have prioritised changes to the draft guideline that will have the greatest impact on readability, clarity and transparency of the route from evidence to recommendations. Reformatting the information referred to in the comment and presenting it in GRADE profiles would not change the developers' conclusions in relation to the evidence, and so the suggested change has not been made
205.	SH	NETSCC – Referee 1	110	Full	General		3.1 How far are the recommendations based on the findings? Are they a) justified i.e. not overstated or understated given the evidence? b) Complete? i.e. are all the important aspects of the evidence reflected?	This is not a stakeholder comment but text from the covering proforma designed to prompt the stakeholder to comment on specific aspects of the guideline. As such no response is required from the guideline developers
206.	SH	NETSCC – Referee 1	1	Full	General		Given the number of statements for which, at present, there is no supporting evidence shown, it is difficult to assess this. Assuming that the statistical	The footnotes containing effect sizes etc were omitted from the draft guideline in error and they have been reinstated in the revised guideline. That said, the developers agree that there was a

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							evidence has simply been omitted in most instances, and the statements are indeed correct, then even so there is a lack of available evidence. Hence much of the guidance is based on the experts' consensus.	general lack of relevant evidence to inform guideline recommendations. This is documented in the evidence to recommendations sections of the full guideline
207.	SH	NETSCC – Referee 1	112	Full	General		3.2 Are any important limitations of the evidence clearly described and discussed?	This is not a stakeholder comment but text from the covering proforma designed to prompt the stakeholder to comment on specific aspects of the guideline. As such no response is required from the guideline developers
208.	SH	NETSCC – Referee 1	1	Full	General		Many of the studies identified involved very low numbers of children, and whilst this is commented on in some instances, it is not consistently acknowledged. I am also a little confused whether some of the studies were excluded on small sample sizes (Appendix H), when some of the included studies only had small numbers (e.g. Newman et al, 12 children).	Thank you for your comment. The guideline developers did not always specify a minimum sample size in the guideline review protocols. The differences in the quality of the published evidence for each intervention precluded a global approach to defining inclusion/exclusion criteria in terms of study design or sample size. The developers aimed to include the best quality data available to inform recommendations and, where possible, limited included studies to those that reported comparative data. Where inclusion criteria for a particular review question did stipulate restriction by sample size this is indicated in the corresponding protocol in Appendix D. Amendments have also been made to the lists of excluded studies in Appendix E to reflect the fact that the studies referred to in the comment were excluded for reasons other than small sample size
209.	SH	NETSCC – Referee 1	1	Full	General		As detailed elsewhere, the descriptions of the included studies in most chapters is very brief; with little mention of possible limitations in the main text.	Details of the quality assessment for each included study, including limitations (risk of bias), are presented in Appendix K. This is in accordance with the NCC-WCH template for the full guideline. In a report of this length it is not possible to include every detail in the main text,

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								but the summary quality assessment for each study (very low, low, moderate or high) is included in the main text versions of the GRADE tables
210.	SH	NETSCC – Referee 1	115	Full	General		Chapter 5 – the review question was to compare orthoses vs no orthoses, but 3/4 comparisons were of differing orthoses. Whilst this may be completely relevant, perhaps this needs commented on?	The review questions are presented as a historical record of the broad review questions agreed by the guideline development group at the start of guideline development. To change them at this stage would incur a great deal of editing across numerous documents and have no impact at all on the guideline recommendations. Full details of all the aspects to be considered under each review question are, however, presented in the detailed review protocols (see Appendix D)
211.	SH	NETSCC – Referee 1	1	Full	General		4.1 Is the whole report readable and well presented? Please comment on the overall style and whether, for example, it is easy to understand how the recommendations have been reached from the evidence. I found this report quite difficult to read. Whilst there is a lot of information, the report does not seem to have proof-read, adding to the difficulties. There has clearly been different lead authors of different chapters, with the result that whilst some parts read well, others could do with some further details and more consistency.	The guideline developers have tried to improve the clarity and presentation of all the guideline documents within the timescale for submitting the revised guideline to NICE. All versions of the revised guideline have been proofread. Additionally all guideline documents will be copy edited before publication. Unfortunately it is not possible to undertake copy editing before the stakeholder consultation or the pre-publication check
212.	SH	NETSCC – Referee 1	1	Full	General		Formatting/layout of bullet points are inconsistent throughout the document.	The guideline developers have tried to improve the clarity and presentation of all the guideline documents within the timescale for submitting the revised guideline to NICE. All versions of the revised guideline have been proofread. Additionally all guideline documents will be copy edited before publication, and any remaining

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								issues with inconsistent use of bullet points will be resolved then. Unfortunately it is not possible to undertake copy editing before the stakeholder consultation or the pre-publication check
213.	SH	NETSCC – Referee 1	1	Full	14	footnotes	Repetition of footnotes with the same information for example on p14, the same footnote is given 3 times – to be changed for final document?	The footnotes to recommendations have been edited so that the same footnote appears only once on each page
214.	SH	NETSCC – Referee 1	1	Full	4 26		There are a large number of abbreviations, but at present no abbreviation list, which has made the guideline at times tricky to read for someone with little detailed knowledge of this area. In particular, I would suggest there should be no abbrevations (unless in common use) in the Guideline summary.	The revised guideline includes a list of abbreviations The full guideline summary lists all the recommendations and research recommendations included in the guideline. The style of the summary (including whether or not abbreviations are used) is, therefore, largely determined by the NICE editorial style and as such the guideline developers cannot necessarily control the extent to which abbreviations are (or are not) used
215.	SH	NETSCC – Referee 1	1	Full	General		Inconsistency in the depth of information presented in the different chapters. Information in Chapters 9 and 10 is much more detailed (and helpful) than for many of the preceding chapters.	The description of included studies sections in Chapters 4 to 10 have been standardised to provide an outline of the study design, intervention, comparator (where applicable) and population (including the participants' age ranges and medical conditions) for each included study. A more detailed description of each included study is provided in the evidence tables (Appendix I)
216.	SH	NETSCC – Referee 1	121	Full	20 23		Should Key Research Recommendations be in consecutive number order? Unsure why Recommendation 23 is first on the list.	This change has been made

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217.	SH	NETSCC – Referee 1	122	Full	27	22	Delete "we".	This change has been made
218.	SH	NETSCC – Referee 1	1	Full	General		There are a number of missing references throughout the text, for example:	Thank you for your comment. We have addressed your specific points below
219.	SH	NETSCC – Referee 1	124	Full	28	13	"(ref needed").	The correct reference has now been inserted
220.	SH	NETSCC – Referee 1	125	Full	28	44	"(ref needed - SCPE").	The correct reference has now been inserted
221.	SH	NETSCC – Referee 1	126	Full	36	20	"(ref needed").	The correct reference has now been inserted
222.	SH	NETSCC – Referee 1	127	Full	167	20	"(ref needed").	All missing references have been resolved in the revised guideline
223.	SH	NETSCC – Referee 1	128	Full	33	21/22	Should read "observational studies" and need full stop at end of sentence/section.	These changes have been made
224.	SH	NETSCC – Referee 1	129	Full	34	4	Insert "were" between "observational studies" and "included".	This change has been made
225.	SH	NETSCC – Referee 1	130	Full	36	10	"throughout" duplicated.	This typo has been corrected
226.	SH	NETSCC – Referee 1	131	Full	36	12	Missing "t" from "these" at start of line.	This typo has been corrected
227.	SH	NETSCC – Referee 1	132	Full	37		It would be helpful to list the key pre-specified outcomes, for example either at the end of the introduction to each section or perhaps under the Descriptions.	For this guideline there is a common set of prespecified outcome measures that applies across all the review questions. These outcome measures are discussed in detail in Appendix E. For future guidelines the developers will consider including details of outcome measures in the main text, although it is already clear from the GRADE profiles which of the outcomes measures were reported in each of the included studies
228.	SH	NETSCC – Referee 1	133	Full	37	17-23	Inconsistent with references – please give the relevant references for each bullet point/comparisons.	This change has been made

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229.	SH	NETSCC – Referee 1	134	Full	37	17-23	There is no real description of the 10 studies/12 publications. The level of detail given in chapters 9 and 10 is much more helpful and informative, and I would suggest should be given for each of the chapters.	The description of included studies sections in Chapters 4 to 10 have been standardised to provide an outline of the study design, intervention, comparator (where applicable) and population (including the participants' age ranges and medical conditions) for each included study. A more detailed description of each included study is provided in the evidence tables (Appendix I)
230.	SH	NETSCC – Referee 1	135	Full	37	27-36	There are a number of typos in this paragraph.	The typos have been corrected
231.	SH	NETSCC – Referee 1	136	Full	38		In the evidence tables, need to explain what "MD" is – and see comments in section 2.2 above.	The abbreviations used in the tables were not included in the draft guideline but they are included in the revised guideline, and thus MD is now defined
232.	SH	NETSCC – Referee 1	137	Full	48	46	Typos "daily", "maintenance".	These typos have been corrected
233.	SH	NETSCC – Referee 1	138	Full	50	12-13	Sense of sentence?	This paragraph has been reworded for clarity
234.	SH	NETSCC – Referee 1	139	Full	51 52		Number of typos throughout the text.	The typos have been corrected
235.	SH	NETSCC – Referee 1	140	Full	60 72	Tables	Headers under "Number of patients" – need to remove "Mean" throughout the tables in this section.	This change has been made
236.	SH	NETSCC – Referee 1	141	Full	60 72	Tables	Need consistency with headings for outcome measures e.g. sometimes have "(diplegia)", other times not.	Thank you for your comment. Amendments have been made to remove the terms 'hemiplegia' and 'diplegia' from the evidence profiles
237.	SH	NETSCC – Referee 1	142	Full	67	Table	Footnotes are not included in this report.	The footnotes were omitted from the draft guideline in error and they have been reinstated in the revised guideline

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238.	SH	NETSCC – Referee 1	143	Full	72	4	Title of section is "Comparisons to no treatment or no orthosis" but the next line and study seems to compare to types of orthosis?	Thank you for your comment. This incorrect section title has been removed
239.	SH	NETSCC – Referee 1	144	Full	72	13-	Would be helpful to use subheadings, as per the Evidence Profiles section.	Thank you for your comment. An amendment has been made, as suggested
240.	SH	NETSCC – Referee 1	145	Full	73	7	Should this be "two randomised studies"?	Thank you for your comment. This evidence statement has been amended as suggested
241.	SH	NETSCC – Referee 1	146	Full	73	18 (and throughout)	How was the subgroup defined?	Thank you for your comment. The subgroup was defined as participants who were able to go up and down stairs during a barefoot assessment with or without use of a handrail. This is now reflected in the description of included studies section and in the corresponding evidence statements
242.	SH	NETSCC – Referee 1	147	Full	73	41	Should this be "Four randomised studies"?	Thank you for your comment. This has been amended as suggested
243.	SH	NETSCC – Referee 1	148	Full	79	34, 40	Spelling ("othosis").	This typo has been corrected
244.	SH	NETSCC – Referee 1	149	Full	90	48	Should this be "motor tone" as per the outcome header in the summary table?	Thank you for your comment. An amendment to this evidence statement has been made to remove muscle tone and replace it with motor tone as suggested
245.	SH	NETSCC – Referee 1	150	Full	93	5-11	Need to make clear throughout this paragraph that costs presented are annual costs.	Thank you for your comment. This change has been made
246.	SH	NETSCC – Referee 1	151	Full	94	1	"effect" not "affect".	This typo has been corrected
247.	SH	NETSCC – Referee 1	152	Full	94	1	Delete "is" at end of line.	This sentence has been reworded for clarity

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248.	SH	NETSCC – Referee 1	153	Full	113	3	Delete "Although" and replace start of sentence simply with "A statistically significant…"	Thank you for your comment. An amendment has been made to the evidence statement, as suggested
249.	SH	NETSCC – Referee 1	154	Full	116	25-35	There are a number of typos.	The typos have been corrected
250.	SH	NETSCC – Referee 1	155	Full	117	4	Replace "Although" with "However"?	This change has been made
251.	SH	NETSCC – Referee 1	156	Full	118	3, 46, 52	Missing full stops.	The full stops have been inserted
252.	SH	NETSCC – Referee 1	157	Full	118	19	Delete "Regarding the trials of,".	This change has been made
253.	SH	NETSCC – Referee 1	158	Full	119	3-13	Number of typos and missing full stops.	The typos have been corrected and the full stops have been inserted
254.	SH	NETSCC – Referee 1	159	Full	122	43	Missing full stop.	The full stop has been inserted
255.	SH	NETSCC – Referee 1	160	Full	123	12	Missing full stop.	The full stop has been inserted
256.	SH	NETSCC – Referee 1	161	Full	140 144		Change of style regarding placement of e.g. (HIGH) and full stop – consistency?	Thank you for your comment. A consistency check has been performed and amendments made accordingly so that the quality rating comes after the full stop
257.	SH	NETSCC – Referee 1	162	Full	144	35	Insert "was" before identified.	This change has been made
258.	SH	NETSCC – Referee 1	163	Full	146	18	Missing full stop.	This change has been made
259.	SH	NETSCC – Referee 1	164	Full	146	24	Delete first "assessment" in line.	This change has been made
260.	SH	NETSCC – Referee 1	165	Full	147	52	Delete "there".	This change has been made
261.	SH	NETSCC – Referee 1	166	Full	149	11	Delete "be".	This change has been made
262.	SH	NETSCC –	167	Full	149	16	Delete "out", and "outcome" should be	These changes have been made

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		Referee 1					"outcomes".	
263.	SH	NETSCC – Referee 1	168	Full	155 156		?reference to footnotes (4?) but no footnotes given.	This was a reference to a footnote that was omitted in error. The footnotes containing effect sizes etc have been reinstated in the revised guideline
264.	SH	NETSCC – Referee 1	169	Full	186	14	Spelling of "independence".	This change has been made
265.	SH	NETSCC – Referee 1	170	Full	187	19	Insert "the" before "child".	This change has been made
266.	SH	NETSCC – Referee 1	1	Full	General		There are a large number of typos and formatting/layout errors in this document.	Thank you for your comment. We have addressed your specific points below. In addition all guideline documents have been proofread and will be copy edited before publication. Any remaining issues with typos, formatting or layout will be resolved then. Unfortunately it is not possible to undertake copy editing before the stakeholder consultation or the pre-publication check
267.	SH	NETSCC – Referee 1	180	Full	165	103	4.2 Please comment on whether the research recommendations, if included, are clear and justified. This KPI seems to read slightly at odds with the text on the previous page, which states that "access to an orthopaedic opinion (as part of the multidisciplinary team, rather than requiring a further referral)…."	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthopaedic surgeon within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on surgical assessment to highlight when expert advice should be sought
268.	SH	NETSCC – Referee 1	1	Full	General		I would like to express some concerns about this draft guideline. It is not particularly well-written and I suspect has been rushed to submit it "on time", with little attention paid to detail or proof-reading the entire document. There are lots of instances of "missing" information	The footnotes containing effect sizes etc were omitted from the draft guideline in error and they have been reinstated in the revised guideline. The guideline developers are sorry that the stakeholder had to refer to Appendix K for information that should have been presented in the main text

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							from the summary tables within the document, which have made it extremely tedious and time-consuming to review, as I've had to wade through 500+ pages of appendices in an attempt to identify relevant evidence. Many of the evidence statements included are not justified by the 'evidence' (or lack of) given, which makes interpretation of the actual guidance difficult. The (short) draft algorithm is also full of typos and formatting inconsistencies, suggesting a real lack of care and attention to what should have been a relatively easy document to present to a good standard.	The guideline developers have reviewed all the evidence statements to ensure their accuracy, and general improvements to presentation and clarity have been made where possible The developers have also revised the care pathway to reflect the revised versions of the recommendations, and this has included checking for typos
269.	SH	NETSCC – Referee 2	1	Full	General		1.1 Are there any important ways in which the work has not fulfilled the declared intentions of the NICE guideline (compared to its scope – attached) The work has addressed the declared intentions in the scope.	Thank you for your comment
270.	SH	NETSCC – Referee 2	2	Full	General		2.1 Please comment on the validity of the work i.e. the quality of the methods and their application (the methods should comply with NICE's Guidelines Manual available at http://www.nice.org.uk/page.aspx?o=guidelinesmanual).	Thank you for your comment. We have addressed your specific points below

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							Please see my comments in 2.2.	
271.	SH	NETSCC – Referee 2	3	Full	General		2.2 Please comment on the health economics and/or statistical issues depending on your area of expertise. Overall I felt the quality of the economic analysis and its reporting could be improved upon.	The health economics chapter (Chapter 11) now includes a more detailed explanation for the departure from the reference case and specific reasons for the approach for each area where health economic analysis has been provided
272.	SH	NETSCC – Referee 2	4	Full	37		Shouldn't the review question include cost-effectiveness as well as effectiveness?	The review questions are presented as a historical record of the broad review questions agreed by the GDG at the start of guideline development. To change them at this stage would incur a great deal of editing across numerous documents and have no impact at all on the guideline recommendations. Full details of all the aspects to be considered under each review question are, however, presented in the detailed review protocols (see Appendix D)
273.	SH	NETSCC – Referee 2	5	Full	48		The reporting of the economic evidence in this chapter and subsequent chapters is woefully inadequate. No details are provided on how many studies were identified, how many were reviewed and what the nature of the evidence is. I appreciate that there may be very little evidence, but this needs to be stated and details provided on what evidence there is.	No economic evaluations were identified from the literature search. This has now been reported in the health economics statement for this chapter
274.	SH	NETSCC – Referee 2	6	Full	54		There is no suggestion that the recommendations have taken into account the economic evidence.	Where economic evaluations were developed these were presented alongside the clinical evidence for the relevant review question during guideline development meetings. Where economic evaluation was not possible resource use and costs were identified and presented. The

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								guideline developers were given the opportunity to input and make changes to the analyses to best represent UK practice guided by their experience. The economic evidence was used by the guideline developers to consider whether the resource use required to provide each treatment would be considered good value to the NHS in relation to the outcomes of those treatments, including both positive benefits and also adverse events
275.	SH	NETSCC – Referee 2	7	Full	57		In view of the paucity of economic evidence, it is odd that the research recommendations do not include the need for more economic evidence.	All research questions that specify investigation of the effectiveness of particular management options have been changed to specify investigation of clinical and cost effectiveness of those options
276.	SH	NETSCC – Referee 2	8	Full	59		Shouldn't the review question include cost-effectiveness as well as effectiveness? This comment applies to all subsequent review questions.	The review questions are presented as a historical record of the broad review questions agreed by the guideline development group at the start of guideline development. To change them at this stage would incur a great deal of editing across numerous documents and have no impact at all on the guideline recommendations. Full details of all the aspects to be considered under each review question are, however, presented in the detailed review protocols (see Appendix D)
277.	SH	NETSCC – Referee 2	9	Full	76		The health economics section states that the clinical evidence for this question (which question?) was limited, while no mention whatsoever is made of there being any economic evidence. This section then proceeds to describe a very simple cost analysis, the majority of which is repeated verbatim in Chapter 11 on page 193. Strictly, the 'cost analysis' is not a cost analysis in the true sense in that there is no	The comment refers to the review question for this chapter which can be found immediately after the chapter introduction. The clinical evidence for all elements of the othoses review was limited and of low quality. No published economic evaluation of orthoses was identified. This is now stated in the guideline. The title has been changed to cost description

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							comparator. It is merely a cost description.	
278.	SH	NETSCC – Referee 2	10	Full	76		The source of the cost estimate for an AFO needs to be stated.	This has been added into the health economics chapter (Chapter 11)
279.	SH	NETSCC – Referee 2	11	Full	76 77		The statement in line 29 on page 76 that the costs of orthoses are low is contradicted by the statement in line 33 on page 77 that orthoses can be expensive.	Thank you for your comment. The contradiction between these statements has been resolved by removing the statement about orthoses being expensive
280.	SH	NETSCC – Referee 2	12	Full	77		The statement that orthoses are cost-effective (relative to what?) provided certain criteria are met is highly speculative.	Thank you for your comment. This statement has been removed
281.	SH	NETSCC – Referee 2	13	Full	82		In view of the apparent absence of any economic evidence in the literature, the research recommendations should include the requirement for economic evidence.	All research questions that specify investigation of the effectiveness of particular management options have been changed to specify investigation of clinical and cost effectiveness of those options
282.	SH	NETSCC – Referee 2	14	Full	83 95		I could find no mention of economics anywhere in this chapter.	A statement on health economics has been added to this chapter
283.	SH	NETSCC – Referee 2	15	Full	116		No mention is made of their being any economics literature.	This has been added to this chapter
284.	SH	NETSCC – Referee 2	16	Full	116		Which appendix is being referred to in lines 25 and 26?	This has been changed to refer to Chapter 11
285.	SH	NETSCC – Referee 2	17	Full	120 121		There is a statement in line 52 of page 120, continuing into line 1 on page 121 that 'the cost-effectiveness of this will be reviewed elsewhere in this guideline'. It would have been helpful to tell us where this is to be found, as I was unable to locate it.	The cost effectiveness of casting after botulinum toxin type A injections is already included in the health economics section of this chapter. The sentence about it being elsewhere has been removed
286.	SH	NETSCC – Referee 2	18	Full	126		Once again, none of the research recommendations include anything on economic evidence.	All research questions that specify investigation of the effectiveness of particular management options have been changed to specify

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								investigation of clinical and cost effectiveness of those options
287.	SH	NETSCC – Referee 2	19	Full	127 153		I could find no discussion in this chapter on the existence or otherwise of economic evidence beyond the statement in line 46 on page 147 that no evidence was identified to support an economic analysis of CITB. However, in line 11 on page 197 we are told that an economic evaluation was identified in the literature search. Why was this not mentioned/discussed in Chapter 8?	A health economics section has been added to this chapter
288.	SH	NETSCC – Referee 2	20	Full	152		None of the research recommendations include anything on economic evidence.	All research questions that specify investigation of the effectiveness of particular management options have been changed to specify investigation of clinical and cost effectiveness of those options
289.	SH	NETSCC – Referee 2	21	Full	161		Once again, we are told nothing about the economic evidence (or even whether any exists). We are told only that there was not enough evidence to develop a health economic analysis, not even one working backwards from the NICE threshold. Instead we are presented with a very simple cost analysis which, as with that presented for orthoses is not strictly a cost analysis (there is no comparator), but merely a cost description (and not a particularly detailed one at that). As for not being able to work backwards from the NICE threshold due to a lack of evidence, this was not an obstacle in the case of botulinum toxin.	No economic evaluations were identified in the literature. This is now stated in the health economics section for this chapter The reason why a 'what-if' analysis could not be undertaken for this review question is explained fully in the health economics chapter (Chapter 11)

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290.	SH	NETSCC – Referee 2	22	Full	166		None of the research recommendations include anything on economic evidence.	All research questions that specify investigation of the effectiveness of particular management options have been changed to specify investigation of clinical and cost effectiveness of those options
291.	SH	NETSCC – Referee 2	23	Full	185		Reference is made to one paper containing economic evidence, but no discussion is offered of it.	All evidence statements within Chapter 10 for the comparison of selective dorsal rhizotomy plus physical therapy versus physical therapy alone have been revised to reflect the available evidence accurately
292.	SH	NETSCC – Referee 2	24	Full	190		None of the research recommendations include anything on economic evidence.	All research questions that specify investigation of the effectiveness of particular management options have been changed to specify investigation of clinical and cost effectiveness of those options
293.	SH	NETSCC – Referee 2	25	Full	192		The departure from the NICE reference case and the simplistic nature of the economic analyses presented needs stronger justification (see bottom of page 85 of the NICE Guidelines Manual). Overall I think the economic analyses presented are overly simplistic and on occasion contain basic errors (e.g. not using a common base year for costs, not having an explicit comparator and thus not conforming to the definition of an economic evaluation) and do not adhere closely enough to the NICE reference case (e.g. no statement of the question to be addressed and/or the comparators, absence of sensitivity analysis). I appreciate that evidence was limited (this is largely based on assumption on my part as there were virtually no details provided on the economic evidence identified in the	The health economics chapter (Chapter 11) now includes a more detailed explanation for the departure from the reference case and specific reasons for the approach for each area where health economic analysis has been provided

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							systematic reviews), but I feel there is considerable room from improvement.	
294.	SH	NETSCC – Referee 2	26	Full	36		The so-called cost analysis presented here comprises taking the unit costs of community and hospital physiotherapy and OT from the PSSRU document and multiplying them first by 48 to arrive at an annual cost (presumably on the assumption that treatment is provided for 48 weeks of the year) and then multiplying this figure by either 1, 2 or 3 to reflect the number of sessions per week. I reckon this could be done in less than 10 minutes and is not an economic evaluation in any sense of the term.	The cost description prepared for the guideline was produced to look at frequency of physical therapy to give the guideline developers an understanding of the costs of providing physical therapy. The clinical evidence from the guideline review was limited and not useful for producing an economic evaluation. A 'what-if' analysis was suggested by the developers. After much discussion they came to the view that it would not be possible to quantify the mean benefits of physical therapy for the following reasons. • The guideline covers children and young people with considerable variation in impairment, from those with spasticity in affecting a single joint to those with severe spasticity affecting all limbs. • Physical therapy goals are individualised to the child or young person within the family and will change over time and in different contexts. • None of the identified research studies quantified the mean benefit of physical therapy in a way that would be clinically meaningful. • The developers were not able to come to a consensus view on what a single measurable health outcome would be for this group. This explanation has been added to the physical therapy section of Chapter 11. If the stakeholder is able to suggest methodological approaches to address these issues, then this would be useful for future guidelines

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295.	SH	NETSCC – Referee 2	27	Full	58		In this very simple analysis (description) of costs, what is being compared with what? How was the service description developed? Where did the cost of an AFO come from?	Orthoses are used in conjunction with other treatments and so the most likely comparator is no orthosis. This cost description was undertaken with a view to developing a 'what if' analysis comparing orthoses to no active treatment, but this was not possible to develop. Further explanation has been added to the health economics chapter (Chapter 11). The service descriptions were kept in the guideline as they were presented to the guideline development group to take into account the resource implications of the recommendations. How the service descriptions were developed has now been included in Chapter 11, and this includes a reference for the cost of the ankle-foot orthosis
296.	SH	NETSCC – Referee 2	28	Full	96		It is stated in line 33 on page 193 that the evidence from the literature review was unequivocal. If this is referring to the economic evidence, then I beg to differ. There is little or no value added from Table 11.2 Why is the time period for the analysis restricted to one year? Would botulinum toxin not be administered beyond this point?	Details of the economic literature search results have been included in each section of Chapter 11 This table has been retained because it presents costs discussed by the guideline developers The pharmacological activity of botulinum toxin does not seem to last longer than 3-4 months. Repeated injections were suggested, but there was little evidence to support this. Therefore, a model that considered injections over more than 1 year seems unnecessary and would add uncertainty The comparator was oral drug treatment. The cost of 84 10 mg tablets was £1.59. The cost per day for giving 30 mg of oral drug treatment was multiplied by 365 to give an annual cost. Physical therapy costs were assumed to be the same for both treatment arms, and so were not included in

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								the costs
							How was the annual cost of standard care arrived at?	The prices have been updated to 2010/11 The results for the total costs of treatment per year are presented for different scenarios. Given this analysis has no effectiveness evidence, full sensitivity analysis would not be possible The multiplication by 159 was from a previous model and left in the table in error. It has now been removed
							Estimates of the cost of BoNT are in 2009 prices, while the cost of standard care is in 2011 prices. Reference to a baseline analysis in line 25 on page 195 suggests there will be some sort of sensitivity analysis. However, none is presented.	More explanation of the analysis has been added The view of the guideline developers was that in the circumstances described in the evidence to recommendations section the benefits of botulinum toxin type A would justify the costs. The evidence to recommendations section has been expanded to clarify this
							Why have the unit costs in Table 5 (which should be should be labelled Table 11.5) been multiplied by 159? The discussion in lines 28-40 on page 196 needs more explanation. I have very little idea of what it is getting at. It is stated in lines 37 and 38 on page 116 that there is no conclusive evidence	

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							to suggest that BoNT has any impact with respect to reducing pain or improving function, so it is interesting that the authors seem confident that BoNT will achieve a 12 month marginal QALY gain of 0.09 compared to drugs therapy, thus rendering it cost-effective according to the threshold of £20,000 per QALY (page 196 and 197).	
297.	SH	NETSCC – Referee 2	29	Full	127		This is the most detailed economic evaluation, but unfortunately I found it very difficult to follow. I felt there were too many tables with insufficient clear explanation of what was going on. For example, I could find no discussion of Tables 11.19 to 11.20 in the text; it is not clear how certain figures in the tables have been arrived at (e.g. the cost and additional length of stay for a major infection in Table 11.10); costs are presented in three different base years; why are the total costs for infections in table 11.14 less than the cost per patient? I was left wondering why a simple Markov model (or even a decision analytic model) was not contemplated.	Thank you for your comment. The model report has been rewritten. A decision model was developed for this review question
298.	SH	NETSCC – Referee 2	30	Full	154		What year are the reference costs reported in?	All the reference costs have been updated to the most recently published costs (from 2010-11). The cost year has also been reported in this section

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299.	SH	NETSCC – Referee 2	31	Full	167		Is reporting the results of a cost analysis from an unpublished dissertation all that could be done here? Why wasn't an attempt made to work back from the NICE threshold?	Further acknowledgment of the low quality of this evidence has been included in the revised guideline Further explanation regarding economic evaluation for this subject has been included in the health economics chapter (Chapter 11)
300.	SH	NETSCC – Referee 2	3	Full	General		3.1 How far are the recommendations based on the findings? Are they a) justified i.e. not overstated or understated given the evidence? b) Complete? i.e. are all the important aspects of the evidence reflected? As outlined in my comments in section 2.2, there is little evidence of the extent to which the recommendations have taken into account the economic evidence.	Where economic evaluations were developed these were presented alongside the clinical evidence for the relevant review question during guideline development meetings. Where economic evaluation was not possible resource use and costs were identified and presented. The guideline developers were given the opportunity to input and make changes to the analyses to best represent UK practice guided by their experience. The economic evidence was used by the guideline developers to consider whether the resource use required to provide each treatment would be considered good value to the NHS in relation to the outcomes of those treatments, including both positive benefits and also adverse events
301.	SH	NETSCC – Referee 2	3	Full	General		4.1 Is the whole report readable and well presented? Please comment on the overall style and whether, for example, it is easy to understand how the recommendations have been reached from the evidence. In general, I felt the report was readable, but that there is room for improvement, e.g. there are an awful lot of long tables in the report which don't help readability. There is also a tendency to not present	Thank you for your comments. In response to the general comment, the guideline developers appreciate that presentational issues are important and all the stakeholder comments will help to improve readability of future guidelines. Given the timescale for responding to the stakeholder comments, the developers prioritised issues of accuracy in relation to the clinical and cost effectiveness evidence alongside issues that directly affect interpretation of evidence to inform recommendations. Where possible the developers have also improved the general clarity and presentation of the text

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							enough detail. For example, on page 115 in line 5 reference is made to four children having experienced an adverse event requiring hospitalisation, but we are not told out of how many. Another example on the same page is in line 12 where a cross over RCT is discussed, but no reference is given.	In relation to the specific comments regarding adverse events: • page 115, line 5 - further information regarding hospitalisations which was provided in the evidence tables has now been added to the main text of the full guideline for clarity • page 115, line 12 - Reddihough 2002 is now cited in the text to clarify which study the data come from
302.	SH	NETSCC – Referee 2	34	Full	General		4.2 Please comment on whether the research recommendations, if included, are clear and justified. As outlined in section 2.2, despite there being an obvious dearth of economic evidence, none of the research recommendations relate to the need for more economic evidence.	All research questions that specify investigation of the effectiveness of particular management options have been changed to specify investigation of clinical and cost effectiveness of those options
303.	SH	North Bristol NHS Trust	1	Full	167	21	SDR involves the selective division of sensory nerve roots from L1, not from L2	This error has been corrected
304.	SH	North Bristol NHS Trust	2	Full	168	32	While understanding that limiting the studies reviewed to randomised controlled trials and large non-randomised patient series with over 200 patients may increase the rigor of this review, it needs to be stated that this review is only addressing a very small proportion of the total body of published evidence on SDR. This review is therefore limited and cannot be viewed as a comprehensive analysis of the clinical efficacy of SDR.	Thank you for your comment. By inserting the sentence to which you refer, the guideline developers are indeed acknowledging the limits of this review. NICE systematic reviewing methodology does not aim to be exhaustive. NICE reviews seek to determine the comparative effectiveness of interventions using the best quality evidence to inform recommendations. Studies which do not compare different treatments or different aspects of treatment are not ordinarily included, and they were not prioritised for consideration in this guideline review

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305.	SH	North Bristol NHS Trust	3	Full	169	45	This line refers to five RCT's – as far as I am aware there have only been three RCT's on SDR.	This typo has been corrected
306.	SH	North Bristol NHS Trust	4	Full	169	51	Mortality rates were not reported because there were no deaths. Considering that death is extremely unlikely after a surgical procedure such as SDR it is appropriate that an RCT does not report a mortality rate.	The view of the guideline developers was that death was a potential adverse effect of selective dorsal rhizotomy, and that it was important to highlight this in the guideline review
307.	SH	North Bristol NHS Trust	5	Full	182	14	In one of the RCT's only a mean of 27% of sensory nerve rootlets were divided. This does not reflect the procedure undertaken currently. The results of the RCT's need to be described in a way that reflects the significant difference between this and the other two RCT's.	Thank you for your comment. The developers have made an amendment to the evidence to recommendations section to reflect the comment
308.	SH	North Bristol NHS Trust	6	Full	185	34	This presumably refers to the paper by Buckon et al, 2004. Spasticity was not an end-point in this study, presumably because orthopaedic surgery does not affect spasticity to a significant degree. To state that this study showed no difference with respect to spasticity is inaccurate and misleading. The other important conclusions of this paper need to be mentioned, particularly that self-care skills, mobility, and social function gains were seen earlier and with greater frequency in the SDR group. As here this paper is referred to within a paragraph on health economics, it may be appropriate to point out that all these benefits are likely to have a significant impact on the overall health economics of SDR and further research is needed to define them.	The sentence this comment refers to is: 'In the comparison of SDR plus physical therapy versus soft tissue surgery no evidence was identified in relation to reduction of spasticity or optimisation of movement.' This reflects the clinical evidence for selective dorsal rhizotomy plus physical therapy compared to orthopaedic (soft tissue) surgery which states that no studies reported reduction of spasticity or optimisation of movement. It has been stated in this paragraph that no evidence of a difference was identified. In the revised guideline this is emphasised further by noting that 'no evidence of a difference' is not the same as 'evidence of no difference' For the other outcomes for this comparison, the health economics section reflects the conclusions of the guideline review of the clinical evidence, which is based on the outcomes that the developers prioritised for consideration

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309.	SH	North Bristol NHS Trust	7	Full	186	45	The GDG concludes that there is no 'high-quality evidence of a consistent and sustained (long-term) improvement in motor function or pain control', yet refers to 'anecdotal evidence from an unpublished report' suggesting that 'SDR may achieve such outcomes'. There are several published peer-reviewed studies documenting the long-term outcome of SDR, and it would seem appropriate that the GDG evaluate these reports before resorting to anecdotal evidence in unpublished work.	The developers agree that published reports do exist regarding outcomes at up to 2 years, but outcomes over much longer periods and into adult life would be important. The evidence to recommendations section has been revised to clarify this
310.	SH	North Bristol NHS Trust	8	Full	187	31	There are several studies, which, although relatively small, demonstrate long-term efficacy after SDR and confirm that functional and kinematic gains made after SDR are maintained in the long term, up to twenty years in one study.	No studies reporting outcomes at between 2 and 20 years met the inclusion criteria for the guideline review. The developers' view is that outcomes over longer periods than 2 years would be important and further research is needed to address this
311.	SH	North Bristol NHS Trust	9	Full	188	32	The NICE interventional procedure guidance (373) published in December 2010 concluded that the 'evidence on efficacy is adequate' and that 'the procedure may be used provided that normal arrangements are in place for clinical governance and audit'. It appears that the conclusions drawn from the current document are in contradiction to this. It states that there is 'a lack of evidence supporting a clinical benefit of SDR in relation to optimisation of function.' It underlines clinical research as the only way forward, and even defines 'criteria for identifying children and young people to	NICE interventional procedures guidance evaluates the safety and efficacy of interventional procedures used for diagnosis or treatment, whereas NICE clinical guidelines evaluate clinical and cost effectiveness. If a procedure is found to be clinically and cost effective, the clinical guideline development group will recommend its use in practice. In circumstances when there is considerable uncertainty about the clinical or cost effectiveness of a procedure, the guideline development group may decide to make an 'only in research' recommendation. In the case of selective dorsal rhizotomy, the guideline development group concluded that there was insufficient evidence to demonstrate the clinical and cost effectiveness of the intervention, and this

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							whom SDR could be offered as part of research'. This document needs to explain why its conclusions are so significantly different from the IP guidance published in December 2010.	is why an 'only in research' recommendation has been made
312.	SH	North Bristol NHS Trust	10	Full	188	45	It would be relevant to discuss how it is proposed that this 'research' is going to be funded.	Discussion of potential funding streams is beyond the guideline development group's remit
313.	SH	North Bristol NHS Trust	11	Full	188	49	Although these six criteria are relevant to patient selection for SDR, other issues are equally important. These include femoral head cover on hip radiographs and changes on brain MRI scans. It also needs to be emphasised that children cannot be selected for SDR on the basis of lists of criteria alone. A formal multidisciplinary assessment is necessary, and each decision needs to be taken on an individual basis. In each case it needs to be confirmed that SDR is the optimal treatment for the child at that particular time, and all other options need to be considered. In addition, the multidisciplinary panel must take into account the family's expectations and ability to undertake rehabilitation.	The list provided is merely an indication of clinical criteria. The guideline elsewhere fully supports the importance of an individualised, goal-focused approach based on a multidisciplinary assessment
314.	SH	North Bristol NHS Trust	12	Full	189	20	SDR does not produce muscle weakness. By reducing spasticity, SDR unmasks the weakness inherent in spastic diplegia. This weakness recovers with physiotherapy. We do not believe that appropriately selected children will lose other skills, such as standing or walking, permanently after SDR.	The guideline developers have revised this section to emphasise the importance of post-operative strengthening physiotherapy. The reference to permanent loss of skills has been deleted
315.	SH	North	13	Full	189	31	Femoral head cover is an important	The developers have revised the text to highlight

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		Bristol NHS Trust					selection criterion for SDR. It is well established that children with a Reimer's index over 40% should undergo hip surgery prior to SDR. For lower levels of cover, SDR, by reducing hip adductor spasticity, has been shown to lead to an improvement.	the possible need for hip surgery before selective dorsal rhizotomy
316.	SH	North Bristol NHS Trust	14	Full	189	45	This paragraph is misleading. Intrathecal baclofen is hardly ever an alternative to SDR – in our experience, the two therapies work best for two different categories of CP children, SDR for GMFCS 2 to good 4's, ITB for GMFCS 5 and poor 4's. We would believe that only a very small number of children will overlap when evaluated by an experienced multidisciplinary panel. There is evidence that SDR is superior to botulinum toxin A injections (Wong et al, 2005).	Thank you for your comment. The guideline developers recognised that the usual groups for whom selective dorsal rhizotomy and intrathecal baclofen have been considered are indeed different. The evidence to recommendations section has been revised to clarify this
317.	SH	North Bristol NHS Trust	15	Full	190	1	This paragraph needs to clarify that SDR has been available in several institutions throughout the world over the last thirty years – these include, among others and apart from St Louis, other major cerebral palsy units such as Vancouver, Montreal, Milwaukee, Minneapolis-St Paul, New York and Cape Town as well as centres in Europe, Japan, Korea and Australia. I would agree that large long-term studies are lacking, but it is well known that such studies in cerebral palsy are particularly costly. I agree that we have an opportunity to address this in the UK.	Thank you for your comment. This change has been made
318.	SH	North	16	Full	190	14	We would not believe that clinical	This research recommendation does not place

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		Bristol NHS Trust					equipoise persists for SDR for spastic diplegia. We would not encourage the development of randomised controlled trials in the continued investigation of SDR for this indication.	any restriction on the study design to be used in future research. The guideline developers recognise that conducting further randomised controlled trials in this area could be difficult, but the research could equally be conducted using observational studies, or even non-comparative studies. The guideline developers do not believe that the current evidence is strongly in favour of offering selective dorsal rhizotomy to children and young people with spasticity
319.	SH	North Bristol NHS Trust	17	Full	211	7	We would agree that SDR is at least cost-neutral. We believe that SDR is almost certainly cost-effective; this would have to be studied formally within the NHS environment. From the tables in the document, despite the low patient numbers, there is a clear suggestion that the number of surgical episodes is lower for post-SDR patients. In our experience, the total inpatient days for SDR patients would probably be far lower than this. Early SDR has been shown to reduce the need for orthopaedic surgery more than late SDR (Chicoine et al, 1997). It also reduces the need for Botulinum toxin injections (£1440 per session in our paediatric hospital) and regular orthoses changes (up to £400 each). In addition, there are other issues where cost is hard to measure, including improved quality of life for the child and the family (including, as most parents say, relief of nocturnal leg pain and improvement in sleep), and improvement in mobility and independence.	Thank you for your comment. Determining the cost effectiveness of selective dorsal rhizotomy would require good quality data on long-term effectiveness and the risks related to treatment, which was not available from published literature. Thus, there remains considerable uncertainty surrounding the effectiveness of selective dorsal rhizotomy Further long-term research is needed as this is a costly and invasive treatment, although in carefully selected children and young people it may have considerable benefits that would include improvement in quality of life Health-related quality of life, which can be measured using child-friendly versions of standard tools, could be assessed at regular intervals in a long-term study and could be used to develop a cost effectiveness analysis

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320.	SH	North Bristol NHS Trust	1	Full	General		I note that there is no paediatric neurosurgical representation on this panel.	The guideline development group constituency was agreed by a scoping group that included staff from NICE, the NCC-WCH and the guideline development group chair. The scoping group sought views from registered stakeholder organisations on the guideline development constituency before guideline development began. The agreed guideline development group constituency included two paediatric neurologists and an orthopaedic surgeon with an interest in spasticity in children and young people. A further orthopaedic surgeon was appointed as an external adviser to the guideline development group in relation to neurosurgery, specifically selective dorsal rhizotomy
321.	SH	Royal College of General Practitioners	1	Full	General		The NICE guideline and the full guideline are thorough in their approach of spasticity in non progressive disorders as an isolated symptom and sign, seemingly focussed on evaluating newer, more complicated and more expensive treatments - surgical, intrathecal and injections. There was a GP in the GDG! It seems aimed at specialists tempted by them (in the face of challenging lack of progress or disability) and capable of prescribing or implementing them. There as a lack of context, holistic evaluation, how to ensure continuity, access benefits, respite care, equipment, carer support and support for the child or young person, very difficult. Clearly the guideline had to be limited in scope - but it could have been	The developers considered this concern carefully. As you point out the guideline was limited by the scope which excluded the holistic management of spasticity. Nevertheless the recommendations emphasise individualised care and appropriate goal setting throughout in partnership with the child or young person and their parents or carers. The developers have also revised the recommendations about how care is delivered in light of stakeholder comments generally to make the structure of care as flexible as possible by introducing the concept of a network team that ensures continuity of care. The developers have also added a new recommendation specifically about support groups

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							improved by having reference to these.	
322.	SH	Royal College of Nursing	1	Full	General		The Royal College of Nursing welcomes proposals to develop this guideline. It is timely.	Thank you for your comment
323.	SH	Royal College of Nursing	2	NICE	General		Many young people with cerebral palsy die prematurely from secondary respiratory infections yet there is no mention of dysphagia in the guideline at all. We, however, acknowledge that the scope does not cover the management of co-morbidities including feeding difficulties but it is not clear if this dealt with elsewhere. Will this be covered in another guideline? We consider that reference should be made in this guideline to that effect.	Dysphagia was not included in the guideline scope. The guideline developers are not aware whether any other NICE guidance is due to be developed for children and young people with dysphagia
324.	SH	Royal College of Nursing	3	NICE	General		Some individuals may find some of the language used offensive for example, 'deformity' where 'distortion' could be used, 'management' where 'care and support' could be used – we, however recognise that the word 'management' was used in the scope but consider that 'care and support's is a better term to use.	Thank you for your comment. The developers share the view that the word management is more in keeping with the guideline's scope and have continued to use it for consistency and because it is a relevant and commonly used clinical term. Careful consideration was given to whether the term deformity was potentially offensive but the developers concluded that it was used appropriately (that is, only in relation to specific clinical conditions where it would be the most commonly understood terminology amongst healthcare professionals). The developers were also concerned that the suggested alternative of distortion did not meet these criteria and could be misinterpreted
325.	SH	Royal College of Nursing	4	NICE	General		The guideline and proposals seem to be more of a medical model and owned by healthcare professionals rather than care in partnership with family and	The guideline recommendations emphasise many key aspects of the partnership between healthcare professionals and children and young people with spasticity, and their parents or carers,

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							person/ child/ family centred.	including the need for access to a network of healthcare professionals working in an integrated fashion. The guideline includes a key recommendation on the importance of partnership with the child or young person and their family in developing and implementing management programmes. In the revised guideline recommendations the concept of partnership with the child or young person and their family has been further strengthened. A specific example of where the recommendations have been inserted or revised to emphasise this are the new recommendation about carefully considering the impact of spasticity in children and young people with cognitive impairments and being aware that the possible benefit of treatments may be difficult to assess in a child or young person with limited communication. The revised guideline recommendations also emphasise the importance of the transition process being overseen by the network team
326.	SH	Royal College of Nursing	5	NICE	General		There does not appear to be any emphasis on transfer of skills and knowledge to families.	One of the guideline development group's key priorities for implementation covers these issues and makes explicit the need for information and education; the need for training for children and young people and their families is implicit. Further recommendations in the revised guideline contain specific reference to training for children and young people and their families, for example in relation to physical therapy programmes
327.	SH	Royal College of Nursing	6	NICE	General		The guideline suggests orthopaedic surgery as a 'fix' when some may consider that the real issue is often due to lack of competent, family based and evidenced postural care.	The guideline developers fully recognise the importance of postural care, and there are guideline recommendations regarding this intervention that aim to prevent or delay development of contractures and skeletal deformities. The recommendations regarding

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								orthopaedic surgery are made in the context of these recommendations, that is, in the knowledge that every child or young person with spasticity should have had physical therapy before surgery. The guideline developers have now included a recommendation that all children and young people with spasticity should be assessed promptly by a physiotherapist and, where necessary, an occupational therapist
328.	SH	Royal College of Nursing	7	NICE	General		In our view, publication of the guidelines without a radical rethink will perpetuate the perceived failure of therapy services over the past thirty years to protect or restore body shape, muscle tone and quality of life. The worry is that if the guidelines recommend interventions that are not suitable for the children/parents and carers, it will be a missed opportunity to improving the care and support of children with cerebral palsy. We would suggest working in partnership with parents/carers to identify appropriate interventions. This will aid implementation. As an example of ineffective intervention - for many years families have been directed to deliver "stretching" even though the Cochrane review of "stretching" concludes that it is ineffective. We are aware of a child who was put on	The guideline developers fully recognise the importance of working in partnership with parents and carers. Indeed, one of the key priorities for implementation emphasises the importance of this. The developers recognise the importance of physical therapy in its varied forms, and they made specific recommendations in this regard. One such recommendation is the one about taking account of the views of the child or young person and their parents or carers, the likelihood of achieving intended goals of treatment, and the implications for the child or young person and their family in implementing the plan (including time and effort involved and potential individual barriers) when formulating a physical therapy programme. The developers believe this recommendation addresses the concerns expressed by the stakeholder

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							the "at risk register" because the family refused to carry out a technique which they considered would hurt their child.	
329.	SH	Royal College of Nursing	8	NICE	General		We would welcome recommendations for the training of those who care for children with cerebral palsy so that they can combine their knowledge of the child together with their understanding of the condition to make sure the child receives quality care, provided with dignity and respect.	One of the guideline development group's key priorities for implementation covers these issues and makes explicit the need for information and education; the need for training for children and young people and their families is implicit. Further recommendations in the revised guideline contain specific reference to training for children and young people and their families, for example in relation to physical therapy programmes
330.	SH	Royal College of Nursing	9	NICE	General		The guidelines as they stand do not seem offer consideration to the impact of medically induced alteration of tone to thermoregulation issues; particularly when the population involved may be compromised with regard to both reflex and heat seeking/heat avoidance components of thermoregulation.	Thank you for this comment. The guideline developers recognise the concerns about thermoregulation in some children and young people with spasticity. The group did not, however, consider that the treatments considered in the guideline would have an impact on this
331.	SH	Royal College of Nursing	1	NICE	9	21	Add as an additional paragraph "Equipment provision • Ensure timely provision of any orthotic or postural support equipment that is needed to enhance the effects of the treatments above and to ensure long term benefit"	The revised guideline includes a recommendation stating that the network team should ensure that children and young people have timely access to any equipment that is relevant to their needs and management programme (for example, postural management equipment such as sleeping, sitting or standing systems)
332.	SH	Royal College of Nursing	1	NICE	8	8	Replace 'Management' with 'care and support'	The developers considered that the word management is more in keeping with the guideline's scope and have continued to use it for consistency and because it is a relevant and commonly used clinical term
333.	SH	Royal College of	1	NICE	8	12	Add " - related to objective outcomes"	The developers agreed that objective outcome measures could be a useful way of assessing

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		Nursing						achievement of goals for some children and young people. However, they considered it would be unhelpful to add this without further guidance about what measures should be used. As this would depend on the child or young person's individual needs it would not be possible to give comprehensive advice in a recommendation aimed at all children and young people covered by the guideline
334.	SH	Royal College of Nursing	1	NICE	10	1.1.4	Under the heading "Offer a management programme that is.." add: • " in line with government policy regarding patients and their families accessing individualised health budgets"	This change has not been made because none of the evidence reviewed for the guideline was relevant to the suggested amendment, nor are the issues referred to in the suggestion clearly within the guideline development group's remit
335.	SH	Royal College of Nursing	1	NICE	8	16	Replace 'Management' with 'care and support'	The developers considered that the word management is more in keeping with the guideline's scope and have continued to use it for consistency and because it is a relevant and commonly used clinical term
336.	SH	Royal College of Nursing	1	NICE	8	17	Re word to read: " relevant information, educational materials and accredited training"	The developers considered that training has been covered where relevant in the physical therapy recommendations. There is a recommendation that the training the child or young person or their parents or carers might need should be taken into account when considering who should deliver physical therapy. There is also a recommendation that parents and carers involved in delivering postural management programmes should be offered training
337.	SH	Royal College of Nursing	1	NICE	8	20	Add in 'family based training' as an additional bullet point	The developers considered that training has been covered where relevant in the physical therapy recommendations. There is a recommendation that the training the child or young person or their parents or carers might need should be taken into

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								account when considering who should deliver physical therapy. There is also a recommendation that parents and carers involved in delivering postural management programmes should be offered training
338.	SH	Royal College of Nursing	1	NICE	8	21	Insert "Suitable orthotic and postural support equipment which may include appropriate wheelchairs and sleep systems"	The revised guideline includes a recommendation stating that the network team should ensure that children and young people have timely access to any equipment that is relevant to their needs and management programme (for example, postural management equipment such as sleeping, sitting or standing systems)
339.	SH	Royal College of Nursing	1	NICE	10	25	1st bullet point in section 1.1.5 - Re-word to read: " relevant information, educational materials and accredited training"	The developers considered that training has been covered where relevant in the physical therapy recommendations. There is a recommendation that the training the child or young person or their parents or carers might need should be taken into account when considering who should deliver physical therapy. There is also a recommendation that parents and carers involved in delivering postural management programmes should be offered training
340.	SH	Royal College of Nursing	1	NICE	11	16	After 2nd bullet point in section 1.1.6: Insert • Symmetry of body shape	The developers considered that this would be covered by the bullet about secondary consequences of spasticity
341.	SH	Royal College of Nursing	2	NICE	11	9	After 2nd bullet point in section 1.1.7: Insert • Will protect and restore their body shape in line with World Health Organisation's recommendation to provide postural care Ref: World Health Organisation "Better Health, better lives: children and young	The recommendation reflects the World Health Organization's International Classification of Functioning, Disability and Health terminology, namely body function and structure and activity and participation (see World Health Organization International Classification of Functioning, Disability and Health, available from www.who.int/classifications/icf/en/.). Several stakeholders have expressed satisfaction with this approach

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							people with intellectual disabilities and their families" priority 5 "Ensure good quality mental and physical health care" EUR/51298/17/PP/5 October 2010	
342.	SH	Royal College of Nursing	2	NICE	8	26	Add" - monitor for dysphagia - Monitor for pain and distress" as additional bullet points	The developers agree that pain is an important consequence of spasticity and have now included it in the recommendation. The scope does not include the management of dysphagia
343.	SH	Royal College of Nursing	2	NICE	9	1	Orthopaedic surgery should be considered only after all non invasive interventions have been explored especially good quality family based postural care including night time sleeping position awareness.	The guideline developers fully recognise the importance of postural care, and there are guideline recommendations regarding this intervention that aim to prevent or delay development of contractures and skeletal deformities. The recommendations regarding orthopaedic surgery are made in the context of these recommendations, that is, in the knowledge that every child or young person with spasticity should have had physical therapy before surgery
344.	SH	Royal College of Nursing	2	NICE	12	1.2	It is hard to understand the rationale for the emphasis in Section 1.2 on various physiotherapy treatments, which seem to be contrary the findings of Bower's (2001) randomised controlled trial which indicated that:- "The results of this trial suggest that for children aged 3 – 12 years with bilateral CP at levels 111 or below on the GMPCS, altering their routine physiotherapy by increasing its intensity for a period of six months has very little effect upon the outcome of gross motor function or performance at the end of this time." Bower, E., Mitchell, D., Burnett, M.,	Thank you for your comment. The introduction to the chapter on physical therapy has been expanded to explain the guideline developers' prioritisation of active-use therapy and other techniques that contribute to the objectives of strengthening, stretching and postural management for consideration in the review conducted for the guideline Bower 2001 reports outcomes for a variety of techniques administered with routine or enhanced intensity. Comparison between different intensities of physical therapy when applied to multiple techniques with mixed aims was not included in the guideline review protocol. The guideline does include a recommendation which addresses intensity of a specific technique (task-focused active-use therapy) because evidence was

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							Campbell, M. J. and McLellan, D.L. (2001) Randomized Controlled Trial of Physiotherapy in 56 children with cerebral palsy followed for 18 months. APCP Journal September 2001 Issue 100 p22 – 40	identified for inclusion in this respect
345.	SH	Royal College of Nursing	2	NICE	12	18	After 1st bullet point in section 1.2.2: Insert • Protecting and restoring body shape	The developers considered that the meaning of this suggestion would be covered by the bullet about delaying or preventing complications
346.	SH	Royal College of Nursing	2	NICE	12	25	After 1st bullet point in section 1.2.3: Insert • The need for the child and family to self manage the condition	The guideline developers recognise that physical therapy might often be delivered by the child or young person or their family as part of self-management. The recommendation about considering who should deliver physical therapy specifically acknowledge this
347.	SH	Royal College of Nursing	2	NICE	12	28	After 2nd bullet point in section 1.2.3: Insert • The need for timely provision of orthotic and postural support equipment	Thank you for your comment which highlighted an omission in the recommendations. The developers have added a recommendation that the network team should ensure that children and young people have timely access to any equipment that is relevant to their needs and management programme (for example, postural management equipment such as sleeping, sitting or standing systems) to the principles of care section as this would be relevant to all interventions, not just physical therapy
348.	SH	Royal College of Nursing	2	NICE	13	26	After 2nd bullet point in section 1.2.9: Insert • Offer objective measurement of body symmetry	The developers considered that this would be covered by the bullet about secondary consequences of spasticity
349.	SH	Royal College of Nursing	2	NICE	15	1.3	Suggest change heading to read: 1.3 Orthoses and postural support systems	The developers have reviewed all the headings in the recommendations and standardised them where possible

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350.	SH	Royal College of Nursing	2	NICE	15 19	General	Section 1.3- Throughout this section equipment should be referred to as "orthoses and postural support systems" as appropriate. There is no point in having an acceptable orthosis and then leaving a child in a wheelchair that does not fit or which restrains them in an inappropriate upright position so that they fall forwards and/or sideways. Leaving a child in a destructive posture for ten hours each night will have a negative impact on their body shape, balance and spasticity.	Thank you for your comment which highlighted an omission in the recommendations. The developers have added a recommendation that the network team should ensure that children and young people have timely access to any equipment that is relevant to their needs and management programme (for example, postural management equipment such as sleeping, sitting or standing systems) to the principles of care section as this would be relevant to all interventions, not just orthoses
351.	SH	Royal College of Nursing	3	NICE	15	1.3.1	Suggest re-word to read: "Consider orthoses and postural support systems, including sleep systems and wheelchairs for children and young people with spasticity to:"	Thank you for your comment which highlighted an omission in the recommendations. The developers have added a recommendation that the network team should ensure that children and young people have timely access to any equipment that is relevant to their needs and management programme (for example, postural management equipment such as sleeping, sitting or standing systems) to the principles of care section as this would be relevant to all interventions, not just orthoses
352.	SH	Royal College of Nursing	3	NICE	15	1.3.1	In the list of bullet points add: • Protect and restore critical proportions of the chest to maintain optimal internal capacity of the abdomen and thorax Reference: Hill, S and Goldsmith, J (2010). Biomechanics and prevention of body shape distortion The Tizard learning Disability Review Vol 15 Issue 2	The publication cited in the comment was not included in the review as it did not meet the inclusion criteria. The developers recognise this very specific suggestion may be an important consideration for some children and young people, however, they considered that it was a somewhat less common clinical indication overall. They concluded that this is covered indirectly by the bullet in the recommendation about considering orthoses to improve posture and later in the guideline in the recommendations about

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							pages 15-29. 2010	using body trunk orthoses for the management of spasticity with co-existing scoliosis or kyphosis
353.	SH	Royal College of Nursing	3	NICE	18	1.3.15	Add the following bullet points: • Provide a sleep system along with the necessary training for the child and carers so that it is used properly and safely • Consider the implications regarding behavioural response of the child, • Consider achieving thermal comfort when both the behavioural and reflex components of thermoregulation may be compromised • Train and support the family/carer to carry out comprehensive Safety Planning for the introduction of therapeutic night positioning • Train the family/carer so that they can combine specialist knowledge with their encyclopaedic understanding of the child's condition and of the child, to make safe and humane decisions as the child's condition changes on a daily basis	Thank you for this comment The revised guideline includes a recommendation stating that the network team should ensure that children and young people have timely access to any equipment that is relevant to their needs and management programme (for example, postural management equipment such as sleeping, sitting or standing systems) The developers considered that training is covered where relevant in the physical therapy recommendations. There is a recommendation that the training the child or young person or their parents or carers might need should be taken into account when considering who should deliver physical therapy. There is also a recommendation that parents and carers involved in delivering postural management programmes should be offered training The developers recognise the concerns about thermoregulation in some children and young people with spasticity. The group did not, however, consider that the management options considered in the guideline would have an impact on this The developers considered that the point that implications regarding the behavioural response of the child or young person should be considered was covered by the recommendation that states that the management programme should take into account its possible impact on the individual child

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								or young person and their family. The developers also felt that the issue of combining the knowledge of parents or carers with that of healthcare professionals was covered by the recommendation that states that network team should help children and young people and their parents or carers to be partners in developing and implementing management programmes
354.	SH	Royal College of Nursing	3	NICE	9	16	After Orthopaedic Surgery... add Orthopaedic surgery should not be offered without adequate postural care	The revised guideline includes a recommendation to provide an appropriately adapted physical therapy programme after treatment with orthopaedic surgery, as an essential component of the treatment programme
355.	SH	Royal College of Nursing	3	NICE	9	18	Replace 'deformity' with 'distortion'	Careful consideration was given to whether the term deformity was potentially offensive but the developers concluded that it was used appropriately (that is, only in relation to specific clinical conditions where it would be the most commonly understood terminology amongst healthcare professionals). They were also concerned the suggested alternative of distortion did not meet these criteria and could be misinterpreted
356.	SH	Royal College of Nursing	3	NICE	9	20	Replace 'deformity' with 'distortion' and add "that displacement should be evidenced by the taking of regular and accurate body shape measurements"	This recommendation has been merged with another and therefore the comment is no longer relevant
357.	SH	Royal College of Nursing	3	NICE	General		It was very difficult to comment on this version of the guideline; there were no line numbers to refer to, which meant that reviewers had to physically count the lines in order to make appropriate reference to the page/ line the comments relate to.	Thank you for your comment. The template for the NICE guideline is determined by NICE and the consultation draft was published in accordance with this

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358.	SH	Royal College of Nursing	3	NICE	4	11	After "…secondary complications of spasticity" insert "Secondary complications of motor disorders in general can lead to the development of habitual destructive postures which lead to distortion of body shape, predictable patterns of chest distortion and reduction of internal capacity of the abdomen and thorax"	Other stakeholders requested that the introduction be shortened considerably and this has been achieved by removing some of the more technical aspects of the previous text. To add in the further details requested by this stakeholder would run counter to the general aim of shortening the introduction and so this change has not been made
359.	SH	Royal College of Nursing	3	NICE	4	12	After "Therapy should be tailored to meet the problems faced by the individual child or young person" insert "and should be home based and family centred with the emphasis on transferring clinical skills to the main carers (usually parents and/or siblings). Any therapy provided should be evidence based and have demonstrable positive outcomes for the child."	Other stakeholders requested that the introduction be shortened considerably and this has been achieved by removing some of the more technical aspects of the previous text. To add in the further details requested by this stakeholder would run counter to the general aim of shortening the introduction and also the suggested additions do not reflect any specific recommendations contained in the guideline. This change has, therefore, not been made
360.	SH	Royal College of Nursing	3	NICE	6	5	After "….patient's needs and preferences" insert "with the intention of enabling the family and carers to self manage the	This section is standard text in the NICE guideline template, but it is agreed that the standard text is not entirely appropriate for the population covered by this guideline. The Patient and Public Involvement Programme at NICE has offered to

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							condition in line with Department of Health guidelines and personal health budgets"	help the NICE editor ensure that this section is made appropriate for the population covered by the guideline, and the guideline developers welcome this. The guideline developers have made the NICE editor aware of this comment
361.	SH	Royal College of Nursing	4	NICE	6	18	After "Good communication between healthcare professionals and patients is essential" insert "and needs to lead to robust person centred care planning that is supported by evidence-based written information tailored to the patient's needs	This section is standard text in the NICE guideline template, but it is agreed that the standard text is not entirely appropriate for the population covered by this guideline. The Patient and Public Involvement Programme at NICE has offered to help the NICE editor ensure that this section is made appropriate for the population covered by the guideline, and the guideline developers welcome this. The guideline developers have made the NICE editor aware of this comment
362.	SH	Royal College of Paediatrics and Child Health	1	Full	General	General	This is a clear and comprehensive document.	Thank you for your comment
363.	SH	Royal College of Paediatrics and Child Health	2	Full	General	General	Is it too late to consider the editorial in the current November Dev. Med. (From 'one size fits all' etc. Mayston M ; 53: 11, page 969) which makes a number of good points and includes 10 relevant references?	The cut-off date for the systematic searches was 8 August 2011 and no publications published after that date will be included. The publication cited in the comment is an editorial rather than a primary research report and so it would be excluded in any case. The developers have, however, considered the list of publications cited in the editorial, all of which were published before the cut-off date for the searches. Two articles published in 2011 (Law 2011; Sakzewski 2011) were not identified in the systematic searches conducted for the guideline and they are relevant to the review question on physical therapy. These

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								publications have now been included in the guideline, although their inclusion has not changed any of the recommendations
364.	SH	Royal College of Paediatrics and Child Health	3	Full	General	General	In general it is a useful guideline. We are disappointed that there is no mention of sleep systems in the guidance. These are currently popular with therapists but also costly and it would be good to have guidance about their use (or not). Para 1.7.6 is poorly worded and hard to understand. There is no mention of how those administering botulinum should be trained to do so.	The revised guideline includes a recommendation stating that the network team should ensure that children and young people have timely access to any equipment that is relevant to their needs and management programme (for example, postural management equipment such as sleeping, sitting or standing systems)
365.	SH	Royal College of Paediatrics and Child Health	4	Full	5	1.4.4	Should also include "promotes independence".	Thank you for your comment. The developers considered that this would be an important issue for some children and young people more than others and would be covered by the recommendation that the management programme should be individualised and goal focused
366.	SH	Royal College of Paediatrics and Child Health	5	Full	14	1.5.74	Should include "entenox".	The developers considered that this was already covered by the term analgesic and they did not wish to be more specific about particular drugs to be used
367.	SH	Royal College of Paediatrics and Child Health	6	Full	19	103	Orthopaedic surgeons are an integral part of the multi-disciplinary team that manages each child or young person with cerebral palsy and should be part of the team from the point of diagnosis onwards, so that, for example, the highest standards of hip surveillance are being practiced, with correct interpretation of clinical and radiological	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthopaedic surgeon within the network team has been emphasised in the revised recommendations. The developers have also revised the recommendations on surgical

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							assessments. This is especially important as at the moment, the guideline does not give any clear guidance about hip surveillance where the first x-ray shows no or minimal hip migration. Holistic assessment of the child or young person is about more than hip surveillance and orthopaedic surgeons bring specific expertise to the team that is essential for many aspects of assessment. Orthopaedic surgeons should be considered as integral team members who bring expert clinical skills, rather than a colleague to refer to when the hips start migrating. This latter approach risks referrals being made too late, such that more invasive interventions may be required. This may well have implications for the numbers of paediatric orthopaedic surgeons required to provide such a service, but is essential if the highest standards of care are to be delivered in an equitable way. We would like to suggest that all children with evidence of spinal deformity should be referred to a specialist spinal orthopaedic surgeon, rather than just 'an orthopaedic surgeon', as specific expertise is required to monitor and manage the spine and not all orthopaedic surgeons have this expertise.	assessment to highlight when expert advice should be sought The developers have revised the recommendations about clinical and radiological monitoring of the hip and made a new recommendation that requires that the network's agreed care pathways include a pathway for hip monitoring to ensure the timely referral to expert care The developers have made a recommendation that states that surgeons should be experienced in in the concepts and techniques of performing orthopaedic surgery in children and young people with spasticity and considered that this would cover the request for specialist spinal surgeons
368.	SH	Royal College of Paediatrics	7	Full	19 (and	108 (and 13-	With regard to hip surveillance, although recommendation 108 (page 19) offers advice if there is increased migration	The developers have revised the recommendations on clinical and radiological monitoring to clarify which children and young

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		and Child Health			164)	30)	percentage (x-ray every 6 months), there is no guidance about the frequency of x-rays required at the different GMFCS levels if the original x-ray shows no or minimal migration. It would be most helpful if the guideline could be clear on this, as it is an area where a big difference could be made, as evidence by experience in the Nordic countries and Australia. It is very disappointing that the guideline does not give clear advice on this as the evidence is substantial and important publications have not been considered. Please can the GDG consider this and ensure such advice is included, weighing up the potential for benefit with risks of radiation exposure, especially to developing reproductive organs. It would be helpful if the guideline discussed the evidence for and against other ways than x-ray of doing hip surveillance, for example, fluoroscopy and the economics around these alternatives. Important references not considered in the guideline include: Hagglund G, Andersson S, Duppe H, Lauge-Pedersen H, Nordmark E, Westbom L. Prevention of dislocation of the hip in children with cerebral palsy: the first ten years of a population based prevention programme. *J bone Joint Surg* 2005;87-B:95-101 and Wynter M, Gibson N, Kentish M, Love SC,	people should be offered X-rays and/or referred for surgical assessment. In particular they have recommended healthcare professionals within the network team should consider offering annual X-rays for children and young people in GMFCS level III, IV or V. The developers did not consider it appropriate to recommend repeat X-rays for those in GMFCS level I or II. They have, however, emphasised the need for clinical monitoring and recommended that a surgical assessment should be undertaken if, at any stage, there is concern, based on either clinical findings or radiological monitoring, about hip displacement or spinal deformity

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							Thomason P, Graham HK. Consensus statement on hip surveillance for children with cerebral palsy: Australian standards of care. Australasian Academy of cerebral palsy and developmental medicine. 2008. www.cpaustralia.com.au/ausacpdm Graham, H.K., *Consensus statement on hip surveillance for children with cerebral palsy*, in *The First international meeting on the management of the hip in cerebral palsy*. 2010: Liverpool. Gordon, G.S. and Simkiss, D.E., *A systematic review of the evidence for hip surveillance in children with cerebral palsy.*Journal of Bone & Joint Surgery - British Volume, 2006. **88**(11): p. 1492-6.	
369.	SH	Royal College of Paediatrics and Child Health	8	Full	20	1.5.1 11	Assess child and families engagement in post-operative rehabilitation.	Thank you for your comment. The developers agree with the need to engage the family in post-operative rehabilitation and felt that this had been covered in the recommendation to discuss and agree with the child or young person and their parents or carers a rehabilitation programme and how and where it will be delivered before undertaking surgery. Recommendations that appear earlier in the guideline have been clarified and strengthened to ensure that children and young people and their parents or carers understand the need for physical therapy following orthopaedic surgery
370.	SH	Royal College of	9	Full	23	1.6.1 9	Assess false positive and false negative rate for ITB test doses.	This (key) research recommendation is about evaluating the clinical and cost effectiveness of

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		Paediatrics and Child Health						continuous pump-administered intrathecal baclofen. It is not possible to include research on intrathecal baclofen testing in this research recommendation. The guideline developers have, however, included in the revised guideline a new research recommendation for evaluating the predictive accuracy of intrathecal baclofen testing for identifying those children and young people who respond well to continuous pump-administered intrathecal baclofen treatment
371.	SH	Royal College of Paediatrics and Child Health	10	Full	28	44	The reference on SCPE required is: http://www-rheop.ujf-grenoble.fr/scpe2/site_scpe/index.php It would be helpful if classification of CP was consistent throughout the guideline to avoid confusion and facilitate comparison of like-with-like. Classification (as per SCPE) should be: • Unilateral • Bilateral • Spastic predominant • Dyskinetic predominant (with dystonic predominant and choreo-athetoid predominant subtypes) • Ataxic.	Thank you. The correct Surveillance of Cerebral Palsy in Europe reference has now been inserted The terminology in the recommendations has been revised as suggested. The developers have continued to use alternative terms in the full guideline where necessary. Further explanation can be found in the introduction to the full guideline
372.	SH	Royal College of Paediatrics and Child Health	11	Full	29	3-4	Although the grading system suggested is simpler than the GMFCS, the guideline ought to promote the universal use of the GMFCS otherwise this will make comparisons of outcomes between different groups and services very challenging.	As the Gross Motor Functional Classification System is not yet widely used and understood by non-healthcare professionals, it may be appropriate to use a simpler grading system when communicating with schools, for example. This has been clarified in the text

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373.	SH	Royal College of Paediatrics and Child Health	12	Full	29	5-7	MACS has been validated much more than e.g. BMFM and is the more widely accepted tool for assessing u/l function. See references: Eliasson AC, Krumlinde Sundholm L, Rösblad B, Beckung E, Arner M, Öhrvall AM , Rosenbaum P The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability *Dev Med Child Neurol* (2006), 48: 549-554 Plasschaert VF, Ketelaar M, Nijnuis MG, Enkelaar L, Gorter JW. Classification of manual abilities in children with cerebral palsy under 5 years of age: how reliable is the Manual Ability Classification System? Clin Rehabil. 2009 Feb;23(2):164-70. Imms, Carlin J, Eliasson AC. Stability of parent reported manual ability and gross motor function classification of cerebral palsy Dev Med Child Neur, 2009 May 21	The developers recognise the strengths of the Manual Ability Classification System and have highlighted its potential value in the introduction to the guideline
374.	SH	Royal College of Paediatrics and Child Health	13	Full	154	General	The chapter on 'Orthopaedic Surgery', didn't appear to include *assessment in a gait lab* prior to any decision about surgery.	Evaluation of the effectiveness of gait analysis using a machine in a gait laboratory (or otherwise) was not prioritised for consideration in the guideline and so it is not covered specifically in the chapter on orthopaedic surgery. The developers' did, however, extract details of gait analysis where it was relevant to the reviews conducted for the guideline (for example, in relation to reports of walking velocity in studies

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								that evaluated the effectiveness of orthoses)
375.	SH	Royal College of Paediatrics and Child Health	14	NICE	General	General	This is a helpful guideline that should aid the management of spasticity in children and young people. Welcome advice is offered throughout on communication between local multidisciplinary teams and more specialised regional teams.	Thank you for your comment. The developers have changed the terminology around delivery of care to define a network of care which incorporates local and regional services. The recommendations continue to emphasise the need for good communication between professionals in the network
376.	SH	Royal College of Paediatrics and Child Health	15	NICE	General	General	The recommendations will have significant implications for how services are delivered for children and young people with motor disorders including cerebral palsy and it would be helpful for this to be made explicit in the guideline as a driver to raising standards of competent care in an equitable way. Not all districts offer specialist care for this group of children and young people; for example, many child development units only see pre-school children, with many children with motor disorders including cerebral palsy being seen in general and community paediatric clinics by clinicians with variable levels of expertise. We welcome these recommendations, especially the requirement for the team members to be experienced in the management of spasticity but would welcome a clearer message about the need for specialist, competent care.	Thank you for your comment. The developers acknowledge that delivery of care varies from area to area and have revised the recommendations by replacing the local multidisciplinary child development team with a more flexible structure called the network team. Within this the recommendations continue to emphasise what expertise should be available to all children and young people at a local or regional level and the need for professionals in the network team to be experienced in the management of spasticity in this group. The importance of this being implemented with a view to increasing consistency of care across England and Wales has been indicated by identifying it as a key priority for implementation
377.	SH	Royal College of Paediatrics and Child Health	16	NICE	General	General	It is good to see that the ICF is embedded throughout the guideline, that the views of the individual and their family are given such prominence and that planning goals with the individual	Thank you for your comment

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							and their family in a holistic way is encouraged.	
378.	SH	Royal College of Paediatrics and Child Health	17	NICE	General	General	This guideline usefully describes individual components of treatment but not a cohesive strategy for any individual. Therefore, it is not possible to determine the best evidenced-based treatment of unilateral or bilateral CP from detection to adulthood. Such developmentally based guidance would be most helpful.	The developers considered this concern carefully. The recommendations emphasise individualised care and appropriate goal setting throughout in partnership with the child or young person and their parents or carers, supported by appropriate monitoring to inform changes to the management programme throughout the child or young person's development. The developers have also revised the recommendations about how care is delivered in light of stakeholder comments generally to make the structure of care as flexible as possible by introducing the concept of a network team that ensures continuity of care. The developers have also added new recommendations specifically about support groups and transition to adult services
379.	SH	Royal College of Paediatrics and Child Health	18	NICE	General	General	Unilateral and bilateral cerebral palsy should be used as descriptors consistently (rather than the intermittent use of other terms such as diplegia).	Thank you for your comment. The terminology in the recommendations has been revised as suggested. The developers have continued to use alternative terms in the full guideline where necessary. Further explanation can be found in the introduction to the full guideline
380.	SH	Royal College of Paediatrics and Child Health	1	NICE	10	1.1.1	The principle of linking local multidisciplinary teams to regional specialist centres is excellent, but in practice co-ordinated care is not always well managed nor appropriately funded. It would be helpful to make some reference to these challenges by including a recommendation in the Principles of Care section such as – 'Wherever possible, care should be provided through appropriately funded clinical networks involving local	The developers have revised the recommendations and adopted your suggested terminology of a network. In particular the recommendations in the principles of care section have been revised to make it explicit what expertise would be needed in the network team at a local and regional level. This structure is deliberately flexible as the complexity of the condition entails that it would not always be appropriate for the same healthcare professionals to be involved in the care of every child or young person

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							multidisciplinary teams and regional specialist centres'.	
381.	SH	Royal College of Paediatrics and Child Health	2	NICE	10	1.1.1, 1.1.2, 1.1.3	It is recommended that a locality should have a team for children and young people with spasticity linked to a regional centre. Members of the team are specified. However, it would be really helpful if there could be some mention of the network of skills required to guide service provision based, for example, on the estimated prevalence of those who require botulinum treatment or hip surgery or the other treatments related to spasticity management that are discussed in the guideline.	Thank you for your comment. The developers have revised the recommendations and adopted your suggested terminology of a network. In particular the recommendations in the principles of care section have been revised to make it explicit what expertise would be needed in the network team at a local or regional level. Unless otherwise specified it implicit that the person doing the action would be the most appropriate member of the network team. This structure is deliberately flexible as the complexity of the condition entails that it would not always be appropriate for the same healthcare professionals to be involved in the care of every child or young person
382.	SH	Royal College of Paediatrics and Child Health	2	NICE	11 12	1.1.10, 1.1.11, 1.1.12	These 'general principle' recommendations seem out of place and may be better included in the later sections dealing with the individual treatments mentioned.	The developers have reviewed the sequence of recommendations throughout the guideline and reorganised them as appropriate. In particular, two of the recommendations highlighted in the comment are now in the section on physical therapy
383.	SH	Royal College of Paediatrics and Child Health	2	NICE	12	1.1.12	Good communication between regional specialist centres and local multidisciplinary teams is very important. This could be facilitated if there was a recommendation in this Principles of Care section for spasticity management services to be provided through appropriately funded clinical networks.	Thank you for your comment. The developers have revised the recommendations and adopted your suggested terminology of a network. The recommendations continue to emphasise the need for good communication between professionals in the network
384.	SH	Royal College of Paediatrics and Child Health	23	NICE	19 24	1.4 and 1.5	Pain due to spasticity. In section 4, certain oral drugs are suggested for use in pain. In section 1.5 botulinum toxin is suggested as a treatment for focal pain. Could guidance be given as to when to try each of these treatments (is a	It is difficult to give a precise recommendation to determine which of these drugs is to be preferred in an individual child or young person. More than one indication may, for example, lead to a decision to use a particular form of drug treatment

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							particular sequence recommended?).	
385.	SH	Royal College of Paediatrics and Child Health	24	NICE	21	1.5	At what age should botulinum toxin be considered? Is there a minimum age?	The developers considered this issue in relation to all sections of the guideline and concluded that it would be inappropriate to specify any age groups in the recommendations because development in this population is highly individualised. Instead they considered that decision making should be based on clinical indications and individual needs. This is made explicit in this section of the guideline in the recommendations that state when to consider botulinum toxin (for example, one would be less likely to consider botulinum toxin for a very young child based on lack of fine motor function in the upper limb as this would not be expected at such an age anyway). The developers acknowledge that the guidance is not as specific as that given in the summary of product characteristics for this drug and have added a footnote to clarify when informed consent is needed

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386.	SH	Royal College of Paediatrics and Child Health	25	NICE (and Full)	43 (and 164)	1.7.5	Hip Surveillance in CP I am concerned that reference in text doesn't include the Consensus Statement on Hip Surveillance for Children with Cerebral Palsy: Australian Standards of Care 2008. An International Meeting on the Management of the Hip in Cerebral Palsy: Liverpool 11/2/2010 came to a consensus of slightly less aggressive surveillance than the Australian guidance The Greater Manchester Cerebral Palsy network held a meeting of interested professionals in 2010 to discuss the Australian Guidance and Liverpool presentations We concluded that- For 'severe' unilateral CP (extensive plantar flexion of the ankle with limited ROM at the knee and hip during swing and stance phase) and bilateral CP GMFCS III hip x rays should be annual from 30 months until skeletal maturity For bilateral CP GMFCS IV and V first hip x ray should be at 18 months and annually until skeletal maturity As in 1.7.5 the following are cause for concern suggesting need for hip x-ray: • Significant tonal abnormality • Reduction of abduction range <	Thank you for your comment. The developers considered your concerns carefully and have revised the recommendations on clinical and radiological monitoring to clarify which children and young people should be offered X-rays and/or referred for surgical assessment to identify possible hip displacement. It was not possible to include these publications in the systematic review, as they did not meet the inclusion criteria. However the developers were aware of the publications through clinical practice and took account of them when redrafting their recommendations. For example, they now recommend that the network team should consider performing annual X-rays in all children and young people with bilateral cerebral palsy in GMFCS level III, IV or V. The developers' deliberations about these publications are detailed in full in the translation of evidence to recommendations for the orthopaedic surgery chapter

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							30 degrees • Asymmetry of range of movement especially abduction • Leg length discrepancy/ scoliosis • Asymmetrical posterior skin crease • Hip pain/ persistent disturbed sleep • Parents report problem with cares • Developmental dysplasia of the hip.	
387.	SH	Royal College of Physicians		Full	General		The RCP wishes to endorse the response submitted by the BSRM on this consultation.	Thank you for your comment
388.	SH	Royal College of Psychiatrists	1	Full	General		Our comments are as follows; from the little the contributor knows it looks very good.	Thank you for your comment
389.	SH	Royal College of Psychiatrists	2	full	General		The emphasis is person centred which is always as an extra in physical health.	Thank you for your comment
390.	SH	Royal College of Psychiatrists	3	Full	General		Some information about support groups for information and support would help.	The guideline developers have included a new recommendation about offering children and young people and their parents or carers contact details of patient organisations that can provide support, befriending, counselling, information and advocacy. NICE does not permit specific patient organisations to be recommended, but the lay version of the guideline (Understanding NICE

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								Guidance) will include details of relevant organisations
391.	SH	Scope	2	NICE	3	6	as a group of practitioners we would like to raise a query as to the definition of muscle spasticity. Current published research may question the involvement of velocity; referring to spasticity surrounding the muscle being in a heightened state of readiness. It would be very useful to have the reference attached to aide understanding.	According to the template, citations for background information are not normally included in the introduction to the NICE guideline. The corresponding section of the full guideline does provide references
392.	SH	Scope	3	NICE	3	21	again references are required to validate data collection	According to the template, citations for background information are not normally included in the introduction to the NICE guideline. The corresponding section of the full guideline does provide references
393.	SH	Scope	4	NICE	3	27	Interesting point - the link with chronic gastrointestinal disorders but emphasis here is spasticity as an effect rather than the causation, does this also need to be reflected.	Thank you for your comment. The developers agree that these disorders do not in themselves make spasticity worse but increase the impact that spasticity has on the child or young person. The introductory text in the NICE guideline has been shortened considerably to conform to the NICE template and the text referred to in the comment was deleted as part of this editing. The introduction in the full guideline has, however, been edited to reflect the issues raised by the stakeholder
394.	SH	Scope	5	NICE	4	20	we acknowledge that the GMFS is a good reference for functional classification (but is not a measure for spasticity alone) so it would be more useful to know if there is a more appropriate measure for baseline spasticity.	Thank you for your comment. Spasticity-specific outcome measures have been taken into account in the systematic reviews that underpin the guideline recommendations. The Gross Motor Function Classification System (GMFCS) is, however, the only standardised outcome measure cited in the recommendations and that is why it is defined here. The GMFCS is not used in isolation

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								in the recommendations, but alongside clinical indications that include spasticity
395.	SH	Scope	6	NICE	4	23	should include the evaluating of therapy intervention as you cannot select and use the most appropriate interventions unless you can weigh them up against practice. this guideline as a document doesn't help inform choices based on evidence based practice, it simply provides an overview without reference to information sources	Thank you for your comment. The developers considered this point carefully but concluded that it would not be possible to be entirely prescriptive about which of the interventions considered in the guideline would be most appropriate in every case due to the complexity of the condition and the variation in the individual needs of children and young people whose care the guideline is intended to cover. The developers have strived to provide comprehensive advice about the clinical indications for specific interventions and the need for them to always be considered within the context of the child or young person's overall management plan. They have also recommended that all children and young people have access to a network of care that will provide access to a team of healthcare professionals experienced in the care of children and young people with spasticity. These healthcare professionals should, therefore, be capable of using their clinical judgment to determine the relative value of treatments at an individual level The text referred to in the comment has been deleted from the introduction to the NICE guideline as part of the editing process. The corresponding text in the full guideline introduction sets the scene for the guideline developers' consideration of the evidence and formulation of recommendations taking account of the evidence and it has, therefore, been retained
396.	SH	Scope	7	NICE	8	12	evidence based practice should be at the forefront using outcome measures to justify interventions and support costings	The developers have strived to provide evidence-based recommendations for practice. Given the paucity of evidence in this field, however, clinical

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							to ensure access and provision of facilities e.g. hydrotherapy. Consistency within best practice should also be at the forefront to increase transparency.	consensus has also been used to ensure that children and young people with spasticity have access to treatments that are considered by clinicians to be effective, even if this has not been established unequivocally in a trial setting. The entire guideline has been developed in accordance with the NICE guideline development process and the overarching objectives of NICE guidance, which are to reduce variation in practice and ensure equality of access to interventions that are clinically and cost effective. The selection as a key priority for implementation of the recommendation about helping children and young people and their parents or carers to be partners in developing and implementing the management programme does not negate the other guideline recommendations that set out specific circumstances in which particular management options (physical therapy, use of orthoses, treatment with oral drugs, botulinum toxin or intrathecal baclofen, and orthopaedic surgery) should be considered and the relationships between those management options needed to ensure effective use of resources. As part of the consideration of the evidence, the developers sought studies that reported objective outcome measures. In terms of the guideline recommendations, the developers agree that objective outcome measures could be a useful way of assessing achievement of goals for some children and young people. However, they considered it would be unhelpful to add this without further guidance about what measures should be used. As this would depend on the child or young person's individual needs it would not be possible to give comprehensive advice in a

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								recommendation aimed at all children and young people covered by the guideline. The guideline also includes a recommendation about the need to record and share the child or young person's individualised goals within the network team and, where appropriate, other people involved in their care which the developers considered would increase transparency in decision making and help to ensure individual needs were identified and met
397.	SH	Scope	8	NICE	8	17	could this be defined to inform professionals of specific best practice documents i.e. reference information could this be defined to inform professionals of specific best practice documents i.e. reference information	Given that the purpose of the information and education materials is to enable the child or young person and their parents to be partners in their individualised management programme, the developers did not think it was possible or appropriate to specify exactly what information and educational materials would be necessary for each child or young person and their family. The developers felt strongly that the level and type of information would depend on a large variety of factors such as the specific aspects of the child or young person's condition, their current level of understanding about spasticity, their age, general level of education, first language and co-existing conditions, as well as local service arrangements
398.	SH	Scope	9	NICE	8	25 26	and the use of outcome measures - to support efficacy and evidence based practice	The developers agree that objective outcome measures could be a useful way of assessing achievement of goals for some children and young people. However, they considered it would be unhelpful to add this without further guidance about what measures should be used. As this would depend on the child or young person's individual needs it would not be possible to give comprehensive advice in a recommendation aimed at all children and young people covered by the guideline.

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							ould the role of an experienced clinician e.g. specialist nurse, be acknowledged within neurology services. ould the role of an experienced clinician e.g. specialist nurse, be acknowledged within neurology services.	The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. In particular the recommendations in the principles of care section have been revised to make it explicit what expertise would be needed in the network team at a local or regional level, including nursing expertise
399.	SH	Scope	10	NICE	9	2	we would like to highlight that this document has not made any reference to deep brain stimulation which whilst has limited research availability on efficacy is used as a treatment, and for a small number of individuals this may be a treatment for consideration.	Thank you for your comment. Deep brain stimulation was discussed during the scoping phase in collaboration with stakeholder organisations but was eventually excluded as it was considered to be of lower priority than the included topics
400.	SH	Scope	11	NICE	9	6	where does OT come into this? this needs quantifying as to what that can offer i.e. management of spasticity, regulating of spasticity or giving compensatory strategies to accomodate etc, etc	The developers have clarified the role of the occupational therapist throughout the guideline, for example, by specifying that an occupational therapist should be included in the network team, and they have expanded the recommendation referred to in the comment to state that all children and young people with spasticity should be assessed promptly by a physiotherapist and, where necessary, an occupational therapist
401.	SH	Scope	12	NICE	10	12	he level of experience is so important in the management of spasticity and we wholly agree that should be recognised in the team provision	Thank you for your comment
402.	SH	Scope	13	NICE	10	19 20	evidence based outcome measured consistent for transparency of provision not restricted by lack of resources	The developers agree that objective outcome measures could be a useful way of assessing achievement of goals for some children and young people. However, they considered it would

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								be unhelpful to add this without further guidance about what measures should be used. As this would depend on the child or young person's individual needs it would not be possible to give comprehensive advice in a recommendation aimed at all children and young people covered by the guideline. The guideline also includes a recommendation about the need to record and share the child or young person's individualised goals within the network team and where appropriate other people involved in their care. The developers considered that this would increase transparency in decision making and help to ensure individual needs were identified and met. Resourcing and the provision of NHS services are not part of NICE's remit and so no recommendations have been made in this regard in the revised guideline
403.	SH	Scope	14	NICE	11	9	how can this provide a baseline in the management of spasticity? there is an ethical issue here as you cannot restrict access to interventions based on service availability- this becomes a post code lottery and does not support fair access to healthcare ou need to list the evidence based secondary consequences in order to inform professionals appropriately and reduce subjectivity i.e. referencing standardised assessment tools	The guideline developers were unable to identify the relevance of this comment in relation to page 11, line 9 of the consultation draft. If the comment relates to the draft recommendation stating that before starting treatment regional specialist centres should ensure that local multidisciplinary child development teams have allocated resources for locally provided post-treatment services, then the developers would like to reassure the stakeholder that this recommendation has been deleted because allocation of resources is outside the guideline development group's remit
404.	SH	Scope	15	NICE	11	10	xtra bullet point - appropriate outcome measures that are SMART	The developers agree that objective outcome measures could be a useful way of assessing achievement of goals for some children and young people. However, they considered it would be unhelpful to add this without further guidance

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								about what measures should be used. As this would depend on the child or young person's individual needs it would not be possible to give comprehensive advice in a recommendation aimed at all children and young people covered by the guideline.
405.	SH	Scope	16	NICE	11	16	How do you measure and monitor the progression of spasticity	This would be achieved through the clinical judgement of members of the network team
406.	SH	Scope	17	NICE	11	17	you need to list the evidence based secondary consequences in order to inform professionals appropriately and reduce subjectivity i.e. referencing standardised assessment tools	Examples of the secondary consequences of spasticity have been added to the recommendation for clarity. The developers agree that standardised assessment tools could be a useful way of assessing secondary consequences for some children and young people. However, they considered it would not be helpful or possible to provide comprehensive advice on this because the consequences of spasticity are highly varied (for example, they could include pain or musculoskeletal complications) and therefore the best type of assessment would also be very varied. The developers considered that the recommendations regarding the expertise of the healthcare professionals in the network team who are responsible for monitoring would ensure that those carrying out such monitoring would be able to use their clinical judgement to identify the most appropriate form of assessment
407.	SH	Scope	18	NICE	11	24	there is an ethical issue here as you cannot restrict access to interventions based on service availability- this becomes a post code lottery and does not support fair access to healthcare	This recommendation has been deleted
408.	SH	Scope	19	NICE	12	14 15	again need to identify OT role in relation to PT, as this document gives the impression that the PT covers all	The developers have clarified the role of the occupational therapist throughout the guideline, for example, by specifying that an occupational

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							interventions with lip service paid to mentioing OT.	therapist should be included in the network team, and they have expanded the recommendation referred to in the comment to state that all children and young people with spasticity should be assessed promptly by a physiotherapist and, where necessary, an occupational therapist
409.	SH	Scope	20	NICE	12	21 22	appropriate outcome measures of spasticity	The developers agree that objective outcome measures could be a useful way of assessing achievement of goals for some children and young people. However, they considered it would be unhelpful to add this without further guidance about what measures should be used. As this would depend on the child or young person's individual needs it would not be possible to give comprehensive advice in a recommendation aimed at all children and young people covered by the guideline
410.	SH	Scope	21	NICE	13	23	could both of these be quantified and evidence based on informing how this could carry over into every day practice	The original recommendation referred to low-load active or passive stretching over 24 hours without further clarification. In the revised guideline these interventions have been clarified as follows: • periods of low-load active stretching, during which the child or young person themself engages in activities aimed at improving range of movement, and • periods of sustained low-load passive stretching using positioning with equipment and/or orthoses or serial casting
411.	SH	Scope	22	NICE	16	4	stimulation of plantar and palmar reflexes may actually be disadvantageous or harmful as people may push against them and so this needs assessment by a skilled clinician rather than a prescriptive approach	Thank you for your comment. The recommendations have been revised throughout to clarify the roles of different healthcare professionals and who should be delivering care by defining the network of care. The importance of having an orthotist within the network team has been emphasised in the revised

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								recommendations. The developers have also revised the recommendations on orthoses to highlight when expert orthotic advice should be sought
412.	SH	Scope	23	NICE	16	17	can you recommend a frequency as some teams may only meet annually, bimonthly etc etc	Thank you for your comment. The developers believe that the stakeholder may have misinterpreted the recommendation. The purpose of this recommendation is to ensure that the orthosis is checked every time the child or young person comes into contact with a member of the network team rather than to identify how frequently the team should meet. The developers considered the general issue of timing of appointments, referral, etc carefully, but as this is an issue relating to service delivery they were limited by the remit of the clinical guideline. The commissioners of the guideline (NICE) require that recommendations giving specific timings for interventions should be supported by strong evidence because they can have significant resource implications. The developers were aware that variation in service delivery exists in England and Wales but thought that it was unlikely that there would be direct evidence to support a specific recommendation. For this reason it was decided during the guideline scoping phase to prioritise questions about the effectiveness of treatments as these would be more likely to be answered by a systematic review of research evidence. Consequently the developers did not have sufficient information from the body of evidence that was considered for the guideline to make detailed recommendations on the frequency or timing of appointments

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								However, in acknowledgement of their clinical consensus that all children and young people should have access to the services necessary for their individual needs, and that delayed access could result in avoidable harm, the developers have emphasised in the very first recommendation in the guideline (which is also a key priority for implementation) that the network of care should use agreed care pathways supported by effective communication and integrated team working. The developers consider that this would minimise the risk of children and young people being exposed to delays in treatment provision or review
413.	SH	Scope	24	NICE	17	5	extra bullet point - stimulate reflexes which can have negative effect on positioning	Thank you for your comment. The developers considered that this concern would be covered in the recommendations that advise healthcare professionals to balance the possible benefits against risks when considering an orthosis and to ensure that orthoses are appropriately designed for the individual child or young person and are sized and fitted correctly, seeking expert advice from an orthotist within the network team if necessary
414.	SH	Scope	25	NICE	17	17	extra bullet point - stimulate reflexes which can have negative effect on positioning	The developers were unsure which recommendation the stakeholder was referring to as there are no bullet points in the recommendation on line 17 of page 17. The developers consider that the concern expressed in the comment would be covered by the recommendations that advise healthcare professionals to balance the possible benefits against risks when considering an orthosis and to ensure that orthoses are appropriately designed for the individual child or young person and are sized and fitted correctly, seeking expert advice

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								from an orthotist within the network team if necessary
415.	SH	Scope	26	NICE	19	21	spiral splint applications to increase/ decrease supination/ pronation as required for midline functional positioning	In this guideline, the available evidence for upper limb orthoses, including wrist-hand orthoses, was reviewed. No specific evidence relating to 'spiral splints' was identified for inclusion
416.	SH	Scope	27	NICE	19	24	as a team of clinicians we fully acknowledge the importance of orthotics however it is necessary to acknowledge the difference in managing posture and managing spasticity, the latter of which this document is seeking to address and not the symptoms. if we are to address all secondary intervention requirements then this should include other aspects such as sensory dynamic orthoses (lycra suits).	The developers consider that the stakeholder may have misunderstood the scope of the guideline which includes early musculoskeletal complications associated with spasticity caused by non-progressive brain disorders. The difference between postural management and the use of orthoses is acknowledged by the fact that postural management is considered in the section of the guideline that relates to physical therapy, as opposed to the section that relates to the use of orthoses. Nevertheless, the developers are of the view that the interventions in the guideline are mostly used in combination and goals for the use of one treatment may overlap with those of another. The important issue, therefore, is for specific treatments to be considered in the context of the child or young person's overall management programme and this is reflected in the recommendations
417.	SH	Scope	28	NICE	20	23	and respiratory complications	In this recommendation drowsiness is given as an example of one of the potential adverse effects that could be experienced with the use of oral drugs. The developers considered that the recommendation was broad enough to take account of the stakeholder's concern without amending the wording
418.	SH	Scope	29	NICE	21	19	limiting safety of weight bearing i.e. plantar flexed, inverted foot position posing reduced stability of ankle joint,	The developers considered that this would be covered by the bullet about focal spasticity impeding gross motor function

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							altered biomechanics and possible fracture	
419.	SH	Scope	30	NICE	22	10	see earlier comment, last point page 11. also highlights the issue of access to service provision versus lack of engagement	The view of the guideline developers is that the effectiveness of certain management options for children and young people with spasticity (namely treatment with botulinum toxin or intrathecal baclofen, and orthopaedic surgery) is dependent on adjunctive treatment with physical therapy or the use of orthoses. The revised guideline strengthens the recommendations in this respect, for example, by including a recommendation that healthcare professionals should ensure that children and young people and their parents or carers understand that following botulinum toxin treatment, intrathecal baclofen treatment or orthopaedic surgery an appropriately adapted programme of physical therapy will be an essential component of the overall treatment programme. The recommendations are not, therefore, concerned with service provision. As with all NICE clinical guidelines, the recommendations are formulated on the understanding that all recommended management options should be made available throughout the NHS in England and Wales
420.	SH	Scope	31	NICE	24	9	swallowing and breathing difficulties - are these general side effects or specific to having parts of anatomy botoxed e.g. salivary glands. as a group of therapists we haven't ever come across a consultant who has explained or even acknowledged any risks associated with Botox apart from possible flu like symptoms	The evidence regarding adverse effects for botulinum toxin was limited. The developers were, however, aware that it can spread to muscles adjacent to the injection site and so there is an increased risk of swallowing and breathing difficulties if it is injected around the shoulders and neck. The developers were also aware that it can spread from distant sites, such as the legs, and so if a child or young person already has disordered breathing and swallowing, a further

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								small reduction in these functions may precipitate respiratory failure or aspiration, and so care should be taken whichever muscle is injected into. The evidence to recommendations section in the full guideline has been expanded to reflect this
421.	SH	Scope	32	NICE	25	10/11	is this a warning or recommendation using the term 'be aware'.	As suggested in the stakeholder comment, the phrase used in the recommendation is intended to raise awareness of an important issue, rather than simply being a warning. The term 'be aware' has been used as an alternative to 'consider' which has a specific meaning in NICE recommendations relating to the strength of the recommendation
422.	SH	Scope	33	NICE	27	9	this is the first time in this document that assessment of joint range of movement has been mentioned, however this should be a primary assessment requirement to most of the interventions mentioned in this paper. objective measurement can be used as an outcome measure however we acknowledge issues of reliability.	The developers agree that assessment of range of movement is crucial and this is emphasised throughout the guideline, not just in this specific instance. The draft recommendation included the word 'joint' and in the revised guideline this word has been deleted for accuracy and consistency with the other recommendations that refer to range of movement
423.	SH	Scope	34	NICE	31	10	classic issue presenting and good to see it on list however from OT perspective hand function has to be the predominating issues.	The developers considered that all of the bullets in the list, including hand function, were potential indicators for orthopaedic assessment and the relative importance of these indications would vary on an individual basis
424.	SH	Scope	35	NICE	31	16	following the last point we need to consider individuals who do not have functional hand use however planned surgical intervention may be indicated if digit position and fixed joints compromise vascular supply to the point where urgent surgery becomes a requirement (e.g. one of our clinicians has first hand experience of a young	Although the concern expressed in the comment is not covered explicitly, the recommendation highlights that problems arising from contractures are not limited to function. The developers considered that the recommendation was broad enough to ensure that children and young people with the clinical indications described in the comment would have access to a surgical assessment and that the healthcare professionals

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							man, thumb adducted across palm, fixed under adjacent two digits resulting in an amputation.	who perform the assessment would have the necessary expertise to identify and act on any associated vascular problems
425.	SH	Scope	36	NICE	31	23	or parent!! how many C&YP have had surgery due to parents needs. this reflects on whole document as we do need to question what we do at the request of parents as opposed to sound clinical reasoning	The developers were unclear which recommendation the stakeholder was referring to as there is no mention of parents on the page referred to in the comment. The developers have worked with the NICE editor to ensure that all the recommendations are patient centred
426.	SH	Scope	37	NICE	32	28	some orthopaedic surgery is addressing postural management not spasticity, again could cloud clarity of purpose of document	The developers consider that the stakeholder may have misunderstood the scope of the guideline which includes early musculoskeletal complications associated with spasticity caused by non-progressive brain disorders. The developers are of the view that the interventions in the guideline are mostly used in combination and goals for the use of one treatment may overlap with those of another. The important issue, therefore, is for specific treatments to be considered in the context of the child or young person's overall management programme and this is reflected in the recommendations
427.	SH	Scope	38	NICE	36	3	great research question as there is very little out there, however the importance focuses on the medical model, the reality could well reflect societal barriers.	Thank you for your supportive feedback on this key research recommendation. In NICE guidelines, all research recommendations, and indeed all clinical recommendations, must be linked to the evidence reviewed in the guideline. As societal barriers were not clearly within the guideline scope the developers did not consider it appropriate to amend the research recommendation as suggested
428.	SH	Scope	39	NICE	36	7	this is confusing re the statement being made; i.e. do you mean such individuals are likely to have reduced selectivity of	This phrase summarises the guideline developers' interpretation of the evidence relating to selective dorsal rhizotomy, which is explained in detail in

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							movement- if so then the statement needs to reflect this.	the evidence to recommendations section in the full guideline
429.	SH	Scope	40	NICE	36	17	we are slightly confused by the title of postural management as we find that whilst the entire document moves between postural management and spasticity it doesn't really bridge the gap between the two and so confuses the papers purpose.	The developers acknowledge that if this heading and the associated research question are considered in isolation from the rest of the guideline it is not immediately clear that both refer to postural management in children and young people with spasticity. However, this reflects the NICE editorial style in which it is no longer practice to include the name of the underlying condition in every recommendation. The context of the guideline implies that every clinical recommendation and every research recommendation relates specifically to children and young people with spasticity
430.	SH	Scope	41	NICE	36	19	it is interesting that you have selected this question however what makes the question of ability in standing frames any more worthy of discussion than alternative interventions and different age groups	NICE research recommendations are required to be meet certain criteria, including feasibility of conducting the proposed research. Thus, while the guideline developers would have liked to have recommended research in many areas relating to physical therapy, they struggled to identify research questions that could be investigated without withholding treatments that are already available through the NHS and considered to be helpful for children and young people with spasticity, even in the absence of unequivocal research evidence. The developers highlighted the advantages of devising research programmes concerned with evolution of existing clinical practice, rather than comparing a particular physical therapy intervention with no intervention. The research question referred to in the comment was identified as a key priority for research on these grounds (that is, it proposes research that is defensible in that it will compare different

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								modalities of an approach to physical therapy that is already in widespread use)
431.	SH	Scope*	1	NICE	3	3	are there any plans for a similar document relating to adults i.e 19+ as these issues are just as prevalent within the older UMNL population and the C&YP needs don't halt beyond this age	Thank you for your comment. The population covered by the guideline reflects the remit issued by the Department of Health. The developers are not aware of any published NICE guidance, nor any in development, for the management of spasticity in adults

These organisations were approached but did not respond:

Alder Hey Children's NHS Foundation Trust
AOP Orphan Pharmaceuticals
Association of Paediatric Anaesthetists of Great Britain and Ireland
Association of Paediatric Chartered Physiotherapists
Birmingham Children's Hospital NHS Foundation Trust
Bradford District Care Trust
Brighton and Sussex University Hospital NHS Trust
British Academy of Childhood Disability
British Association for Community Child Health
British Association of Paediatric Urologists
British Association of Bobath Trained Therapists
British Association of Music Therapy
British Medical Association
British Medical Journal
British National Formulary
British Orthopaedic Association

* Note: The Guideline Review Panel did not review or comment on the stakeholder comments submitted by Scope or the guideline developers' responses to these comments

British Paediatric Neurology Association
British Psychological Society
British Society for Children's Orthopaedic Surgery
Cambridge University Hospitals NHS Foundation Trust
Cambridgeshire Primary Care Trust
Camden Link
Care Quality Commission (CQC)
Central Lancashire Primary Care Trust
Cerebra
Cerebra
Cochrane Developmental, Psychosocial and Learning Problems
Criminal Justice Womens Strategy Unit
Department for Communities and Local Government
Department for Education
Department of Health, Social Services and Public Safety - Northern Ireland
Dorset Primary Care Trust
George Eliot Hospital NHS Trust
Go Kids Go
Great Ormond Street Hospital
Great Western Hospitals NHS Foundation Trust
Health Protection Agency
Health Quality Improvement Partnership
Healthcare Improvement Scotland
Humber NHS Foundation Trust
Information Centre for Health and Social Care
International Neuromodulation Society
Johnson & Johnson
KCARE
Lambeth Community Health
Lancashire Care NHS Foundation Trust
Leeds Primary Care Trust (aka NHS Leeds)
Leeds Teaching Hospitals NHS Trust
Liverpool Community Health
Liverpool PCT Provider Services

Liverpool Primary Care Trust
McTimoney Chiropractic Association
Medicines and Healthcare products Regulatory Agency
Mencap
Ministry of Defence
Mother and Child Foundation
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Patient Safety Agency
National Public Health Service for Wales
National Spinal Injuries Centre
National Treatment Agency for Substance Misuse
NHS Clinical Knowledge Summaries
NHS Connecting for Health
NHS Coventry Community Health Services
NHS Direct
NHS Islington
NHS Manchester
NHS Plus
NHS Sheffield
NHS West Essex
North Somerset Primary Care Trust
North Tees and Hartlepool NHS Foundation Trust
Office of the Children's Commissioner
Patients Watchdog
Peacocks Medical Group
PERIGON Healthcare Ltd
Robert Jones & Agnes Hunt Orthopaedic & District Hospital NHS Trust
Royal Berkshire NHS Foundation Trust
Royal College of Anaesthetists
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists

Royal College of Pathologists
Royal College of Radiologists
Royal College of Surgeons of England
Royal Pharmaceutical Society
Royal Society of Medicine
Salisbury NHS Foundation Trust
Sandwell Primary Care Trust
Scottish Centre for Children with Motor Impairments
Scottish Intercollegiate Guidelines Network
Sensory Integration Network
Sheffield Childrens Hospital
Social Care Institute for Excellence
Society for Research in Rehabilitation
Society of British Neurological Surgeons
Society of Chiropodists & Podiatrists
Solent Healthcare
South Asian Health Foundation
Southampton University Hospitals Trust
St Jude Medical UK Ltd.
The College of Social Work
The Princess Royal Trust for Carers
The Rotherham NHS Foundation Trust
Unite - the Union
United Lincolnshire Hospitals NHS
University of Sheffield
Warrington Primary Care Trust
Welsh Government
Welsh Scientific Advisory Committee
Western Cheshire Primary Care Trust
Western Health and Social Care Trust
Wolfson Neurodisability Service, The
Worcestershire Acute Hospitals Trust
York Hospitals NHS Foundation Trust