National Institute for Health and Clinical Excellence

Spasticity in children
Scope Consultation Table

SH = Registered Stakeholders. These comments and responses will be posted on the NICE website after guideline development begins.

Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
SH	Alder Hey children's NHS Foundation	1	3.1	Needs to specifically mention spasticity can arise more rapidly following an acquired brain injury eg. Severe head injury. I think this is important to put in here because the issues that arise in management of spasticity in these children (principally in-patient, medically intensive situations) are quite different from cerebral palsy which is a chronic, community-led condition.	Thank you, we agree. The Guideline Development Group will take these issues into consideration when drafting recommendations.
SH	Alder Hey children's NHS Foundation	2	3.1h	It mentions that spasticity can arise in head trauma, etc. but I think above emphasis needs to be noted – that the rate at which it appears, the timeliness of assessments and interventions, the impact of comorbidities is fundamentally different in spasticity following acquired brain injury compared to cerebral palsy	Thank you, we agree. The Guideline Development Group will take these issues into consideration when drafting recommendations.
SH	Alder Hey children's NHS Foundation	3	3.1j	There is not enough about the upper limb spasticity. This is because the lower limb and mobility take up a lot of the thinking and management in these children. However managing upper limb spasticity is important in quadriplegia as well as hemiplegia (where it is mentioned as an issue).	Thank you. The Guideline Development Group will take upper limb spasticity in quadriplegia into consideration when drafting recommendations. We will be moving away from using the terms monoplegia, diplegia and quadriplegia in

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					reference to cerebral palsy. Instead, we will use the terms unilateral and bilateral and severity. The degree of severity is determined for walking by GMFCS and for upper limb function by the Manual Ability Classification Score. However, the majority of papers in the literature will use the older terminology and so we will continue to employ them when assessing the evidence
SH	Alder Hey children's NHS Foundation	4	3.2c	Should also mention plaster casts, splints	Thank you. Casts and splints have now been specified in section 3.2c as suggested
SH	Alder Hey children's NHS Foundation	5	3.1k	I do not agree that functional abilities necessarily decline because of spasticity rather than weakness. Certainly do not agree that functional abilities deteriorate "specifically" because of spasticity. I think this is important in guidelines about management, because treatments to improve spasticity may make weakness worse, and could equally worsen functional abilities in the long term whilst improving spasticity related symptoms.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. The text has now been amended to say "The functional abilities of children with spasticity often deteriorate over time. The cause of the progression is not often identified. It may include

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					weakness, posturing, contracture, dystonia, ataxia or other motor disorders. Incorrect diagnosis and high expectations can all lead to functional deterioration. Effective management of spasticity and other motor problems could be important in preventing functional decline."
SH	Alder Hey children's NHS Foundation	6	3.2a	Aim of improving spasticity may also be to improve symptoms of spasticity itself such as pain. Not sure if this is encompassed with "disability" or whether it counts as an impairment.	Thank you. We have included reduction of pain as an outcome for the guideline (please see section 4.4) Also the text in this section has been amended to "The aims of managing spasticity are to minimise the effect that it has on the child – treat pain, improve motor function, improve ease of care, and prevent the consequences of spasticity…."
SH	Alder Hey children's NHS Foundation	7	3.2f	The role of orthopaedic surgery in managing spasticity is slightly confused. There are orthopaedic interventions which aim to have the consequence of reducing spasticity. Then there are orthopaedic interventions which treat the consequences of the spasticity or its associated motor problems eg. hip stabilisation surgery may not reduce spasticity, but simply treat the consequence of spasticity and associated immobility on hip subluxation. This is also a general	Thank you. It will not be possible to review all the orthopaedic procedures used in the management of the motor problems in a child with spasticity. We will look at the role of orthopaedic surgery – in

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				comment on the other interventions eg. physiotherapy interventions – the treatment may be for the associations of spasticity rather than for treating spasticity per se.	the management of spasticity and its early complications. This would include interventions which lengthen or realign muscles, or reduce bony torsion because they are close to the management of spasticity and can be achieved in the life of the GDG. However , later complications such as dislocated hips or scoliosis are excluded to maintain the scope's focus.
SH	Alder Hey children's NHS Foundation	8	4.1.2c	Should mention the impact of comorbidities on feasibility of the treatment. Adverse effects of drug medications, for example.	Thank you. The scope now includes the management of dystonia, choreoathetosis and muscle weakness when these conditions present in children with spasticity and the GDG will consider feasibility of treatment. We have included adverse effects of interventions as an outcome for the guideline (please see section 4.4)
SH	Alder Hey children's NHS Foundation	9	4.3.1b	Orthoses are often not used to reduce contractures, but to improve foot ankle stability for stance ie for goal at function level, not goal at impairment level. Their use in established or evolving contracture is a separate issue. Orthosis use to reduce spasticity itself is unlikely. Thus looking at goal of treatment is an important distinction because if the guideline searching strategy is to look at unfeasible things like improvement in spasticity as a result of using orthosis, the result will inevitably be "no evidence of benefit, chuck baby out with bathwater	Thank you for this helpful comment. We are considering orthoses for prevention and treatment of contractures and improvement in function (such as mobility) and not for reducing spasticity.

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				now".	We do not ordinarily include outcomes in our search strategies in order to keep the search broad and capture as many studies as possible. Therefore it is unlikely that we will miss any published study on a particular subject for that reason
SH	Alder Hey children's NHS Foundation	10	4.3.1	Functional or neuromuscular electrical stimulation should be included somewhere.	Thank you. This will be considered as a physiotherapy intervention
SH	Alder Hey children's NHS Foundation	11	4.4	Achievement of individualised goals should be an outcome. There is much work on goal attainment scaling, visual analogue scales etc. This is more like real-life clinical practice compared to the RCTs where the goal of intervention may be different from child to child, rather than saying whether the GMFM changed a little bit.	Thank you. Attainment of individualised goals will be considered where evidence is available in the literature and a key task for the GDG will be to ensure the guideline reflects real life clinical practice.
SH	Alder Hey children's NHS Foundation	12	General	I think the guideline should differentiate at regular intervals, what is done to improve spasticity itself, versus what is done to manage a consequence or association of the spasticity. Many of the interventions are not intended to reduce spasticity itself, eg orthoses above. Some interventions aim sometimes to reduce spasticity, and sometimes to reduce a sequel of spasticity eg. serial casting. Reduction of the spasticity may be necessary to undertake an intervention which treats a consequence of spasticity eg. orthosis for improved stance which is not tolerated due to spastic posturing within the orthosis. These are somewhat complex interventions and I	Thank you. The management of spasticity and its consequences requires a multi-disciplinary approach and we trust that the guideline will reflect this. If we looked at interventions that purely managed spasticity, it would exclude important components and members of the MDT. We

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				believe the appropriate research methodology is not the classic RCT but more like the complex intervention studies, non-randomised multiple baseline methods (before-and-after studies) etc. I hope the search strategy is not as limited as Cochrane reviews which are singularly unhelpful in this field.	wish to look at overall management of spasticity, its consequences, and the common motor co-morbidities, but to be pragmatic about what can be achieved by this group. The literature review will be broad as we recognise that study designs other than conventional RCTs eg before and after studies may be valid for inclusion
SH	Alder Hey children's NHS Foundation	13	4.4f And general	Given that quality of life is an outcome measure, I fail to see how the specific issues of spasticity and associated dysphagia, need for nutritional support, avoidance of aspiration risk and general feed management can be divorced from the other main issues. In short, if attention to nutrition is not one of the mainstays of management, other interventions will fail to achieve their optimal objective and quality of life measures will also be affected. Mark Dalzell (Consultant Paediatric Gastroenterologist)	Thank you. The management of nutrition in cerebral palsy, pseudo-bulbar palsies and indeed all severe neurological disorders in children has been revolutionised by the use of gastrostomies, better management of reflux and avoidance of aspiration pneumonias. This has enhanced quality of life and increased life expectancy for this group of children and young people. It is a large field of evidence and perhaps is deserving of a guideline in its own right. There are many general health factors that influence severity and management of spasticity which, if ignored by the

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					clinician, can render interventions ineffective. These include poor nutrition, pain from reflux, pain from other sources – bones, teeth, UTIs – anxiety, dehydration etc. However, we need to be pragmatic about how much evidence the GDG can consider and this remains outside the scope.
SH	Allergan	SH	3.2e point 3	We would like to comment that only two of the commercially available botulinum toxin A preparations are licensed for use in spasticty associated with cerebral palsy. It should also be noted that when considering dosage, The Summary of Product Characteristics (SPC) for the two preparations of botulinum toxin type A state that: The doses are specific to each preparation and are not interchangeable with other preparations of the toxin. Therefore we suggest that doctors consult the appropriate SPC for the product being used, in order to obtain product-specific dosage recommendations.	Thank you. These issues will be taken into consideration when drafting the recommendations, however the guideline is mainly concerned with the effectiveness of botulinum toxin in general and not dosing or a specific preparation in particular. If botulinum toxin is recommended in the guideline then clinicians will still need to refer to the BNFC and the SPC for this additional information
SH	Allergan	1	3.2e point 3	Published consensus guidelines on the use of Botulinum toxin in children with spasticity associated with cerebral palsy indicate that multi level injections are well accepted:- 2003:Spasticty Ass with Cerebral Palsy in children: guidelines for use of botulinum A toxin (Kooman et al) 2006 & 2009: European consensus table on botulinum toxin for children with Cerebral Palsy. (Heinen et al)	Thank you. We will consider these references in our reviews if they meet the relevant inclusion criteria

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				2009: French clinical guidelines from the AFSSAPS –awarded a grade 2 for the evidence supporting use of botulinum toxin A to improve active functioning of upper and lower limbs	
SH	Allergan	3	4.3.1d	There is limited evidence supporting long term use of botulinum toxin A versus placebo. Consideration should be made to the practicalities of patient recruitment, and related ethical considerations for such studies.	Thank you. We will include the best available published evidence and critically appraise each paper for consideration and interpretation by the GDG. .
SH	Allergan	4	4.4	We would comment that goal attainment and pain management should also be considered in the list of outcomes.	Thank you. Reduction of pain is already included in the list of outcomes and goal attainment would be considered as part of optimisation of movement and function.
SH	APCP	1	4.3.1a And b	The use of serial casting in treating soft tissue is worthy of investigation.	Thank you. This will be considered as a physiotherapy intervention
SH	APCP	2	General	Comparison of Botulinum Toxin type A with Serial Casting. versus Serial Casting alone in tissue lengthening	Thank you. This comparison will be considered if literature meeting our inclusion criteria is available
SH	Association of Paediatric Chartered Physiotherapists	1	Title	More appropriate to talk about the management of a motor disorder than 'spasticity' Spasticity alone only one of so called positive features of an Upper motor neurone lesion whereas the document refers to management of negative features such as weakness lack of selective movement etc.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness when these

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			General	Are we at risk of throwing the baby out with the bathwater - if the guideline finds no evidence for any of the interventions in managing spasticity, does that mean that they will be discredited in the management of the child with a non-progressive brain injury?	conditions present in children who also have spasticity. The full title has been amended to "Non-progressive brain disorders in children and young people: management of spasticity, co-existing motor disorders and their early musculoskeletal complications"
SH	Association of Paediatric Chartered Physiotherapists	2	3.1b	A more specific definition of spasticity is required, 'dysregulation of muscle tone' what is described here is co-contraction and aphasic muscle activity not necessarily just spasticity	Thank you. We have amended this definition in response to comments. Sections 3.1 a and b now read "Spasticity is defined as a sign found in some motor disorders which is 'characterised by hyperexcitability of the stretch reflex, resulting in a velocity-dependent increase in tonic stretch reflexes (muscle tone) with exaggerated tendon jerk'. It is one components of the upper motor neuron syndrome. Spasticity is a common and often serious abnormality affecting motor function. Spasticity results in an increased resistance to passive movement of a muscle through

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					hyperactive stretch reflexes causing rapid and strong contraction of the muscle. This dysregulation of tone with movement can result in a wide range of clinical manifestations and functional impairments
SH	Association of Paediatric Chartered Physiotherapists	3	3.1d	A more up to date definition of CP such as that proposed in 2009 by Rosenbaum may be more appropriate.	Thank you. We are now using the suggested definition
SH	Association of Paediatric Chartered Physiotherapists	4	3.1c -h	Is this also including hereditary spastic paraplegia?	Thank you. Hereditary spastic paraplegia will not be included as this is a progressive disorder**.**
SH	Association of Paediatric Chartered Physiotherapists	5	3.1j	Maybe the European Classification should be used and Gross Motor Classification System more commonly used in neurodisabilty.	Thank you. Page: 10 We will use the European Classification system, the GMFCS for gross motor abilities and the Manual Ability Classification Score for upper limb function. However, we recognise that we will have to refer to the former methods of classifying CP by topography and severity as this is how they will be classified in all except the most recent literature.
SH	Association of Paediatric	6	3.1k	No evidence to support that deterioration caused by spasticty whereas is evidence to support weakening effects	Thank you. We are now including the management of

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	Chartered Physiotherapists				dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. The text has now been amended to say "The functional abilities of children with spasticity often deteriorate over time. The cause of the progression is not often identified. It may include weakness, posturing, contracture, dystonia, ataxia or other motor disorders. Incorrect diagnosis and high expectations can all lead to functional deterioration. Effective management of spasticity and other motor problems could be important in preventing functional decline."
SH	Association of Paediatric Chartered Physiotherapists	7	3.1l	Dislocation is presumably referring to hips?	Thank you. We have clarified "hip dislocation" in the text as shoulder, elbow and ankle dislocations occur more infrequently
SH	Association of Paediatric Chartered	8	3.1m	Need to mention use of postural management and Specialist equipment	Thank you. We recognise that postural management will be prescribed by physiotherapists

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	Physiotherapists				and that this has various components. This has been mentioned in the section as suggested
SH	Association of Paediatric Chartered Physiotherapists	9	3.1n	Would be very hard to prove treatment of spasticity alone would bring this about look at long term evidence post selective dorsal rhizotomy evidence with	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity.
SH	Association of Paediatric Chartered Physiotherapists	10	3.2c	'encouraging the use of compensating movements' this is incorrect could be replaced with 'discouraging and preventing postures and movement that lead to disability and deformity, and encouraging postures and movement that improve function'	Thank you. We agree with your suggested wording and have amended our text accordingly
SH	Association of Paediatric Chartered Physiotherapists	11	3.2c	Only specifies a couple of interventions via PT should leave general or need to list all varieties	Thank you. Whilst we would not specify all possible physiotherapy interventions in the scope, we will undertake a broad literature search and review evidence meeting our inclusion criteria which will be defined after discussion with the GDG
SH	Association of Paediatric	12	3.2f	Orthopaedic surgery does not have a direct effect on spasticity but does manage both the positive and negative effects of UMNS	Thank you.

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	Chartered Physiotherapists				We have amended the text which now reads "Orthopaedic surgery has a major role in the management of early and late consequences of spasticity." We will look at the role of orthopaedic surgery in the management of spasticity and its early complications. This would include interventions which lengthen or realign muscles, or reduce bony torsion.
SH	Association of Paediatric Chartered Physiotherapists	13	4.3.2d	Hippotherapy is not a play therapy it is a specialised subsidiary of physiotherapy	Thank you. We agree and have amended our text to remove hippotherapy
SH	British Academy of childhood disability	1	Page 2	d) definition of cerebral palsy – the text in my opinion should define the condition of cp more precisely and refer to the more widely used definition of Mutch et al where there is this crucial reference to the motor problem not being progressive but changing or / and in addition refer too to the newer definition of Rosenbaum et al 2009	Thank you. We have amended our definition to reflect Rosenbaum's newer definition in response to comments
SH	British Academy of childhood disability	2	j	j) more recently we are using the term bilateral and unilateral cerebral palsy and moving away from di – quad and hemi plegia, this is in partnership with encouraging clinicians to describe children and young people using the GMFCS in order we achieve some standardisation. It may be helpful to refer to the GMFCS in the text.	Thank you. We will use the European Classification system, the GMFCS for gross motor abilities and the Manual Ability Classification Score for upper

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					limb function. However, we recognise that we will have to refer to the former methods of classifying CP by topography and severity as this is how they will be classified in all except the most recent literature.
SH	British Academy of childhood disability	3	3.2. Current practice 4/3.2	a) ..minimise disability short and long term a) it is said that assessment will not be covered but surely there will be some descriptors of degree of disability / motor functional difficulties? There will be within the subgroups a spectrum of disability and some description will be necessary (in my opinion a GMFCS level would suffice) but this will be an assessment surely?	Thank you. We will not be assessing the evidence for the use of different diagnostic techniques and assessments. However, this information will be reported where it pertains to descriptions of the populations included in the evidence, where it is the unit of outcome assessment for interventions and from this, where the GDG considers specific recommendations for different subgroups are clinically relevant
SH	British Association of Prosthetics & Orthotics	1	4.3.1b	Scoliosis management is vital to the development and management of children with cerebral palsy and therefore should be included.	Thank you. We agree that management of scoliosis in cerebral palsy is essential. However, there is a limit to how much of the consequences of spasticity the GDG will be able to look at. Therefore, we have decided to look at the immediate and short term

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					consequences of spasticity that would involve orthopaedic surgery where the intervention may have an immediate impact on spasticity or its symptoms such as pain and loss of function. We will not be looking at the later consequences of spasticity such as dislocation and scoliosis.
SH	British Association of Prosthetics & Orthotics	2	4.3.1b	Stretching and positioning orthoses should be included contracture control devices to leg maintain joint range of motion for instance.	Thank you. These are included in the scope as part of postural management and management of the consequences of spasticity.
SH	British Association of Prosthetics & Orthotics	3	4.3.1b	Dynamic Elastomeric fabric orthoses should be included as evidence is showing long term changes in outcome	Thank you. We would not specify the inclusion of this orthotic intervention in the scope, but will review its evidence of effectiveness, if the studies meet our inclusion criteria
SH	British Association of Prosthetics & Orthotics	4	4.3.1	The terms" mild moderate and severe" are now out dated and not recognised. The Gross motor function classification scale (GMFCS) is now the generally acknowledged descriptor of severity and has been verified.	Thank you. We will use the European Classification system, the GMFCS for gross motor abilities and the Manual Ability Classification Score for upper limb function. However, we recognise that we will have

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					to refer to the former methods of classifying CP by topography and severity as this is how they will be classified in all except the most recent literature
SH	British Paediatric Neurology Association	1	General Comment	This guideline development is most welcome in principle, but we have major concerns about the scope. We have made a number of specific comments as below, but the two greatest concerns relate to the focus purely on spasticity, and the description of the guideline.	Thank you. As part of our response to stakeholder comments, the scope has been reviewed and we are now including the management of dystonia, choreoathetosis and muscle weakness where these conditions present in children who also have spasticity.
SH	British Paediatric Neurology Association	2	General comment on title of guideline	The document refers in large part throughout to Cerebral Palsy. It is helpful to acknowledge that other conditions such as acquired brain injury can lead to similar problems. However, a large proportion of children with Cerebral Palsy do not have brain injury eg may have a developmental brain malformation. Furthermore, up to 16% of MRI brain scans in children with Cerebral Palsy show no abnormalities at all. By using the term "non-progressive injury" this actually is restrictive rather than inclusive, in that it excludes a far greater number of children with Cerebral Palsy than are accommodated by including other later causes of acquired brain injury.	Thank you. The full title has been amended to "Non-progressive brain disorders in children and young people: management of spasticity, co-existing motor disorders and their early musculoskeletal complications" We have now changed the definition of cerebral palsy to say "permanent disorders of movement …….attributed to a non-progressive disturbance" to be consistent with the

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					Rosenbaum definition of CP. However the guideline will still address acquired brain injury
SH	British Paediatric Neurology Association	3	General comment on spasticity focus	Spasticity is just one feature of the upper motor neuron syndrome which includes hypertonia (which can be spasticity and/or dystonia – see Sanger et al 2003*), weakness and poor motor control. These facets are inextricably intertwined to impact on level of functional ability. We are concerned that focus on spasticity in isolation is artificial. The 2001 WHO document "International Classification of Functioning, Disability and Health" was intended to replace the model of impairment, disability and handicap and instead stress level of function and participation. Focusing only on spasticity is looking at impairment which seems a retrograde step. We appreciate that to provide an overview of the management of Cerebral Palsy may be beyond any individual guideline. However, we are concerned that to focus on spasticity in isolation is potentially detrimental. We respectfully suggest that the focus should be expanded to consider Motor Disorders in Cerebral Palsy, with reference made in the text that children with later acquired brain injury may have similar clinical problems. *Sanger et al (on behalf of Task Force on Childhood Motor Disorders) Classification and Definition of Disorders Causing Hypertonia in Childhood. Pediatrics 2003 Vol. 111(1) pp. e89-e97.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. Children with later acquired brain injury will also be included in the guideline, and when clinically relevant specific recommendations will be considered for this group
SH	British Paediatric Neurology	4	General comme	This is a transcript from the recent House of Lords debate on Health (4/11/09): Cerebral Palsy, Tabled by Lord Hameed. 5.40 Baroness Thornton (for the government) 4 Nov 2009 : Column	Thank you. We are now including the

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	Association		nt on wider political debate	GC79 "My noble friend Lord Macdonald referred to dystonia and medication. I want to put on the record that NICE has been commissioned to produce guidance on the management of spasticity in children with cerebral palsy. That will include medicines effective in dystonia."	management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. Both children with cerebral palsy and children with later acquired brain injury will be included in the guideline
SH	British Paediatric Neurology Association	5	3.1a	'Spasticity' is not a motor disorder: it is a sign found in certain motor disorders	Thank you. We have amended our text to reflect your suggestion and in accordance with the terminology provided by Rosenbaum.
SH	British Paediatric Neurology Association	6	3.1b	It is incorrect to say that "Normally when a muscle stretches, a reflex is triggered to pull this muscle back to its 'resting ' state". This is physiologically wrong. What happens normally is that muscles passively return to their resting position or return to this position by voluntary contraction. Agonist and antagonist muscles act in concert to act as brakes and accelerators during movements but this activity is not reflex in nature. Reflexes are hardly ever elicited in normal motor tasks e.g. walking or using one's hands and arms.	Thank you. We agree that our description was incorrect and have amended this to "Spasticity is a common and often serious abnormality affecting motor function. Spasticity results in an increased resistance to passive movement of a muscle through hyperactive stretch reflexes causing rapid and strong contraction of the muscle.. This dysregulation of tone with movement can result in a wide range of clinical manifestations and functional impairments."

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SH	British Paediatric Neurology Association	7	3.1b	"A hyperactive response to the stretch reflex" or "a resistance to passive movements" are not the same thing since a resistance to passive movements can occur in electrically silent muscles. Also increases in the viscous properties of muscle produces electrically silent resistance to rapid stretches.	Thank you. We agree that our description was incorrect and have amended section 3.1b to "Spasticity is a common and often serious abnormality affecting motor function. Spasticity results in an increased resistance to passive movement of a muscle through hyperactive stretch reflexes causing rapid and strong contraction of the muscle. This dysregulation of tone with movement can result in a wide range of clinical manifestations and functional impairments."
SH	British Paediatric Neurology Association	8	3.1b	…"dysregulation of muscle tone"…If this is occurring 'at rest' e.g. in a chair or lying, this amounts to abnormal postures which have nothing to do with 'spasticity' which is velocity- dependent. Abnormal postures are part of the movement disorder and do, however lead to a wide range of complications of function and to deformity.	Thank you. We agree that our description was incorrect and have amended section 3.1b to "Spasticity is a common and often serious abnormality affecting motor function. Spasticity results in an increased resistance to passive movement of a muscle through hyperactive stretch reflexes causing rapid and strong contraction of the muscle. This dysregulation of tone with movement can result in a wide range of clinical manifestations

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					and functional impairments."
SH	British Paediatric Neurology Association	9	3.1d	We respectfully request that the definition of Cerebral Palsy used is that of the most recent International Consensus Document: "Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems." Rosenbaum et al, The Definition and Classification of Cerebral Palsy, DMCN 2007, vol 49, Suppl 109, p8-11.	Thank you. We agree and have amended the text accordingly to reflect the suggested definition
SH	British Paediatric Neurology Association	10	3.1g	If it is quite common for children with spastic cerebral palsy to have other motor disorders, why is spasticity more important than the other motor components such as abnormal movement patterns, dystonia or weakness?	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity.
SH	British Paediatric Neurology Association	11	3.1i	Up to 16% of MRI brain scans in children with Cerebral Palsy are normal. Up to 31% have white matter abnormalities without cortical involvement (Robinson et al DMCN 2009 51(1): 39-45). Therefore at least 47% of children with Cerebral Palsy do not have cortical damage noted on MRI brain imaging. Even in those with cortical involvement, the precise topographical distribution has not been shown to have a direct influence on the imbalance between antagonistic muscles across a joint.	Thank you. We have now changed the term to say "non-progressive disturbance to be consistent with the Rosenbaum definition of CP. (However the guideline will still address acquired brain injury as well).

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				Postural abnormalities are due to abnormalities in movements and postures: they are not due to spasticity and do not depend on the stretch reflex. Postural abnormality may also be due to dystonia and posturing in the absence of spasticity	Dystonia has now been included in the guideline, but only in children in whom spasticity is also present.
SH	British Paediatric Neurology Association	12	3.1j	Although the terms diplegia, quadriplegia and hemiplegia are still used commonly in clinical practice, most clinicians now recommend describing the pattern of limb involvement as either bilateral or unilateral. This is to avoid confusion in distinguishing between diplegia and quadriplegia (see A F Colver, T Sethumadhavan Arch Dis Child 2003). The severity of upper and lower limb functional impairment can then be sub-classified using specific tools such as the Gross Motor Function Classification Score (GMFCS) for lower limbs, and Manual Ability Classification Score (MACS) for the upper limbs. It is misleading to imply that children with diplegia need intervention to learn to walk. The intervention may enhance performance but the walking is a long-recognized developmental process.	Thank you. We will use the European Classification system, the GMFCS for gross motor abilities and the Manual Ability Classification Score for upper limb function. However, we recognise that we will have to refer to the former methods of classifying CP by topography and severity as this is how they will be classified in all except the most recent literature.
SH	British Paediatric Neurology Association	13	3.1j	The sub-group of children with total body involvement is notoriously difficult to classify. In the recent Gainsborough* paper, clinicians found this type of cerebral palsy most difficult to classify: Half called it dystonic, dyskinetic or dystonia-dyskinesia and half called it spastic quadriplegia. This shows that the contribution of spasticity to the overall movement disorder of cerebral palsy needs careful definition and ascertainment. * Dev Med Child Neurol. 2008 Nov;50(11):828-31.Validity and reliability of the guidelines of the surveillance of cerebral palsy in	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. The GDG will be aware of the

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				Europe for the classification of cerebral palsy. Gainsborough M, Surman G, Maestri G, Colver A, Cans C.	difficulties in classification of the movements disorders when reviewing the literature.
SH	British Paediatric Neurology Association	14	3.1k	Functional decline over time is multifactorial. Weakness and muscle contracture and joint deformity play a dominant role in this decline, not spasticity. In fact as muscles tend to contracture, the ability to elicit velocity-dependent stretch reflexes declines naturally. Dystonia may worsen considerably as the child faces increasing physical and intellectual demands and these may provoke pain in the context of reduced joint ranges owing to contracture. It is important to recognise this deterioration in the title or at least very early in the introduction of this manuscript. Apart from correct diagnosis, and classification, this deterioration is perhaps the most important clinical aspect of management. Although the pathological description of "non-progressive brain injury" is correct, it is in fact, the progressive disability which requires acknowledgment, surveillance, prevention and management, especially during the transition to young adulthood when the demands of normal teenage life become more dominant in determining the health of the individual. Health encompasses physical and social health, including the effects on participation in education, relationships, driving and transport, employment, all of which can be progressively affected by the individual's ability which declines over time. The cause of the progression is not often identified. It may include weakness, posturing, contracture, dystonia, ataxia or other motor disorders. Incorrect diagnosis and high expectations can all lead to functional deterioration. While therapy tailored at spasticity specifically may be appropriate, omission to search for other causes of reversible deterioration will lead to decline in function and missed therapy opportunity.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. The full title has been amended to "Non-progressive brain disorders in children and young people: management of spasticity, co-existing motor disorders and their early musculoskeletal complications" We have made amendments to section 3.1 to reflect your comment

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SH	British Paediatric Neurology Association	15	3.1l	Velocity –dependent spasticity does not produce abnormal postures: abnormal motor planning produces abnormal postures. Dystonia and contracture may all produce abnormal postures. The pattern and reversibility can be helpful in identifying the most likely cause of the posturing.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity.
SH	British Paediatric Neurology Association	16	3.1n	There is no randomized controlled trial evidence that spasticity management prevents musculoskeletal deformities. Orthopaedic surgical planning may have been modified following intrathecal baclofen implants in one study* *Gerzertsen et al1998: Intrathecal baclofen and infusion and subsequent orthopaedic surgery in patients with spastic cerebral palsy. J Neurosurgery 88, 1009-1013.	Thank you.
SH	British Paediatric Neurology Association	17	3.2a -d	This section is about management of cerebral palsy, not about the management of spasticity. This summary of the role of physiotherapy omits a wide range of therapeutic strategies including muscle strengthening and postural management	Thank you. The text in these sections has been amended in response to stakeholder comments. Muscle strengthening will be included as we have now included the management of muscle weakness as long as these children also present with spasticity. Postural management will also be considered
SH	British Paediatric Neurology Association	18	3.2f	Orthopaedic Surgeons commonly play a lead role in direct spasticity management (e.g. Botulinum toxin injections), and in isolated cases surgery to modify the spasticity directly (e.g. Oswestry Selective Dorsal Rhizotomy program).	Thank you. We have amended the text which now reads "Orthopaedic

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				However, whilst bony and soft tissue surgery has a major role to play in the management of the musculo-skeletal consequences of spasticity, it does not directly influence the spasticity itself. In addition to Paediatric Orthopaedic specialists, Botulinum toxin A injections are often administered to children by a wide range of other specialists including paediatricians, paediatric neurologists, paediatric neurodisability specialists, specialist physiotherapists, and adult neurologists.	surgery has a major role in the management of early and late consequences of spasticity. "
SH	British Paediatric Neurology Association	19	4.1.1b	This sub grouping is artificial and of debatable merit for the purposes of this guideline	Thank you. We will be moving away from using the terms monoplegia, diplegia and quadriplegia in reference to cerebral palsy. Instead, we will use the terms unilateral and bilateral. However, the majority of papers in the literature will use the older terminology and so we will have to continue to employ them when assessing the evidence
SH	British Paediatric Neurology Association	20	4.1.2c	We are concerned that children with dystonia will be included in relation to management of the spasticity element alone. Whilst very experienced clinicians may be alert to the issues, we felt that many inexperienced clinicians may not appreciate the co-morbidity of dystonia, which may be the greater component. This may lead to delay in diagnosis, lack of response and possible missed treatment opportunity.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity.

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					The management of the child with a pure dystonia will not be reviewed but the GDG will bear in mind this important co-morbidity when making recommendations. .
SH	British Paediatric Neurology Association	21	4.3.1	Notwithstanding our major concerns about the focus on spasticity alone, we are concerned that the key clinical issues to be addressed here are eclectic, and will fall far short of a rigorous evidence based application of the management of even spasticity in Cerebral Palsy and other related disorders.	Thank you for this helpful comment. The scope no longer focuses on spasticity alone. The scope now also includes the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. We believe that during consultation key clinical management areas that are relevant to stakeholders have been identified. The clinical and lay members of the Guideline Development Group will aim to take a practical view when forming recommendations for consultation.
SH	British Paediatric Neurology Association	22	4.3.2a	We are concerned that if the focus is indeed on spasticity, that there should be a clear message on assessment and monitoring of response. Only then can therapy guidelines be translated to clinical practice, and the effect of the applied therapy be measured, reproduced and translated to functional improvement	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with

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					spasticity. We will not be examining the evidence for diagnosis and assessment of spasticity, (comparing Ashworth score with Tardieu scale for example) however assessments made to estimate degree of disability / motor functional difficulties will be reported as described in the intervention studies and specific recommendations considered for different subgroups if clinically relevant
SH	British Paediatric Neurology Association	23	4.4a	Relevant to comment on 4.3.2 a, we do not understand how following these guidelines will be able to show a reduction in spasticity without clear advice on assessment and monitoring	Thank you. We will not be examining the evidence for diagnosis and assessment of spasticity, (comparing Ashworth score with Tardieu scale for example) however assessments made to estimate of degree of disability / motor functional difficulties will be reported as described in the intervention studies and specific recommendations considered for different subgroups if clinically relevant
SH	British Paediatric Neurology Association	24	4.4b -f	These are excellent outcomes to measure.	Thank you

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SH	British Society of Rehabilitation Medicine		4.3.1a	This, or a separate point here, or 4.2 (healthcare setting), would also be an appropriate place to consider a multidisciplinary approach to spasticity in children.	Thank you. We support a multidisciplinary approach The multidisciplinary guideline development group, will include health care professionals and lay members. A multidisciplinary approach will be taken throughout the guideline development and where appropriate reflected in the recommendations.
SH	British Society of Rehabilitation Medicine	1	3.1l	Uncorrected deformities may also cause difficulties in caring of themselves, not just due to pain, impaired function and reduced mobility. It may be more accurate to include caring amongst this list, rather than them being a cause of difficult care. We would also suggest it is 'uncorrected deformities and spasticity' as spasticity of itself may cause these problems, even without the deformity. We would suggest adding lying and seating and further notable problems.	Thank you. We have amended the text in response to your comment Which now reads "Uncorrected deformities in spastic cerebral palsy can cause pain, impair function, reduce mobility and cause difficulties in caring for the child""
SH	British Society of Rehabilitation Medicine	2	3.1m	Difficulties also in development of social and educational roles and growing independence expected in paediatric development, thus reducing educational and societal opportunities. This (and employment opportunities) could be considered as a separate paragraph. The distinction in category between 3.1l and m is not clear. ICF terminology could be used to assist in this distinction if the working party is familiar with it and if thought that the audience would also be familiar with it. Otherwise, one system would be to have one paragraph about mobility, seating and functional activities, one about caring, one about participatory issues (socialisation, education and employment), and one about pain and secondary deformity.	Thank you. . We have made amendments to section 3.1 to reflect your comment and those of other stakeholders

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SH	British Society of Rehabilitation Medicine	3	3.2d	Aids and appliances are also used and issued, other than just orthotics. Specialised seating and posture management is the remit of various disciplines (varies regionally and within services) and is a key aspect of management in many – (may be physiotherapy, occupational therapy or clinical bioengineer led- in some areas seating is managed by regional disablement services). It may also be useful to refer to use of orthotics rather than 'bracing' as this is only one aspect of what orthoses are designed to do. There are several related issues concerned with orthoses that affect their use, such as their comfort and cosmesis.	Thank you. We have amended the wording of the text to remove "bracing" as suggested. Whilst aids and appliances that directly affect spasticity and its early consequences will be considered, the broad range of devices used in this group of children eg wheelchairs, standing frames, hoists, adapted cutlery etc, will not be covered. The GDG makes recommendations on interventions according to what is clinically and cost effective regardless of current service provision
SH	British Society of Rehabilitation Medicine	4	3.2e	This addresses pharmacological and surgical issues and not general well health advice to reduce those aspects of impairment or disease or lifestyle which may precipitate or aggravate spasticity. Advice on general issues such as posture, skin integrity, pain management, constipation management etc is also of value. This could go as a preliminary point at the start of section 3.2.	Thank you. The management of spasticity and its consequences requires a multi-disciplinary approach and we trust that the guideline will reflect this. There are many general health factors that influence severity and management of spasticity

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					which, if ignored by the clinician, can render interventions ineffective. Posture management is now acknowledged within section 3.2, however, skin integrity and pain management are large topic areas which are not unique to spasticity and could be guidelines in their own right. In fact, the guideline for constipation in children is due for publication soon. We need to be pragmatic about how much evidence the GDG can consider and this remains outside the scope however, a key task for the GDG will be to ensure the guideline reflects real life clinical practice.
SH	British Society of Rehabilitation Medicine	5	3.2e	Botulinum toxin B could also be included.	Thank you. We have now amended the scope and added Botulinum Toxin B to the Key clinical issues that will be covered
SH	British Society of Rehabilitation Medicine	6	3.2e	There is significant evidence of the usefulness of botulinum toxin in spasticity management including in Cerebral Palsy. Many clinical indications remain unlicensed and it is hardly practicable to expect pharmacological industries to gather data for these licences at this stage. Routine practice has moved on beyond this.	Thank you.
SH	British Society of Rehabilitation Medicine	7	3 final	Could also include refilling and cover rota for baclofen pumps as an issue where provision is limited.	Thank you. We recommend what is

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			paragraph		clinically effective and cost effective to inform service provision. Specific issues related to how services are organised are outside the scope of the guideline
SH	British Society of Rehabilitation Medicine	8	4.1.1	Orthopaedic surgeons may well indicate that skeletal maturity is not yet fully reached at 19 years.	Thank you.
SH	British Society of Rehabilitation Medicine	9	4.3 introductory paragraph	A first point about consideration of the issues raised in our point 4 could be included here.	Thank you. As before, we acknowledge that the management of spasticity and its consequences requires a multi-disciplinary approach and we trust that the guideline will reflect this. There are insufficient resources available to examine the evidence for all areas, and the focus of this guideline remains overall management of spasticity and the common motor co-morbidities and their consequences,
SH	British Society of Rehabilitation Medicine	10	4.3.1a	Also occupational therapy.	Thank you. We have made this amendment in response to your comment
SH	British Society	11	4.3.1b	Also specialised seating, sleep systems and posture management.	Thank you. We have amended

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	of Rehabilitation Medicine			Also other aids and appliances.	the text to include postural management.
SH	British Society of Rehabilitation Medicine	12	4.3.1c	Also cannabinoids and gabapentin.	Thank you. We have not added cannabinoids and gabapentin as there is no recent evidence to consider their inclusion to be a key clinical priority for children
SH	British Society of Rehabilitation Medicine	13	4.3.1d	Also botulinum toxin type B.	Thank you. We have now amended the scope and added Botulinum Toxin B to the Key clinical issues that will be covered
SH	British Society of Rehabilitation Medicine	14	4.3.1f	Also to improve posture and care needs.	Thank you. We have added posture improvement to the section in response to your comment
SH	British Society of Rehabilitation Medicine	15	4.3.1	There is no reference to appropriate interface with transition services to adulthood nor to vocational/occupational entry for persons with disability. This could be with regard to timing, mechanism and types of service. We would suggest that transition, and responsibilities and provision for continued interventions such as baclofen pump refilling are addressed at an early stage.	Thank you. We agree these issues are important and suggest this should be another guideline topic. These issues remain outside of the scope of this current guideline so that it retains its focus.
SH	British Society of Rehabilitation Medicine	16	4.3.1 and 3.2e	Functional electrical stimulation may have an effect on spasticity, as well as function, in children, and there is a literature concerning this area. Perhaps it could be considered as another modality to address.	Thank you. Electrical stimulation is included in the scope as an intervention
SH	British Society of Rehabilitation Medicine	17	4.4	If the outcomes are meant to be hierarchical I would suggest that improvement of function and an addition of improvement in care (for those very disabled young people where optimised care is going to be	Thank you. We are satisfied that we have

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				the main route to a good quality of life) should come above improvement in spasticity. You might also consider a caveat with the reduction in spasticity statement as it only being of use if it improves some measure of pain, function, quality of life or care.	outlined the main outcomes which are not given in a hierarchical list.
SH	British Society of Rehabilitation Medicine	18	4.4e	Acceptability and tolerability in children and young people: this should refer both to tolerability of treatment and aids/orthotics etc provided and to acceptability and tolerability of the level of impairment, activity and participation experienced by the child and carers by the disease process, its natural history, the treatment incurred and the consequences of lack of treatment. Transition might also be considered here, in that the mode of giving botulinum toxin and use of orthoses in childhood can significantly affect a child's acceptance of these forms of treatment in adulthood – for instance we have had problems in adult services with young people having been put off botulinum toxin by the associated use of a GA or midazolam.	Thank you. Acceptability and tolerability will only be included in relation to the treatment offered.
SH	Cambridge PCT		Page 5 section e)	I would suggest that Botulinum injections came before ITB as is more common in practice	Thank you. We have reordered this section as suggested
SH	Cambridge PCT		General	Well done	Thank you
SH	Great Ormond Street Hospital	1	1	We understand from the guideline scoping meeting this is the title given to NICE by government and feel it could offer valuable and much needed guidance on drug and surgical management of spasticity in Children, however, the contents does not appear to fit the title.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. Both children with cerebral palsy and children with later acquired non-progressive brain injury will be included.

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					The full title has been amended to "Non-progressive brain disorders in children and young people: management of spasticity, co-existing motor disorders and their early musculoskeletal complications"
SH	Great Ormond Street Hospital	2	2	As the remit of these guidelines to clarify and provide the best evidence available it would seem appropriate to go back to the commissioners and suggest some changes to the scope of the guideline at this stage. Other NICE guideline examples such as Managing Multiple sclerosis, or pharmacological management of Neurogenic pain could suggest alternatives such as a more specific guideline 'Drug and surgical management of Spasticity in Children and Young people with a non-progressive brain injury' or more wide reaching 'Management of Motor disorders in Children and Young people with Cerebral Palsy.'.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. Both children with cerebral palsy and children with later acquired non-progressive brain injury will be included. The full title has been amended to "Non-progressive brain disorders in children and young people: management of spasticity, co-existing motor disorders and their early musculoskeletal complications"
SH	Great Ormond Street Hospital	3	3.1a	The way spasticity is referred to in this document implies this alone is the motor disorder and the main cause of motor problems in this population. However, as stated, we know it is only one feature of the Upper Motor Neurone syndrome, therefore to develop a guideline which appears so wide ranging in content but does not address the other motor effects appears misguided.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these

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					children also present with spasticity.
SH	Great Ormond Street Hospital	4	3.1b	We feel there is a need to clarify the physiology behind spasticity.	Thank you. This section has been amended in response to stakeholder comments
SH	Great Ormond Street Hospital	5	3.1d	We would advise the use of the consensus definition of CP by Rosenbaum/Bax 2006 Dev med Ch N 2007,49 8-12. We feel it is important to suggest the progressive nature of the disability despite the diagnosis of a non progressive brain injury	Thank you. We are now using the suggested classification
SH	Great Ormond Street Hospital	6	3.1h	We would advise a defined upper age limit on definition to clarify classification of CP or acquired brain injury	Thank you. We are now applying Rosenbaum's definition and as such an upper age limit to define CP is not precisely specified but given as two to three years, We have added this to the scope as suggested
SH	Great Ormond Street Hospital	7	3.1j	While we understand that the mixed audience for this document may find this terminology familiar we would advise the use of the 2000 SCPE surveillance of CP definitions in terms of classification of distribution, type of tone disturbance. The Gross Motor Function Classification System is used internationally and becoming the functional definition of choice in most tertiary services and there referrers.	Thank you. We have made amendments to the scope which reflect your suggestion
SH	Great Ormond Street Hospital	8	3.1k	Weakness in CP is a significant limiting factor on function and often more so than spasticity and less amenable to therapy. Secondary complications of the developing immature musculoskeletal system are caused by muscle imbalance of any cause, particularly in the	Thank you. We are now including the management of dystonia,

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				mobile child. The body weight:strength ratio needs of the adolescent with CP are well described by Gage and these plus lever arm dysfunction are causes of deteriorating physical function.	choreoathetosis and muscle weakness as long as these children also present with spasticity.
SH	Great Ormond Street Hospital	9	3.2a - m	The interventions outlined are more holistic in their objectives and aim to manage wider movement disorder effects not just spasticity as alluded to in 3.2a.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity.
SH	Great Ormond Street Hospital	10	3.2c	Physiotherapy regimes are used to manage the negative effects of the child's movement disorder including spasticity, not to treat spasticity, and to limit unhelpful compensatory movements/strategies that will give rise to a future deterioration in function. This description underplays the wider role.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. The section has been amended in response to stakeholder comments
SH	Great Ormond Street Hospital	11	3.2d	Upper limb orthoses are far more common now we would suggest removing 'less frequently'	Thank you. We have made an amendment as suggested
SH	Great Ormond Street Hospital	12	3.2e	We believe the 2006 NICE guidance on SDR is in need of updating. (Mr W Harkness Neurosurgeon GOSH -original working party) SDR is much more commonly used in USA and Australia, with good patient selection the results can be good. The evidence for spinal and hip deformity following SDR is not clear. As this is a true treatment for spasticity, and one we are asked about by the families we serve, we	Thank you. The Interventional Procedure guideline on SDR is currently being updated and is due for publication in October 2010

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				feel this should be included in the guidelines.	As such, SDR is outwith the scope of this guideline.
SH	Great Ormond Street Hospital	13	3.2f	Orthopaedic surgery manages the deformity which results from the movement disorder, as stated at the end of the paragraph, and not spasticity. It has an important role but needs to be put into context. The underlying UML persists and spasticity returns once the muscle contractile filaments recover optimal length.	Thank you. This section has been amended to "Orthopaedic interventions including surgery have a major role in the management of the consequences of spasticity…."
SH	Great Ormond Street Hospital	14	4.1.1b	We refer again to the SCPE CP classification	Thank you. We will be moving away from using the terms monoplegia, diplegia and quadriplegia in reference to cerebral palsy. Instead, we will use the terms unilateral and bilateral and severity. The degree of severity is determined for walking by GMFCS and for upper limb function by the Manual Ability Classification Score. However, the majority of papers in the literature will use the older terminology and so we will have to continue to employ them when assessing the evidence
SH	Great Ormond Street Hospital	15	4.1.2c	It is very difficult to comment on treatment of spasticity alone when co morbidities of dyskinesia are often present and will have a greater or lesser effect on the child's functioning. These need to be assessed,	Thank you. We are now including the

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				evaluated and treated concurrently.	management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. We will not be examining the evidence for diagnosis and assessment of spasticity, (comparing Ashworth score with Tardieu scale for example) however assessments made to estimate f degree of disability / motor functional difficulties will be reported as described in the intervention studies and specific recommendations considered for different subgroups if clinically relevant
SH	Great Ormond Street Hospital	16	4.3.1	We would like to see much clearer definitions e.g. SCPE classification and GMFCS	Thank you. We will be moving away from using the terms monoplegia, diplegia and quadriplegia in reference to cerebral palsy. Instead, we will use the terms unilateral and bilateral and severity. The degree of severity is determined for walking by GMFCS and for upper limb function by the Manual Ability Classification Score. However, the majority of papers in the literature will use the older

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					terminology and so we will have to continue to employ them when assessing the evidence
SH	Great Ormond Street Hospital	17	4.3.2d	Hippo therapy is a treatment mode and not considered play therapy	Thank you. We have removed "hippotherapy" from the scope
SH	Great Ormond Street Hospital	18	4.3.2f	We would like SDR revised and updated see comment 12	Thank you. The Interventional Procedure guideline on SDR is currently being updated and is due for publication in October 2010 As such, SDR is outwith the scope of this guideline.
SH	Great Ormond Street Hospital	19	4.3.2g	We would like scoliosis included as part of the orthopaedic management.	Thank you. We agree that management of scoliosis in cerebral palsy is essential. However, there is a limit to how much of the consequences of spasticity the GDG will be able to look at. Therefore, we have decided to look at the immediate and short term consequences of spasticity that would involve orthopaedic surgery where the intervention may have an immediate impact on spasticity

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					or its symptoms such as pain and loss of function. We will not be looking at the later consequences of spasticity such as dislocation and scoliosis.
SH	Great Ormond Street Hospital	20	4.3.2h	Some of these co-morbidities are highly significant for causing pain and exacerbating spasticity and should at least be acknowledged to that effect. No spasticity management service would discount these when addressing problematic spasticity and our training of referrers always includes this.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. However, we do not have sufficient resources to review other comorbidities unrelated to movement disorders and these remain outwith the scope.
SH	Great Ormond Street Hospital	21	4.4.1b	Need to use the WHO guidance on Participation and inclusion.	Thank you. The suggested guidance is generic to all treatments and conditions and would not be cited in this guideline. However, NICE methodology (see NICE guidelines manual 2009) includes consideration of equalities whilst drafting the scope and developing the guideline
SH	Great Ormond	22	4.4.1f	Quality of life indicators are a strong feature of international	Thank you

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	Street Hospital			collaborative studies and good indicators of treatment success.	
SH	Great Ormond Street Hospital	23	General	We found the document easy to read which is important given the mixed audience who will receive it. However the document has to serve many purposes and therefore needs to have the robust definitions clinicians can use to support their interventions. We would be concerned that the most up to date, peer reviewed language is used with agreed terminology to make this document credible from the start. It would be useful to suggest tools and standards to benchmark services for children with spasticity and movement disorders.This is a huge piece of work which undoubtedly will have resource implications. Our service users may be looking for guidelines on the treatment of spasticity, but we feel more than just this, they want a guideline for holistic management of the child or young person, to support decision making in a way that addresses the motor disorder in the context of participation and inclusion. Thank you.	Thank you We will be moving away from using the terms monoplegia, diplegia and quadriplegia in reference to cerebral palsy. Instead, we will use the terms unilateral and bilateral and severity. The degree of severity is determined for walking by GMFCS and for upper limb function by the Manual Ability Classification Score. However, the majority of papers in the literature will use the older terminology and so we will have to continue to employ them when assessing the evidence We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity. The NICE implementation team will work with the GDG towards completion of the guideline to develop accompanying tools for use in front line NHS services

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SH	Leeds Teaching Hospitals NHS Trust	1	3.1k	Muscle weakness does often contribute to the deterioration in motor abilities with increasing age through childhood-particularily axial and pelvic girdle muscle weakness Treatment of spasticity as a component of an overall management programme which includes maintaining fitness,physio programme, environmental adaptations,educational adjustments is important in preventing functional decline.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity.
SH	Leeds Teaching Hospitals NHS Trust	2	3.1l	Deterioration in independent walking (with or without aids) is common in the teenage years in severe spastic cerebral palsy and maintenance of precarious walking ability may no longer be a relevant goal to the young person and requires review of overall management. **....in dressing and toileting** and in access to education and play	Thank you. Section 3.1m and n have been amended in response to your comment and those of other stakeholders.
SH	Leeds Teaching Hospitals NHS Trust	3	3.2e	Botulinum-: but there are RCT's showing reductions in spasticity with treatment	Thank you. Evidence from RCTs meeting the relevant inclusion criteria for the guideline will be reviewed and used to draft recommendations
SH	Leeds Teaching Hospitals NHS Trust	4	3.2f	Orthopaedic surgery has a major but limited role in mangement in the older child. Weakening of spastic muscles following surgery does at times lead to loss of functional abilities. The demands on the child and family of a physical rehabilitation and care management programme following surgery are considerable and often underestimated by clinicians. Orthopaedic surgery is of value in carefully selected children as part of an overall management programme. Considerable clinical experience is needed to select children who would benefit from surgery.	Thank you. The GDG will consider evidence of surgical interventions in conjunction with the associated rehabilitation package where details are given in the literature. We would also provide a description of the participants

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					including their selection criteria to the study where this is available in the literature
SH	Leeds Teaching Hospitals NHS Trust	5	4.1.2c	The majority of the children with spastic cerebral palsy have comorbidities – and the presence of comorbidities affects the outcome of spasticity management eg severe learning difficulties is an important factor in determining success of a rehab. programme following lower limb surgery, or the degree of improvement gained by managing spasticity of arm/hand function for for example computer use. Recording comorbidities is essential in any outcome studies.	Thank you. We are now including the management of dystonia, choreoathetosis and muscle weakness as long as these children also present with spasticity**.**
SH	Leeds Teaching Hospitals NHS Trust	6	4.3.1	How will severity of spasticity be defined and more important how will functional consequences of the interventions listed a to h be assessed. We suggest that the domains of the ICF (WHO) be used where possible	Thank you. We will be moving away from using the terms monoplegia, diplegia and quadriplegia in reference to cerebral palsy. Instead, we will use the terms unilateral and bilateral in accordance with SCPE. The degree of severity is determined for walking by GMFCS and for upper limb function by the Manual Ability Classification Score. However, the majority of papers in the literature will use the older terminology and so we will have to continue to employ them when assessing the evidence. Components of the ICF (WHO)

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					are expected to be covered in the outcomes specified in section 4.4 We will report the functional consequences of an intervention according to the domains of the ICF (WHO) where the outcomes are documented in this way in the evidence
SH	Leeds Teaching Hospitals NHS Trust	7	4.3.1d	....and relieve pain	Thank you. Reduction of pain is given as an outcome in Section4.4d
SH	Leeds Teaching Hospitals NHS Trust	8	4.4a	Please see 4.3.1 above ie effect on activity and participation.	Thank you. Components of the ICF (WHO) are expected to be covered in the outcomes specified in section 4.4 We will report the functional consequences of an intervention according to the domains of the ICF (WHO) where the outcomes are documented in this way in the evidence
SH	Medtronic	1	General	Medtronic welcomes the scope of this guideline and the recognition and inclusion of intrathecal baclofen pump therapy within the scope to reduce spasticity, maintain motor function and improve quality of life	Thank you.

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				in children with moderate to severe spastic diplegia, hemiplegia and quadriplegia.	
SH	Royal College of Nursing	1	General	The draft scope is comprehensive and seems appropriate. The RCN welcomes proposals to develop this guideline.	Thank you.
SH	Royal College of Paediatrics and Child Health	1	General	The RCPCH welcomes this guideline. We think the scope is a thorough and comprehensive document, with the below comments.	Thank you.
SH	Royal College of Paediatrics and Child Health	2	General	We note that spasticity often with a dynamic component is a major disabling feature. Anecodotal evidence supports that it is difficult to get funding for treatments from PCTs and dependent on evidence that is not always easy to sift. We note a poster presentation at EPNA in Autumn 2009 about an audit on botulinum toxin assessment clinic outcome data, which secured funding from a PCT.	Thank you for these helpful comments . We hope the publication of this guideline will help patients achieve acess treatments, based on expert advice and a comprehensive review of the relevant literature although we would point out that conference proceedings are not included in search strategies.
SH	Royal College of Paediatrics and Child Health	3	3.1j 4.1.1.b 4.3.1	We note that relatively old terminology is used in subgroups/classification. We suggest referral to The Definition and Classification of Cerebral Palsy. Developmental Medicine and Child Neurology. February 2007. Volume 49 Issue s109, pp1-44	Thank you. We will be moving away from using the terms monoplegia, diplegia and quadriplegia in reference to cerebral palsy. Instead, we will use the terms unilateral and bilateral in accordance with SCPE. The degree of severity is determined for walking by GMFCS and for upper limb function by the Manual Ability

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					Classification Score. However, the majority of papers in the literature will use the older terminology and so we will have to continue to employ them when assessing the evidence. We will not be using the suggested ICF domains
SH	Royal College of Paediatrics and Child Health	4	4.3.1 4.3.2 4.4	We think the exclusion of assessment of spasticity will not allow clinicians to assess/measure outcomes such as reduction of spasticity or optimisation of movement and function. We suggest including objective measures, such as modified Ashworth scale or functional outcomes, e.g. Gross Motor Function Measure (GMFM). This will allow consideration of each issue in relation to the severity of spasticity.	Thank you. While we will not be examining the evidence for diagnosis and assessment of spasticity, (comparing Ashworth score with Tardieu scale for example) we will however consider assessments made to estimate the degree of disability / motor functional difficulties as reported and described in the intervention studies.
SH	Royal College of Paediatrics and Child Health	5	4.4	We think that pain relief and the effect of spasticity control on the quality of life of the child and carers should be included as outcomes.	Thank you. Reduction of pain and quality of life for the child are already included as outcomes in section 4.4. Examining quality of life outcomes for carers is outwith the scope of this guideline but the guideline developers will be aware from their experience of

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					these important contextual issues and can take them into account as they form practical and implementable recommendations