

Stroke in Childhood

**Clinical guideline for diagnosis, management
and rehabilitation**

May 2017

Appendix 6

Contains:

- Stakeholder consultation comments

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The Royal College of Paediatrics and Child Health (RCPCH) is a registered charity in England and Wales (1057744) and in Scotland (SC038299).

Appendix 6: Stakeholder consultation comments

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

All typographic and grammatical errors have been corrected, and as such comments pertaining to these are not included below.

Stakeholder	Comments	Developers response
ARNI Institute for Stroke Rehabilitation	This is a most well prepared document – just a quick note in reading Stakeholders. Both Connect and Fighting Strokes no longer exist as Charities.	Thank you for your comment. the stakeholder list has been revised to indicate that although they were involved in the scope consultation the charities now no longer exist.
BIOS member Co-Founder and past Co Lead, current Steering Committee member of BIOS Special Interest Group for Special Educational Needs	Specify vision /functioning vision. If child has field loss or loss of vision impairs rehabilitation or habilitation if vision had not developed prior to stroke	Thank you for your comment. While there was no evidence of awareness, the following text has been added 'Similarly assessment by an audiologist should be considered on an individual basis. The GDG were conscious that sensory issues may impact on rehabilitation outcomes' and added the below recommendations to the section: <ul style="list-style-type: none"> Consider that an individual's sensory functions (e.g. hearing and vision) may change over time and therefore require reassessment. Be aware that children with sensory impairments may benefit from specialist support services, e.g. vision impairment teacher support and hearing impairment support.
BPNA - Vascular Group	We are concerned that currently there is no real awareness of the occurrence of stroke in childhood. Awareness of stroke symptoms (i.e. FAST) in childhood will require a public health campaign and education for general paediatricians similar to that undertaken in adults.	Thank you for your comment. Awareness of stroke symptoms (ie. FAST) in childhood will require a public health campaign and education for general paediatricians similar to that undertaken in adults has been added as a facilitator and barrier of the guideline.

BPNA - Vascular Group	There will need to be a clear systems improvement and request of scans at <1 hour for all children with possible stroke this is for it undertaking and then transferring to the regional centre. This is clearly desirable but considerable improvements will have to be made.	Thank you for your comment. It was felt that this comment is covered elsewhere in the guideline, with regard to challenges to the existing systems.
BPNA - Vascular Group	There is going to need to be development of clear local multidisciplinary guidelines. Training locally in A&E and general paediatrics in tertiary and surrounding DGH hospitals- surrounding recognition and then pathways to follow for patients with possible stroke.	Thank you for your comment. The following text has been included 'Important areas for training across all healthcare and education sectors include recognition of the clinical features of childhood stroke, the necessity of seeking urgent medical advice and activating the relevant clinical pathway. It is also important that public awareness of childhood stroke is improved and children and young people should be included in public health campaigns aimed at increasing awareness of stroke in general.'
BPNA - Vascular Group	<p>Thrombolysis as first line is to be considered if a clot is visible- this is as part of Delphi consensus statement.</p> <p>Although we realise that not all centres able to undertake thrombectomy this is the way in which adult stroke is moving and this surely should be considered if experience present and practical.</p> <p>There is also some nervousness surrounding thrombolysis. If this is to be taken forward there needs to be a national register that is managed collating data on demographics, procedure, PedNIHSS and outcome (PSOM)-cause of stroke etc. as well as any adverse effects. This can then be audited as number will be small.</p>	Thank you for your comment. The guideline audit section has been revised to suggest that a registry of all childhood stroke cases should be established to collect data on novel treatments and their outcomes.
BPNA - Vascular Group	Why is focal cerebral arteriopathy not a contraindication to thrombolysis?	Thank you for your comment. This is not a contraindication because it cannot be diagnosed on the basis of occlusive thrombus; which is the patient group who would be eligible for thrombolysis.

BPNA - Vascular Group	Utilising tools with robust psychometric properties where these exist: this is vague and not very helpful.	Thank you for your comment. The recommendation has been revised to 'Avoid delay before commencing baseline assessment of functioning. Depending on the child's individual circumstances the initial focus may be on body structures and functions as well as activity and participation. Where possible, use tools with established robust psychometric properties.'
BPNA - Vascular Group	GAS should be included here as it is free and we are not being allocated additional funds for any of this work. It is mentioned in the discussion but not the recommendation.	Thank you for your comment. GAS has been added to recommendation 9.3.10, where it also mentions other goal setting tools such as Perceived Efficacy in Goal Setting (PEGS) and Canadian Occupational Performance Measure (COPM).
British Academy of Childhood Disability	Can we please state Occupational therapy, Physiotherapy, Psychologists, Speech and language therapy (as per the list in the audit tool) individually as it can become lost in 'allied health professions'.	Thank you for your comment. These recommendations have been revised to 'Provide clinical assessment of a child's body structures and functions and activities, by members of the relevant hospital multidisciplinary team (MDT) (including occupational therapists, physiotherapists, speech and language therapists), as soon as possible during hospital admission (within 72 hours), with consideration of the child's age and developmental abilities' and 'Initiate early liaison with community-based medical, nursing, occupational therapists, physiotherapists, psychologists, orthoptists, speech and language therapists and other allied health professionals to establish links with local networks'. The GDG felt that adding psychologists was not necessary at this stage.
British Academy of Childhood Disability	<p>Can this be rephrased in a family centred way?</p> <p>Practitioner's interactions with children and families are as important as the services they provide (Entwistle, Prior, Skea & Francis, 2008; Trivette & Dunst, 2007). Positive collaboration with children and families influence health outcomes through improved satisfaction with the service, greater adherence to treatment routines and increased carer well-being (Fischer & Ereaut, 2011; Michie, Miles & Weinman, 2003; Dunst, Trivette & Hamby, 2007; Joosten et al., 2008).</p> <p>Assessment should focus on the priority areas for the child and</p>	Thank you for your comment. The text has been revised to 'rehabilitation following ABI aims to harness opportunities to remodel neuronal connections, to adapt and learn, and to compensate for missing skills ²⁵⁸ . The environment (physical, social and attitudinal) is a key consideration in identifying factors that may support or impede response to intervention in the short and longer term.'

	<p>family. These are determined through sensitive discussions with families and could include areas such as: Getting back to school, eating meals together, walking, getting dressed, having a conversation etc. Priority areas should help focus further assessments at component or impairment level as required and help prevent over-assessment.</p>	
British Academy of Childhood Disability	<p>Can we please state Occupational therapy, Physiotherapy, Psychologists, Speech and language therapy (as per the list in the audit tool) individually as it can become lost in 'allied health professions'.</p>	<p>Thank you for your comment. This recommendation has been revised to read 'Plan discharge with input from the child or young person and their family and the MDT (medical, nursing and allied health professionals including education staff, occupational therapists, physiotherapists, orthoptists, psychologists, speech and language therapists) prior to discharge from hospital. If the child has been admitted for an extended period, this may involve more than one meeting and should occur in a time-frame that allows all necessary support to be in place on discharge'.</p>
British Academy of Childhood Disability	<p>Can this be rephrased in a family centred way?</p> <p>Practitioner's interactions with children and families are as important as the services they provide (Entwistle, Prior, Skea & Francis, 2008; Trivette & Dunst, 2007). Positive collaboration with children and families influence health outcomes through improved satisfaction with the service, greater adherence to treatment routines and increased carer well-being (Fischer & Ereaut, 2011; Michie, Miles & Weinman, 2003; Dunst, Trivette & Hamby, 2007; Joosten et al., 2008).</p>	<p>Thank you for your comment. The text has been revised to 'Paediatric rehabilitation following ABI aims to harness opportunities to remodel neuronal connections, to adapt and learn, and to compensate for missing skills. The environment (physical, social and attitudinal) is a key consideration in identifying factors that may support or impede response to intervention in the short and longer term.'</p>
British Academy of Childhood Disability	<p>Not sure the paper Crossen 2010 proposing the use of ICDIH should be uncritically included as this classification has now been superceded by ICF, so people shouldn't be suggesting its use. The authors quoted may think QoL is important (and few would argue) and might therefore think that needs including as well as the ICF, but the way this sentence in the guideline is worded does not really make sense.</p>	<p>Thank you for your comment. This recommendation has been revised to read 'Plan discharge with input from the child or young person and their family and the MDT (medical, nursing and allied health professionals including education staff, occupational therapists, physiotherapists, orthoptists, psychologists, speech and language therapists) prior to discharge from hospital. If the child has been admitted for an extended period, this may involve more than one meeting and should occur in a time-frame that allows all necessary support to be in place on discharge'.</p>

British Academy of Childhood Disability	<p>The hospital based multidisciplinary team should:</p> <ul style="list-style-type: none"> - Work together to formulate and agree individualised goals across health domains to develop a unified and coordinated approach across disciplines. - Actively involve the child and young person and family in goal setting and decision making around intervention plans. - Consider the child or young person and family priorities when looking at rehabilitation options' <p>This should be more strongly worded - work together with the child and family to establish priorities and rehabilitation options</p>	<p>Thank you for your comment. This recommendation has been revised to:</p> <p>'The multidisciplinary team should work in active partnership with the child or young person and family in:</p> <ul style="list-style-type: none"> • formulation and agreement of individualised goals across health domains to develop a unified and coordinated approach across disciplines. • goal setting and decision making around intervention plans. • identification of priorities when considering rehabilitation options'
British Academy of Childhood Disability	<p>Mention here of family centred principles should be included as suggested in previous points.</p>	<p>Thank you for your comment. It was agreed to add in the following text, 'At all times the child or young person and family should be central to goal setting and decision-making. In providing rehabilitation there should be an emphasis on developing a positive collaborative working relationship with the child or young person and family in conjunction with delivery of the intervention modality.'</p>
British Academy of Childhood Disability	<p>The 45 minutes per day of each type of therapy – don't know which stage of the rehab process this applies to and think this should be stated. If later (community rehab) perhaps needs a sentence saying that 'therapy' should be integrated into normal activities where possible. I worry that families may expect some sort of hands on therapy input to that degree if they were to read the guideline and clearly that would be inappropriate, as would making children do 'exercises' for that length of time unless it was part of normal sport, learning etc. – therefore please can this be rephrased to having involvement from each appropriate therapist as it may be that the child does not need to be pulled away to engage in a 'therapy programme' if the aim is to integrate into home/school/community.</p>	<p>Thank you for your comment. It was agreed to remove 'The GDG agreed by consensus that this could be applied to children as well who show similar gains from rehabilitation, depending on the age of the child and their tolerance of treatment' and revise the text to include 'In children, tolerance of rehabilitation varies according to factors including cognitive, behavioural, communication and motor functioning and developmental age and abilities. Other factors such as fatigue can also impact engagement in intensive intervention. While the GDG agreed that the principle of identifying a target dose is desirable, it is difficult to prescribe this across all age ranges and abilities. Intervention that targets identified areas of priority for the child and family, at a frequency that enables rehabilitation goals to be met is desirable, however there are a number of key considerations. These include the</p>

		focus on daily life activities and participation (i.e. integration of rehabilitation in the context of home and school life), the coordination and agreement between professionals of intervention targets informed by the priorities of the child or young person and their family, and their willingness and ability to actively participate. The identification of a target dose and intensity for a rehabilitation programme is an important component in prescribing intervention to maximise outcomes.'
British Academy of Childhood Disability	<p>"Deliver any rehabilitation intervention in partnership with the young person and family."</p> <p>Can we please add: Focus on what the child and family need to, want to or are expected to do. Motor interventions should not be considered in isolation as every activity requires a combination of multiple body functions and structures. Focus on the outcomes and work backwards from there.</p>	Thank you for your comment. This recommendation has been revised to read 'Deliver rehabilitation intervention focused on what the child or young person and family need to, want to, or are expected to do. Motor interventions should be focused on functional goals and undertaken with consideration of the whole child and their needs and abilities across all domains of health.'
British Academy of Childhood Disability	<p>Can we please add in something like:</p> <p>Focus on the priority areas for the child and family to support coordination of services and reducing the overall burden of multiple services and professionals being involved?</p>	Thank you for your comment. A new recommendation has been added: 'Communicate the priorities of the child, young person and family to health care education and social care professions.'
British and Irish Orthoptic Society member	There is mention of sensory impairment but none specifically to vision.	Thank you for your comment. For information on 'vision', please refer to section 9.1, 9.3.2.
British and Irish Orthoptic Society member	Review questions mention sensory impairment but not vision specifically, there is a concern that visual impairment will be overlooked.	Thank you for your comment. For information on 'vision', please refer to section 9.1, 9.3.2.
<p>British and Irish Orthoptic Society member</p> <p>Co-Founder and past Co Lead, current Steering Committee member of BIOS Special Interest Group for Special Educational Needs</p>	Need to mention vision and vision impairment teacher support if required	<p>Thank you for your comment.</p> <p>While there was no evidence of awareness, the following text has been added 'Similarly assessment by an audiologist should be considered on an individual basis. The GDG were conscious that sensory issues may impact on rehabilitation outcomes' and added the below recommendations to the section:</p>

		<ul style="list-style-type: none"> Consider that an individual's sensory functions (e.g. hearing and vision) may change over time and therefore require reassessment. Be aware that children with sensory impairments may benefit from specialist support services, e.g. vision impairment teacher support and hearing impairment support.
<p>British and Irish Orthoptic Society member</p> <p>Co-Founder and past Co Lead, current Steering Committee member of BIOS Special Interest Group for Special Educational Needs</p>	Need to add vision function	<p>Thank you for your comment. While there was no evidence of awareness, the following text has been added 'Similarly assessment by an audiologist should be considered on an individual basis. The GDG were conscious that sensory issues may impact on rehabilitation outcomes' and added the below recommendations to the section:</p> <ul style="list-style-type: none"> Consider that an individual's sensory functions (e.g. hearing and vision) may change over time and therefore require reassessment. Be aware that children with sensory impairments may benefit from specialist support services, e.g. vision impairment teacher support and hearing impairment support.
<p>British and Irish Orthoptic Society member</p> <p>Co-Founder and past Co Lead, current Steering Committee member of BIOS Special Interest Group for Special Educational Needs</p>	Need to add specific vision/functioning vision to highlight importance	<p>Thank you for your comment. While there was no evidence of awareness, the following text has been added 'Similarly assessment by an audiologist should be considered on an individual basis. The GDG were conscious that sensory issues may impact on rehabilitation outcomes' and added the below recommendations to the section:</p> <ul style="list-style-type: none"> Consider that an individual's sensory functions (e.g. hearing and vision) may change over time and therefore require reassessment.

		<ul style="list-style-type: none"> Be aware that children with sensory impairments may benefit from specialist support services, e.g. vision impairment teacher support and hearing impairment support.
<p>British and Irish Orthoptic Society member</p> <p>Co-Founder and past Co Lead, current Steering Committee member of BIOS Special Interest Group for Special Educational Needs</p>	<p>Concerns:</p> <p>Aim is to highlight to professionals stroke in children does cause visual problems as in adults. Infants having had a stroke may not have developed visual process so cannot complain of a problem as do not know what missing.</p> <p>During my clinical experience I have seen several children in special schools and in clinics that have had a stroke and vision not been investigated and they are coping with significant problems. In my opinion Vision /Visual functioning needs to be separated from sensory issues to highlight the importance of investigation and specific support during childhood and learning when vision is impaired.</p>	<p>Thank you for your comment. however, it was felt that the text was adequate due to insufficient evidence for this section.</p>
British Aphasiology Society	<p>It would be worthwhile considering guidelines internationally in a short chapter (e.g., USA, Germany; topic may be part of adult stroke guidelines of may not cover all areas; e.g., http://www.awmf.org/leitlinien/detail/II/024-018.html for TBI in children), this time or in future, in order to cover evidence outside the UK and foster consistency of recommendations and approaches internationally as appropriate (e.g., see M. Alrasbi, A. Sheikh, Comparison of international guidelines for the emergency medical management of anaphylaxis, Allergy 2007: 62: 838-841)</p>	<p>Thank you for your comment; however, it was felt that this is outside of the guideline scope.</p>
British Aphasiology Society	<p>Something missing in that sentence; please perform detailed editing of the guideline text to prevent orthographic errors and missing parts of a sentence</p>	<p>Thank you for your comment. This error has been rectified.</p>
British Aphasiology Society	<p>dysphagia actually is taken to belong to SLT, too; since sometimes aphasia is used, sometimes dysphasia, sometimes communication problems, it will be difficult for an SLT to find the important parts of recommendations.</p>	<p>Thank you for your comment. There is inconsistency in the use of the terms 'dysphasia' and 'aphasia' in the literature, and the terms are often used interchangeably. This may be why they came up separately in the searches and therefore are listed separately in Table 3.1. These have now been combined in Table 3.1.</p>

		SLTs are aware of these issues and therefore it was felt that they will not have difficulties searching the document.
British Aphasiology Society	What is the difference between dysphasia and aphasia here? Or do you mean dysphagia (swallowing disorder) instead of dysphasia? If not, I would recommend not continuing to use the outdated term dysphasia, but only use the term aphasia (and, if appropriate, attribute to different severity levels, low severity in case of dysphasia, high severity in case of aphasia; or does aphasia even mean mutism here?); in any case, the frequency of swallowing disorders would be very important to know, since dysphagia increases risk of pneumonia at all stages of recovery.	<p>Thank you for your comment. As there is inconsistency in the use of the terms 'dysphasia' and 'aphasia' in the literature the GDG have combined the 2 terms in the sequelae table; sometimes using the more inclusive terms of speech, language or communication difficulties. SLTs are aware of these issues and therefore it was felt that they will not have difficulties searching the document.</p> <p>There was no data found on frequency of dysphagia, so this is difficult to include in the table; however, the GDG have highlighted the need for swallowing assessment in chapter 5's recommendations.</p>
British Aphasiology Society	dysphasia appears to be taken to cover dysphagia and dysarthria, which is not sensible; dysphagia are swallowing disorders and dysarthria speech motor disorders, which is of course not the same, even though they are both treated by Speech and Language Therapists (SLTs); aphasia (language disorders, in overt and written production or comprehension) is not mentioned here at all, which is very unfavourable.	Thank you for your comment. The text has been revised to read 'Levels of acute speech, language and swallowing abilities were assessed ¹¹⁰ using a number of standardised and non-standardised tools. These assessment tools included Ranchos Los Amigos Cognitive Scale, Verbal Motor Production Assessment of Children, Frenchay Dysarthria Assessment, Schedule of Oral Motor Assessment, Paramatta Hospitals Assessment of Dysphagia, and a non-standardised feeding trial. Impairments were identified in some children when using all of the tools, but no discussion on the usefulness or usability of the tools was' for clarity.
British Aphasiology Society	For aspiration, which might be linked to swallowing disorders, SLTs should be consulted immediately as well.	Thank you for your comment. The GDG have reworded this to read 'Withhold oral feeding (eating and drinking) until the swallow safety has been established'. The reason for this was because it was agreed that an SLT will come in at a much later stage.
British Aphasiology Society	Altogether, there is not much on aphasia for the acute phase, and there are terminological inaccuracies.	Thank you for your comment. The GDG didn't list aphasia as a complication, nor was motor disorders, memory difficulties etc. listed. These are all covered information on sequelae and in the Early Functional Assessment section but using more general activity limitation terms in line with ICF.

British Aphasiology Society	again, speech disorders and language disorders are not the same; thus, aphasia is not covered here, even though impaired language needs to be assessed and treated, too, since language skills are crucial for learning and communication.	Thank you for your comment. however, it was felt that the text was adequate.
British Aphasiology Society	<p>The definitions altogether look better here; however, the crucial term aphasia is not mentioned here. Please cover all main SLT domains (aphasia, dysarthria, voice, hearing, swallowing) and define them properly.</p> <p>If you did not find evidence for SLT in children in the UK using your method, it should be referred to SLT for adults (e.g., RCSLT guidelines)! In a RefMan PubMed recherche (childhood aphasia), I found 40 results, some of which looked informative, including a Children's acquired aphasia screening test.</p> <p>Are there really no assessments or therapies in the UK to be explicitly recommended here (my main clinical experience stems from Germany, I am working in the UK for 2 years now, so I cannot spontaneously recommend materials just now without further recherche and investigation)? The importance of speech and language for further development needs to be explicitly stated, I think (especially evident at school age, when new information is acquired via written and spoken language, which again builds the basis for later social integration and employability).</p> <p>Thus, the area of speech and language is in my view not properly defined and covered. Please let me know if I could be of any help to improve the guidelines in this respect, if you agree with my view (I am highly specialised in acquired and developmental speech and language disorders).</p>	<p>Thank you for your comment. Please note that inclusive speech, language and communication difficulties are included. Section 9.3.4 has been revised with the text 'Receptive or expressive aphasia, dysarthria, dysfluency and dysphonia have been described in studies on outcomes of childhood stroke'.</p> <p>With regard to the latter part of your comments, the GDG feel that they cannot take intervention evidence from the adult literature - depending on the age at which the stroke occurs children may still be developing language skills.</p> <p>The results of the search are likely to be sequelae papers, not intervention literature. The Children's Acquired Aphasia Screening Test is limited to children aged 3-7 years. In practice SLTs will select assessments and interventions developed for children with developmental speech and language or neurodevelopmental disorders. Assessments and interventions for adults may be used for adolescents.</p> <p>It was felt that this level of detail is beyond the scope of the guideline and feel that the recommendations in 9.3.4 adequately cover the importance of speech and language for interpersonal communication and educational achievement.</p>
British Association for Community Child Health	Should be a , after communication skills otherwise hard to understand what is being said	Thank you for your comment. This has been amended.
British Association for Community Child Health	Neuropsychologist support is extremely limited. In our area access is only through Tertiary Centre	Thank you for your comment. This point has been merged with the below; however, it was felt that by leaving the text as is this would show that pressure needs to be placed upon

		services in order for additional services to be considered. The idea is that if support is not available then the child should be moved to the appropriate service. This emphasises and highlights the importance of access.
British Association for Community Child Health	SENCo now known as SENDCo	Thank you for your comment. This has been amended.
British Association of General Paediatrics	It is a very useful guideline. As a general paediatrician I agree the aims to have imaging done within the hour are ambitious but better aim earlier than later! I just wonder if point 5.2.3 could be a bit more specific in terms of managing hypotension and hypertension. I guess if the diagnosis is suspected we would be discussing with the paediatric neurology team but at the frontline, I'd like to be more armed.	<p>Thank you for your comment. This recommendation has been update to:</p> <p>Children and young people with AIS should only receive blood pressure-lowering treatment in the following circumstances:</p> <ul style="list-style-type: none"> • in patients who are otherwise eligible for intravenous (IV) thrombolysis but in whom systolic blood pressure exceeds 95th percentile for age by more than 15% • hypertensive encephalopathy • end organ damage or dysfunction, e.g. cardiac or renal failure
British Association of General Paediatrics	<p>There have been a couple of wise general paediatric heads involved in the generation of this guideline (thanks to Michelle Barber for representing the BAGP!) but as usual this is a very subspecialty expert opinionated document.</p> <p>There is currently no lack of detailed guidance on all sorts of conditions of variable frequency. As it is common, they aspire to a gold standard and level of intervention and attention to detail which increasingly contrasts with the shortcomings of acute paediatric practice provision we are all experiencing at the moment. This guideline is no exception. On 160 pages it outlined management suggestions which – although important – will be neigh impossible to deliver in practice. The guideline features comments like:</p> <p>“Be aware that the following non-specific symptoms can be</p>	Thank you for your comment. The facilitators and barriers to implementation section is something that the GDG have discussed and revised accordingly.

	<p>present in a child presenting with stroke: Nausea or vomiting, Fever “Or: CT scanning/CNS imaging is to take place within one hour of presentation.</p> <p>I don’t know about your place of work but in my hospital kids often do not get even triaged within one hour of attendance, such is the workload.</p> <p>As this is the benchmark your departments’ practice will be measured against I suggest you familiarise yourself with this guideline and send in your comments. Of course, this is a relatively rare condition and in a typical DGH you are likely to see no more than one patient a year, the more it is important that this guideline is clear, concise and practical.</p> <p>Don’t get me wrong, if my child was to come to hospital with suspected stroke, I would want him to be assessed and treated in line with the recommendations of THIS guideline.</p> <p>But, by default this guideline is over inclusive and ambitious in relation to hyperacute diagnosis and management standards based on –well – very little evidence indeed. As a result it is unwieldy and will be a challenge to sift through at three o’clock on a Saturday morning when such a child arrives at your door step. As it is also sadly default, there is no assessment of the resource implications and no meaningful implementation support.</p>	
British Association of Stroke Physicians	A summary or overview of the key recommendations would be useful, especially of the acute management section where speed of treatment is important	Thank you for your comment. Please note that a summary document will be produced to accompany the published guideline, and these will be listed in the front of the guideline document.
British Association of Stroke Physicians	There is no clear definition of stroke given – does it include SAH, how does it differ for TIA? Is evidence of tissue damage on neuroimaging required?	<p>Thank you for your comment. A definition of ‘stroke’ has been added to the populations covered in the scope, as below:</p> <p>The guideline will cover children and young people (aged 29 days to 18 years at time of presentation) with acute arterial</p>

		<p>ischaemic stroke (AIS) (acute focal neurological disorder with imaging evidence of cerebral infarction in a corresponding arterial distribution) and haemorrhagic stroke (HS) up until their transition to adult care. These will be collectively referred to as 'stroke'. Transient ischaemic attack (TIA) is difficult to diagnose in children and a vascular aetiology can only be confidently attributed if there is an image correlated in the brain or cerebral circulation. Many children with TIA symptoms will have brain infarction and therefore TIA is not considered separately in this document.</p>
British Association of Stroke Physicians	Consider recommending that for a subsection of patients where thrombolysis is being considered the images should be reviewed immediately rather than within one hour as this will delay administration of TPA	Thank you for your comment. This recommendation has been updated to 'Initial scan images should be reviewed on acquisition and if necessary transferred immediately to the regional paediatric neuroscience centre for review.'
British Association of Stroke Physicians	It might be useful to acknowledge that in commissioning services there are differences between the devolved nations and comment on the geographical applicability of this guideline to the whole of the UK	Thank you for your comment. As per the scope, the guideline is set within the context of healthcare structures in the UK, and is intended to help inform clinical decisions of all UK paediatricians, other healthcare professionals involved in the regulation or practice of the care of children and young people affected by stroke, at any stage of their care and rehabilitation, as well as non-healthcare professionals involved with educational/social services. Sections may also be of relevance to education and social care professionals.
British Association of Stroke Physicians	It is not clear from the document how to investigate or manage TIA (is this in the remit of this document?)– a neurological deficit which has resolved (in 24hours) is a TIA rather than a stroke	<p>Thank you for your comment. A definition of 'stroke' has been added to the populations covered, as below:</p> <p>The guideline will cover children and young people (aged 29 days to 18 years at time of presentation) with acute arterial ischaemic stroke (AIS) (acute focal neurological disorder with imaging evidence of cerebral infarction in a corresponding arterial distribution) and haemorrhagic stroke (HS) up until their transition to adult care. These will be collectively referred to as 'stroke'. Transient ischaemic attack (TIA) is difficult to diagnose in children and a vascular aetiology can only be confidently attributed if there is an image correlated in the brain or cerebral circulation. Many children with TIA</p>

		symptoms will have brain infarction and therefore TIA is not considered separately in this document.
British Association of Stroke Physicians	This recommendation “Withhold enteral feeds until the safety of feeding has been established” is not clear. Does it mean check that the NG tube is in the correct place? If so are there guidelines for this here or elsewhere?	Thank you for your comment. It was felt that this recommendation was detailed adequately, and that this is a generic care parameter which should be familiar to paediatric staff. During GDG discussion, this was revised to ‘Withhold oral feeding (eating and drinking) until the swallow safety has been established’ in light of other stakeholder comments.
British Dietetic Association	<p>We are concerned that the statement under ‘management’ – “refer to dietitian if necessary” - does not provide enough guidance and is open to interpretation by individual clinicians. We would suggest the following statement: All children admitted to a hospital setting under the CQC regulation 14 require a nutritional assessment, this will determine whether a child is at nutritional risk and requires further assessment and subsequent intervention by a paediatric dietitian.</p> <p>For nutritional guidelines – refer to Chapter 29 ‘Feeding Children with Neurodisabilities’ from Clinical Paediatric Dietetics, 4th edn, ed V Shaw, 2015, Wiley Blackwell, ISBN 978-0-470-65998-4.</p>	Thank you for your comment. This point has been revised to your suggestion of ‘all children admitted to a hospital setting require a nutritional assessment, monitoring of weight, and referral to paediatric dietitian.’
British Dietetic Association	Following a swallow assessment, <u>all</u> children require a full nutritional assessment by a Paediatric Dietitian to determine whether they require nutritional intervention. For nutritional guidelines – refer to Chapter 29 ‘Feeding Children with Neurodisabilities’ Clinical Paediatric Dietetics, 4th edn, ed V Shaw, 2015, Wiley Blackwell, ISBN 978-0-470-65998-4.	Thank you for your comment. It was felt that the recommendations were adequate.
British Dietetic Association	If specialist multidisciplinary feeding services are unavailable in the local area, refer to the local Paediatric Dietitian. The local Paediatric Dietitian can contribute to the child’s assessment for appropriate nutritional support, e.g. tube feeding, or can provide advice regarding a texture modified diet.	Thank you for your comment. It was felt that the recommendations were adequate. It is recognised that many specialised services include a dietitian within their team.
British Dietetic Association	At present there is no specialist dietetic guidance for stroke in childhood. To our knowledge only one systematic review has addressed this and found evidence to be lacking (1). Authors strongly recommended research aimed at identifying interventions for oropharyngeal dysphagia in children. Therefore,	Thank you for your comment. The text was felt adequate as is.

	<p>the BDA Paediatric Group recommends that guidance on nutritional management for this group should be as for children with neurodisabilities. This can be found in Clinical Paediatric Dietetics as indicated in the attached comments.</p> <p>We hope this helps and please do not hesitate to contact us if we can be of further help.</p> <p>(1) Morgan AT, Dodrill P, Ward EC. Interventions for oropharyngeal dysphagia in children with neurological impairment. Cochrane Database Syst Rev 2012; 10:CD009456.</p>	
British Society for Haematology Paediatric Subcommittee	<p>Well written evidence based review</p> <p>Good use of Delphi panel</p>	Thank you for your comment.
British Society for Haematology Paediatric Subcommittee	<p>Genetic: need to add Protein S deficiency</p> <p>Acquires: Need to add acquired Protein C and Acqd protein S deficiency.</p>	Thank you for your comment. Acquired protein C and S deficiency cause purpura fulminans and they are unmistakeable with necrotic skin patches. Children are likely to die from DIC if untreated and the presentation would not be with AIS alone. Lower than normal C and S levels would occur in the context of any child with any cause of DIC but again this would not present with stroke.
British Society for Haematology Paediatric Subcommittee	Need to mention congenital pupura fulminans (homozygous protein C or S def) and acquired purpura fulminans especially post varicella. These are definitive reasons to screen for protein C or protein S but agree outside of this setting it is not helpful.	Thank you for your comment. A congenital patient is born with AIS, blindness and nectrotic patches all over their skin and rampant DIC. Again-acquired post VZV does no present with stoke-it presents with rapidly progressive skin necrosis.
British Society for Haematology Paediatric Subcommittee	I am concerned at the wording of consideration of alteplase. Until further evidence is available I would only support in setting of clinical trial.	Thank you for your comment. The term 'TPA' has been used where necessary and it was agreed that this is something that should be included into a registry.
British Society for Haematology Paediatric Subcommittee	The lack of consanguinity does not exclude the possibility of rare bleeding disorder	Thank you for your comment. It was felt that the question still needs to be asked as it would increase the risk significantly.
British Society of Haematology	<p>Screening for antiphospholipid antibodies is likely to be the most relevant test in terms of detecting a prothrombotic tendency.</p> <p>Was testing for anti-beta glycoprotein I considered? This is felt, in many scenarios, to be more relevant than anti-cardiolipin</p>	Thank you for your comment. The recommendation under section 6.1.2 has been revised to 'lupus anticoagulant and ACLA, and discuss beta 2GPI testing with haematology if necessary '.

	antibodies although I appreciate that this test may not be available in all laboratories.	
College of Occupational Therapists	Can we please state Occupational therapy, Physiotherapy, Psychologists, Speech and language therapy (as per the list in the audit tool) individually as it can become lost in 'allied health professions'.	Thank you for your comment. These recommendations have been revised to 'Provide clinical assessment of a child's body structures and functions and activities, by members of the relevant hospital multidisciplinary team (including occupational therapists, physiotherapists, speech and language therapists), as soon as possible during hospital admission (within 72 hours), with consideration of the child's age and developmental abilities' and 'Initiate early liaison with community-based medical, nursing, occupational therapists, physiotherapists, psychologists, orthoptists, speech and language therapists and other allied health professionals to establish links with local networks'. The GDG felt that adding psychologists was not necessary at this stage.
College of Occupational Therapists	<p>Can this be rephrased in a family centred way?</p> <p>Practitioner's interactions with children and families are as important as the services they provide (Entwistle, Prior, Skea & Francis, 2008; Trivette & Dunst, 2007). Positive collaboration with children and families influence health outcomes through improved satisfaction with the service, greater adherence to treatment routines and increased carer well-being (Fischer & Ereaut, 2011; Michie, Miles & Weinman, 2003; Dunst, Trivette & Hamby, 2007; Joosten et al., 2008).</p> <p>Assessment should focus on the priority areas for the child and family. These are determined through sensitive discussions with families and could include areas such as: Getting back to school, eating meals together, walking, getting dressed, having a conversation etc. Priority areas should help focus further assessments at component or impairment level as required and help prevent over-assessment.</p>	Thank you for your comment. The text has been revised to 'Paediatric rehabilitation following ABI aims to harness opportunities to remodel neuronal connections, to adapt and learn, and to compensate for missing skills ²⁵⁸ . The environment (physical, social and attitudinal) is a key consideration in identifying factors that may support or impede response to intervention in the short and longer term.'

College of Occupational Therapists	Can we please state Occupational therapy, Physiotherapy, Psychologists, Speech and language therapy (as per the list in the audit tool) individually as it can become lost in 'allied health professions'.	Thank you for your comment. This recommendation has been revised to read 'Plan discharge with input from the child or young person and their family and the MDT (medical, nursing and allied health professionals including education staff, occupational therapists, physiotherapists, orthoptists, psychologists, speech and language therapists) prior to discharge from hospital. If the child has been admitted for an extended period, this may involve more than one meeting and should occur in a time-frame that allows all necessary support to be in place on discharge'.
College of Occupational Therapists	Can this be rephrased in a family centred way? Practitioner's interactions with children and families are as important as the services they provide (Entwistle, Prior, Skea & Francis, 2008; Trivette & Dunst, 2007). Positive collaboration with children and families influence health outcomes through improved satisfaction with the service, greater adherence to treatment routines and increased carer well-being (Fischer & Ereaut, 2011; Michie, Miles & Weinman, 2003; Dunst, Trivette & Hamby, 2007; Joosten et al., 2008).	Thank you for your comment. This text has been revised to 'Paediatric rehabilitation following ABI aims to harness opportunities to remodel neuronal connections, to adapt and learn, and to compensate for missing skills ²⁵⁸ . The environment (physical, social and attitudinal) is a key consideration in identifying factors that may support or impede response to intervention in the short and longer term.'
College of Occupational Therapists	'The hospital based multidisciplinary team should: - Work together to formulate and agree individualised goals across health domains to develop a unified and coordinated approach across disciplines. - Actively involve the child and young person and family in goal setting and decision making around intervention plans. - Consider the child or young person and family priorities when looking at rehabilitation options' This should be more strongly worded - work together with the child and family to establish priorities and rehabilitation options	Thank you for your comment. This recommendation has been revised to: 'The MDT should work in active partnership with the child or young person and family in: <ul style="list-style-type: none">• formulation and agreement of individualised goals across health domains to develop a unified and coordinated approach across disciplines.• goal setting and decision making around intervention plans.• identification of priorities when considering rehabilitation options'.

College of Occupational Therapists	Mention here of family centred principles should be included as suggested in previous points.	Thank you for your comment. It was agreed to add in the following text, 'At all times the child or young person and family should be central to goal setting and decision-making. In providing rehabilitation there should be an emphasis on developing a positive collaborative working relationship with the child or young person and family in conjunction with delivery of the intervention modality.'
College of Occupational Therapists	<p>"In the recently published Royal College of Physicians (RCP) national clinical guideline for stroke (RCP 2016) it was recommended that individuals should accumulate at least 45 minutes of each appropriate therapy every day, at a frequency that enables them to meet their rehabilitation goals, and for as long as they are willing and capable of participating and showing measurable benefit from treatment. The GDG agreed by consensus that this could be applied to children as well who show similar gains from rehabilitation, depending on the age of the child and their tolerance of treatment."</p> <p>Can this be rephrased to having involvement from each appropriate therapist as it may be that the child does not need to be pulled away to engage in a 'therapy programme' if the aim is to integrate into home/school/community.</p>	Thank you for your comment. It was agreed to remove 'The GDG agreed by consensus that this could be applied to children as well who show similar gains from rehabilitation, depending on the age of the child and their tolerance of treatment' and revise the text to include 'In children, tolerance of rehabilitation varies according to factors including cognitive, behavioural, communication and motor functioning and developmental age and abilities. Other factors such as fatigue can also impact engagement in intensive intervention. While the GDG agreed that the principle of identifying a target dose is desirable, it is difficult to prescribe this across all age ranges and abilities. Intervention that targets identified areas of priority for the child and family, at a frequency that enables rehabilitation goals to be met is desirable, however there are a number of key considerations. These include the focus on daily life activities and participation (i.e. integration of rehabilitation in the context of home and school life), the coordination and agreement between professionals of intervention targets informed by the priorities of the child or young person and their family, and their willingness and ability to actively participate. The identification of a target dose and intensity for a rehabilitation programme is an important component in prescribing intervention to maximise outcomes.'

College of Occupational Therapists	<p>“Deliver any rehabilitation intervention in partnership with the young person and family.”</p> <p>Can we please add: Focus on what the child and family need to, want to or are expected to do. Motor interventions should not be considered in isolation as every activity requires a combination of multiple body functions and structures. Focus on the outcomes and work backwards from there.</p>	Thank you for your comment. This recommendation has been revised to read 'Deliver rehabilitation intervention focussed on what the child or young person and family need, want, or are expected to do. Motor interventions should be focussed on functional goals and undertaken with consideration of the whole child and their needs and abilities across all domains of health.'
College of Occupational Therapists	<p>Can we please add in something like:</p> <p>Focus on the priority areas for the child and family to support coordination of services and reducing the overall burden of multiple services and professionals being involved?</p>	Thank you for your comment. A new recommendation has been added: 'Communicate the priorities of the child, young person and family to health care education and social care professions.'
College of Paramedics (individual response)	I am concerned that there is not suitable reference to how children present to the NHS, and in particular no guidance in relation to the telephone triage system. Furthermore, 15 million patients a year present to NHS111 (around 10% of which are ambulance) and around 11million to 999 of which around 7 million end up being face to face contact) and 15 million to Emergency Departments. But around 100 plus million to primary care. What isn't clear is where these patients present to and then onto a guidance and recommendations around triage systems, telephone consultation nor other relevant information. NHS Pathways is currently the Clinical Decision Support System for all 111 calls and 50% of 999 calls.	<p>Thank you for your comment.</p> <p>Recommendation 4.1 has been reworded to read as follows 'Community medical services and ambulance services (including call handlers, telephone triage and advice services such as National Health Service (NHS) 111 and primary care reception staff) should be trained to recognise children and young people with symptoms suggesting an acute stroke as an emergency requiring urgent transfer to hospital'</p>
College of Paramedics (individual response)	It is excellent that London Ambulance has been involved in the development of these guidelines and that their Deputy Medical Director was the representative. Further, having the College of Paramedics as identified stakeholders is useful. However, it could be seen as a weakness that only London Ambulance was involved as it is a very unique service in terms of service delivery, clinical delivery and demographics and geography. An ambulance, frontline, paramedic would have been useful too to ensure that the guidance makes sense to frontline service delivery and the profession that delivers pre-hospital care. That	Thank you for your comment. Your comments will be taken on board and the GDG will consider seeking input from an ambulance, frontline, paramedic when the guideline is reviewed in 3-years' time.

	<p>is certainly no criticism of the LAS representative who is well respected, merely that it would be considered a weakness by some not have involved a paramedic as part of the group. I would argue it is mitigate to some extent by stakeholder consultation. It would also be useful to see how these guidelines will link into the ambulance pre-hospital guidelines published by AACE.</p>	
College of Paramedics (individual response)	<p>This is a helpful diagram but is predicated on services in the regions being able to meet these ideals – otherwise hopes could be raised, but services may not be there to meet them. This doesn't mean it should be implemented, but probably needs to be taken in the real world context.</p> <p>Just assessing FAST is limiting and excludes certain strokes, including posterior circulatory symptoms. I believe that the guideline should include the use of the FAST test, but make it clear that this isn't the key discriminator, but clinical impression is decision maker. Also reference to other tools, such as the MEND exam should be made.</p>	<p>Thank you for your comment. The guideline does note, in section 3.1, that 'While there are no validated diagnostic stroke scores in children; application of the FAST is reasonable, although absence of FAST criteria does not exclude stroke. A further advantage of using FAST is that it is now a tool very familiar to professionals in the pre-hospital and emergency setting', so it has been acknowledged that just assessing FAST is limiting. The respective recommendation also notes this.</p>
College of Paramedics (individual response)	<p>The language here needs some attention – first responders as a term in the USA is not interchangeable here in the UK, as the UK first responders are generally unqualified volunteers as parts of community scheme. Also aggressive triage is not a helpful term either. This section needs re-wording to talk about prehospital clinicians, paramedics, ambulance clinicians, NHS111 and other clinicians and urgent referral and transfer into specialist centres for children with suitable stroke services. It needs to talk about hospital pre-alert messages for acute paediatric stroke and that these pathways need to be setup across the system. It also needs to build in a system of feedback to the clinicians. This same pathway needs to be in place for 999, 111, GPs, EDs and other primary/community healthcare facilities.</p>	<p>Thank you for your comment. Working with the LAS Deputy Medical Director on the GDG, this paragraph has been reworded to the following 'It is apparent that the identification and management of childhood stroke leaves much room for improvement. Some of these areas that need to be addressed include awareness of the possibility of stroke and recognition of signs and symptoms by the whole spectrum of clinical practice and subsequent triage and urgent transfer to appropriate emergency departments supported by acute paediatric services, emergent imaging, referral to and advice from a regional paediatric neuroscience centre facilitated by a regional paediatric intensive care transport service. A pre-alert or priority call to trigger an appropriate team-based response in the emergency department is recognised as being an important component of the pre-hospital care of a child with a suspected stroke.</p>

		<p>Reorganising the care of acute childhood stroke in this way will be challenging at many levels, but the use of networks already in existence might facilitate this. Key to change is an attitudinal shift in the approach of clinicians to childhood stroke. The pathway proposed, involving many clinicians, liaison between secondary and regional centres and rapid acquisition and transfer of neuroimaging, coordinated by a regional paediatric transfer service, already operates for paediatric head injury. A challenging aspect of the pathway proposed in this guideline is the identification of children who can benefit from hyperacute IV thrombolysis without delay, and initiation of treatment in the emergency department or general paediatric unit.</p> <p>It is acknowledged that not every element of the care pathway proposed will be available at every DGH. The proposed pathway aims to act as a framework and local protocols will need to be developed to deliver the care goals set out. This will need to include consideration of which personnel need to be involved (including how they should be contacted), the care setting and other specifics such as clinical monitoring and drug dosing’.</p>
College of Paramedics (individual response)	<p>These recommendations are not either a) using the modern nomenclatures for the component parts of the health and social care systems, neither from 999 nor NHS111 and b) do not recognise that a number of these groups are supported by triage/clinical decision support systems, which need to be updated to incorporate these recommendations. Training needs to occur too. C) I do not believe that using FAST as the sole discriminator provides enough sensitivity for stroke. FAST is a validated tool in adults and thus should only be used as a tool, alongside other neurological assessment tool and practice to identify a focal neurological defect of sudden onset or indeed the other symptoms identified within the flow-chart on the next page.</p>	<p>Thank you for your comment. While FAST is not validated in children, there isn’t a tool that is to our knowledge. It therefore becomes a reasonable alternative.</p> <p>There are of course a wide range of clinical practice guidelines and decision-support tools that may need to be modified when this is published, but it is not within our scope to do this. There are a series of recommendations based on the best-available evidence or consensus.</p> <p>In light of this, ‘Children and young people seen by ambulance clinicians, or primary care providers outside hospital with the sudden onset of acute focal neurological symptoms should be screened for hypoglycaemia with a capillary blood glucose,</p>

		and for stroke using a simple screening tool such as FAST ('Face, Arms, Speech Time'). Where these are normal or negative, but stroke is still suspected, the acute stroke pathway should be used' has been added.
Community Child Health CSAC	Overall this is very helpful especially for acute management. As it is a very rare happening it will be imperative to have easy to follow local guidelines based on this document.	Thank you for your comment.
Different Strokes	It will be important to make sure these guidelines are made as widely available and accessible as possible. Positive feedback: "I think that if the recommendations are followed to the letter we would have a fantastic service for our children. The problem as always will be staffing and expertise. I think these could make a great difference."	Thank you for your comment.
Different Strokes	Pleased that they attempt to close the gap between current adult and children services for stroke: "I have had a look at these guidelines and I must say that I was unaware of the discrepancies in care between adults and children but guess it makes sense with the medics seeing these patients so infrequently."	Thank you for your comment.
Different Strokes	<p>We appreciate that you end with these sentences: "Due to the current state of child stroke services, a number of the recommendations outlined in this guideline are aspirational and as such will require additional resources. These additional resources will likely be needed at all stages of the care pathway, from additional training or materials to raise awareness of childhood stroke symptoms, to increased rapid access to diagnostic imaging equipment and specialist clinicians, and support and advocacy services for stroke survivors and their families."</p> <p>But could sections 9 and 10 make a more explicit reference to the importance of peer support and the role that charitable and voluntary organisations have to play in this, also more information about emotional/counselling support for families and how/where to access this?</p>	<p>Thank you for your comment. It was agreed to add in the below recommendation to the chapter which covers The needs of the family during the planning of care/rehabilitation.</p> <p>'Consider the role of the charitable and voluntary sectors in ongoing support and care. This may include independent advocacy for a young person and family.'</p>

Former CONNECT	<p>In the introduction the guidelines make the distinction between habilitation and rehabilitation following stroke for children and young adults who are developing skills and adults who grieve the loss of skills. A point well made.</p> <p>However, I think there could be much merit in collaboration between experienced and skilled rehabilitation therapists and the paediatric therapists in maximising knowledge and combining expertise in the management of childhood stroke. I say this for several reasons:</p> <p>The incidence of stroke in childhood /young people is very small - you say that teams may not see more than 1 -5 people a year. Whilst paediatric teams have much expertise in paediatric therapy, their direct experience of stroke is likely to be limited locally (refer to p103) and there may well be merit in collaborating with rehabilitation experts to support and enrich the treatment and of the child/young person involved and their families. Indeed this could present as a wonderfully rich two-way learning, for the maximum benefit of the beneficiaries.</p> <p>Such collaboration might be occasional at the start, but could gradually increase to facilitate a much smoother transfer at 18.</p>	Thank you for your comment. Please note that the guideline address planning for transition in the appropriate section. It was felt that collaboration, in reference to rehabilitation, does not need to be highlighted here in the introduction unless it appears as a global statement in relation to all aspects of care.
Former CONNECT	P 43 stroke care pathway recommendations - it stipulates the specialists that should be involved ...emergency medicine, paediatric medicine, anaesthetics, intensive care, and radiology. I think the wider multi-disciplinary team is missing here. They can even at the hyper acute stage offer chest management, etc. They will be of an increasing importance as the child travels further down the stroke pathway.	Thank you for your comment. It was felt that this may detract from focus on the acute pathway. There is a lot relating to MDT working later in the guideline.

Former CONNECT	Refers to informed decision making as far as possible. I would like to suggest that where a child has communication disability of cognitive overlay, it may be very helpful to have the speech and language therapist and possibly the occupational therapist involved to make quite sure that the child is presented information in as an accessible way as possible to be given the opportunity to make decisions.	Thank you for your comment. Please note that this recommendation has been revised to read 'The parents/carers and young people should be actively involved in decision making. This may require modification of information to meet the communication needs of the individual child or young person, with the support of a speech therapist and/or occupational therapist'.
George Still Forum	I was unable to find reference of Moya Moya as an aetiological factor for Childhood stroke. Mentioning this would be useful to make the guideline inclusive	Thank you for your comment. This can be found in Table 6.1. Conditions/factors are which associated with an increased risk of AIS in children and young people.
George Still Forum	For the longer term care early participation of Community Neurodisability team consisting Of Neurodisability expert community Paediatrician will be beneficial for the long term care that Childhood stroke should be recommended , per UK service setting.	Thank you for your comment. It was outside of the guideline scope to include and list every specialty.
HemiHelp	<p>I found this an excellent guideline – comprehensive and easy for a non-specialist like myself to read. Having been a lay member of the NICE Childhood Spasticity GDG (I have a son with hemiplegia), I appreciate the challenges it presented, in particular the lack of RCTs or other solid evidence base. I believe, however, that the combined experience of GDG members produced a better guideline then and has done so again now.</p> <p>Eighty percent of children with hemiplegia have the congenital form of the condition, and only 20% the acquired form, so HemiHelp tends to advise families to seek more specific help with ABI from other more specialist organisations such as Headways and the Child Brain Injury Trust. We have, however, had presentations on childhood stroke at our medical professional conferences, although they have usually concentrated on the problem of timely diagnosis. I was not aware of other important factors such as the problem of assembling multidisciplinary neurovascular teams in regional centres, and the uncertainty around using acute interventions known to be effective in adults for children.</p>	Thank you for your comment.

	<p>The CIMT/bimanual debate will of course run and run, but the message seems to be that they are both effective if practiced frequently and intensely enough!</p> <p>I particularly liked the emphasis in your guideline on wider issues such as coordination between clinicians and communication with families and young people, the need for long term follow-up and reassessment of rehabilitation/therapy needs and provision of a key worker for the child. You also dealt well with the problems around transition to adult medical and social services (which many HemiHelp members have found to be a nightmare).</p> <p>In short, I have only good things to say about this guideline, which I think will be of great use to families, young people and education professionals as well as clinicians.</p>	
Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	<p>Overall the evidence base is weak so evidence from research in adults is used extensively. It would help to have a formal rationale for this process considering how biological differences might affect risks and benefits.</p> <p>There is no mention at all in the guideline of the single most effective treatment for stroke in adults - stroke units. I accept that they don't exist in paediatrics but lessons from adult stroke unit research should be at least as important as in thrombolysis. While there is mention of care pathways there need to be much more specific recommendations about the organisation of care, staffing levels etc.</p> <p>The audit section needs to be more robust. Participation in audit should be a requirement.</p>	<p>Thank you for your comment. The introduction section (1.2) has been revised in light of your comment and makes reference to 'It is important to recognise the biological differences between children and adults when considering the aetiology and management of stroke. The paucity of high quality research evidence relating to childhood stroke will be apparent throughout this document and therefore in many cases it has been necessary to exercise clinical judgement in interpreting research evidence in adult populations for use in this guideline. There are also major differences in the structure of clinical care for adults and children. The efficacy of stroke units in improving outcomes in adult stroke is clearly established; however, given the low frequency of childhood stroke it seems reasonable to tap into existing networks of hospital and community care for children with acquired neurological disorders without losing sight of issues specific to stroke.'</p>

Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	<p>Suggest inclusion of reference to AHPs, education and social care staff are included in recommendations related to point 5 (coordinated care, ideally with a named key contact to provide consistent support and who is knowledgeable about brain injury) in section 1.2.</p> <p>Continuing and routine surveillance by a multidisciplinary team will be necessary over the long term as children's circumstances and their situations change in order to prevent secondary sequelae.</p>	<p>Thank you for your comment. The GDG felt that this comments is not appropriate for entry in this section because this is the section that summarises what came out of the parent workshops. The guideline does actually emphasise the importance of coordinated work between health, education and social care professionals in the pages above.</p> <p>The young person and parent workshops held to inform the guidelines identified six areas of priority to be considered in care delivery, and as such it is not possible to include that 'continuing and routine surveillance by a multidisciplinary team will be necessary over the long term as children's circumstances and their situations change in order to prevent secondary sequelae'.</p>
Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	Too many recommendations start 'consider'. Not helpful; e.g. 'Consider treating both ruptured and un-ruptured aneurysms.'	Thank you for your comment. The term 'consider' was what was agreed by GDG, and the evidence does not enable anything more robust.
Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	Disappointing no move to develop specialist stroke services	Thank you for your comment. This has been mentioned within the introduction section (1.2).
Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	In places almost becomes a textbook rather than a guideline	Thank you for your comment.
Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	Not convinced that sensible to keep separating sickle from the rest	Thank you for your comment. The reason SCD is separate from the rest is due to the management being different.
Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	Recommendations detailed in 5.2.3 correctly, in our opinion, indicates the withholding of feeding until the safety of feeding has been established. We would suggest that this recommendation should be strengthened by incorporating reference to drinking as well as feeding and, furthermore, that as dehydration can have its own dangers it might be appropriate to indicate a time limit for assessment of dysphagia and more detailed investigation i.e. perhaps by a specialist speech and language therapist.	Thank you for your comment. This recommendation has been updated to 'Withhold oral feeding (eating and drinking) until the swallow safety has been established'.

Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	Recommendation detailed in 5.3.3. We would suggest the addition of the speech, language and communication functions are added to the list as it is important to establish the level of understanding for the involvement in treatment decisions and also to determine, at an early stage, basic methods of communication.	Thank you for your comment. Please note that this is already listed under 'communication' under bullet 'Assess activity limitations'.
Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	We particularly welcomed the clarity of the Introduction- 8.1. It is important that local healthcare team as well as those from education and social care are aware of consequences and needs and should be cognisant of the fact that these may not depend upon the severity of the stroke.	Thank you for your comment.
Intercollegiate Stroke Working Party (ICSWP) of Royal College of Physicians (RCP)	Recommendations detailed in 8.1.4. We would suggest that the relevant staff detailed here are added to in order to ensure that staff from education (if relevant to case) are included particularly given the information from the Glang study which is referenced earlier in this section.	Thank you for your comment. This recommendation has been revised to 'Plan discharge with input from the child or young person and their family and the multidisciplinary team (MDT) (medical, nursing and allied health professionals including education staff, occupational therapists, physiotherapists, orthoptists, psychologists, speech and language therapists) prior to discharge from hospital. If the child has been admitted for an extended period, this may involve more than one meeting and should occur in a time-frame that allows all necessary support to be in place on discharge.'
London Ambulance Service NHS Trust	<p>In line 1009 we make mention of the fact that FAST is not validated for use in children.</p> <p>Should we therefore change the wording in 1226 to read "Children seen by ambulance clinicians, or primary care providers outside hospital with the sudden onset of focal neurological symptoms should be screened for hypoglycaemia with a capillary blood glucose, and for stroke using a simple screening tool e.g. FAST (Face, Arms, Speech Time)</p>	Thank you for your comment. This has been revised to read 'Children and young people seen by ambulance clinicians, or primary care providers outside hospital with the sudden onset of acute focal neurological symptoms should be screened for hypoglycaemia with a capillary blood glucose, and for stroke using a simple screening tool such as FAST ('Face, Arms, Speech Time'). Where these are normal or negative, but stroke is still suspected, the acute stroke pathway should be used.'

London Ambulance Service NHS Trust	<p>Unless a change as above is agreed, there is a typo:</p> <p>Children seen by ambulance clinicians, or primary care providers outside hospital with the sudden onset of focal neurological symptoms should be screened for hypoglycaemia with a capillary blood glucose, and for stroke using <u>a</u> validated tool e.g. FAST (Face, Arms, Speech Time)</p>	Thank you for your comment. This typo has been amended.
London Ambulance Service NHS Trust	<p>1. Non-rebreathing oxygen mask should read high-flow oxygen mask.</p> <p>2. SaO2 should read SpO2 (SaO2 refers to saturation of oxygen in arterial blood; SpO2 is this level measured by pulse Oximetry).</p> <p>3. The target saturation of > 92% is considerably lower than the general recommendation and practice that sick children with a reduced level of consciousness are placed on high-flow oxygen. The potential neuroprotective benefit of a lower target saturation in a patient who is subsequently diagnosed as having a stroke may be less than the risk of withholding oxygen in a patient with another diagnosis. It is possible that some Trusts will feel uncomfortable adopting this recommendation.</p> <p>4. Should there be a statement to the effect that crews should consider the possibility of meningococcal disease?</p>	<p>Thank you for your comment.</p> <ol style="list-style-type: none"> 1. This has been revised to read 'high flow' 2. This has been corrected 3. The GDG felt that >92% was reasonable 4. It was felt that the text was sufficient, without mention of meningococcal disease
London Ambulance Service NHS Trust	Use of term 'paramedic' limits relevance to non-paramedic personnel that may attend these patients; suggest use medical or ambulance	<p>Thank you for your comment. The text has been revised to 'This guideline provides examples of how referral and management pathways might be improved going forward. These begin from the point of referral or the activation and response of emergency medical services and go through to long-term community care, covering the management pathway from the acute setting to the more elective management of neurovascular disorders in children and young people. The guideline also discusses the activation of regional retrieval services to expedite time-critical imaging and transfer to a facility that will hasten the hyperacute management of.'</p>
London Ambulance Service NHS Trust	As above; suggest use ambulance clinicians	Thank you for your comment. The text has been revised to read 'The management of stroke in adults is well

		commissioned and has led to pathways that allow early recognition and rapid transfer directly to stroke centres. In light of the current organisation of paediatric services within the UK, sick children and young people will be taken to the nearest acute paediatric unit. This is appropriate to ensure early triage and that the child is in a place of safety, but must be combined with a general raising of the level of awareness in the community and amongst healthcare professionals to facilitate early recognition and appropriate onward care of children and young people with suspected.'
London Ambulance Service NHS Trust	As above; suggest use ambulance	Thank you for your comment. The text has been revised to read 'The management of stroke in adults is well commissioned and has led to pathways that allow early recognition and rapid transfer directly to stroke centres. In light of the current organisation of paediatric services within the UK, sick children and young people will be taken to the nearest acute paediatric unit. This is appropriate to ensure early triage and that the child is in a place of safety, but must be combined with a general raising of the level of awareness in the community and amongst healthcare professionals to facilitate early recognition and appropriate onward care of children and young people with suspected.'
National Advisory Committee for Stroke in Scotland	Given that this guidelines covers people up to the age of 18 years I am surprised that illicit drugs are not mentioned as a possible cause for ischaemic stroke. We note later reference under intracerebral bleeding.	Thank you for your comment. While illicit drug use was not added to Table 6.1, this was added to the recommendation below which considers specific conditions which, although have not been scrutinised in case-control analyses, are linked with childhood AIS and may be clinically important in relevant cohorts.
National Advisory Committee for Stroke in Scotland	Consider the role of drug testing where illicit drug use is considered.	Thank you for your comment. It was felt that the role of drug testing should not be added to the suggested recommendations, as it was added to the recommendations in 6.1.1.
National Advisory Committee for Stroke in Scotland	In adult practice we always use a loading dose of aspirin or clopidogrel to ensure an early onset of effect. Should this be considered in children given that any absolute effect is likely to be greatest in the first day or two?	Thank you for your comment. It was felt that a loading dose of aspirin or clopidogrel, to ensure an early onset of effect, should not be considered as a recommendation due to the lack of evidence surrounding this.

National Advisory Committee for Stroke in Scotland	The statement that in adult practice thrombectomy has been shown to be superior to iv thrombolysis is misleading. The majority of the evidence supporting thrombectomy has tested thrombectomy following iv thrombolysis versus iv thrombolysis alone – the studies have not compared the two treatments. I agree the NNT for thrombectomy is lower than for iv thrombolysis	Thank you for your comment. The text in 6.2.3 has been revised to read 'There were no randomised controlled trials identified comparing endovascular treatment of arterial ischaemic stroke in paediatric patients against medical treatment with IV thrombolysis. However, the GDG noted that current adult studies indicated superiority of recanalisation therapy (following IV thrombolysis) over IV thrombolysis alone.'
National Advisory Committee for Stroke in Scotland	Transitioning to adult stroke services – lack of acknowledgement that there is lack of clarity about what they will really be transitioning to –given lack of stroke specific long-term support/rehab services	Thank you for your comment. The terminology has been revised and it is felt that transition is covered sufficiently in chapter 8-10.
National Advisory Committee for Stroke in Scotland	Given almost complete lack of robust evidence for any intervention in childhood stroke we are surprised the guideline committee have not suggested establishing international research networks to help set up adequately powered trials	Thank you for your comment. this suggestion has been added to the guidelines' research recommendations which will be reviewed by the GDG.
Northern Ireland Chest Heart and Stroke Association	In reference to the small evidence base for management of AIS in children, and given the low numbers of AIS patients, it would be reasonable to implement a (?compulsory) registry of all children affected by stroke, especially to include those treated with Thrombolysis or Endovascular intervention, akin to the SITS registry database for adults. Whilst this would not be randomised evidence, it would provide significant data to compare outcomes and system variations for children with AIS.	Thank you for your comment. This has been added as an audit point.
Northern Ireland Chest Heart and Stroke Association	When considering risk factors for AIS in teenagers, do not forget illicit drug use, esp cocaine, and 'new generation' amphetamine mimics (previously known as 'legal highs'). These appear to be potent causes of arterial occlusion and dissection in young people, and we see this regularly in adult stroke medicine. The prevalence of use of these drugs also appears to be rising	Thank you for your comment. The term 'other recreational drugs' has been added.
Northern Ireland Chest Heart and Stroke Association	Consider adding this to the recommendations- ' Consider urine/serum toxicology for illicit substances, depending on clinical suspicion'	Thank you for your comment. It was felt that using the term 'consider' was sufficient for this recommendation.

Northern Ireland Chest Heart and Stroke Association	Catheter angiography could also be considered in patients with unexplained, recurrent ischaemic or haemorrhagic stroke where no other cause has been found after comprehensive, non-invasive investigation	Thank you for your comment. It was felt that the investigation of recurrent events was not within the scope of the guideline.
Northern Ireland Chest Heart and Stroke Association	I wonder if a maximum dose of 75mg aspirin at onset of AIS is appropriate in a larger child, e.g. 50kg, in the age range 15-18?	Thank you for your comment. This recommendation has been revised to 'Prescribe and deliver 5mg/kg of aspirin up to a maximum of 300mg within 24 hours of diagnosis of AIS in the absence of contraindications (e.g. parenchymal haemorrhage). After 14 days reduce dose of aspirin to 1mg/kg to a max of 75mg'.
Northern Ireland Chest Heart and Stroke Association	IN the indications for decompressive hemicraniectomy, I feel a note about imaging should be included, akin to that in the adult guidelines- 'signs on CT of an infarct of at least 50% of the MCA territory with or without additional infarction in the territory of the anterior or posterior cerebral artery on the same side, or infarct volume greater than 145 cubic centimetres on diffusion-weighted MRI.' This will ensure patients with undiagnosed non convulsive status epilepticus, or another reason from drop in consciousness do not proceed inappropriately to surgery	Thank you for your comment. An additional recommendation (below) has been added to the recommendations for Indications for referral to neurosurgery in children and young people with AIS: 'while not validated in children, signs on CT of an infarct of at least 50% of the MCA territory with or without additional infarction in the territory of the anterior or posterior cerebral artery on the same side'
Northern Ireland Chest Heart and Stroke Association	Infarction in the territory of the anterior or posterior cerebral artery on the same side, or infarct volume greater than 145 cubic centimetres on diffusion-weighted MRI.' This will ensure patients with undiagnosed non convulsive status epilepticus, or another reason from drop in consciousness do not proceed inappropriately to surgery	Thank you for your comment. An additional recommendation (below) has been added to the recommendations for <i>Indications for referral to neurosurgery in children and young people with AIS</i> : 'while not validated in children, signs on CT of an infarct of at least 50% of the MCA territory with or without additional infarction in the territory of the anterior or posterior cerebral artery on the same side'
Northern Ireland Chest Heart and Stroke Association	Add the word 'extensive'- When cross-sectional imaging (computerised tomography (CT) or magnetic resonance imaging (MRI)) have ruled out EXTENSIVE, established infarction in the ischaemic territory.	Thank you for your comment. The word 'extensive' has been included.

<p>Northern Ireland Chest Heart and Stroke Association</p>	<p>The time limit of 4.5 hours for endovascular treatment of anterior circulation may exclude some patients from treatment inappropriately- consider using the wording in the adult guideline which more accurately reflects the RCTs that inform these guidelines - i.e. Patients with acute ischaemic stroke should be considered for combination intravenous</p> <p>thrombolysis and intra-arterial clot extraction (using stent retriever and/or aspiration techniques) if they have a proximal intracranial large vessel occlusion causing a disabling neurological deficit (National Institutes of Health Stroke Scale [NIHSS] score of 6 or more) and the procedure can begin (arterial puncture) within 5 hours of known onset.</p> <p>Patients with acute ischaemic stroke causing a disabling neurological deficit (a National Institutes of Health Stroke Scale [NIHSS] score of 6 or more) may be considered for intraarterial clot extraction (using stent retriever and/or aspiration techniques, with prior intravenous thrombolysis unless contraindicated) beyond an onset-to-arterial puncture time of 5 hours if: the large artery occlusion is in the posterior circulation, in which case treatment up to 24 hours after onset may be appropriate; a favourable profile on salvageable brain tissue imaging has been proven, in which case treatment up to 12 hours after onset may be appropriate.</p> <p>If this is not considered appropriate, I would suggest adding a short statement to say that ‘many of the listed contraindications may be regarded as relative in the setting of a significant, potentially disabling stroke and a decision regarding the risk-benefit of thrombolysis needs to be taken with each individual case’.</p>	<p>Thank you for your comment. The recommendations have been revised in light of the comments received.</p>
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Northern Ireland Chest Heart and Stroke Association	<p>It is well recognised in adult stroke medicine that listing contraindications to thrombolysis as absolute will exclude many patients from brain saving treatment. I understand the uncertainties in paediatric medicine, but I would suggest including the below in the relative contraindication section-</p> <p>Unknown time of symptoms onset, unless last known to be well >12 hours previous</p> <p>Patient who would decline blood transfusion if indicated.</p> <p>Persistent systolic blood pressure > 15% above the 95th percentile for age while sitting or supine</p> <p>Prior stroke, major head trauma, or intracranial surgery within the past three Months</p> <p>Stroke related exclusion criteria:</p> <p>Mild deficit (Paediatric National Institute of Health Stroke Scale (PedNIHSS) < 4) at start of alteplase infusion or at time of sedation for neuroimaging, if applicable</p> <p>Severe deficit suggesting very large territory stroke, with prealteplase PedNIHSS > 24, regardless of the infarct volume seen on Neuroimaging</p> <p>Low molecular-weight heparin (LMWH) within past 24 hours, DEPENDING ON DOSE GIVEN (aPTT and INR will not reflect LMWH effect)</p>	<p>Thank you for your comment. An introduction has been added, which reads 'As previously stated, the TIPS trial of hyperacute IV tPA in children closed due to non-recruitment and is therefore unlikely that a robust evidence base establishing efficacy of this treatment will become available. The role of IV therapy is a major area of concern for the clinical care of children with AIS and therefore the GDG felt it was important to make a recommendation around this, with ratification via Delphi consensus process (see Section 2.9). The GDG felt it reasonable to base the following contraindications to thrombolysis on the exclusion criteria which is specified in the protocol of the TIPS study.'</p>
Paediatric Intensive Care Society	<p>Congenital or Acquired Heart Diseases predominantly those with higher risk of thromboembolism such as single ventricle circulation, dilated cardiomyopathy or intracardiac shunts (atrial septal defect).</p>	<p>Thank you for your comment. It was agreed to leave the text as is, due to Table 6.1 providing sufficient detail.</p>
Paediatric Intensive Care Society	<p>Thromboembolism complications or air embolism secondary to cardiopulmonary bypass applied during congenital heart surgery.</p> <p>Cardiac interventionism with application to endovascular devices such as vascular stents or occluding devices.</p>	<p>Thank you for your comment. It was agreed to leave the text as is, due to Table 6.1 providing sufficient detail.</p>

Paediatric Intensive Care Society	Consider to perform echocardiography (i.e.: undiagnosed ASD)	Thank you for your comment. The recommendation in relation to 'echocardiogram' already exists where it lists the investigations that should be carried out in children and young people with a diagnosis of AIS. The text has been clarified to read 'echocardiogram (to identify structural lesions and R to L shunts)'.
Paediatrician with Cardiology Expertise on behalf of British Congenital Cardiac Association	PFO is very common in young children and there is no evidence to show that bubble echo would be helpful in that age group. Most paediatric centres would not be able to cope with the referrals that this recommendation would trigger. Qualifying the statement to define the group of children may be helpful if this is a cost effective investigation. Please define the study which led to this recommendation.	Thank you for your comment. The recommendation to evaluate 'echocardiogram' has been clarified to read 'echocardiogram (to identify structural lesions and R to L shunts)'.
Paediatrician with Cardiology Expertise on behalf of British Congenital Cardiac Association	Right to left shunts are easily detected in children by normal 2D Echo, making bubble ECHO unnecessary. Only the older teenagers may require bubble ECHO, so should be left at discretion of Echocardiographer if deemed necessary to rule out right to left shunts.	Thank you for your comment. The recommendation to evaluate 'echocardiogram' has been clarified to read 'echocardiogram (to identify structural lesions and R to L shunts)'.
Paediatrician with Cardiology Expertise on behalf of British Congenital Cardiac Association	<p>Could you please define the following aspects better.</p> <ul style="list-style-type: none"> • Define 'stroke with confirmed thromboembolic aetiology' • Age group when bubble contrast echo should be considered, if 2d echo/colour doppler is normal • Indication for closure of atrial communication if proven 	Thank you for your comment. While there is no mention of 'stroke with confirmed thromboembolic aetiology', with regard to bubble contrast echo, the following text has been added to section 6.1.2 'Although Right to Left (R to L) intracardiac shunts are associated with AIS in young people, their role in the aetiology of childhood AIS is unclear; however, clinical experience suggests that they may be relevant in a minority of cases. The necessity for a bubble study in addition to a standard echocardiogram should be discussed with the cardiology team in light of the patient's clinical and radiological presentation. If a R to L intracardiac shunt is detected, further management should be decided on a case-by-case basis and should involve discussion between the treating neurologist and cardiologist. Factors to consider are stroke subtype, other risk factors and features of the R to L shunt.'

		The indication for closure of atrial communication if proven, or management, is not covered by the guideline as is not within the remit and should be discussed with a cardiologist.
Paediatricians with Expertise in Cardiology	<p>I would like to highlight a case of stroke in a young adolescent with stroke we treated effectively in a timely fashion by working collaboratively with adult stroke consultants. We have presented this case in the World Stroke Conference in Hyderabad 2016. I am attaching the abstract of this case.</p> <p>You may want to consider this way of exploiting an expertise which is already present in many DGH units.</p>	Thank you for your comment.
RCPCH Children and Young People's Engagement Team	<p>Is there a definition provided of the age that "young person" relates to where it is not attributed to the feedback from the YP/PC focus groups?</p> <p>There are a number of references throughout directed only at YP /PCs that is also applicable to children. Without being overt in the reference to the full age span of infants, children and young people, my concern is that this becomes inconsistent and leaves potential for gaps to appear. In our work it has become clear that we need to refer to infants, children and young people in all cases where it directly relates to the full age range. It has also been noted young people in our work in 2016, that whilst children is the legal definition that is a catch all, young people (age 11+) do not wish to be termed as a "child".</p> <p>Also it should be noted that the UNCRC is clear that the right for ICYP to involvement in decisions that affect them is across all ages, with article 23 referencing specifically those with disabilities or additional needs to also be involved. Need to be clear in the wording of recommendations (see some examples noted below) on how the recommendation meets this duty when only referencing young people or without further reference to appropriate methods.</p>	Thank you for your comment.
RCPCH Children and Young People's Engagement Team	As per comment one	Thank you for your comment, the recommendation has been revised in light of your suggestion.

	<p>Need to ensure information shared is age appropriate, visual and that there are copies provided for both ICYP and P/C.</p> <p>& Us® RCPCH Voice Bank 2016 evidence can be provided regarding this request from ICYPF</p>	
RCPCH Children and Young People's Engagement Team	<p>As per comment one</p> <p>Need to ensure information shared is age appropriate, visual and that there are copies provided for both ICYP and P/C.</p> <p>& Us® RCPCH Voice Bank 2016 evidence can be provided regarding this request from ICYPF</p> <p>Key worker is an idea that has been raised from parents/carers and young people in our Long Term Conditions consultation in 2016 (non stroke experienced)</p>	Thank you for your comment, the recommendation has been revised in light of your suggestion.
RCPCH Children and Young People's Engagement Team	<p>As per comment one</p> <p>Need to ensure information shared is age appropriate, visual and that there are copies provided for both ICYP and P/C.</p> <p>& Us® RCPCH Voice Bank 2016 evidence can be provided regarding this request from ICYPF.</p>	Thank you for your comment, the recommendation has been revised in light of your suggestion.
RCPCH Children and Young People's Engagement Team	<p>As per comment one</p> <p>Need to ensure information shared is age appropriate, visual and that there are copies provided for both ICYP and P/C.</p> <p>& Us® RCPCH Voice Bank 2016 evidence can be provided regarding this request from ICYPF</p> <p>The need for face to face with online back up /leaflet back up has been noted in the Voice Bank 2016 with reference to the need for visual materials to be provided for those with LLDD.</p>	Thank you for your comment, the recommendation has been revised in light of your suggestion.

RCPCH Children and Young People's Engagement Team	<p>As per comment one</p> <p>Need to ensure information shared is age appropriate, visual and that there are copies provided for both ICYP and P/C.</p> <p>& Us® RCPCH Voice Bank 2016 evidence can be provided regarding this request from ICYPF</p>	<p>Thank you for your comment, the recommendation has been revised in light of your suggestion.</p>
RCPCH Children and Young People's Engagement Team	<p>We appreciate the importance and gravitas given to this vital stage of health care.</p> <p>Please also consider /make reference to the need to plan involvement of ICYPF in discharge planning as early as possible.</p> <p>Note need raised through the Voice Bank for additional time, single point of contact for questions, use of an advocate to capture ICYP questions (Voice Bank data suggests YP withhold questions from parent so as not to worry them), provide alternative means to trigger questions (Voice Bank suggestions – iPad, pre-printed question sheets from ICYPF feedback previously), provide materials to share with key audiences such as extended family, education, GP, provide opportunity for ICYP and PC to meet separately with lead clinician in a way that is well managed and supported (& Us® RCPCH Voice Bank 2016)</p>	<p>Thank you for your comment. With regard to making reference to the need to plan involvement of ICYPF in discharge planning as early as possible, the first recommendation in 8.1 has been revised to read 'Plan discharge with input from the child or young person and their family and the multidisciplinary team (medical, nursing and allied health professionals (including occupational therapists, physiotherapists, psychologists, speech and language therapists)) prior to discharge from hospital. If the child has been admitted for an extended period, this may involve more than one meeting and should occur in a time-frame that allows all necessary support to be in place on discharge.'</p> <p>The section which relates to 'timely individualised information' in the introduction has been revised to 'timely individualised information including the opportunity for the young person to raise questions and meet with professionals separately to parents (if preferred)'.</p>
RCPCH Children and Young People's Engagement Team	<p>Mental health - We appreciate the importance and gravitas given to this vital stage of health care.</p>	<p>Thank you for your comment.</p>
RCPCH Children and Young People's Engagement Team	<p>Need to ensure information shared is age appropriate, visual and that there are copies provided for both ICYP and P/C.</p> <p>& Us® RCPCH Voice Bank 2016 evidence can be provided regarding this request from ICYPF</p> <p>being made a way of the Education Health Care Plan process with support from their Rehab team /key worker</p> <p>Reference needed to the "SEND local offer" a mandated</p>	<p>Thank you for your comment. The guideline has been updated to mention 'age appropriate' information should be made available throughout.</p> <p>The recommendations have been revised in light of these comments.</p>

	<p>provision of respite, support and activities for children and young people in a local area as part of the Children and Families Act 2014</p> <p>reference need for signposting to voluntary sector support (national /local)</p> <p>reference needed regarding Care Act 2014 and provision of carers assessments for siblings and families to access support.</p>	
RCPCH Children and Young People's Engagement Team	<p>Guideline 138 10.01 No line number indicated (see third paragraph on page). We whole heartedly agree that it's important that young people are given the opportunity to 'voice their opinion' about their future but would like consideration to make a further statement in that it's equally important for children and young people's opinions to be listened to, taken seriously and given due consideration when making plans for their transition of care. This is underpinned in Article 12 of the United Nations Convention on the Rights of the Child (1989).</p>	Thank you for your comment.
RCPCH Children and Young People's Engagement Team	<p>Our own team's consultations with children and young people, parents and carers who live with long terms conditions have resulted in the following recommendations from service users which we are relevant for these guidelines and could be included as well:</p> <p>Increase use of technology – emailing letters for appointments or information, user friendly websites, use of apps and tablets to support questions from children, young people and families</p> <p>Create long term condition passports to support information tracking and sharing and reduce repetition</p> <p>Increase awareness and support for mental health connected to long term conditions</p> <p>& Us® RCPCH Voice Bank 2016</p>	<p>Thank you for your comment. A recommendation on the use of technology in recommendation 9.4, in relation to 'The needs of the family during the planning of care/rehabilitation' has been included.</p> <p>The inclusion of the text 'The creation of a long-term condition passport can support information sharing and reduce repetition.' has been added to recommendation 10.1.</p>

RCPCH Children and Young People's Engagement Team	Mention of the role of an independent advocate to support the voice of ICYP in the full life journey of care and support detailed in this document.	Thank you for your comment. A recommendation on considering the role of the charitable and voluntary sectors in ongoing support and care has been included. This may include independent advocacy for a young person, in relation to 'The needs of the family during the planning of care/rehabilitation'.
Royal College of Nursing	I had no comments back from key members I sent to.	Thank you for your response.
Royal College of Physicians	The RCP are grateful for the opportunity to respond to the above consultation. We don't have any comments to submit but would like to support the guidelines.	Thank you for supporting these guidelines.
Royal College of Speech and Language Therapists	It is worth repeating key points in each section as professionals have a tendency to only read the section which applies to them e.g. we would go straight to rehabilitation and miss out acute care guidance.	Thank you for your comment. however, it was felt that it would be preferred to not be repetitive on this matter.
Royal College of Speech and Language Therapists	We also suggest adding that continuing and routine surveillance by a multidisciplinary team will be necessary over the long term as children's circumstances and their situations change in order to prevent secondary sequelae.	<p>Thank you for your comment. The GDG felt that this comments is not appropriate for entry in this section because this is the section that summarises what came out of the parent workshops. The guideline does actually emphasise the importance of coordinated work between health, education and social care professionals in the pages above.</p> <p>The young person and parent workshops held to inform the guidelines identified six areas of priority to be considered in care delivery, and as such 'continuing and routine surveillance by a multidisciplinary team will be necessary over the long term as children's circumstances and their situations change in order to prevent secondary sequelae' was not able to be included.</p>
Royal College of Speech and Language Therapists	The RCSLT think the research questions detailed in rehabilitation and long-term needs seem thorough and overarching.	Thank you for your comment.
Royal College of Speech and Language Therapists	The RCSLT suggest whether this should include a time-window to assess the swallow process. It currently says ' <i>Withhold enteral feeds until the safety of feeding has been established</i> ' which is correct; however, it may add clarity to add a timescale.	Thank you for your comment. It was felt that specific timescale could not be included as this will depend on the state of consciousness.

Royal College of Speech and Language Therapists	The RCSLT believe that recommendations detailed in here correctly, indicates the withholding of feeding until the safety of feeding has been established. We would suggest that this recommendation will be strengthened by incorporating reference to drinking as well as feeding and, furthermore, that as dehydration can have its own dangers it might be appropriate to indicate a time limit for assessment of dysphagia and more detailed investigation i.e. perhaps by a specialist speech and language therapist.	Thank you for your comment. This recommendation has been updated to 'Withhold oral feeding (eating and drinking) until the swallow safety has been established'.
Royal College of Speech and Language Therapists	The RCSLT suggest that the addition of the speech, language and communication functions are added to the list as it is important to establish the level of understanding for the involvement in treatment decisions and also to determine, at an early stage, basic methods of communication.	Thank you for your comment. Please note that 'communication' is already listed under bullet 'Assess activity limitations'.
Royal College of Speech and Language Therapists	We particularly welcome the clarity of this Introduction. It is important that local healthcare teams as well as those from education and social care are aware of consequences and needs, and should be cognisant of the fact that these may not depend upon the severity of the stroke.	Thank you for your comment.
Royal College of Speech and Language Therapists	We would suggest that the relevant staff detailed here is added to, in order to ensure that staff from education (if relevant to case) are included particularly given the information from the Glang study which is referenced earlier in this section.	Thank you for your comment. This recommendation has been revised to 'Plan discharge with input from the child or young person and their family and the MDT (medical, nursing and allied health professionals including education staff, occupational therapists, physiotherapists, orthoptists, psychologists, speech and language therapists) prior to discharge from hospital. If the child has been admitted for an extended period, this may involve more than one meeting and should occur in a time-frame that allows all necessary support to be in place on discharge.'
Royal College of Speech and Language Therapists	RCSLT believe the recommendations for dysphagia to be comprehensive.	Thank you for your comment.
Scottish Stroke AHP Forum	Firstly we would like to congratulate you on producing this guideline – what a lot of work. Secondly, we mostly see adult strokes so some of our comments may not be pertinent.	Thank you for your comment.

Scottish Stroke AHP Forum	There is no mention of a timely swallow assessment as there is for adult stroke	Thank you for your comment. It is felt that the recommendations are sufficient.
Scottish Stroke AHP Forum	Should speech assessment be included here?	<p>Thank you for your comment. This is the list of clinical questions the work adhered to, as agreed during the scope of this work. This cannot therefore be revised.</p> <p>There are also recommendations surrounding communication within section 5.2.</p>
Scottish Stroke AHP Forum	No mention of family here	Thank you for your comment. Recommendation 8.1 has been revised to include mention of families - 'Plan discharge with input from the child or young person and their family and the multidisciplinary team (MDT) (medical, nursing and allied health professionals including education staff, occupational therapists, physiotherapists, orthoptists, psychologists, speech and language therapists) prior to discharge from hospital. If the child has been admitted for an extended period, this may involve more than one meeting and should occur in a time-frame that allows all necessary support to be in place on discharge'.
Scottish Stroke AHP Forum	? audiology assessment – hearing loss following stroke	Thank you for your comment. Recommendation 9.1 has been revised to include mention of hearing and vision, 'Consider the need for assessment for hearing and vision on an individual basis.'
Scottish Stroke AHP Forum	No mention of balance problems	Thank you for your comment, however, there was no evidence on balance problems and as such information on this was not included.
Scottish Stroke AHP Forum	Felt this was quite prescriptive for so little evidence. Need some active wrist and finger extension for CIMT.	Thank you for your comment. It was felt that wrist and finger extension were more of adult-related, and not relevant for the paediatric population. The section is based on clinical experience.
Scottish Stroke AHP Forum	Where is the evidence for 'follow one of two best evidenced models, intense or distributed'?	Thank you for your comment. This recommendation point has been revised to 'Treatment should be focussed on maintaining normal levels of the appropriate coagulation factor for a period of intense treatment and then prophylactic treatment to prevent recurrence.' for clarification.

Scottish Stroke AHP Forum	GAS is not mentioned in goal planning although earlier was recommended.	Thank you for your comment. GAS has been added to recommendation 9.3.10, where it also mentions other goal setting tools such as Perceived Efficacy in Goal Setting (PEGS) and Canadian Occupational Performance Measure (COPM).
Sickle Cell Young Stroke Survivors	We are concerned that these areas will not be covered. Most children with sickle cell do suffer from Haemorrhagic stroke and other kinds of stroke. If these strokes are not prevented or managed, it can eventually lead to long-term complication in the future in communication, cognition and mobility problems. Whilst, most of the clinical guidelines of this document (p.84), is aimed at managing and preventing this grave complication.	Thank you for your comment; however other types of stroke are outside the remit of the guideline.
Society for Research in Rehabilitation	<p>Thank you for inviting SRR members to contribute to this consultation. We have focused on sections 1, 2, 9, 11, 12. I have collated responses and submit them here as if from a single commentator.</p> <p>Overall, SRR welcomes this updated and expanded guideline and congratulates the GDG, and large numbers of other contributors, on your achievements. We commend the coverage (from hyperacute to long term support), the multidisciplinary focus, the use of the ICF framework, the transparent methodology, the decision to use Delphi in specific instances, the inclusion of evidence from related populations (e.g. TBI and CP), the logical flow of the written guideline and the accessible layout and writing style.</p> <p>The guideline has clearly benefited from the inclusive ethos of the GDG and has a strongly child and family-centred approach that should aid its implementation into practice. We look forward to seeing the booklet for parents and carers.</p> <p>We note with concern that recent advances, especially in the clinical care of adults with ischaemic stroke, are not seen in services for children with AIS and the poverty of research investment for childhood stroke. Your observations should be of</p>	Thank you for your comment. A recommendation on this has been added.

	<p>help to policy-makers keen to reduce any inequities. We support your ambition to mobilise synergies between child and adult stroke services whilst mindful of key differences between them and your practical suggestion of a national registry.</p> <p>Suggestions for changes are listed below (one per line).</p>	
Society for Research in Rehabilitation	Add links between sections to signpost the reader	Thank you for your comment. Please refer to the contents page to review the guideline structure.
Society for Research in Rehabilitation	Some subsections would benefit from shortening, rewording for clarity, adding definitions (e.g. motor learning) and editing for consistency across the guideline (some text in 'linking the evidence' would fit better in 'evidence summary' subsections. You may already be finalising these during the consultation period but the following specific examples may help.	Thank you for your comment; however, at this late stage it was felt not appropriate to change the format of the guideline.
Society for Research in Rehabilitation	A useful box but it disrupts the flow of 7 bullets and would be better moved after the recs. 3rd bullet in box 9.1 needs rewording and split into 2 sentences.	Thank you for your comment. The mentioned recommendation has been revised accordingly.
Society for Research in Rehabilitation	Some recs are wordy and could be shortened for clarity.	Thank you for your comment, unfortunately these were the recommendations that have been approved by the guideline development group.
Society for Research in Rehabilitation	Unclear why 6 th bullet is specific to hospital. Also applies to community teams.	Thank you for your comment. Reference to 'hospital-based' within these recommendations has been removed.
Society for Research in Rehabilitation	Consider adding when to do things (other than immediately) and specifically mention need to offer reviews	Thank you for your comment. It was felt that the text was adequate as is.
Society for Research in Rehabilitation	<p>Clarify what's meant by ...'NDT in isolation'</p> <p>Could move discussion of Novak 2014 to 9.4.1.1. evidence summary.</p>	Thank you for your comment. 'In isolation' has been removed from the text and changed the composition of the paragraph.

Society for Research in Rehabilitation	<p>CIMT is more than use of arm restraint so clarify if you're saying here that an arm restraint alone is effective without the usual package of CIMT.</p> <p>Effective is a relative not an absolute. Add here (and throughout sect 9) what it is more effective than.</p>	<p>Thank you for your comment. The following text has been added to section 9.3.1:</p> <p>'This approach is targeted at individuals with hemiparesis and involves applying a constraint to the less affected arm and hand, and intensive highly repetitive task-based practice with the more affected hand and arm.'</p>
Society for Research in Rehabilitation	1st paragraph would fit better elsewhere. Contains vague sentences "other interventions"	Thank you for your comment; however, at this late stage it was felt not appropriate to change the format of the guideline.
Society for Research in Rehabilitation	<p>1st 3 recs would fit better in 9.3 as they are general principles not specific to motor.</p> <p>Some of 9.4.13 belongs in evidence summary e.g. 8 and 9.</p>	Thank you for your comment; however, as there are no recommendations within section 9.2 these sit within section 9.3.1.
Society for Research in Rehabilitation	Consider changing "the systematic review" to the GDG's review to aid clarity. This applies throughout section 9.	Thank you for your comment; however, it was agreed not to change this.
Society for Research in Rehabilitation	The text in 'linking evidence to recs' should be shortened given that 9.4.2.1. says 'no evidence'	Thank you for your comment. It was agreed that the text presented was adequate.
Society for Research in Rehabilitation	4 th paragraph consider justifying or removing 'positive effects were noted' given the rest of the sentence.	Thank you for your comment. The text has been updated to 'One study detailed a pilot study on the effects of carbonated liquids compared with non-carbonated liquids on swallow function in ABI. The small number of stroke participants showed no change on the intervention, however, the numbers were too small to draw conclusions.'
Society for Research in Rehabilitation	Not all subsections in 9 are consistently what the heading suggest e.g. some of 9.4.3.2 content probably belongs in 9.4.3.1.	Thank you for your comment; however, it was agreed to leave the text as is as this was felt to be adequate.
Society for Research in Rehabilitation	Aggregate bullets 7 & 8 (on AAC) as they seem to say largely the same thing.	Thank you for your comment. These points have been merged and now read 'Offer referral to AAC services where children and young people have significantly impaired language understanding and/or expressive speech/language that are contributing to activity and participation limitations, such as Communication Matters, where information on UK-wide AAC assessment services (including Specialist Commissioning in England) can be found.'

Society for Research in Rehabilitation	<p>As these are recs for communication it seems strange that the 2nd bullet starts with neuropsych and ends with refer to SLT where there is concern about communication. Should it not start with refer to SLT?</p> <p>It is also unclear who this is for i.e. are you recommending that every child with stroke gets a neuropsych assessment when they start or return to school but only those with communication concerns get SLT referral. I doubt this was your intended meaning. This issue of clarifying who the recs are intended for could be improved throughout section 9 (and possibly elsewhere).</p>	Thank you for your comment; however, it was agreed to leave the text as is as this was felt to be adequate.
Society for Research in Rehabilitation	2 nd bullet is duplicated.	Thank you for your comment. Points 2 and 3 have been merged.
Society for Research in Rehabilitation	4 th paragraph, specify which type of medication (Backeljauw).	Thank you for your comment; however, it was agreed to leave the text as is as this was felt to be adequate.
Society for Research in Rehabilitation	<p>5th paragraph clarify meaning “for cognitive outcome ...internalising symptoms”. It may help to use the ICF terms.</p> <p>6th paragraph reword – what is an “increased effect on children”?</p> <p>7th paragraph 1st long sentence does not make sense “may not be sensitive...showed improvement”</p> <p>Final paragraph clarify whether this (Karch 2013) is absence of evidence or evidence of absence</p> <p>Overall this is long with an unexpected emphasis on IQ tests given that rehab would not aim to change those and it doesn't fit with the ethos of the ICF framework and principles of rehab.</p> <p>Expected to see OT mentioned here.</p>	<p>Thank you for your comment. The symptoms depression, anxiety, withdrawal and in parent-child interactions have been added to the 5th paragraph.</p> <p>The text has been revised to ‘There is evidence that memory and cooperative learning are improved through teaching metacognitive techniques (e.g. reasoning, decision-making, and ability to show insight and awareness). One study described the problem-solving training approach, which emphasises metacognitive principles, led to improvements in goal-directed functional behaviour.’ in the 6th paragraph.</p> <p>It has been noted that in relation to the Karch paper, this was an absence of evidence.</p>

Society for Research in Rehabilitation	<p>Expected recs to start with identification of the problems but instead they start with training parents to deliver cog rehab.</p> <p>Expected a rec on providing information to children and families to explain the underlying cognitive causes of difficulties and their possible impacts on daily life, now and in the future, to normalise them and offer strategies to manage these.</p>	<p>Thank you for your comment. These recommendations have been re-ordered, and the following recommendations have been added:</p> <ul style="list-style-type: none"> • Consider education for the child/young person and their family on the impact of identified cognitive weakness on daily life activities and appropriate compensatory strategies. • Consider skills training in a functional context to improve daily life abilities impacted by cognitive impairment.
Society for Research in Rehabilitation	Curious that the neuropsych assessment is not mentioned here, yet it is in the communication section.	Thank you for your comment. The guideline does have a recommendation in section 9.4 which states 'Assess physical, social, academic, attitudinal and environmental factors that may impact on the child/young person with stroke.' It was felt that this was sufficient.
Society for Research in Rehabilitation	This is intended to be on the needs of families . There are 10 recommendations that may indirectly meet needs but a striking absence of any recommendations specifically for the families own health, well-being, social and financial situation e.g. nothing on the Carers Act	Thank you for your comment. A recommendation has been added in section 9.4 stating 'Consider the impact of stroke on the health, social and economic wellbeing of family members and make onward referrals as necessary to support the broader family.'
Society for Research in Rehabilitation	In presenting evidence summaries it would be useful to say where there are obvious evidence gaps for commonly offered practice/interventions i.e. some sections appear to take the bottom-up approach of being driven by the interventions researchers chose to investigate. That approach sometimes shifts the focus to a review of fairly irrelevant evidence (interventions that are easy to research) and distracts policy-makers from realising there are important evidence gaps for more complex real-life interventions. Instead of this, a top-down approach may help NIHR commissioning.	Thank you for your comment. While there was limited to no evidence the guideline has tried to make this as clear as possible. The research recommendations section (chapter 12) has a well thought out list of areas which could be improved/researched to provide the necessary evidence.
Society for Research in Rehabilitation	Yes, an audit (mirroring the adult SSNAP) is a good idea, likely to improve services, reward those who make extra efforts and motivate those who fall below the benchmark.	Thank you for your comment.

Society for Research in Rehabilitation	<p>We assume these are incomplete in this draft. There are only 2 and they are rather vague.</p> <p>Given the comments throughout about the paucity of research investment it may be worth highlighting key areas to bring to research funders attention.</p> <p>Alternatively you might recommend a research prioritisation activity, including key stakeholders, such as the influential one conducted into adult stroke rehab by Pollock with the James Lind Alliance.</p>	Thank you for your comment. Chapter 12, research recommendations, has been revise in line with received comments.
The Children's Trust	"Levels of acute dysphasia" – We think this should read dysphagia as dysphasia (which is now called aphasia in up to date literature) doesn't fit the context here.	Thank you for your comment. In section 5.2 the text has been revised to read 'of acute speech, language and swallowing abilities were assessed ¹¹⁰ using a number of standardised and non-standardised tools. These assessment tools included Ranchos Los Amigos Cognitive Scale, Verbal Motor Production Assessment of Children, Frenchay Dysarthria Assessment, Schedule of Oral Motor Assessment, Paramatta Hospitals Assessment of Dysphagia, and a non-standardised feeding trial. Impairments were identified in some children when using all of the tools, but no discussion on the usefulness or usability of the tools was included' for clarity.
The Children's Trust	Para re spectrum of difficulties – no mention of cognition and communication specifically, just refers to mental functions which we think isn't explicit enough; also no mention of participation being impacted upon by mood/emotional status.	Thank you for your comment. It was felt that this section was adequately detailed.
The Children's Trust	mentions speech and language but no use of the term cognitive-communication difficulties (CCD) – CCD is more prevalent in TBI but features are evident following stroke and needs to be recognised as a term.	Thank you for your comment. It was felt that this section was adequately detailed.
The Children's Trust	Little weight given to the importance of supporting adjustment to the stroke and helping support wellbeing – of the child and family network.	Thank you for your comment. It was agreed for a new point to be added to section 9.2, as follows, 'The recognition of the need to support the child/young person and family in adjusting to changed abilities and circumstances.'

The Children's Trust	Not much mention of fatigue and sleeping patterns which are important to get right in order to improve outcomes and attend school and take part in other activities.	<p>Thank you for your comment. The below text has been added to section 9.2:</p> <p>'In children, tolerance of rehabilitation varies according to factors including cognitive, behavioural, communication and motor functioning and developmental age and abilities. Other factors such as fatigue can also impact engagement in intensive intervention. While the GDG agreed that the principle of identifying a target dose is desirable, it is difficult to prescribe this across all age ranges and abilities. Intervention that targets identified areas of priority for the child and family, at a frequency that enables rehabilitation goals to be met is desirable, however there are a number of key considerations. These include the focus on daily life activities and participation (i.e. integration of rehabilitation in the context of home and school life), the coordination and agreement between professionals of intervention targets informed by the priorities of the child or young person and their family, and their willingness and ability to actively participate. The identification of a target dose and intensity for a rehabilitation programme is an important component in prescribing intervention to maximise outcomes'</p>
The Children's Trust	It is worth repeating key points in each section as professionals have a tendency to only read the section which applies to them e.g. we would go straight to rehabilitation and miss out acute care guidance.	Thank you for your comment. The recommendations will be provided in accompanying information, as well as a summary within the final guideline.
UK Forum on Haemoglobin Disorders	'UK Forum on Haemoglobin Disorders' NOT 'UK Forum on Haematology Forum'	Thank you for your comment This error has been corrected.
UK Forum on Haemoglobin Disorders	<p>Provide MRI in a clinically timely manner for both AIS and HS patients for improved diagnostic resolution at follow-up if not obtained as the initial imaging investigation, with MRI being provided within 24 hours if initial CT is negative and stroke is still suspected.</p> <p>We are concerned that in patients with SCD presenting with clinical symptoms suggestive of stroke and negative CT, that MRI</p>	Thank you for your comment. It was felt that within 24 hours does not necessarily mean after 24 hours.

	should be performed asap and that a delay of up to 24 hours is unacceptable and would delay exchange transfusion.	
UK Forum on Haemoglobin Disorders	Specialities that should be involved in the immediate assessment and management of a child with possible stroke include: emergency medicine, paediatrics, anaesthesia, intensive care and radiology. Care should be consultant-delivered at the earliest possible opportunity. If patients have SCD then haematologists should also be involved in care	Thank you for your comment. The recommendations have been revised to 'Care should be consultant delivered at the earliest opportunity, involving a multi-specialty team according to the child's clinical need'.
UK Forum on Haemoglobin Disorders	We were very pleased to see the box referring specifically to SCD and agree with its content 'Sickle Cell Disease Initiate exchange transfusion without delay in children with sickle cell disease with suspected stroke'	Thank you for your comment.
UK Forum on Haemoglobin Disorders	<p>'Transfusion therapy is well established in the acute management of stroke related to sickle cell disease but whether exchange transfusion is better than simple top-up transfusion is not established. Recommendations have been made after assessing the limited evidence.'</p> <p>Hulbert et al 2006 showed that the recurrence rate of stroke in patients with SCD was significantly lower in patients who had an initial exchange transfusion (21% recurrence) rather than a simple transfusion (57% recurrence). A better recommendation may be to offer exchange transfusion unless the patient has a very low Hb (<60g/l) when you would perform a simple transfusion first.</p>	Thank you for your comment. It was felt that what is said in the relevant section and reference the Hulbert paper was adequate. It was not felt that a particular Hb was specified and that there was suggestion to top-up if there is going to be a long delay. As such no changes were made to the text.
UK Forum on Haemoglobin Disorders	We were concerned that it was not made clear that there is no evidence of the role of thrombolysis in SCD and patients should be treated with transfusion therapy, rather than thrombolysis.	Thank you for your comment. Please refer to the last point within recommendations 6.2.1, which reads 'Prioritise exchange transfusion over thrombolysis'.
UK Forum on Haemoglobin Disorders	It may be helpful to explain what the different methodologies are for performing exchange transfusion (i.e. manual exchange or automated exchange).	Thank you for your comment. The guideline will not be able to explain what the different methodologies are for performing exchange transfusion as this is outside the scope of this guideline.
UK Forum on Haemoglobin Disorders	It would be helpful to say explicitly that thrombolysis should not be used in SCD unless there are specific indications. The last 4 bullet points on p 69 all refer to SCD, but this is not made clear.	Thank you for your comment. It was felt that this sits where most appropriate.

UK Forum on Haemoglobin Disorders	We would recommend cross reference to recent NICE guidelines which have recommended automated exchange for the management of long term transfusion therapy in patients in SCD.	Thank you for your comment. This appropriate NICE guidance has been added as a further reading point.
UK Forum on Haemoglobin Disorders	Suggest hydroxycarbamide is used instead of hydroxyurea	<p>Thank you for your comment. It has been noted that hydroxycarbamide is the recommended EU name, and hydroxyurea in the USA and most academic publications.</p> <p>The recommended name of hydroxycarbamide has been used, adding hydroxyurea in parentheses the first time it is used.</p>
UK Forum on Haemoglobin Disorders	We wondered if it may be helpful to have a recommendation that children with SCD on long term transfusion for prevention of stroke are referred to an adult unit where transfusion therapy can continue to be provided and that they are supported to continue transfusion during and after the transitional period. This is not a major problem in the UK, but in the US many children are not able to continue transfusion therapy into adulthood.	Thank you for your comment. The following recommendation has been added, 'Children with sickle cell disease (SCD) on long-term transfusion for prevention of stroke should be referred to an adult unit where transfusion therapy can continue to be provided and support is given to continue transfusion during and after the transitional period.'
UK Forum on Haemoglobin Disorders	Thank you for asking us to review this very comprehensive document which will improve the care of children with stroke in the UK.	Thank you for your comment.
UK Swallowing Research Group	<p>Symptom and frequency table. No mention of dysarthria, but aphasia and dysphasia are separate. Is there a reason to differentiate aphasia and dysphasia or was it meant to be dysarthria?</p> <p>In cases of children I've seen admitted with unidentified stroke, dysarthria and subtle dysphagia has been a common feature that went unnoticed and attributed to tiredness or being lazy in older children or just 'off their food'. Additional recognition of aphasia vs dysarthria for many junior physicians (even those working within adult stroke units) can be hugely variable. They often identify a problem but may not recognise this as aphasia.</p>	<p>Thank you for your comment. While dysarthria may be a presenting feature, it may not have been high up in the list of symptoms in the papers referenced in this table. Studies do not often differentiate between lack of speech due to motor control problems (dysarthria) and lack of speech due to language problems (dysphasia); some children will have a mix. Dysarthria is possibly subsumed under either dysphasia or, more typically, aphasia.</p> <p>Strictly speaking dysphasia should be impaired speech/language and aphasia is a complete lack of speech/language; however, they are often used interchangeably and this may be why they came up separately in the searches and therefore are listed separately in Table 3.1.</p>

		<p>In section 5.2 the text has been revised to read ‘Levels of acute speech, language and swallowing abilities were assessed using a number of standardised and non-standardised tools. These assessment tools included Ranchos Los Amigos Cognitive Scale, Verbal Motor Production Assessment of Children, Frenchay Dysarthria Assessment, Schedule of Oral Motor Assessment, Paramatta Hospitals Assessment of Dysphagia, and a non-standardised feeding trial. Impairments were identified in some children when using all of the tools, but no discussion on the usefulness or usability of the tools was included.’ for clarity.</p>
UK Swallowing Research Group	Again dysarthria maybe a factor to consider not just aphasia in this table	<p>Thank you for your comment. The guideline cannot differentiate between dysarthria and dysphasia on this occasion. The S in FAST is simply Speech and refers to speech being “slurred or strange”, and this would cover both dysarthria and dysphasia.</p> <p>The Suspect Stroke part of the pathway has been revised to ‘slurred or strange speech’, rather than the more technical term of ‘aphasia’, as this would be more appropriate and provide a better link to the FAST test in the emergency Services box.</p>
UK Swallowing Research Group	Depending on medical needs of the child, they can be as acknowledged admitted for a longer period of time. ‘Rehabilitation’ for therapist’s starts in the acute setting and the order of flow chart which depicts it as only starting after discharge may be confusing to parents?	<p>Thank you for your comment. A reference point has been added to Diagram 1.1, which notes that ‘while Diagram 1.1 follows the structure of the guideline, it is acknowledged that rehabilitation starts within the acute setting through to community care.’</p>
UK Swallowing Research Group	<p>Great to see these ideas which reflects our current practice. Links with community and acute always poses difficulties as often no identified therapists who can attend discharge planning meetings in advance, especially as childhood stroke cases are not massively common.</p> <p>In the case of SLT’s depending on the acquired symptoms after a stroke they may go to multiple different SLT’s in the community setting e.g. mainstream school therapist, feeding specialist etc.</p>	<p>Thank you for your comment. The following text has been added to section 8.1 ‘Health professionals working in specialist children’s hospitals can have a role in supporting community-based clinicians in providing specialist advice on management and rehabilitation beyond discharge.’</p>

	<p>which poses extra difficulties in accessing and facilitating smooth discharge.</p> <p>An Early Supported Discharge model with acute setting therapists outreaching to support bridging service to community to smooth transfer and transference of therapeutic skills for that particular child may be a model to consider.</p>	
UK Swallowing Research Group	<p>Whilst drooling is mentioned, limited information about awareness of oral hygiene needs (particularly in low GCS or NBM children) and/or lack of saliva being of just as much importance in bulbar evaluation of functions after stroke. Within adult services oral hygiene after stroke is strongly acknowledged and evidenced. Behavioural management of saliva also not mentioned here, particularly important in retraining saliva swallows after stroke as first steps in raising laryngeal sensory awareness/cough response and progression to oral trials.</p>	<p>Thank you for your comment. Table 5.1 has been revised under the section for 'Swallow dysfunction' and this now includes mention of eating, drinking and saliva control .It was felt inappropriate to revise the text in any further way due to there being limited evidence and this being an issue for a small percentage of the paediatric population.</p>
UK Swallowing Research Group	<p>Thorough section and discusses voice disorders; dysarthriphonia being a symptom I have often seen in children and pure dysphonia/aphonia completely missed on neonatal units until SLT Ax.</p> <p>Education to children about understanding their acquired communication difficulties after stroke critical to influencing engagement and motivation for therapy. Acute SLT's role in particular may just be focusing on adjusting to sudden loss or change to fluency or competency with language and should be highlighted as a part of therapeutic intervention. Psychological adjustment to changed communication for individual child and family should also be recognised particularly of note in teenage stroke. Training to conversation partners/people significant in that child's everyday interactions to raise awareness.</p>	<p>Thank you for your comment. As noted in the scope of the guideline, the neonate population was not covered. The recommendations in section 9.3.4 have been revised to:</p> <p>Offer referral to SLT when there are parental or professional concerns about communication skills, language understanding, expressive language or poor intelligibility due to persisting motor speech disorders (dysarthria and dyspraxia), dysfluency or voice disorders</p>

UK Swallowing Research Group	<p>Good to see this is well recognised. We often recommend children who we see in the acute setting even with apparently resolved acquired communication difficulties to be routinely followed up in the school setting at least 3 and 6 months post discharge to ensure continued progression with learning.</p> <p>Identification that EHCP may well change as sequelae evolves overtime.</p>	<p>Thank you for your comment. It was felt necessary to include an additional recommendation under section 9.3.4 and 9.3.8:</p> <p>Be aware that a child or young person's needs may evolve or change over time necessitating reassessment and review of any statutory supports in place e.g. the EHCP.</p>
UK Swallowing Research Group	No mention of dietitian in therapies list?	Thank you for your comment, 'dietitian' has been added to this list.

