Stroke rehabilitation in adults Consultation on draft scope

Stakeholder comments table plus developers response

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
British Association of Stroke Physicians	General	General	We are so pleased to see such a huge breadth of relevant and important topics considered in this rehabilitation guideline scope. There seems to be a well organised and structured approach.	Thank-you for your comment
British Association of Stroke Physicians	General	General	Given stroke service reconfiguration, with hyperacute stroke care becoming more centralised, there is some debate as to whether ASUs should all be co-located on HASU sites, or whether there should be a hub and spoke model, with ASUs at each local DGH. There are obviously pros and cons. Delays in transfer, disruption of rehab and distance from home are potential issues. Since this is an essential part of the early patient journey/rehabilitation we would welcome this aspect of organisation of care and the evidence behind this being reviewed in the document.	Thank-you. This aspect of organisation of stroke care has not been prioritised for evidence review, but the Guideline Committee will bear your comment in mind when refreshing relevant recommendations
British Association of Stroke Physicians	General	General	There is variation across the country in provision of early supported discharge and we feel this document should address this specifically. Transfer from hospital to community is increasingly important as patients may go directly from a regional HASU to a local ESD team	Thank-you. Several Stakeholders have suggested the evidence on ESD should be reviewed and it is now included in the revised scope.
British Association of Stroke Physicians	General	General	Nutrition does not seem to be highlighted. Patients may have RIG/PEG in the community or need dietician input due to poor oral intake as a consequence of a stroke.	Thank-you. Advice on nutrition is given in NICE guideline CG32: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition.
British Association of Stroke Physicians	General	General	Expand on cognition due to significant impact of pre-existing cognitive problems on rehabilitation as well as those new cognitive difficulties identified (some of which may be transient such as delirium)	Thank you for raising this important point; we will consider this when reviewing relevant recommendations pertaining to cognition.
British Association of	General	General	Visual impairment should be considered both as a pre-existing problem that impacts outcome and also as a consequence of some stroke syndromes. Assessments and recommendations should reflect this.	Thank-you. The Guideline Committee will consider visual assessment and the



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Stroke Physicians				need for onward referral for orthoptic advice. This would cover any ongoing problem, pre-existing or new.
British Association of Stroke Physicians	General	General	We would welcome a review of fatigue interventions including their cost effectiveness.	Thankyou. A review of assessment of fatigue is included but no specific intervention has been put forward in stakeholder comments
British Association of Stroke Physicians	General	General	We would welcome inclusion of hearing impairment as an important cause of post stroke disability.	Thank-you. We agree that assessment of hearing impairment would be a useful addition to the scope, and have now included this.
British Association of Stroke Physicians	General	General	Inclusion of the role of carer/family with early involvement and recognition of carer strain	Thank-you. The existing guideline acknowledges the role of carers in several places and these recommendations will be retained.
British Association of Stroke Physicians	General	General	The committee should at least comment on whether vagal nerve stimulation comes within remit.	Thank you for highlighting this interesting technique. The current evidence base is not of sufficient quality for the committee to prioritise for review in these guidelines
British Association of	General	General	The committee should consider decision making about rehabilitation in patients who have limited life expectancy (from stroke, extreme old age, or other illnesses), or who have moderate to severe	Thank-you. Your point is appreciated, but the

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Stroke Physicians			pre-stroke impairments (from frailty or other conditions). Guidance here is very important for practising stroke physicians.	Guideline is about the process of rehabilitation. Decisions about suitability for rehab must take into account a variety of factors in each case, and we believe these need to be made on an individual basis.
British Association of Stroke Physicians	General	General	We hope to have a role in continuing to support the development of this guideline which will help to develop and recognise excellent practice for our recovering stroke patients.	Thank-you.
British Association of Stroke Physicians	General	General	Swallowing rather than oral feeding is listed under 4. specific problems and interventions. I think oral feeding is a better term as it takes into account other determinants such as posture, cough, oral control and environment etc.	Thank-you. We agree, and have changed this.
British Association of Stroke Physicians	General	General	Explicit consideration of remote/virtual approaches to rehab, which have been relevant this year, and might prove to be for a while (and again, when the next pandemic strikes) in future	Thank-you. We agree and have included this in the revised scope.
British Association of Stroke Physicians	General	General	Sleep disruption as another potentially relevant important and modifiable non-motor adverse stroke outcome.	Thank-you. This has not featured in other stakeholder feedback and has not been prioritised for inclusion.
Brain and Spinal Injury Charity (BASIC)	general	general	Very limited information about the role of the voluntary sector and how they play an important role in supporting stroke clients in maintaining and progressing their physical and cognitive abilities to promote and maintain independent living. Supporting them and their carers with their emotional needs when many still claim a feeling of being 'abandoned once the input of the NHS has finished'	Thank-you. We have specifically included a representative from the voluntary sector in the guideline committee so that their role in assessment,

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			The NHS Long term plan does suggests that the NHS should work in partnership with voluntary organisations to continue with the rehabilitation of people with a stroke, monitor progress, advice and support; this would be cost effective as prevention of re-admission should be reduced.	planning and intervention can be incorporated in the guideline.
Faculty of Homeopathy	General	General	 We believe acupuncture is a cost-effective innovative treatment that should be considered within the final scope for this guideline. With respect to overall recovery of motor function, it has shown efficacy and could be included integral to stroke management rather than ancillary. Hence an acupuncturist may even be considered within the stroke team. Acupuncture is a mainstream treatment within certain regions, e.g. part of an integrated approach using Traditional Chinese Medicine within China for stroke patients. Several studies could be mentioned, such as: Hai-Qiao Wanga, Effects of acupuncture treatment on motor function in patients with subacute hemorrhagic stroke: A randomized controlled study. Complementary Therapies in Medicine 49 (2020) 102296 https://doi.org/10.1016/j.ctim.2019.102296 Design: One hundred and thirty-four patients with subacute hemorrhagic stroke were randomized to receive acupuncture treatment plus conventional treatment group) or conventional treatment only (control group). Blinded evaluation was based on Fugl-Meyer Assessment, Barthel Index with an intention-to-treat analysis. For those patients who were able to walk, a three-dimensional gait analysis system was employed to objectively record spatiotemporal and kinematic parameters. Results: Compared with control group, the treatment group showed a significantly greater over-time improvement in total Fugl-Meyer, lower-limb Fugl-Meyer, but not in upper-limb Fugl-Meyer and Barthel Index. The spatiotemporal parameters of velocity, step length, cadence, step width all showed significant difference between the 2 groups. The velocity in treatment group decreased unexpectedly at ay 14, then increased sharply and overcame control group at day 28. The treatment group also showed a significantly greater increase in peak circumduction, peak hip hiking, hip range of motion, knee range of motion and a tendency for the ankle range of motion. Seung-Jin Lee, S	Thank-you. The role of acupuncture in managing shoulder pain and spasticity will be considered.

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			 Aim: Scalp acupuncture (SA) for stroke recovery has been widely used in many Asian countries. This paper conducted a systematic review and meta-analysis to assess the evidence of SA for use in integrated stroke management. Methods: Systematic searches of 16 electronic databases were conducted for articles published through June 2012. All randomized controlled trials that compared SA as a sole or adjunct treatment with any relevant controls for stroke were included. Results: In total, 21 studies were included. Fourteen of these studies dealt with acute or subacute stroke patients. Of these 14 trials, 8 used the total efficacy rate as the main outcome, and their meta-analysis showed a favorable effect on outcomes of SA plus conventional care compared to conventional care alone (medication (p = 0.007) and rehabilitation (p = 0.02)). Conclusions: This review showed positive but limited effectiveness of SA as an adjunct treatment to the conventional care. The major limitation was the poor methodological quality of the included trials. Sham-controlled, well-designed trials with a standardized therapeutic method are needed. 	
Different Strokes	General	General	There is no mention in the draft scope of mental health services. Although I understand that the focus is on rehabilitation, all stroke survivors should receive a comprehensive mental health assessment at point of discharge from hospital and at later dates as appropriate. The emphasis of the document is largely on physical rehabilitation, with some focus on cognitive impairment but very little mention of emotional or behavioural difficulties post-stroke	Thank-you. The scope is mainly concerned with the topics which require updating. Section 1.5 in the existing guidance deals with the issues you mention and these recommendations will be retained.
Different Strokes	General	General	With regards to question 2 above – 'What issue or issues do you think are most important to address regarding the organisation and planning of stroke rehabilitation services'. There has to be a holistic approach to this. Too often stroke survivors feel abandoned after leaving hospital, not knowing where to turn. All stroke survivors should (i) receive a follow up review with the hospital stroke team (ii) receive adequate support from their GP (iii) have access to a stroke nurse post- discharge to provide ongoing support (iv) be provided details as a matter of course of third sector organisations which can support their ongoing recovery	Thank-you for your suggestions. The Guideline Committee will consider these points when we are refreshing the current recommendations on organisation and planning.
Different Strokes	General	General	With regards to question 2 above – 'What issue or issues do you think are most important to address regarding the organisation and planning of stroke rehabilitation services'. It is so	Thank-you. Stroke survivors will be part of our guideline

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			important that stroke survivors play a full and comprehensive role in the planning of such services. Too often all the emphasis is on input from clinicians, and crucially important as this is, this must be balanced with people with real lived experience of being a stroke survivor.	committee and will therefore play a full part in our recommendations on organisation and planning. It is beyond the Guideline's remit to guarantee that they will be included in planning in individual regions or localities.
Association of Chartered Physiotherapists in Neurology	General	General	The draft does not mention nor link to appropriate guidance on 'functional diagnoses' or 'functional neurological disorder' these should be referenced as a regular occurrence in clinical acute stroke services and community services, reference only may be useful because clarity is needed between very different treatment approaches after clinical diagnosis is confirmed.	Thankyou. Whilst functional disorders comes within the remit of the differential diagnosis of people with suspected stroke it is not within the remit of these guidelines which are for people with confirmed strokes.
Association of Chartered Physiotherapists in Neurology	General	General	There is lack of guidelines around the management of spasticity in stroke patients. There are examples where spasticity is used as an example e.g. splinting, complications, but there is no clear recommendations about the management of spasticity. Considering the RCP developed the Spasticity in Adults: Management Using Botulinum Toxin (2018) and the positive results from the recent EUBOS trial you would think there would be some link or consideration from NICE. Spasticity is a major component of post-stroke complications, and is one that people need clear guidance on. Having a section on Spasticity in line with the RCP guidelines, would allow for a better point of reference for clinical staff, as well as support the need for service change and the promotion of therapy injectors and MDT spasticity clinics.	Thank-you. Management of spasticity, and specifically the role of botulinum toxin, is included in the scope (please see point 4 in section 3.3, and Table 3, of the final scope)
Association of Chartered	General	General	ACPIN wishes the panel to consider the inclusion of mental health/mood and falls prevention.	Thank you for highlighting this important post stroke



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Physiotherapists in Neurology				sequela. Falls prevention would fall outside the stroke specific remit of these guidelines. We would refer to NICE Guideline CG161 Falls in older people: assessing risk and prevention
Royal College Of Nursing	General	General	The Royal College of Nursing (RCN) welcomes proposals by NICE to update the Stroke Rehabilitation guidance. The draft scope seems comprehensive.	Thank-you.
Royal College of Occupational Therapists	General	General	 The document needs to describe more fully, the role of occupational therapy in stroke rehabilitation in the same way that orthoptists, speech therapy and physiotherapy are included, i.e. the document does not fully reflect what is happening in practice. For example: Participation in daily tasks and self management using app based therapy – is an emerging area that should be in scope of guideline. Effects of assistive technology-based occupational therapy on community-dwelling people recovering from stroke https://doi.org/10.1080/10400435.2020.1789900 Home-based technologies for stroke rehabilitation: A systematic review, https://doi.org/10.1016/j.ijmedinf.2018.12.001. Tele-Rehabilitation after Stroke: An Updated Systematic Review of the Literature https://doi.org/10.1016/j.jstrokecerebrovasdis.2018.05.013 	Thankyou. The purpose of the scope is not to describe the role of any group of healthcare professionals but to set out the topics which will be reviewed in this guideline update. Some interventions are clearly the remit of a specific profession, hence the reference to Speech therapy and to orthoptists (but not physiotherapists) at appropriate points.

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Royal College of Occupational Therapists	General	General	 Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Cost saving of app based and remote teletherapy to aid executive functioning, planning and performance in daily living tasks e.g.: Cramer SC, Dodakian L, Le V, et al. Efficacy of Home-Based Telerehabilitation vs In-Clinic Therapy for Adults After Stroke: A Randomized Clinical Trial. <i>JAMA Neurol</i>. 2019;76(9):1079–1087. doi:10.1001/jamaneurol.2019.1604 Modified Multiple errands test in home setting Valérie Poulin, Nicol Korner-Bitensky, Louis Bherer, Maxime Lussier & Deirdre R. Dawson (2017) Comparison of two cognitive interventions for adults experiencing executive dysfunction poststroke: a pilot study, Disability and Rehabilitation, 39:1, 1-13, DOI: 10.3109/09638288.2015.1123303 	Thank-you. We agree that teletherapy/telerehabilitatio n should be considered and have included this in the revised scope.
Royal College of Occupational Therapists	General	General	 What issue or issues do you think are most important to address regarding the organisation and planning of stroke rehabilitation services? What are the key questions which you think need to be answered? Issue of how services support the return to community participation and social inclusion – post acute and transition home. Q- how are people effectively supported to manage higher level cognitive impairments and participate in preferred occupations of self care, work, leisure, driving, parenting, caring for others. Q- What is the cost/ benefit to society of high intensity rehab at each stage of pathway Britta Tetzlaff, Anne Barzel, Anne Stark, Gesche Ketels & Martin Scherer (2020) To what extent does therapy of chronic stroke patients address participation? A content analysis of ambulatory 	Thank you for raising these points. We appreciate that these strategies do not have 'harms' and that such interventions are highly valued by stroke survivors. We aim to add to the narrative in the new guidelines to this effect. Reviews of intensity and frequency of therapy, and of community partipation

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			physical and occupational therapy based on the International Classification of Functioning, Disability, and Health framework.	interventions, will be included.
AbbVie	General	General	Identification of post-stroke spasticity (PSS) Although the draft scope includes the topic of 'screening and assessment', in which recommendations will be 'refreshed from existing guideline using the expertise and experience of the committee members', AbbVie would like to highlight the specific need for the identification of post-stroke spasticity (PSS). PSS has a disabling effect through pain and reduced movement and mobility, affecting 19-38% of the post-stroke population in England ¹ . The clinical and cost-effectiveness of interventions (such as Botox®) in reducing PSS has been recognised as a key topic in the draft scope, but it is of primary importance to also include the identification of PSS. Early identification of PSS is crucial as patients need identification and treatment earlier to address gaps in current care. Early identification of PSS may also lead to early treatment with Botox® which has been shown to be highly beneficial for patients: • Botox® has been shown to provide a sustained reduction in post-stroke upper-limb spasticity when combined with rehabilitation in patients as early as 2–12 weeks post-stroke ³ . Functional use of the arm and hand was not adversely affected. • Botox® can result in long-term gains in people with sudden onset neurological conditions such as stroke. • If used appropriately in the early phases of rehabilitation, it may prevent soft tissue shortening arising from the combined effect of spasticity and limb immobility. This may potentially help to avoid learned disuse and facilitate neurological recovery. • In some patients with regional spasticity (e.g. a paretic upper limb), a one-off serial approach with injections into several different muscle groups over a relatively short time window (6–12 weeks) ha	Thank you for your extensive comments on this important subject. Identification of spasticity has not been raised as an issue in other stakeholder comments, nor in the surveillance report, and has not been prioritised for a review. The management of spasticity will be reviewed however which clearly demands prior identification and will likely lead to more clinical focus going forwards.

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			 in curtailing upper limb spasticity, and has led to a good functional recovery in a small number of cases⁴. Botox[®] was shown to reduce spasticity and contractures after stroke and effects lasted for approximately 12 weeks. Botox[®] also reduced the need for concomitant contracture treatment and did not interfere with recovery of arm function⁵. Botox[®] 300-400 U is safe and effective in improving ankle Modified Ashworth Scale (MAS), Clinical Global Impression of Change (CGI), and Goal Attainment Scale (GAS) scores in all patients with post-stroke lower limb spasticity regardless of time since stroke. Earlier initiation of Botox[®] (≤24 vs >24 months since stroke) provided benefit to patients with some improvements in muscle tone and global functioning as measured by physician global response scale and goal attainment; and suggest that early intervention may lead to improved patient outcomes⁶. 	
			 References: ¹NICE (2014): Draft Scope, Botulinum toxin type A for treating upper and lower limb spasticity associated with stroke. ²Jörg Wissel, Ganesh Bavikatte, Maria Matilde de Mello Sposito, Alessandro Picelli, Paul Winston, Aleksej Zuzek, Development of an Early Identification Tool in Post-Stroke Spasticity (PSS): The PSS Risk Classification System, Archives of Physical Medicine and Rehabilitation, Vol. 101, Issue 11, 2020, Pg. 35, ISSN 0003-9993, https://doi.org/10.1016/j.apmr.2020.09.101. ³Rosales RL, Kong KH, Goh KJ, Kumthornthip W, Mok VC, Delgado-De Los Santos MM, Chua KS, Abdullah SJ, Zakine B, Maisonobe P, Magis A, Wong KS. Botulinum toxin injection for hypertonicity of the upper extremity within 12 weeks after stroke: a randomized controlled trial. Neurorehabil Neural Repair. 2012 Sep;26(7):812-21. doi: 10.1177/1545968311430824. Epub 2012 Feb 27. PMID: 22371239. ⁴Turner-Stokes L, Ashford S. Serial injection of botulinum toxin for muscle imbalance due to regional spasticity in the upper limb. Disabil Rehabil. 2007 Dec 15;29(23):1806-12. doi: 10.1080/09638280701568205. PMID: 18033605. ⁵Lindsay C, Ispoglou S, Helliwell B, Hicklin D, Sturman S, Pandyan A. Can the early use of botulinum toxin in post stroke spasticity reduce contracture development? A randomised controlled trial. Clinical Rehabilitation. October 2020. doi:10.1177/0269215520963855 	

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			⁶ Patel AT, Ward AB, Geis C, Jost WH, Liu C, Dimitrova R. Impact of early intervention with onabotulinumtoxinA treatment in adult patients with post-stroke lower limb spasticity: results from the double-blind, placebo-controlled, phase 3 REFLEX study. J Neural Transm (Vienna). 2020 Dec;127(12):1619-1629. doi: 10.1007/s00702-020-02251-6. Epub 2020 Oct 27. PMID: 33106968; PMCID: PMC7666298.	
AbbVie	General	General	 Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Relating to the identification of PSS, the following methods are considered current care: Fugl-Meyer assessment scale As part of the SALGOT study¹, the Fugl-Meyer assessment scale was used to assess sensorimotor function, sensation, pain, and joint range of motion in the upper limb. Results showed that sensorimotor function was the most important predictor both for any and severe spasticity 12 months post-stroke. In addition, spasticity 4 weeks post-stroke was a significant predictor for severe spasticity. The best prediction model for any spasticity was observed 10 days post-stroke (85% sensitivity, 90% specificity). The best prediction model for severe spasticity was observed 4 weeks post-stroke (91% sensitivity, 92% specificity). 	Thank-you. Please see previous point. It may be that qualifiers for treatment will include such assessments so these points will come through during the review of spasticity management planned in the scope.
AbbVie	General	General	What issue or issues do you think are most important to address regarding the organisation and planning of stroke rehabilitation services? What are the key questions which you think need to be answered?	Thank-you. The aim of the committee is to produce evidence based guidelines. Issues of accountability for continuation of care raised
			Accountability for the continuation of care in patients who suffered a stroke With various models of care, many patients fall through the gaps; notably only a small percentage are reviewed at 6-months post-stroke. Approx. 21% of review-eligible patients had their review	here is a different issue and not part of the remit.

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			information entered onto the Sentinel Stroke National Audit Programme (SSNAP) clinical audit by both acute and post-acute teams ¹ .	Management of spasticity is included in the scope
			 How can Health Care Professionals (HCPs) involved in the management of stroke be compelled to provide these vital milestone checks? Would assigning a patient to a specific clinician for their post-stroke rehabilitation on discharge from hospital be of use? How do patients get signposted to appropriate treatment as flagged at these checks? How would a universal approach and standardised questionnaire be implemented to avoid postcode prescribing? 	
			Spasticity recognition and management gaps	
			There are major gaps in UK centres regarding the recognition and management of post-stroke spasticity.	
			 What gaps are there in current service provision? Who will assess for post-stroke spasticity and if identified, who has the skillset to treat? 	
			References: ¹ Royal College of Physicians, Clinical Effectiveness and Evaluation Unit on behalf of the Intercollegiate Stroke Working Party. Sentinel Stroke National Audit Programme (SSNAP) Post- acute organisational audit – Public Report – Phase 2: Organisational audit of post-acute stroke service providers, December 2015. Available at: https://www.strokeaudit.org/Documents/National/PostAcuteOrg/2015/2015- PAOrgPublicReportPhase2.aspx	
University Hospitals Birmingham NHS Foundation	general	general	Question 1 – in light of rapid development of rehab delivery in stroke during the covid19 pandemic, it would be helpful to evaluate the effectiveness of remote rehabilitation interventions such as apps, exercise program websites, psychologicial support groupsas there may be early emerging evidence of the outcomes from these. It would help clinical decision making if there was reference to telerehab as a rehab approach in the guidelines. Innovative practice has included	Thank you. We agree. Tele- rehabilitation has been added to the scope.

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Trust and Birmingham Community Healthcare			delivery of speech and language therapy via video, preventing the need for face masks, monitoring and progression of exercise programs, 1-1 psychology sessions via video, patient led support meetings via zoom, remote visiting and teaching of rehab programs to relatives	
University Hospitals Birmingham NHS Foundation Trust and Birmingham Community Healthcare	general	general	Q2 - what is the clinical and cost effectiveness of using discharge to assess models after stroke? What is the clinical and cost effectiveness of delivering rehabilitation in care home settings? (the draft Integrated Community Stroke Service publication states that all patients should be seen in their own environment after discharge from hospital – patients newly discharged to a care home may not receive rehabilitation currently but under the ICSS should be seen – the purpose and outcomes of this should be explored in order to support the need for resource to deliver this). What is the cost and clinical effectiveness of delivering a review at home/ other to all patients within 3 days of leaving hospital – very mild stroke presentations may currently miss out on a rehab review, and wait for a 6 month assessment before hidden problems such as fatigue or low mood are detected. This would enhance the case for resources needed to deliver the ICSS. Who should deliver a rehab review within 3 days of hospital discharge – could this be done by 3 rd sector and for which patients? What are the cost and clinical effectiveness of rehabilitation stroke units? Which patients benefit and for how long?	Thank you for highlighting this aspect of the care pathway, mainly used for people who are not , or no longer able to benefit from goal directed rehabilitation and require a transfer of care to a care home. By definition, this topic does not fall into the remit of this guideline. I am afraid we are not able to look at specific staffing arrangements so cannot review the 'who does it' questions.
Stroke Association	General	General	 The Stroke Association welcomes the opportunity to provide comment on the draft scope to update the existing guidelines for stroke rehabilitation in adults, and welcomes the update to the guidelines. We have previously provided comment on NICE's original proposal to update the guideline, and this response builds upon those comments. 	Thank-you for your comments. We agree that implementation of current guidance, and access to services, are imperfect and hope that this new guidance
			Stroke remains a leading cause of adult disability in the UK and two-thirds of stroke survivors leave hospital with a disability. Yet, with effective rehabilitation and support, survivors can often make significant strides towards recovery in the first few weeks and months after a stroke. Long-	will help.

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			term personalised support is also essential, and stroke survivors can still benefit from therapy and interventions years after their stroke.	
			Sufficient and recommended rehabilitation for stroke survivors significantly improves quality of life and recovery, benefits communities and society as a whole and generates savings for the economy that could be reinvested into patient care. Clinical guidelines recommend stroke survivors that need physiotherapy receive 45 minutes of rehabilitation therapy every day, which should continue for 'as long as they are willing and capable of participating and showing measurable benefit from treatment'. ¹ These clinical guidelines are widely recognised, used, and highly regarded by the clinical community, and the latest version since the previous NICE guideline iteration.	
			Despite this, we know that access to rehabilitation services across England is patchy and evidence shows that the majority of stroke survivors receive far less than the recommended levels and that too few stroke survivors receive a six-month review following stroke. According to SSNAP's 2018-2019 Annual Report, only 32% of patients are benefitting from a six-month review after stroke, meaning thousands aren't having care and support needs identified and addressed. ² The introduction of the six-month review CQUIN by NHS England and Improvement in 2019 highlights the importance the system places on driving up the number of six-month reviews, which should be allied with strong clinical guidance within the updated guideline. ³ Our Lived Experience of Stroke reports also highlighted that 45% of stroke survivors feel abandoned when they leave the hospital because they aren't getting the help and support they need. ⁴ The COVID-19 pandemic has exacerbated these problems further, and access to rehabilitation services has been severely impacted.	

 ¹ Royal College of Physicians, Stroke guidelines (2016). Available: <u>https://www.rcplondon.ac.uk/guidelines-policy/stroke-guidelines</u>
 ² SSNAP, 2018-2019 Annual Report. Available: <u>https://www.strokeaudit.org/results/Clinical-audit/National-Results.aspx</u>

³ NHS England and Improvement, Practical guidance supporting the 2019-20 CQUIN: Six month reviews for stroke survivors (2019). Available: <u>https://www.england.nhs.uk/wp-content/uploads/2019/04/cquin-1920-</u> 6-month-reviews-for-stroke-survivors-guidance.pdf

⁴ Stroke Association, Lived Experience of Stroke reports (2019). Available: <u>https://www.stroke.org.uk/lived-experience-of-stroke-report/chapter-4-rebuilding-lives-after-stroke</u>

Comments received in the course of consultations carried out by NICE 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 NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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			We welcome the update to these NICE guidelines to help combat this and contribute towards meeting national policy ambitions to improve rehabilitation services for stroke survivors. Though, we remain concerned that there are two separate guidelines for acute and rehabilitation stroke services, which suggests a lack of integration across the pathway. Stroke survivors across England should have equal access to personalised needs-based rehabilitation and life after stroke support, including regular reviews (including at six months). These services should be fully integrated across the stroke pathway, prioritised and invested in.	
Stroke Association	General	General	 Since the existing guidelines were developed there have been significant changes in how rehabilitation services are structured, as well as a number of system-wide initiatives to improve the provision of stroke services. The NHS Long Term Plan, published by NHS England and Improvement in January 2019, includes the following ambitions for stroke rehabilitation: 'Implementation and further development of higher intensity care models for stroke rehabilitation are expected to show significant savings that can be reinvested in improved patient care. This includes reductions in hospital admissions and ongoing healthcare provision. Out of hospital, more integrated and higher intensity rehabilitation for people recovering from stroke, delivered in partnership with voluntary organisations including the Stroke Association, will support improved outcomes to six months and beyond'. 'By 2020 we will begin improved post-hospital stroke rehabilitation models, with full rollout over the period of this Long Term Plan'. 'Interoperable information systems supported by telehealth will aid more timely transfer of information between providers, enabling more effective hyper-acute pathways and improving access to and intensity of rehabilitation'.⁵ 	Thank-you. In developing guidance the NGC will always bear in mind other national policy documents and strive to align with these as far as evidence permits. NICE pathways integrate the various TA's and guidelines relevant to Stroke management.

⁵ NHS England and Improvement, NHS Long Term Plan (2019) Available: <u>https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf</u>, p.64-65

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			Moreover, the National Stroke Programme Delivery Board in England, which our Chief Executive Juliet Bouverie co-chairs with NHS England and Improvement, is positioned to deliver the NHS Long Term Plan ambitions for stroke. Funding has also been approved for rehabilitation pilot sites, which will help develop the evidence base for post-discharge community rehabilitation. Newly established Integrated Stroke Delivery Networks (ISDNs) will be the key vehicle for delivering the NHS Long Term Plan's stroke ambitions locally. As such, the 20 ISDNs across England have a responsibility to take these ambitions forward, ensure guidelines are implemented	
			The draft National Stroke Service Model highlights this ambition, stating that the 'Long Term Plan for the NHS recognises the importance of tackling the growing impact of stroke in England. Integrated Stroke Delivery Networks are the key vehicle for transforming stroke care across the country. Using a full-pathway approach, ISDNs will prevent thousands of patients suffering a stroke through improved diagnosis and access to treatment in 24/7 specialist stroke units. They'll also increase the availability of high quality rehabilitation and ongoing community care to rebuild patients' lives after a stroke. By driving improvements in devastating conditions like stroke, we will save half a million lives over the next decade, and give hundreds of thousands of stroke survivors the chance of a better recovery'. ⁶ Moreover, a key objective for ISDNs is 'delivering specialist stroke-skilled integrated community rehabilitation pathways against a national standard needs- based service specification'. ⁷ The updated service model should be referenced and commented on within the updated guidelines.	
			Since the start of the COVID-19 pandemic, the Stroke Association have also gathered new insight into people's experiences of rehabilitation through a large survey culminating in our 'Stroke recoveries at risk' report. This report demonstrates that getting rehabilitation right is even more pressing than ever.	

⁶ Draft National Stroke Service Model. (2020) Available here: <u>file:///C:/Users/stephanie.thomson/Downloads/ISDN_National_Stroke_Service_Model__DRAFT_October_2020%20(1).pdf</u>, p,3 ⁷ Ibid, p.6

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			The current and future policy context should be reflected within the updated guidelines. NICE should position the updated guidelines within this policy context, which would support implementation and adherence and demonstrate joined-up policy. The updated guidelines must be part of a wider joined-up integrated pathway to ensure every stroke survivor has an integrated recovery journey and people do not fall through the gaps.	
Stroke Association	General	General	 There are large gaps in the current draft scope around community services. The third sector is a valuable partner to delivering rehabilitation services, and should be recognised as such. We remain disappointed to see that the section on third sector organisations is not likely to be updated under the current review. The Stroke Association would like to reiterate the important role third sector organisations play not only in the delivery of services but also in the production and dissemination of patient insight/experience and our crucial role in holding the system to account in adhering to clinical guidance. We help facilitate informal support groups for both those affected by stroke and their carers, which we know are highly valued by stroke survivors in helping them to cope with the effects of their stroke. We also deliver the provision of commissioned support services. As NICE notes in the surveillance review, the NHS Long Term Plan outlines how the NHS will work in partnership with voluntary organisations including the Stroke Association to deliver of hospital, more integrated and higher intensity rehabilitation for people recovering from stroke.⁸ The draft National Stroke Service Model also recognises the importance of the third sector in delivering rehabilitation ambitions. The model notes that 'an integrated service ethos should be fostered between NHS, social care and voluntary sector care delivery to ensure equity of service, access and experience across the stroke pathway, providing a seamless world class service to all patients, communities and backgrounds'.⁹ This should too be reflected in these updated NICE guidelines. 	Thank-you. We agree that the third sector plays a hugely important role in delivering services, although there is no section in the current guideline which deals specifically with this. We have specifically included a representative from the voluntary sector in the guideline committee so that their role in assessment, planning and intervention can be incorporated in the guideline.

⁸ NHS England and Improvement, NHS Long Term Plan (2019) Available: <u>https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf</u>, p.64. ⁹ Draft National Stroke Service Model. (2020) Available here: <u>file:///C:/Users/stephanie.thomson/Downloads/ISDN_National_Stroke_Service_Model_DRAFT_October_2020%20(1).pdf</u>, P.22

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			 Life after stroke support need not only be provided by health and care bodies. Voluntary sector organisations, including the Stroke Association, can help to provide the space and support necessary - through peer support groups, exercise classes and one-to-one engagement - to ensure that stroke survivors are able to access the support they need to continue their recoveries. A section on social and community interventions, including peer support, should be included within the proposed outline for the guideline. A 2016 study found that group therapy was more effective than individual speech and language therapy sessions in encouraging participants to initiate conversation and use a wider range of communication tools, reinforcing the need to use peer support alongside other therapies for effective rehabilitation.¹⁰ Research also shows that 	
			group singing could improve outcomes for people with aphasia. ¹¹ We also have services that are based in hospital or alongside outpatient services, which we know clinicians value as our services pick up the often significant social, practical and emotional issues faced by stroke survivors and their families, freeing up clinical teams to focus on clinical issues. This means their time is used effectively and efficiently which will help ensure better provision of clinical support in and outside of hospital. This should be reflected in any guidance.	
			For example, Stroke Association Connect is an innovation supported by NHS England and Improvement and was developed in response to the COVID-19 pandemic. The service is a telephone based support service for stroke survivors following discharge. A recent 3 month evaluation of this service shows that stroke survivors felt less abandoned, were more aware of the support available to them and NHS teams recognised the benefits of the service to both them and their patients. Moreover, almost one in five had a safety concern identified by the Stroke Association staff member, which was then reported back to their NHS team.	
Stroke Association	General	General	The draft scope makes no reference to the importance and need for six month reviews. This is a key priority of the National Stroke Programme, as it aims to 'ensure three times as many patients	Thank-you. The current guideline recommends a 6

¹⁰ Fama, M. E., Baron, C. R., Hatfield, B., & Turkeltaub, P. E. (2016). Group therapy as a social context for aphasia recovery: a pilot, observational study in an acute rehabilitation hospital. *Topics in stroke rehabilitation*, 23(4), 276-83.

¹¹ Tarrant, M. (2018) Singing for people with aphasia (SPA): a protocol for a pilot randomised controlled trial of a group singing intervention to improve well-being. Available: https://pubmed.ncbi.nlm.nih.gov/30206095/

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			receive 6 month reviews of their recovery and needs – from 29% today to 90%'. ¹² As referenced previously, too few people receive six-month reviews and the updated guidelines should emphasise the importance of these to stroke survivors and their carers.	month review (rec 1.11.5). We agree that this is important, but since it will not be changed it is not mentioned in the scope, which sets out topics which need updating.
Stroke Association	General	General	 The COVID-19 pandemic has significantly impacted access to rehabilitation therapies for stroke survivors, which may result in long term impact to services and access to them. Our recent 'Stroke recoveries at risk' report found that 'access to rehabilitation services has significantly deteriorated since the Covid-19 pandemic, and is threatening to put stroke recoveries at risk. 39% of stroke survivors who had a stroke this year said they had not received enough rehabilitation therapies, including physiotherapy, occupational therapy and speech and language therapy. This figure is even higher (56%) for those who had their stroke just before the pandemic (in January or February), further suggestion of a 'forgotten' cohort of stroke survivors in the rush to respond to Covid-19. These individuals are now at risk of experiencing more long-term and complex disabilities than they otherwise would have – impacts that are devastating for the stroke survivors themselves and also more costly to the health and social care system'. The short and long term impact of COVID-19 should be reflected in the guidance, as it is likely to pose a lasting challenge to health and care services. We also surveyed stroke clinicians and researchers about the impact of the pandemic on rehabilitation: "The vast majority of moderate to severe have received no rehab. Window of opportunity for max benefit missed () There is no point saving lives if we can't provide rehabilitation to optimise the quality of that life." Stroke professional 	Thank-you. NICE has produced general guidance on Covid-19 since its impact has been felt on management of most chronic conditions. If there are issues specific to Stroke rehabilitation these will be covered in the Guideline itself.

¹² NHS England and Improvement, National Stroke Programme. Available: <u>https://www.england.nhs.uk/ourwork/clinical-policy/stroke/</u>

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			 "Patients are being discharged from hospital sooner than they would, so they are getting less rehab' in hospital, and maybe they are going back to environments where the support is not suitable." Stroke professional "Reduced space and personnel available for rehabilitation; pressure to discharge patients too early, losing opportunity for restoration of independence." Stroke professional "Significant impact on rehab in community as not able to provide face-to-face contact () Community patients have reported feeling "abandoned" [and it] has put pressure on family dynamics as families having to provide more support." Stroke professional While the Covid-19 surge necessitated changes to post-stroke care, it is now vital to fully restore and expand rehabilitation services to meet national guidelines. This is essential to avoid stroke recoveries stalling and prevent the problem getting worse. Failure to do so is likely to lead to increased needs and a rising tide of future demands on already stretched health and care systems. The updated guidelines should consider how to mitigate against the impact of the pandemic on stroke survivors' recoveries. 	
Stroke Association	General	General	 The use of, and guidance for, virtual rehabilitation should be included within the guideline, as we have seen a rise in its use as a result of the ongoing COVID-19 pandemic. In person rehabilitation will also likely run at reduced access for the foreseeable future. Moreover, there's huge potential for virtual methods of rehabilitation and post-stroke support to complement traditional face-to-face approaches in the future. Our Stroke Recoveries at Risk report found that 44% of stroke survivors have had appointments related to their stroke online or over the phone during the pandemic, and 28% have had therapy (including physiotherapy, occupational therapy and speech language therapy) online or over the phone. 52% of stroke survivors were satisfied and only 17% were dissatisfied with the appointments. Respondents generally told us it was a good use of time and resources, and that the appointments 	Thank-you. We agree and have now added tele- rehabilitation to the scope.

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			allaying anxieties about contracting Covid-19. Crucially, phone calls and online appointments have enabled many to continue their stroke recovery.	
			 Stroke survivors commented: "My physio sessions have temporarily moved to FaceTime and it is going ok. We know each other very well and I am three years in my recovery so able to use my experience and knowledge to help it work." Stroke survivor who had their stroke 2018 or before "Telephone consultation instead of attending outpatient appointment. Really good use of time/resources. Felt relaxed. Very efficient." Stroke survivor who had their stroke 2018 or before "Had stroke 6 March stayed only one day as family were worried I would pick up virus. Was very lucky one or other family members stayed with me for four weeks and physiotherapy speech therapist and professionals came in for two weeks. After that telephone calls and lots of video exercises, which helped enormously. Care was excellent." Stroke survivor who had their stroke 2020 	
			A recent study has also shown that it is feasible to deliver group interventions for people with aphasia in the virtual environment. ¹³	
			Unfortunately, virtual methods of healthcare have not been an option for everyone – the number of stroke survivors who had therapy cancelled or postponed is double the number who received therapy online or over the phone, showing that many have gone without their usual rehabilitation support.	
			Furthermore, the guidelines should also recognise that virtual rehabilitation does not work for everyone and a personalised approach to rehabilitation is needed. Many people told us that the appointments did not work for them and some noted that they found it more difficult to communicate than they would have in person. It is important to make sure that no groups,	

¹³ Marshall, J et al (2020). A randomised trial of social support group intervention for people with aphasia: A Novel application of virtual reality. Available: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0239715

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			including those with communication difficulties or those less digitally literate, are disadvantaged. And that virtual rehabilitation does not create inequities in stroke care access. This should be considered within the Equality Impact Assessment for the guideline.	
			As we recommended in our report, it's important that stroke survivors have choices about how they access services and support in the future, so that they can receive the personalised support most appropriate to them. Stroke services should evaluate and incorporate virtual models of stroke rehabilitation and support alongside face-to-face, offering people affected by stroke enhanced choice when accessing support.	
Stroke Association	General	General	Emphasis, and consideration for, the importance of mental health and psychological support is lacking from the current draft scope. Given the suddenness of stroke, and the proliferation of mental health problems that we see after them, it's important the updated guidance fully considers psychological rehabilitation and mental health support as a key component of stroke rehabilitation. Our Lived Experience of Stroke reports, based off the views of over 10,000 stroke survivors and carers, found that three quarters of stroke survivors experienced a change in their mental health. ¹⁴ They may develop depression, anxiety or suicidal thoughts. We would urge NICE to fully consider the importance of emotional and psychological support when updating the guideline.	Thank-you. These are important and are included in the existing guideline. They are not emphasised in the scope because this deals with topics for which there is new evidence and which require updated recommendations.
			Emotional support should also be considered as a wider requirement within the guidelines. When people think about rehabilitation, they're normally referring to physiotherapy, speech and language therapy and occupational therapy, and they often overlook the huge unmet emotional and psychological needs of stroke survivors and carers. However, emotional support services, such as those that the Stroke Association provides, are hugely beneficial and cost effective. For example, the Liverpool Stroke Recovery Partnership Lessons Learned report found that 'where investment of approximately £308,000 was put into stroke clinical psychology and emotional support (Stroke Association) workforce development (supporting clinical pathway enhancement);	

¹⁴ Stroke Association, Lived Experience of Stroke reports. Available: <u>http://www.stroke.org.uk/sites/default/files/conferences/nisc/documents/lived_experience_of_stroke_chapter_1.pdf</u>

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			such service development was seen to be instrumental in supporting financial savings (of approximately £913,000) - far out-stripping investment costs'. ¹⁵	
Stroke Association	General	General	 Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Prioritising and investing in stroke rehabilitation is likely to lead to cost savings to society and the economy. The scale and impact of stroke makes it an extremely costly condition for the health and social care system, and its burden is growing fast. The overall costs of stroke in the UK for those aged 45 years and over is estimated to rise from £26 billion in 2015 to £43 billion in 2025 and £75 billion in 2035, an increase of 194% over 20 years, presenting real societal challenges in future.¹⁶ However, stroke is a recoverable condition, and investment in stroke rehabilitation now will avoid the growing burden of stroke in future. While there are still some research gaps regarding stroke rehabilitation, and the National Stroke Programme stroke rehabilitation pilot project aims to address some of these, it is vital that these guidelines closely track the progress and evaluation of the rehabilitation pilots to make sure they are incorporated and take into account the findings. Many research studies have calculated the savings potential for particular interventions or rehabilitation therapies. For example, extending Early Supported Discharge provision - in 2014, NHS England estimated that extending provision of early supported discharge schemes following a stroke would potentially save 170 lives in England, and deliver a saving of £15,100 per 100,000 people realised. Further research indicates that each stroke survivor who receives Early Supported 	Thank-you. Our standard practice is to do a final literature search toward the end of guideline development, and if new evidence from pilot studies is published at that point it will be captured.

¹⁵ Liverpool Stroke Recovery Partnership; LSRP Lessons Learned, report (2019), p2 ¹⁶ Stroke Association (2014). Research Spend in the UK: Comparing stroke, cancer, coronary heart disease and dementia. Available: http://www.stroke.org.uk/research-spend-uk.

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			Discharge saves the NHS £1,600 over five years. ¹⁷ Moreover, research shows extended community support can enhance stroke survivor experience, and be cost effective. ¹⁸	
			NICE should also take into account SAFE's recent 'The Economic Impact of Stroke' report, which concludes that the cost of stroke to Europe is rising rapidly – 'future costs of stroke care in Europe could increase to €86 billion in 2040 if we fail to invest in stroke prevention, treatments and rehabilitation'. ¹⁹	
			SAFE has used QALYs to 'determine the cost effectiveness of interventions' such as the provision of rehabilitation services. ²⁰ The study concludes community-based (CB) 'rehabilitation for eligible stroke patients generated savings in health and social care costs across the 32 countries of around €180 million'. Moreover 'with informal care costs and productivity losses included, overall costs were €43.6 billion with CB compared with €43.9 billion for current rehabilitation care. Therefore, from a societal perspective, CB rehabilitation for eligible stroke patients would generate savings across the 32 countries of €295 million over a five-year period'. ²¹ Examples of innovative approaches that should be considered for inclusion within this guideline,	
			include NHS England and Improvement's rehabilitation pilots, which should be closely monitored during the development of this guideline for emerging evidence.	
Stroke Association	Equalities Impact Assessmen t	Equalities Impact Assessmen t	We are pleased that the following potential equality considerations have been identified for consideration and review: age; disability; gender reassignment; pregnancy and maternity; race; religion or belief; sex; sexual orientation; socio-economic factors and other definable characteristics.	Thank-you. NICE guidance should apply equally across the country.

¹⁷ British Heart Foundation, Public Health England, Stroke Association, Royal College of General Practitioners, Primary Care Leadership Forum, Blood Pressure UK and British and Irish Hypertension Society (2016). High blood pressure: How can we do better? Data collated and visualised by the National Cardiovascular Intelligence Network (NCVIN) in Public Health England. Available: http://bit.ly/2ju4Q31 ¹⁸ Drummond, A et al. (2020) An extended stroke rehabilitation service for people who have had a stroke: the EXTRAS RCT. Available: <u>https://www.researchgate.net/publication/341733097</u> An extended stroke rehabilitation service for people who have had a stroke the EXTRAS RCT

¹⁹ SAFE, The Economic Impact of Stroke (2020)

²⁰ Ibid, p.50

²¹ Ibid, p.94

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			We know that stroke does not affect everyone equally. The current postcode lottery of rehabilitation means that there is an inequity of provision, and those from economically deprived areas experience worse outcomes after stroke. The updated guideline, using data from SSNAP and other places, must consider how to avoid this inequity of provision and target and improve rehabilitation services in accordance with the greatest need to ensure equitable access for all that can benefit. We would urge NICE to include recommendations within the updated guideline for those delivering rehabilitation to consider how to reduce health inequalities as a key focus of their activity.	
Mid & South Essex Hospitals NHS Foundation trust	General	General	Like hyperacute care, stroke rehabilitation should also be reconfigured to align with the design in each Integrated care system. Currently, in several areas in United Kingdom, stroke rehabilitation is too fragmented with separate pathways for different categories of needs. There is a mix of private provision and NHS provision within the same economy leading to variable and often restrictive criteria being used, often disadvantaging patients. Different rehabilitation services have different contractual obligations and having their own interpretation of ESD (eg some use ESD services after inpatient rehabilitation which impacts on the capacity to discharge patients early from acute services)	Thank-you. NICE guidance should apply equally across the country
Mid & South Essex Hospitals NHS Foundation trust	General	General	Rehabilitation units should be the hub that operates inpatient rehabilitation, early supported discharges, community rehabilitation, 6 months reviews, spasticity treatment pathways and follow up clinics. Such an arrangement will help to identify unmet needs better	Thank-you. The Guideline Committee will consider your comment when revisiting the recommendations on organisation of stroke within the guideline.
Mid & South Essex Hospitals NHS	General	General	Discharging patients from a stroke pathway should involve all disciplines and each involved discipline should write to the hub to highlight ongoing care or outstanding care issues or indeed the unmet needs.	Thank-you. This is covered in the existing guidance (see recs 1.1.4 and 1.1.6).

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Foundation trust				
Mid & South Essex Hospitals NHS Foundation trust	General	General	The hub should maintain centralised rehabilitation pathway records which starts from the point the patient reaches the R point (when a person is deemed ready medically for rehabilitation whilst an inpatient)	Thank-you. We will consider your comment when revisiting the recommendations on organisation of stroke within the guideline.
Mid & South Essex Hospitals NHS Foundation trust	General	General	The concept of R point should become a mandatory process in everyday board rounds. The delays in transfer of care to a rehab setting from the R point should be audited and should be a metric to highlight quality of the stroke care	Thank-you. The Guideline Committee will consider your comment when revisiting the recommendations on organisation of stroke within the guideline.
Mid & South Essex Hospitals NHS Foundation trust	General	General	Each stroke rehabilitation unit should serve a population of about 1.5 to 2 million if can work in an integrated manner with social care, voluntary sector. ESD services should be provided as an outreach from the rehabilitation hub. A recommended bed configuration eg 30 beds/ 1.5 million population should be proposed	Thank-you. NICE guidance does not usually recommend specific service configurations.
Mid & South Essex Hospitals NHS Foundation trust	General	General	The use of remote technology will facilitate assessment of progress remotely and limit the number of physical visits thereby providing scope for efficiency. The guideline should include	Thank-you. We agree and tele-rehabilitation has been included in the revised scope.
Mid & South Essex Hospitals NHS Foundation trust	General	General	Guideline should place an emphasis on bone health following severe stroke	Thank-you. This has not been prioritised by other stakeholders and has not come up in the literature surveillance review so we

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				have not included it in the scope.
Mid & South Essex Hospitals NHS Foundation trust	General	General	Guideline should be prescriptive in the recommendations for VTE prophylaxis with a particular attention to patients discharged home with moderate to severe disability	Thank-you. NICE guideline NG89 venous thromboembolism in the over 16s, covers this for acute stroke and for continuation of therapy post-discharge.
Mid & South Essex Hospitals NHS Foundation trust	General	General	Guidelines should support decision making for placement of gastrostomy tubes at 2 weeks or sooner if it is evident that swallowing is unlikely to improve at 4 weeks. PEG should be inserted at the earliest convenience following the decision when patient is medically stable for the procedure. This would facilitate an early and timely adoption of rehabilitation. The use of mittens/ bridles and other restraints to retain NGT should be supported. If nasogastric tubes cant be placed or retained in place due to repeated pulling or due to other technical challenges, earlier gastrostomy placement should be recommended with a view to prevent starvation beyond 48 hours if non- oral feeding is necessary and deemed appropriate	Thank-you. Advice on nutrition is given in NICE guideline CG32: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition.
Mid & South Essex Hospitals NHS Foundation trust	General	General	Guideline should place special emphasis on positioning patients in bed and chair especially if significant paralysis	Thank- you for this important comment. Positioning and early mobilisation is covered in the new acute stroke guidelines (NG128).
Mid & South Essex Hospitals NHS Foundation trust	General	General	Strong emphasis should be placed on 7 day working of therapists form all disciplines and presence of community and social support 7 days a week	Thank-you. Intensity of rehabilitation will be reviewed as part of this update.

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Mid & South Essex Hospitals NHS Foundation trust	General	General	Patients having HRG contact with acute services whilst in the rehabilitation pathway or during the rehabilitation phase (usually 6 months) should be exception reported and the care plan & provision of care/support should be reviewed and scrutinised	Thank-you. Exception reporting is not part of the guideline remit.
Mid & South Essex Hospitals NHS Foundation trust	General	General	Individuals who fulfil criteria for ESD while in acute services/community support discharge whilst in inpatient rehabilitation unit – should be referred promptly and reasons to be identified and documented if not transferred within acceptable time frames	Thank-you. The evidence on ESD services will be reviewed and this has been added to the scope.
Mid & South Essex Hospitals NHS Foundation trust	General	General	ESD service- should primarily be used for patients discharged from acute services and community support discharge should be primarily for patients discharged from inpatient rehabilitation units - blurring of boundaries can be made if capacity exceeds primary function of these respective teams	Thank-you. The evidence on ESD services will be reviewed and this has been added to the scope
Mid & South Essex Hospitals NHS Foundation trust	General	General	If a referral is received by a rehabilitation team, the referring team should be made aware of a decision in 48 hours with reasons for not accepting. This should be audited	Thank-you. Audit standards will not be part of the guideline update.
Mid & South Essex Hospitals NHS Foundation trust	General	General	There should be a clear advance planning documentation for all patients sent to rehabilitation. The advance care plan, wherever appropriate, should include treatment escalation plans (including referral back to acute service), thresholds for end of life care, and plans that would not disrupt patients' pathway. This requires the rehabilitation service to have adequate medical expertise as it becomes a medically active process. Rehabilitation units are indeed medically active service, and it is a myth that it can be managed without medical expertise.	Thank-you. These issues are covered in NICE guideline NG142 End of life care for adults: service delivery.
Mid & South Essex Hospitals NHS Foundation trust	General	General	Mortality, not achieving rehabilitation goals set, institutional care – all these outcomes should be seen as potentially adverse and audited/scrutinised for improving goal setting/care provision	Thank-you. Audit standards will not be part of the guideline update.

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Mid & South Essex Hospitals NHS Foundation trust	General	General	Could the guideline indicate what process and metrics should represent a well-functioning Rehabilitation system	Thank-you. Audit standards will not be part of the guideline update.
lpsen Ltd	General	General	Can you clarify whether there is any scope to take into account the use of medical or other wearable devices to support patients in their rehabilitation journey and in addition patients' access to telemedicine resources?	Thank-you. We have added tele-rehabilitation to the scope. The Guideline Committee have not yet reviewed the literature and cannot say whether recommendations will include wearable devices.
NHS England and NHS Improvement	General	General	From the primary care perspective, the highly relevant aspects are around home management and self management. Guidance on managing the common symptoms such as fatigue, pain and mood would be helpful.	Thank-you. These areas are covered by the current guidance, and both supported self-care management and management of shoulder pain are topics which will be updated.
NHS England and NHS Improvement	General	General	In version of the original 2013 guidelines, Section 1.4 Cognitive functioning – this references screening and interventions to be completed but does not specify a professional who does this. Whilst cognitive screening and interventions may not in all settings be exclusive to Occupational Therapist, please can consideration be given to referencing occupational therapy (or other professionals) within this section particularly given that cognitive assessment and rehabilitation are a key aspect of their role working with individuals following stroke, in addition to the self-care area. (CH)	Thank-you. As a general principle NICE recommends what should be done but does not specify who should do it, recognising that all HCP's should work within the area of their professional expertise.



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NHS England and NHS Improvement	General	General	Access to specialists/OT/physios/SLT MDTs are important for these patients. (PC)	Thank-you. We agree.
NHS England and NHS Improvement	General	General	Support to care homes on the key symptoms and how to access support is vital (PC)	Thank-you. Rehabilitation post-discharge from hospital is covered in the current guideline CG162 and the recommendations will be retained.
NHS England and NHS Improvement	General	General	Support to carers of patients who have had a stroke would be helpful. (PC)	Thank-you. This is covered in the current guideline CG162 and the recommendations will be retained.
Association of British Neurologists	General	General	Not clear why SAH excluded, unless it means SAH uncomplicated by cerebral damage (infarct or haemorrhage)	Thank-you. We agree and have removed this exclusion.
Chiltern Music Therapy	General	General	 see the 3 areas of the audit data highlights regarding Neurologic Music Therapy: 1. NMT increases patient engagement in therapy 2. NMT meets rehabilitation goals quicker than expected 3. NMT reduces depression and increases emotional wellbeing Our NMT service is effectively meeting the NICE Guideline for Patient Centred Care and supports the Stroke Unit at Wycombe Hospital to meet the requirements of the national Standard. Neurologic Music Therapy should be reviewed as a stand alone intervention but also and more importantly, alongside existing AHP therapies for its impact on engagement and GAS goals 	Thank-you for this information.
Chiltern Music Therapy	General	General	A consistent pathway of care. Within our Bucks stroke services we have been able to offer Neurologic Music Therapy across the pathway from the acute stage, to step-down into rehabilitation, and then continued via our community teams in both groups and/or 1:1 at home. The impacts of COVID-19 have seen us offer our community groups sessions online and we are currently running successful digital NMT aphasia groups to continue supporting this population.	Thank-you for this information.

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Health Education England	General	1.13	 NICE may want to review how the guidance could reflect the move to stroke care that is capabilities based rather than profession based. The guidance currently states, "the roles and responsibilities of the core multidisciplinary stroke rehabilitation team should be clearly documented and communicated to the person and their family or carer." NICE may also want to highlight the training, experience, responsibilities, and competencies of healthcare professionals who provide rehabilitation care in secondary care differ to professionals in a primary care setting. The multi-disciplinary team roles, skills and responsibilities may look different when patients are discharged into community based care. For example, lone working in primary care requires specific skills that are not required for secondary care. NICE will want to encourage an update to the practice based implementation advice for support for education and learning to reflect the updated guidance and to consider community based care. 	Thank-you. The wording will be reviewed and take into account these suggestions.
Health Education England	General	1.1.3	The current NICE guidelines are currently out of date and do not reflect an expanding and specialised multi-disciplinary stroke team. We would encourage NICE to change section to 1.1.3 to include the following: A stroke rehabilitation unit should have a single multi-disciplinary team including specialists in: medicine; nursing; physiotherapy; occupational therapy; speech and language therapy; dietetics; clinical neuropsychology/clinical psychology; social work; orthoptics; skilled rehabilitation support workforce	Thank-you. The Guideline committee will consider your comment when they refresh 1.1.3.

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			 with easy access to pharmacy, medical social workers, orthotics, specialist seating, assistive technology, and information, advice, and support for people with stroke and their family/carers. 	
			 To reflect the modern stroke multidisciplinary team. The following have been removed: social workers - due to the change in Health Care Science, Medical Social Worker are not typically part of the multi-disciplinary team 	
Health Education England	General	1.1.5	 "Members of the core multidisciplinary stroke team should screen the person with stroke for a range of impairments and disabilities, in order to inform and direct further assessment and treatment" We would encourage NICE to also recognise the role "screening²²" can play to support stroke research. Multidisciplinary teams should be encouraged to engage in research activity to help improve shared learning and opportunities for innovation in stroke rehabilitation care. 	Thank-you. The Guideline Committee will try to identify questions which require further research when they look at the evidence.
Royal College Of Nursing	General	002	The Royal College of Nursing (RCN) have just produced the UK Career Framework for Stroke Nurses (2020) which would be useful in refreshing the recommendations in the existing NICE guideline about core multidisciplinary stroke team. This RCN resource outlines the range of career pathways within stroke nursing and the minimum recommended education requirements, in addition to knowledge and skills. It provides a guide for stroke services and employers to develop local career development frameworks for the nursing workforce. Registered nurses working in stroke care can map their career development, as well as assess their skills and knowledge based on this resource and linked resources - https://www.rcn.org.uk/clinical-topics/neuroscience-	Thank-you for this information. Career pathways are not part of the NICE guideline remit.

²² In this response we are using the word 'screening' as it is used in the consultation not to advocate a screening programme out with those approved by the UK National Screening Committee

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Health Education England	General	1.13 & 1.1.9	Alongside an update to the multi-disciplinary team guidance, NICE may want to consider the difference between stroke rehabilitation teams in primary and community care and inpatient care. While section 1.1.9 states that early discharge "should be part of a skilled stroke rehabilitation service and should consist of the same intensity of therapy and range of multidisciplinary skills available in hospital." The guidance should be more explicit and consider the primary care support infrastructure, resourcing and networks that differ from in patient, secondary care.	Thank-you. The Guideline Committee will consider your comments when the relevant recommendations are reviewed. However, detailed reviews of services and organisational structures are not part of the committee's remit.
Royal College of Occupational Therapists	006 - 007	General	Should include psychological support and vocational rehabilitation (to mirror and support NHSE specification)	Thank-you. There are sections in the existing guidance which cover these topics, and these will be retained.
Society for Research in Rehabilitation	006 - 007	003	Table 3; repetitive task training. The FAST-INdiCATE trial provides new evidence that repetition of tasks using a functional strength training approach was not superior to a sensorimotor focussed intervention (Movement Performance Therapy) that should be considered to offer an unbiased guideline around task training.	Thank-you. Intensity and frequency of rehabilitation will be reviewed and this trial will be included.
Society for Research in Rehabilitation	003 - 004	017 - 026 001 - 024	Categorisation of key areas that will be covered in this update: the categorisation of these 'areas' does not come across as logical or comprehensive, which makes it difficult to see if any 'areas' have been omitted. 'Areas' seem to be a mix of impairments, activity limitations and interventions, whilst participation restrictions seem to be under-represented. Some areas have clearly not been included in section 4 (e.g. cognition, emotion, balance and mobility, driving) - there may well be a reason for this but this is currently unclear. At the same time, a number of categories in section 4 (i.e. botulinum toxin, baclofen and spasticity would seem to belong to the same category, but have been listed separately). It is also curious why 'urinary incontinence' is listed but not 'faecal incontinence'? It may be the case that the planned update will integrate the latest with existing guidance in a comprehensive, logically ordered full guideline but this is not clear? Agree with the	Thank-you. Section 4 has been amended. Please note that the scope covers the topics that will be subject of a new evidence review. Some of the areas which you mention as not being included are in the existing guideline and will be

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			authors that the guideline would benefit from being restructured to more clearly follow the flow of people with stroke through different phases and care settings.	retained in this update, but are not prioritised for an evidence review.
Society for Research in Rehabilitation	001	021	How recent is the of evidence underpinning the guidance? What was the end of the search period for the 2019 surveillance review? Its reference list does not seem to include any primary references after 2018? Hence, a logical first step would seem to be for the literature surveillance to be systematically updated from the last search date, to include relevant publications from 2019 and 2020.	Thank-you. Guideline development will include an up to date evidence review. This is standard NICE methodology and separate from the surveillance report. Any relevant recent publications will be included in the formal literature searches when these begin.
Stroke Association	001	023	 In the draft scope under the section 'why is the guideline needed?' we agree with the rationale that 'although stroke is one of the biggest causes of death in the UK, most people survive a first stroke. Thanks to improvements in organised stroke care and new acute treatments, the overall survival rate from first stroke has improved over the past 10 years. This has led to increases in the number of people in the community who need comprehensive post-stroke care and rehabilitation'.²³ We would also add to this section that people are not currently receiving the levels of rehabilitation and support that they should be, according to national guidelines. Improvements in acute care. We recognise that COVID-19 is going to place additional pressures on rehabilitation resource and capacity, and although the stroke pathway is separate, services will still be reliant on the same professionals for delivery. Stroke rehabilitation and support services need investment and resource to improve, as access to them is currently patchy across England creating an unacceptable postcode lottery. Currently, almost 20% of inpatient stroke units are not linked to 	Thank-you for this information. This section of the scope is only intended to be a high level introduction to the topic.

²³ NICE, draft scope. Available here:

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			month review receive one. ^{24 25} Hence, the guidelines are in need of updating to ensure greater compliance.	
			Chapter four of our Lived Experience of Stroke reports found that one in four stroke survivors felt they did not receive enough support when they needed it most and a third of stroke survivors felt that support was restricted to focusing on their medical conditions rather than them as an individual. ²⁶	
			The report also found:	
			 A half of stroke survivors felt they needed support for longer or more frequently. 40% of survivors said they needed longer or more frequent support from physiotherapy services than was provided. 	
			 A third needed more support from speech and language or occupational therapy. People living with a more severe impact of stroke were more likely to say they did not receive enough support. 	
			 Many stroke survivors felt they had more help with other health conditions than their stroke. 	
			• 51% of stroke survivors told us that the support they had received had been more focused on their other health conditions than it had on stroke.	
			• A stroke can affect every part of a person's life, yet a third of stroke survivors told us that support was restricted to focusing on their medical condition rather than them as an individual.	
			• There are differences across the UK in the care and support that stroke survivors receive. It is not a level playing field and some people miss out.	

 ²⁴ <u>https://www.stroke.org.uk/sites/default/files/economic_impact_of_stroke_report_final_feb_2020_0.pdf</u>
 ²⁵ Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP). National clinical audit annual results portfolio March 2016-April 2017. Available: http://bit.ly/1NHYIqH
 ²⁶ Stroke Association, Lived Experience of Stroke reports, Chapter four (2019). Available here: <u>https://www.stroke.org.uk/lived-experience-of-stroke-report/chapter-4-rebuilding-lives-after-stroke</u>

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			Chapter one of our Lived Experience of Stroke report also details the hidden effects of stroke and the variety of impacts. ²⁷ This is another key evidence source, as it details from the patients' perspective the various impacts of stroke. These findings from stroke survivors and their carers should be considered and taken into account when developing the updated NICE guidelines.	
			We would also suggest adding to this section the economic cost of stroke. Stroke is enormously expensive to society and the economy and effective rehabilitation can save money. Conversely, insufficient rehabilitation could lead people to have poor quality recoveries leading them to require even more services, including expensive acute services, further down the line. The overall costs of stroke in the UK is estimated to rise from £26 billion in 2015 to £43 billion in 2025 and £75 billion in 2035. ²⁸	
Kent Community Health NHS Foundation Trust	002	023 - 024	The draft scope states that NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government and Northern Ireland Executive. We feel that whereas all four nations will be making their own guidelines England should be mindful of trying to co-operate and co-ordinate as many people live along the border and many border hospitals take patients living in the neighbouring country and there should be service equity where possible.	Thank-you. Service equity is important, but this is an implementation issue and not part of the scope.
University Hospitals Birmingham NHS Foundation Trust and Birmingham Community Healthcare	002	010	The draft scope is not specific about rehab settings. It would be useful to scope the evidence for rehab stroke units, which patients benefit most, role alongside ESD	Thank-you. ESD is now included for review. However, it is not anticipated that the evidence will allow detailed recommendations about distinct rehab settings.

²⁷ Stroke Association, Lived Experience of Stroke reports, Chapter one (2019). Available here: <u>http://www.stroke.org.uk/sites/default/files/conferences/nisc/documents/lived_experience_of_stroke_chapter_1.pdf</u>

²⁸ Stroke Association (2014). Research Spend in the UK: Comparing stroke, cancer, coronary heart disease and dementia. Available: http://www.stroke.org.uk/research-spend-uk

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University Hospitals Birmingham NHS Foundation Trust and Birmingham Community Healthcare	002	020	Rehab settings are not specific, it would be helpful to clarify the different settings which would ensure that standards for rehab are met throughout the pathway including HASU, ASU, RSU and all community settings	Thank-you. It is not anticipated that the evidence will allow detailed recommendations about distinct rehab settings.
Society for Research in Rehabilitation	003	021 - 023	Further question to consider for vision is; what are the core vision assessments to be undertaken?	Thank-you. Vision assessment will be considered from the viewpoint of identifying those who need a more specialised orthoptic assessment.
Society for Research in Rehabilitation	003	024 - 025	Consider access to treatment in stroke and community services (and linking to Specialised Rehabilitation services).	Thank you. The guideline can recommend access to treatment and services, but implementation is a separate issue.
Stroke Association	003	006	It is important that rehabilitation is available to access for as long as required and where there is a clear need identified, services should be able to continue or 'reopen' rehabilitation for people who are referred back in. This should align with the rehabilitation workstream vision. Some of the definitions and descriptions in the draft scope require clarity. For example, 'continuing impairment' is problematic. We are concerned about what happens to people who may have clinically 'recovered' but then either relapse or have an episode requiring support with psychological problems, for example. The nature of stroke means some people experience	Thank-you. The guideline is applicable to people who have had a stroke, and is open-ended; no post-stroke time limit has been specified in the scope. Recommendations 1.2.8 to 1.2.12 in the existing guideline make clear that

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			 inconsistent and sporadic episodes of impairment and it's very often not linear. We would ask NICE to consider how to ensure the guideline acknowledges and includes those people. Our Stroke Recoveries at Risk report found that it was not only stroke survivors who had their stroke recently who felt their recovery was stalling or going backwards. Those who had a stroke in 2018 or before also reported impacts to their recovery and reduced access to community rehabilitation has had a negative affect even for those who started their recovery journey long before the pandemic. Some respondents highlighted long-term issues they still required support with, such as swallowing problems, memory issues and anxiety. One stroke survivor, who had a stroke in 2018 or before, reflects: "I have felt my mobility worsen as my usual exercise activities were not available (swimming, guided seated yoga). Walking is not as good activity for me and some days I cannot manage a walk."²⁹ The guidelines need to reflect that rehabilitation should be needs based, rather than time limited. Similarly, we would urge the guideline review to take into account the importance of personalised 	the stroke survivor and, where appropriate, their carers should be involved in planning care. These recommendations will be retained.
			care and shared decision-making. The scope references supported self-management, but not patient involvement and shared decision-making.	
Society of British Neurological Surgeons	003	010	 patient involvement and shared decision-making. The SBNS feel they have been repeatedly misled by NICE. When the scope of the SAH guidelines were being developed there was refusal at the scoping meeting to consider rehabilitation within scope despite almost unanimous agreement amongst stakeholders and specifically patients and clinicians that this is one of the most important aspects of the care of this population. This red line this was justified on the basis that it would be included in the stroke rehabilitation guidelines. Despite this, it was not included in the first draft of the stroke rehabilitation guidelines which was raised at the scoping meeting. Rather than either discussing it with the subarachnoid haemorrhage guideline group or making it in scope, the updated stroke rehabilitation document instead has been revised so it now specifically excludes SAH. 	Thank-you. You are correct, and we apologise for the oversight. People with SAH are now included in the scope.

²⁹ Stroke Association, Stroke Recoveries at Risk (2019). Available: <u>https://www.stroke.org.uk/stroke-recoveries-at-risk-report</u>

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			This is a great disservice to SAH patients when in the last national review of SAH by NCEPOD overwhelmingly the greatest shortcoming in SAH services was highlighted to be rehabilitation.	
Stroke Association	003	010	The draft scope currently excludes large groups of people that could benefit from inclusion. For example, 'people who have had a transient ischaemic attack or subarachnoid haemorrhage' are currently excluded. We feel this group should be included within the scope of the guideline as people who have a TIA or subarachnoid haemorrhage may still require rehabilitation. ³⁰ The risk of not including them means that they may fall through the gaps. Moreover, the final scope for the ' <i>Subarachnoid haemorrhage caused by a ruptured aneurysm:</i> <i>diagnosis and management</i> ' guideline notes that rehabilitation will not be included within it and instead the 'guideline will cross refer to the NICE guideline on Stroke rehabilitation in adults'. ³¹ However, this scope doesn't include those who have had a subarachnoid haemorrhage within its remit. We suggest clarifying as to why they are not included and, at the minimum, signposting to the relevant additional guidelines.	Thank-you. The exclusion of SAH survivors has been removed from the scope. We have not removed people who have had a TIA from the exclusion section because this would mean that all recommendations should be applied to this group and this would both overwhelm the current service and be inappropriate for most people who have had a TIA. The international definition of TIA indicates that their symptoms should have resolved within 24hrs. We appreciate there is a body of evidence showing the existence of ongoing issues following TIA but, as currently defined, rehab is not applicable to this group. More research on the

³⁰ Kontou, E, Marion, M et al. (2019) Optimising Psychoeducation for Transient Ischaemic Attack and Minor Stroke Management: a feasibility randomised controlled trial of a psychoeducational intervention after TIA and minor stroke, International Journal of Stroke, p.49

³¹ NICE, Subarachnoid haemorrhage caused by a ruptured aneurysm: diagnosis and management final guideline scope. (2018) Available here: <u>https://www.nice.org.uk/guidance/gid-ng10097/documents/final-scope</u>

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				possible benefits of rehabilitation strategies for TIA patients is required.
University Hospitals Birmingham NHS Foundation Trust and Birmingham Community Healthcare	003	014	The draft scope includes all care settings including secondary – we feel this will not be specific enough when applying the evidence for particular interventions, such as high intensity rehab/ early mobilisation which according to the AVERT trial could be detrimental if applied in the first few days after stroke. The guidelines should make reference to the varied rehab needs at different stages of the patient pathway	Thank-you. The scope states that the guideline will cover all care settings, which means that the scope in its entirety will cover all settings, not that every recommendation is applicable to every setting. Early therapy/mobilisation and specifically the AVERT trial was reviewed by the acute stroke guidelines committee and is covered by the new guidelines (NG128).
University Hospitals Birmingham NHS Foundation Trust and Birmingham Community Healthcare	003	020	Current models of care – agree the scope should be for all parts of the pathway but there is a need to clarify what the current model is – for example in patient rehabilitation and community rehab are both used in rehab pathways and it should be clear that all evidence based interventions should be available to patients in all settings, unless there is evidence that they work best at a particular time point post stroke	Thank-you. Recommendations in the guideline will be applicable to all people undergoing Stroke Rehabilitation unless specific inclusions or exclusions are stipulated.
Stroke Association	003	020	We are pleased that NICE suggest "we may also restructure the guideline to better reflect current models of care". As we highlighted in our response to the original proposal to update the guideline, we remain concerned about the structure of existing stroke-specific guidance. We also set this out in our January 2019 response to the <i>Stroke and transient ischaemic attack in over 16s</i> :	Thank-you. CG162 is not limited to those with continuing impairment 2 weeks post-stroke. It is

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			Diagnosis and initial management update. NICE should review whether the acute and rehabilitation guidelines should remain as two separate guidelines, given the increasing drive for integration across care settings.	applicable to stroke survivors once their acute management is complete, and the same will apply to
			Further, CG 162 states that it covers stroke survivors who have a continuing impairment 2 weeks post-stroke, which leaves a significant gap between the acute care covered in the above guideline, which mostly covers interventions up to 48 hours after onset and only "some interventions up to two weeks". Recommendations should ensure stroke survivors receive the rehabilitation and support they need as soon as they need it.	this update. There are no plans to combine the acute and rehabilitation guidelines, although they are linked in the NICE pathway.
			The draft National Stroke Delivery Model notes that: 'Patients with stroke who have mild to moderate disability and who have been identified as being eligible for ESD should be offered assessment and treatment in the community within 24 hours. Stroke rehabilitation should be offered at the same intensity as stroke unit care (typically daily sessions) and be based on clinical need tailored to personalised goals and outcomes. Patients deemed not requiring ESD intensity should be assessed within 72 hours and provided treatment within 7 days of assessment or earlier, based on clinical judgement and patient choice. The intensity of intervention provided to non-ESD patients is typically less than is offered to ESD patients, however intensity of provision must be established between stroke specialist, survivor and carer, based on clinical need and tailored to personalised goals. The duration of ESD/ICSS input should be needs related and not time limited'. ³²	
			We know that there is a very important window of opportunity for recovery post-stroke in the first few days and weeks after, and the current structure of the two sets of guidance risks not making the most of this key opportunity.	
			Post-acute care has not kept pace with the improvements we have seen in acute care and stroke survivors continue to report they do not get the level and breadth of rehabilitation they want, and many cite feeling abandoned when they leave hospital. Combining the guidelines would send a	

³² Draft National Stroke Service Model. (2020) Available here: <u>file:///C:/Users/stephanie.thomson/Downloads/ISDN_National_Stroke_Service_Model__DRAFT_October_2020%20(1).pdf</u>, P.24

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			strong message to the clinical community about the importance of post-stroke support, whilst also ensuring seamless patient pathways are adequately set out in one robust clinical guideline. We strongly urge NICE to consider combining the two existing guidelines, to elide any perceived gap in service and guideline provision.	
Society for Research in Rehabilitation	004	008 - 024	 There is no mention of sensation or recovery of sensation / perception, which is important and for which there is more evidence emerging particularly around tactile discrimination training for the hand and intensive proprioceptive stimulation for the hand and foot (recent systematic reviews and trials evidence). Music therapy is very specific, and there is literature on active music making, which is different to music therapy. Also should consider other art forms / arts interventions, not just music. 	Thank you for raising this. Whilst we are aware of emerging evidence in this area the quality of evidence to date is not high enough for this topic to be prioritised for review. Clearly more research is needed in this area and the committee will be mindful of suggesting areas that should be prioritised for research. The same applies to music making in general. Music therapy, which as you point out is more specific, will be reviewed.
Society for Research in Rehabilitation	004	008 - 024	Organisation of 'specific problems and interventions' seems less than logical with a mix of impairments, function, over-arching rehabilitation approaches and specific interventions, it would be helpful if this could be ordered in a more coherent way.	Thank-you. This section has been amended.
Society for Research in Rehabilitation	004	003 - 007	Long-term rehabilitation should also include alternative means of provision (linked to supported self-care / self-management) in the community.	Thank-you. Methods of service provision per se has not been prioritised for this update.

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Society for Research in Rehabilitation	004	003 - 007	Consider early intervention as there is more recent evidence on this.	Thank-you. There will be no time limit to evidence within the review. Very early mobilisation was covered in the acute stroke guideines (NG128) and will be cross referenced.
Royal College of Speech and Language Therapists	004	012 - 013	 RCSLT recommends that the statement 'Speech and language therapy combined with app-based therapy tools for aphasia' should be expanded. This is for the following reasons: App based therapy tools for aphasia are speech and language therapy 'App based' is quite narrow - many aphasia tools are available using software programmes or web-based access, apps are only one type of possible platform There are also tools for dysarthria so why has this been limited to aphasia. Can we suggest that this is changed to: Face to face speech and language therapy augmented by computer-based tools for communication therapy 	Thank-you. We have simplified the reference to computer-based tools at this point in the scope. The clinical question is given in section 3.5 (question 4.5) and the terminology is also changed here.
Association of Chartered Physiotherapists in Neurology	004	005	ACPIN strongly suggests that the guidelines provide guidance on length of intervention in addition to frequency and intensity. This would help reduce the disparity currently experienced across sectors and pathways.	Thank-you. Information on duration of rehab was included in this search question when the existing guideline was developed and we will use the same search template. Making recommendations on duration is more difficult because of the variation between individuals but if

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				clear evidence emerges this will be considered.
Faculty of Homeopathy	004	007	 Psychological services should be included in the scope, especially for long-term rehabilitation. Meditation, guided imagery, clinical hypnosis, and biofeedback are cost-effective evidenced-based approaches used in physical medicine and rehabilitation settings that are well-tolerated by patients. There is good evidence for their applications for many areas of rehabilitation, and preliminary evidence for traumatic brain injury and cerebrovascular events. Outcomes are strongest for mental health and quality-of-life indicators and are often less robust for disease-specific physiologic indicators (eg, acute pain). The following studies could be cited: Jessica Pieczynski, Mind-Body Interventions for Rehabilitation Medicine. Phys Med Rehabil Clin N Am 31 (2020) 563–575 https://doi.org/10.1016/j.pmr.2020.07.008 	Thank-you. The reference you provide states that only preliminary evidence is available in cerebrovascular disease. These interventions have not been suggested by other stakeholders and therefore have not been included in the scope.
Fresenius Kabi	004	008	Draft scope currently doesn't reference nutrition support in the wider context of patient care. It references swallowing but nothing beyond this topic.	Thank-you. Advice on nutrition is given in NICE guideline CG32: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition. Cross reference will be made to this guidance
Association of Chartered Physiotherapists in Neurology	004	008	ACPIN strongly suggests that sensory loss, and interventions focused on addressing this, should form another of these sub-points.	Thank-you for raising this. Whilst we are aware of emerging evidence in this area the quality of evidence to date is not high enough



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Association of Chartered Physiotherapists in Neurology	004	008	ACPIN strongly suggests that Functional Electrical stimulation should be included in this section to assess as an intervention. Transcutaneous Electrical Stimulation in normally used for pain relief	for this topic to be prioritised for review. Clearly more research is needed in this area and the committee will be mindful of suggesting areas that should be prioritised for research. Thank-you. Functional electrical stimulation and transcutaneous electrical stimulation will both be considered for appropriate
Association of British Neurologists	004	008	Swallowing rather than oral feeding is listed under 4. specific problems and interventions. Oral feeding is a better term as it takes into account other determinants such as posture, cough, oral control and environment etc.	symptoms. Thank-you. We agree and have amended this.
Faculty of Homeopathy	004	009	 Acupuncture has demonstrated efficacy in specific stroke problems, including dysphagia, for example: Ivy S.Y. Wong, Acupuncture for dysphagia following stroke: A systematic review. European Journal of Integrative Medicine 4 (2012) e141-e150 doi:10.1016/j.eujim.2012.02.001 Background: This systematic review reports an update evaluation and critically appraise on available randomized controlled trials (RCTs) which investigated the effectiveness of acupuncture on dysphagia in stroke rehabilitation. Methods: A literature search was performed to identify all RCTs that investigated the therapeutic effect of acupuncture on dysphagia after stroke from 1966 to 2011. The recruited studies were classified according to the types of participants, types of intervention, outcome measures and results. Results: The current review was based on nine RCTs that showed a positive effect of acupuncture and conventional rehabilitation on dysphagia compared to conventional rehabilitation alone. All 	Thank-you. Acupuncture will be considered in some sections, but as your reference indicates the evidence in dysphagia is not strong and this use of acupuncture has not been prioritised for inclusion.

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			the studies reported short-term effect of acupuncture on dysphagia and no follow-up data were available. Conclusions: The current review appeared to reveal that acupuncture together with conventional rehabilitation has positive effect on dysphagia after stroke. However, it was acknowledged that the concerns in the methodology of the studies in this systematic review, a larger sample, multi- centre, well designed RCTs with homogeneity of outcome measures needs to be carried out before recommending acupuncture as a standard treatment to patients with dysphagia after stroke.	
Faculty of Homeopathy	004	011	Acupuncture for aphasia is another possible innovative treatment to include within the scope. Consider the following study: Jinke Huanga, An overview of systematic reviews and meta-analyses on acupuncture for post- stroke aphasia European Journal of Integrative Medicine 37 (2020) 101133 https://doi.org/10.1016/j.eujim.2020.101133 Introduction: Because current evidence regarding the effectiveness of acupuncture for post- stroke aphasia (PSA) is controversial, we comprehensively evaluated the methodological quality and evidence quality of systematic reviews/meta-analyses (SRs/MAs) on acupuncture for PSA. Methods: SRs/MAs on acupuncture treatment for PSA were searched in eight databases. Assessing the Methodological Quality of Systematic Reviews 2 (AMSTAR-2) and the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) assessments were used to ascertain the methodological quality and evidence quality, respectively. Results: Six SRs/MAs on acupuncture treatment for PSA were included. The evaluation results of AMSTAR-2 showed that the methodological quality of all of the included SRs/MAs was rated as critically low. For GRADE, 14 (14/32, 43.75%) outcomes were rated as very low-quality evidence, 12 (14/32, 37.5%) as low-quality evidence, 6 (6/32,18.75%) as moderate-quality evidence, and O as high-quality evidence. Descriptive analysis results showed that acupuncture combined with speech and language therapy (SLT) appears, to some extent, to improve clinical effectiveness for the treatment of PSA, compared with SLT alone.	Thank-you. Acupuncture will be considered in some sections, but as your reference indicates the evidence in aphasia is not strong and this use has not been prioritised for inclusion.



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			Conclusions: Compared with SLT alone, acupuncture combined with SLT for the treatment of PSA may improve clinical effectiveness, but this conclusion must be considered cautiously due to the generally low methodological quality and evidence quality in the included SRs/MAs.	
Faculty of Homeopathy	004	018	 Acupuncture has also shown measurable benefit for post-stroke shoulder pain. This includes treatment of shoulder-hand syndrome. Two studies to cite are: Jung Ah Lee. Acupuncture for Shoulder Pain After Stroke: A Systematic Review. The Journal of Alternative and Complementary Medicine. Vol 18, No. 9, 2012, pp. 818–823. DOI: 10.1089/acm.2011.0457 The aim of this systematic review was to evaluate the effects of acupuncture for shoulder pain after stroke. Methods: Randomized controlled trials (RCTs) involving the effects of acupuncture for shoulder pain, published between Jan 1990 and Aug 2009, from the National Libraries of Medicine, MEDLINE, CINAHL, AMED, Embase, Cochrane Controlled Trials Register 2009, Korean Medical 	Thank-you. The use of acupuncture for treatment of shoulder pain is in the scope.

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			Database (Korea Institute of Science Technology Information, DBPIA, KoreaMed, and Research Information Service System), and Chinese Database (China Academic Journal). Results: Among the 453 studies that were obtained 7 studies met the inclusion criteria for this review. All of them were RCTs published in China and reported positive effects of the treatment. The quality of the studies was assessed by the Modified Jadad Scores (MJS) and the Cochrane Back Review Group Criteria List for Methodologic Quality Assessment of RCTs (CBRG); the studies scored between 2 and 3 points on MJS, and between 4 and 7 points on CBRG. Conclusions: It is concluded from this systematic review that acupuncture combined with exercise is effective for shoulder pain after stroke. It is recommended that future trials be carefully conducted on this topic.	
			 Shaonan Liu. Acupuncture for Post-stroke Shoulder-Hand Syndrome: A Systematic Review and Meta-Analysis. Frontiers in Neurology www.frontiersin.org April 2019, Vol 10, Article 433. doi: 10.3389/fneur.2019.00433 Background: Shoulder-hand syndrome (SHS) is prevalent in hemiplegic patients after stroke. This systematic review evaluated the safety and efficacy of acupuncture for SHS in stroke patients. Methods: Five English databases (PubMed, Embase, CINAHL, CENTRAL, and AMED) and four Chinese databases (CBM, CNKI, CQVIP, and Wanfang) were searched from their inceptions to January 2019. Randomized, controlled trials that evaluated the add-on effects of acupuncture to rehabilitation for post-stroke SHS were identified. Results: Thirty-eight studies involving 3,184 participants fulfilled the eligible criteria and were included in the review. The overall meta-analysis showed that acupuncture combined with rehabilitation significantly improved motor function (upper-limb Fugl-Meyer Assessment (FMA): 34 studies, mean difference (MD) 8.01, 95% confidence interval (CI) [6.69,9.33]), and reduced pain (visual analog scale (VAS): 25 studies, MD -1.59, 95%CI [-1.86,-1.32]). It also improved activities of daily living (ADL) when compared with rehabilitation alone (ADL: 11 studies, MD 9.99, 95%CI [5.91,14.06]). However, the certainty of evidence of all these outcomes was assessed as "low." Subgroup analyses of acupuncture stimulation types and treatment duration all showed significant add-on effects comparing with rehabilitation alone. There is a lack of detailed reporting of adverse 	

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			events in most of the included studies. [my comment – but acupuncture has demonstrated safety in many other studies]. Conclusions: Acupuncture therapy seems effective for motor function, pain relief and activities of daily living in stroke patients with mild SHS, when it is used in combination with rehabilitation. [My comment – although more studies would be needed to reinforce making recommendations to clinical practice, this is sufficient evidence to include it within this scope].	
Faculty of Homeopathy	004	019	In particular acupuncture may benefit post-stroke spasticity. There are several theories underlying the pathophysiology of spasticity in Traditional Chinese Medicine, which lead to well defined acupoint combination protocols – often involving the liver acupuncture meridian as key acupoints. Example studies are: Yiyi Cai, Electroacupuncture for Poststroke Spasticity: A Systematic Review and Meta-Analysis. Archives of Physical Medicine and Rehabilitation 2017;98:2578-89 http://dx.doi.org/10.1016/j.apmr.2017.03.023 Objective: To evaluate the effects and safety of electroacupuncture (EA) for stroke patients with spasticity. Data Sources: Five English databases (PubMed, EMBASE, CINAHL, Cochrane Central Register of Controlled Trials, Allied and Complementary Medicine Database), 4 Chinese databases etc Study Selection: Randomized controlled trials were included if they measured spasticity with the Modified Ashworth Scale (MAS) in stroke patients and investigated the add-on effects of electroacupuncture to routine pharmacotherapy and rehabilitation therapies. Data Extraction: Information on patients, study design, treatment details and outcomes assessing spasticity severity, motor function, and activities of daily living was extracted. Data Synthesis: In total, 22 trials involving 1425 participants met the search criteria and were included. Conclusions: EA combined with conventional routine care has the potential of reducing spasticity in the upper and lower limbs and improving overall and lower extremity motor function and	Thank-you. The use of acupuncture in the management of spasticity is included in the scope.



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			 Mukul Mukherjee, The Effect of Electro-Acupuncture on Spasticity of the Wrist Joint in Chronic Stroke Survivors. Arch Phys Med Rehabil Vol 88, February 2007. Objective: To quantitatively assess the change in spasticity of the impaired wrist joint in chronic stroke patients after electro-acupuncture treatment. Design: Crossover design. Setting: University medical center research laboratory. Participants: Seven chronic stroke subjects (age, 63.14 7.01y). Intervention: Participants received two 6-week treatment regimens: combined electro-acupuncture and strengthening twice a week, and strengthening twice a week only. Main Outcome Measures: Velocity sensitivity of averaged speed-dependent reflex torque (VASRT); segmented averaged speed-dependent reflex torque (VASRT); segmented averaged speed-dependent reflex torque (VASRT); sugmented averaged speed-dependent reflex torque (VASRT); sugmented averaged speed-dependent reflex torque (SASRT); Modified Ashworth Scale (MAS) scores; and integrated electromyographic activity of the affected wrist flexors during passive stretch of the affected wrist joint. Results: VASRT was reduced significantly in the combined treatment group after the 6-week period, but not in the strengthening-only group; however, no significant immediate effect of electro-acupuncture was observed. MAS scores also showed a significant reduction. SASRT did not differ significantly across different positions of the joint or across velocity; however, significant differences were present between the 2 treatment groups Conclusions: A combination of electro-acupuncture and muscle strengthening exercise for 6 weeks significantly reduced spasticity. The effect of spasticity reduction was consistent across different joint positions and different velocities of passive stretch. 	
Association of Chartered Physiotherapists in Neurology	004	019	ACPIN wishes to highlight the following: Spasticity: will this also include tone in general/will there be a discussion of low tone management/positioning?	Thank you for raising this – unfortunately there is not enough stroke specific evidence for this to be included but the committee will be mindful of this during discussions on spasticity. It is possible for the



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				committee to raised research recommendations as part of the work.
Royal College of Occupational Therapists	004	0019	Lines 21 (baclofen) and 22 (botulinum toxin) should be subsection of spasticity	Thank-you. We agree and this has been amended.
Society for Research in Rehabilitation	004	021	Baclofen is specified, but does not indicate the other systemic pharmacological agents. Is there a reason for this (e.g. the evidence is already included for the other agents and there isn't any update)?	Thank-you. The agents listed in the scope are those which were prioritised following discussion at the national stakeholder workshop.
Society for Research in Rehabilitation	004	022	Botulinum toxin specifically referred to. All three licenced products is probably intended but beneficially to specify this or just indicate toxins (rather than toxin)? Sialorrhea: Botulinum Toxin Injection (Product: Xeomin licenced in the UK for this indication), does this need to be covered given that NICE already have a recommendation on this (and/or reference across)?	Thank-you. This will be a general review of the use of botulinum toxin, not product specific.
Association of Chartered Physiotherapists in Neurology	004	024	ACPIN wishes to encourage the consideration for inclusion: advice on the management of faecal Incontinence too? It would be great to have guidance on the role of community continence teams.	Thank-you. Management of faecal incontinence is covered in NICE guideline CG49 Faecal incontinence in adults: management. Cross-reference will be made to this guidance.
University Hospitals Birmingham NHS Foundation Trust and Birmingham	004	029	Recognising in patient rehab settings is very important, there is a need to differentiate early rehab in HASU and ASU from in patient rehab, and to clarify which patients should need in patient rehab. It would be useful to review the evidence for in patient rehab compared to community based rehab	Thank-you. This topic has not been prioritised for evidence review but the committee will consider it when refreshing the relevant section of the guidance.



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Community Healthcare				
Fresenius Kabi	005	General	Incorporate advice on how to deliver medication to patients suffering from dysphagia	Thank-you. This has not been suggested by other stakeholders and has not been prioritised for evidence review.
Fresenius Kabi	005	General	Ensure dietitians are included as part of MDT	Thank-you. The intention is to recruit a dietitian as a co- opted member when questions relevant to their expertise are being discussed. We agree that dietitians should be part of the stroke MDT.
Brain and Spinal Injury Charity (BASIC)	005	General	Transfer of care from hospital to community. On discharge from the hospital, voluntary sector should be considered to provide exercise advice, including use of power assisted exercise for the survivors of stroke who cannot attend a conventional gym. Virtual reality eg C-Mill, CAREN should also be considered as an option for rehabilitation, as many of the applications require dual tasking:-cognition and physical simultaneously	Thank-you. The tremendous work done by the voluntary sector is acknowledged. NICE makes recommendations for NHS- commissioned services, which might include services provided by third sector organisations, but we don't make recommendations for the third sector per se.
British and Irish Orthoptic Society	005	General	The list of members of the multidisciplinary team which featured in the last guidance is much broader in other guidelines (National Stroke Guidelines 2016) for this same population.	Thank-you. This will be considered when the relevant recommendation is refreshed, but does not

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				require an evidence review and is therefore not stipulated in the scope.
Kent Community Health NHS Foundation Trust	005	General	On transfer of care from hospital to community where early supported discharge is offered to people with stroke who are able to transfer from bed to chair independently or with assistance, as long as a safe and secure environment can be provided we feel that this will need to be reviewed as patients with complex needs can also benefit from ESD. ESD should be based on the needs of patients and potential rather than on their current functional abilities. Commissioning arrangements will need to be reviewed to ensure that workforce numbers reflect the increase in demand as more patients will be discharged home earlier.	Thank-you. A review of ESD has now been included in the scope.
Kent Community Health NHS Foundation Trust	005	General	On the intensity of therapy for patients discharged under early supported discharge we feel that this should be reviewed as intensity need to be patient centred depending on their clinical presentation and rehab needs. Some patients coming home on ESD do not need this level of rehab intensity.	Thank-you. Recommendations 1.2.8 to 1.2.16 in the current guideline CG162 make it clear that rehabilitation should be tailored to the individual patient; and the recommendations which follow state that intense rehab should only apply when people are capable of participating. It is not anticipated that these principles will change in the updated guidance.
Different Strokes	005	General	The draft scope states that there will be no new evidence review. Yet 45% of stroke survivors feel abandoned when they leave hospital, so increased input from stroke survivors is essential here	Thank-you. It is not clear which part of page 5 you are referring to. Evidence reviews will be performed for topics in which

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				significant new evidence has been identified.
Association of Chartered Physiotherapists in Neurology	005	General	Transfer of care from hospital states no new evidence, how does the discharge to assess framework fit as this is now becoming a mainstay of the patients pathway. ACPIN urges consideration and evaluation of impact in this change to the patients pathway.	Thank-you. The committee is not able to review specific service pathways such as 'discharge to assess' as these are not 'evidence based inteventions' as far as we know and tend to be locality specific.
Royal College of Occupational Therapists	005	General	Health and social care interface- economic analysis across health and social care (for instance ESD saving of £1600 per person) (PDF document available upon request).	Thank-you for the information.
Stroke Association	005	General	We are concerned that the draft scope highlights that NICE are not planning on reviewing any new evidence on the section on 'organising health and social care', including stroke units. Given that these guidelines were last updated in 2013, and the stroke landscape has since developed, we would suggest NICE review the most recent evidence for inclusion within the updated guideline.	Thank-you. The sections covering organisation of care will be revised where appropriate so that the flow of patient care is in line with current best practice. The evidence on early supported discharge will be reviewed.
Royal College of Speech and Language Therapists	005	general	What is the rationale for not doing an evidence review for the area of care given in Table 1 <i>organising health and social car</i> ? Service delivery models and organisation of health/social care have been impacted by COVID-19 and new evidence should be examined in light of this.	Thank-you. The sections covering organisation of care will be revised where appropriate so that the flow



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				of patient care is in line with current best practice.
				In relation to Covid-19, the impact has been similar in many chronic conditions and NICE has produced general guidance. If there are stroke-specific issues these will be addressed during guideline development.
Royal College of Occupational Therapists	005	002	Emerging evidence from the ICSW should be considered e.g.: <u>https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr07070/#/full-report</u> <u>https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/10100909/#/</u>	Thank-you for the information. However, both these references relate to acute stroke services.
University Hospitals Birmingham NHS Foundation Trust and Birmingham Community Healthcare	005	002	The table refers to transfer of care from hospital having no new evidence – there is a recent NHSEI publication on discharge to assess models, and a need to discharge a high proportion of all patients from the acure setting in a very short time. This model of working can be detrimental to stroke patient pathways. We are not aware of published evidence that suggests this model is detrimental but feel strongly that early discharge to non stroke specialist settings is poor practice and can prevent access to evidence based rehabilitation. The guidelines should recommend that discharge to access models are only used when part of a full stroke pathway with access to EB rehab	Thank-you. We are aware of the NHSE I report. The developers agree that early discharge to non stroke specialist settings is likely to be detrimental to patient with stroke and not good practice. We are not aware of research specific to stroke patients on D to A pathways. The new guidleline may help advocate for stroke patients not to be transferred with D to A, as facilities used will



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				not be able to deliver the specialist input that is evidence based for stroke survivors.
Society for Research in Rehabilitation	005	002	Table 1; setting goals for rehabilitation. Does have additional evidence and may need to be reviewed as part of this work.	Thank-you. The sections covering organisation of care will be revised where appropriate so that the flow of patient care is in line with current best practice. The evidence on early supported discharge will be reviewed.
Brain and Spinal Injury Charity (BASIC)	006	General	Providing support and information. Use of the voluntary sector to provide long term support (beyond 1 year post stroke) not just for stroke individuals but for carers. Looking particularly at counselling, emotional support, group therapy	Thank-you. The tremendous work done by the voluntary sector is acknowledged. NICE makes recommendations for NHS- commissioned services, which might include services provided by third sector organisations, but we don't make recommendations for the third sector per se.

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Kent Community Health NHS Foundation Trust	006	General	On review of evidence there is a need for the review of the intensity of therapy agreed, as the impact of fatigue and the impact of the grieving process impacting on willingness to engage with therapy has been underestimated.	Thank-you.
Kent Community Health NHS Foundation Trust	006	General	On offering initially at least 45 minutes of each relevant stroke rehabilitation therapy for a minimum of 5 days per week to people who have the ability to participate, and where functional goals can be achieved we feel that from onset this will need to be tailored to patient needs and where appropriate this ambition still being available to be offered where it's realistically and practically possible. Some patients present with fatigue and will not be able to cope with this level of input. Intensity should be based on the needs of the patient and the outcome of the assessment of the treating clinician.	Thank-you. As you say, this recommendation on intensity is only for those able to participate. The preceding recommendations (1.2.8 to 1.2.14) emphasise that rehabilitation must be individualised.
Different Strokes	006	General	The draft scope states that there will be no new evidence review. Yet the planning of rehabilitation needs to be tailored to each individual stroke survivor, and too often specific needs are not taken into consideration. Further input from stroke survivors should be included here.	Thank-you. We agree that rehab needs to be tailored to the individual, and the existing recommendations on Setting goals for, and Planning of, rehabilitation make it clear that this should be done on an individual basis and involve stroke survivors and their carers. No evidence review is planned because there is no new evidence which would lead to a substantial change in these principles.

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Royal College of Occupational Therapists	006	General	These should be in table 3 as they are specific stroke issues which don't fit with the service delivery issues in Table 2.Supported self- management is not the same as self-care management.	Thank-you for these comments The wording has been adjusted accordingly.
			Self-management wouldn't be instead of normal rehabilitation, it would be included as part of the intervention.	
Royal College of Occupational Therapists	006	General	 Scope should include Executive Function if looking at other cognitive domains – including defining assessment, impact and treatment options for cognitive changes resultant from stroke at the chronic stage. Assessment, Development, Reliability, and Validity of the Multiple Errands Test Home Version (MET-Home) in Adults With Stroke Impact Struggling with everyday life after mild stroke with cognitive impairments – The experiences of working age women https://doi.org/10.1177/0308022618800184 	Thank-you for these points. Issues with executive function per se are too specific and do not have a sufficient high quality evidence base to be prioritised for review.
Royal College of Speech and Language Therapists	006	General	 Again, what is the rationale for not planning on doing an evidence review on the sections listed in Table 2. There is huge amounts of evidence that has been published since the last update to the guidance particularly pertaining to: Screening and assessment; goal setting and planning rehabilitation and we would recommend the developers conduct an evidence review. Examples of important new evidence include: Screening and assessment Benfield et al (2020). Accuracy and clinical utility of comprehensive dysphagia screening assessments in acute stroke: A systematic review and meta-analysis. Journal of Clinical Nursing, 29 (9-10), 1527-1538. 	Thank-you. The issue is not whether there is new evidence, but whether there is new evidence which would change or challenge the existing recommendations in CG162. Following this consultation, some of the topics in Tables 1 & 2 will have a full evidence review.

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			Oliveria et al (2019). Dysphagia screening tools for acute stroke patients available for nurses: A systematic review. Nursing Practice Today, 6 (3). DOI: <u>https://doi.org/10.18502/npt.v6i3.1253</u>	
			Antipova et al (2019). Diagnostic accuracy of clinical tools for assessment of acute stroke: a systematic review. BMC Emergency Medicine, 19 (49), DOI: <u>https://doi.org/10.1186/s12873-019-0262-1</u>	
			Goal setting in rehabilitation	
			Brown et al (2020). A narrative review of communication accessibility for people with aphasia and implications for multi-disciplinary goal setting after stroke. Aphasiology. DOI: 10.1080/02687038.2020.1759269	
			Smit et al (2019) Goal-setting in geriatric rehabilitation: a systematic review and meta-analysis. Clinical Rehabilitation, 33 (3), 395-407.	
			Planning rehabilitation	
			Manning et al (2019). Perspectives of people with aphasia post-stroke towards personal recovery and living successfully: A systematic review and thematic synthesis. PloS One DOI: https://doi.org/10.1371/journal.pone.0214200	
			Shilpa et al (2019). Stroke Survivors' Perspectives on Post–Acute Rehabilitation Options, Goals, Satisfaction, and Transition to Home. Journal of Neurologic Physical Therapy, 43 (3), 160-167.	
Brain Injury Matters	006	001	In the 'draft scope' of the guideline in section '1.3 Providing support and information', NICE plans to complete, 'No evidence review: [and] retain recommendations from existing guideline'	Thank-you. The recommendations in areas of the guideline which are
			From the current literature and our experience in Brain Injury Matters (NI) providing support and information to patients with acquired brain injury (ABI), including stroke, and their families we	not subject to a new evidence review will nonetheless be re-

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			would of advocate the guideline development group consider the following additional recommendations.	considered by the guideline committee and may be refreshed. The committee
			• Ensure that there is a whole family approach to providing information and support. Partners, spouses, parents, siblings and any dependent children of the person who has experienced a stroke should be identified and offered appropriate information and support.	will consider your comments and suggestions during that process.
			• Each family member will have different levels of understanding, concerns and needs, throughout the patient journey, so it is important for each to have the opportunity and be encouraged to ask questions. Furthermore, face to face, telephone or video opportunities should be provided to enable further enquiry for patients and / or the whole family, once the initial information has been processed.	
			• Families should be given the contact details of statutory and voluntary organisations which can offer support throughout the patient journey, and in subsequent months and years.	
			The current guideline in Section 1.3 states that 'information needs' and delivery methods must be 'identified'. As stroke results in a diverse range of biopsychosocial impacts for each person and their families. To enhance the standard of information provision a general outline of topics for healthcare staff, patients and their families to be aware of, could help identify areas of information need and form the basis of further personalisation of information and support required.	
			The work by Holloway (2019), Tyermann (2017) and Oyesanya (2017) used systematic reviews and meta-synthesis designs to analyse qualitative data focusing on the experience of people after ABI.	
			They identified a range of specific information needs including: normalising family's emotional responses, support available for patient and family, solutions for practical issues, information about ABI, medical procedures, test results, injury, prognosis, diagnosis, prescribed medications,	
			 behavior management, possible interventions and rehabilitation expectations. In addition to the suggested information needs they also reported the importance of the means and manner of delivery. Patients and their families preferred when information was: tailored to the whole family than simply the injured person, delivered at a time when members were not in an extremely heightened or emotional state, used accessible, appropriate language, 	

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			 was up-to- date and specific to the relative and delivered in an honest, frank, sensitive manner with empathy and compassion. The means of communication that were appreciated involved written information to revisit and process in their own time, telephone access to have the opportunity to ask questions and family meetings to ensure clear and consistent information. Identifying the range of information needs, the means and manner of delivery to be utilized will help to standardise and improve the quality of support and information. It could also help to overcome the situational and practical factors that reduce the effectiveness of information delivery and improve the efficiency of identifying and meeting the information needs of each patient and enable families to feel less apprehensive and more prepared to take on a care role for a loved one. 	
			Extracts from systematic reviews and meta-synthesis of qualitative literature have been collated below to evidence and underpin the suggested guidance and discussion above: <u>Holloway (2019)</u> asked participants if they were: "given the information you needed to understand brain injury and services? More than twice as many individuals reported that they were not given information required to understand brain injury and relevant services A few noted that they had felt well supported by professionals and family. In these instances, the professionals concerned were identified as working with the whole family rather than simply the injured	
			person" <u>Tyermann (2017)</u> , reports on the findings of 11 separate papers (published between 1998 and 2015) that: "many parents stressed the need for information and understanding. This included information about ABI, medical procedures, prognosis, support available, behaviour management, as well as practical issues such as car parkingKnowing typical emotional responses was also seen as helpful: 'well it's like, your feelings change all the time, from day to day, even from minute to minute at the beginning. It would have helped to know that what we felt was normal not madness'. These information needs were particularly important as many parents had little or no prior knowledge of ABIwhich led to confusion.	

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			 When these information needs were met, many parents reported feeling relief and reassurance, and were less frustrated, fearful and apprehensive. It was essential that information was accessible so parents could understand the language and have the opportunity to ask questions. Unfortunately, many felt that the information provided was insufficient and some believed staff felt they would not understand or did not require the information. Increasingly the parents in one study described increasingly independent sources of information accessing books, the internet and talking to other parents. Parents also stressed the importance of when and how the information was delivered as heightened emotions made it difficult for parents to absorb information. Written information had been processed. Many parents responded positively when information was given honestly, sensitively but frankly with empathy and compassion." Oyesanya (2017), in their systematic review identified 6 studies (published between 1991 and 2012) which discussed the theme of "perceived need for information." "Throughout the patient's hospital stay, families reported an intense need for information, wanting to know about their loved one's injury and their prognosis. Families reported wanting information and was consistent, easy to understand, specific to their relative (not probabilities or statistics), with frequent updates. Many family members reported the following sub-themes: a) lack of understanding of information:Although family members could repeat information on the patient's status, some reported that that they "had not grasped the meaning of the information; and d) wanting certain types of information:Although family caregivers were uncertain about the injury and what it meant for the patient and themselves. Family members sough knowledge and understanding relating to the injury, including verbal and written information about diagnosis, prognosis, results of tests, prescr	

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			 barriers. Those who had difficulty communicating with staff had doubts about their own abilities to provide effective care to the patient after discharge. Sometimes, when it was not easy to access desired information, family members used both subtle and explicit techniques to obtain information, such as asking direct questions, observing, or even eavesdropping on patient-staff interactions. Having to seek information in this manner made family members feel as if they were going it alone. Finally, family members reported that family meetings with staff were very helpful in receiving information. However, families stated more family meetings were necessary to make sure there was clear and consistent information being communicated. <u>Wanting no assumptions</u>: Many family members reported being overwhelmed, even if they had prior experience visiting other sick family members in the hospital, or even if they had healthcare experience was a barrier, as staff made assumptions about their levels of knowledge about ABI, thus limiting information provided to them. Family caregivers reported that, regardless of healthcare experience, they wanted as much information as possible to help them become knowledgeable about the patient's status and necessary future care". Oyesanya, T The experience of patients with ABI and their families during the hospital stay: A systematic review of qualitative literature. Brain Inj. 2017; 31(2): 151–173 Tyerman E, Eccles FJR, Gray V. The experiences of parenting a child with an acquired brain injury: A meta-synthesis of the qualitative literature. Brain Inj. 2017;31(12):1553-1563. Holloway, M. and Tasker, R., 2019. The Experiences of Relatives of People with Acquired Brain 	
			Injury (ABI) of the Condition and Associated Social and Health Care Services. Journal of Long- Term Care, (2019), pp.99–110	
University Hospitals Birmingham NHS Foundation Trust and Birmingham	006	001	The table refers to intensity of rehab, and duration. In line with findings from the AVERT study, the guidelines should address the evidence base for very early mobilisation early rehabilitation	Thank-you. Early mobilisation (including AVERT) were reviewed as part of the acute stroke clinical guideline (NG128) and so will be cross referenced in this guideline

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				comment
Community				but not formally reviewed
Healthcare				again.
University	006	001	Early mobilisation is not included as a new area for the guideline and we feel the AVERT study	Thank-you. Early
Hospitals			should be included	mobilisation (including
Birmingham NHS				AVERT) were reviewed as part of the acute stroke
Foundation				clinical guideline (NG128)
Trust and				and so will be cross
Birmingham				referenced in this guideline
Community				but not formally reviewed
Healthcare				again.
University	006	001	Intensity and duration are included, but frequency is not covered. The AVERT study refers to early	Thank-you. Early
Hospitals			mobilisation as short frequent bursts of eg sitting up or walking. Reviewing the evidence for	mobilisation (including
Birmingham NHS			frequency would assist in the interpretation and application of the 45 min 5x per week therapy	AVERT) were reviewed as part of the acute stroke
Foundation			targets and should be part of the scoping.	clinical guideline (NG128)
Trust and				and so will be cross
Birmingham				referenced in this guideline
Community				but not formally reviewed
Healthcare				again.
Society for	006	001	Table 2; reference to intensity of stroke rehabilitation - might be helpful to break this down into	Thank-you for your
Research in			general rehabilitation, and the upper limb for which there is new evidence about intensive sensory	suggestion. The guideline
Rehabilitation			and motor training.	committee will consider this.
Society for	006	001	Table 2; Supported self-care management. Sure it is but just in case: TACAS (Fu et al) needs to be	Thank-you.
Research in		001	included	indin you.
Rehabilitation				
British and Irish	006	002	When reviewing evidence, it will be essential to review evidence that comes from studies other	Thank-you. Evidence
Orthoptic			than randomised controlled trials, for example, diagnostic accuracy studies, epidemiology studies	reviews will be dependent
Society			using standardised assessment strategies, etc.	on the specific question
				posed. We agree that

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				diagnostic questions need diagnostic accuracy studies.
Society for Research in Rehabilitation	006	002	When reviewing evidence, it will be essential to review evidence that comes from studies other than randomised controlled trials, for example, diagnostic accuracy studies, epidemiology studies using standardised assessment strategies, etc.	Thank-you. Evidence reviews will be dependent on the specific question posed. We agree that diagnostic questions need diagnostic accuracy studies.
Brain Injury Matters	006	003	In the 'draft scope' of the guideline in section '1.11 Long-term health and social support', NICE plans to complete, 'No evidence review: [and] retain recommendations from existing guideline'	Thank-you. Topic areas will be subject to evidence review in this update if it
			 In the introduction to the current guideline (CG162) page 2, in the section 'Your responsibility', the current guideline states: "Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties. It is noted in a report by Clements (2019) for Cerebra and the University of Leeds, that the United Nations Convention on the Rights of Persons with Disabilities (2006) was ratified by the UK in 2008. They also note that while it has not yet been formally incorporated into domestic law, the courts have made reference to it in several judgements. 	appears that there is new evidence which will alter the existing recommendations in CG162. It was not felt that there is new evidence that would necessitate any substantial change to those within section 1.11. However, the Guideline committee will review all recommendations and may make alterations, and your comments and references (thank-you for these) will be
			 We would therefore suggest that the guideline committee consider: 1) Updating section '1.11 Long-term health and social support' 2) Consider prefacing an updated section 1.11 with the following: "Local commissioners and providers of healthcare have a responsibility to provide 'long-term health and social support' with due regard to the United Nations Convention on the Rights of Persons with Disabilities (2006) which was ratified by the UK in 2008." 	considered at that point in development.

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			We feel that the United Nations Convention on the Rights of Persons with Disabilities enshrines the overarching principle for the provision for 'long term health and social support'. The particular sections of the UNCRPD highlighted below demonstrate its relevance, as a whole, to the topic of 'long-term health and social support':	
			Article 1 "The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."	
			Article 19 "the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community"	
			Article 26 "shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life."	
			 Article 30 Participation in cultural life, recreation, leisure and sport "shall take appropriate measures to enable persons with disabilities to have the_opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society. 5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures: 	

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			 (a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels; (b) To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources" 	
			We have identified four research papers, published between 2004 and 2020. These report unmet needs related to long-term health and social support. The relevant conclusions have been highlighted below, with some additional papers in the bibliography.	
			Fraas et al (2007) administered surveys to clinicians and programme participants, "To determine the effectiveness of a community-based programme for meeting the long-term needs of survivors of acquired brain injuryemotional, social and cognitive needs are the most important needs The needs that participants found to remain unmet include social support for caregivers, transportation issues and community education. This community-based, posts-rehabilitation programme for survivors of ABI appears to effectively meet many long-term needs."	
			Muldoon et al (2019), highlights the benefits and crucial role of social participation, "identification with social groups can protect and enhance healthchanges in their social networks and social group memberships after injury. Identity loss and reduced social support were described as disabling. Engagement in meaningful group activity with others affected by ABI and access to affected peers enabled new group-based resources such as social support. In this way, group activity can be seen as a form of identity enactment that can drive social cure effects. Similarly, adaptation to life after injury was demonstrably linked to social identity processes pointing to the importance of a social cure approach to rehabilitation."	
			Odumuyiwa et al (2019) completing a needs analysis to demonstrate how access to social care services requires improvement found that "Survivors of acquired brain injury (ABI) experience long-term cognitive, behavioural, psychological and social consequences often overlooked by health and social care providers, as are the implications for family members 2) types of services	

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			required (tailored, specialist and interdisciplinary care) and 3) poor access to services (associated with; lack of understanding of ABI among professionals, the hidden nature of ABI, organisational structures and a lack of available services)The study concluded that professionals need training to understand the needs of ABI survivors and their families and that services need to be provided in a long-term, integrated manner."	
			<u>Stiekema et al (2020)</u> concludes that, "Although the long-term consequences of acquired brain injury are frequent and diverse, care and support over the longer term is an under-addressed issue The overarching need for continuity of care from the transition to home onwards provides important implications for supporting the process of learning how to live well with brain injury."	
			 References Clements (2019) Direct Payments for Disabled Children and Young People and their Families – Report by Cerebra and the University of Leeds. http://www.lukeclements.co.uk/wp- content/uploads/2019/10/2019-Final-Report-02.pdf (accessed 30/11/2020) The United Nations. (2006). Convention on the Rights of Persons with Disabilities. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with- disabilities.htmll (accessed 30/11/2020) Fraas M, Balz M, Degrauw W. Meeting the long-term needs of adults with acquired brain injury through community-based programming. Brain Inj. 2007 Nov;21(12):1267-81. Muldoon OT, Walsh RS, Curtain M, Crawley L, Kinsella EL. Social cure and social curse: Social identity resources and adjustment to acquired brain injury. European Journal of Social Psychology, 2019, 49(6), 1272-1282. Odumuyiwa T, Kennedy M, Norman A, Holloway M, Suffield F, Forrest H, Dicks H. Improving Access to Social Care Services Following Acquired Brain Injury: A Needs Analysis. Journal of Long- Term Care, 2019, pp.164-175. Stiekema APM, Winkens I, Ponds R, De Vugt ME, Van Heugten CM. Finding a new balance in life: a qualitative study on perceived long-term needs of people with acquired brain injury and partners. Brain Inj. 2020 Feb 23;34(3):421-429. 	
			Bibliography	

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			 Dams-O'Connor K, Landau A, Hoffman J, St De Lore J. Patient perspectives on quality and access to healthcare after brain injury. Brain Inj. 2018;32(4):431-441. Lannoo E, Brusselmans W, Van Eynde L, Van Laere M, Stevens J. Epidemiology of acquired brain injury (ABI) in adults: prevalence of long-term disabilities and the resulting needs for ongoing care in the region of Flanders, Belgium. Brain Inj. 2004 Feb;18(2):203-11. Turner BJ, Fleming J, Ownsworth T, Cornwell P. Perceived service and support needs during transition from hospital to home following acquired brain injury. Disabil Rehabil. 2011;33 (10):818-29. 	
Royal College of Occupational Therapists	006	003	 The addition into the Scope guideline of supporting return to Community and Social Participation (review and define interventions that support social interaction/wellbeing/participation in multiple life domains) would be beneficial. Chronic stroke patients have limitations in activity and restrictions to participation, even after few years of stroke onset, particularly regarding applying knowledge, use of communication devices, domestic life, major life areas and community, social and civic life. DOI: 10.3233/NRE-192754 There has been a recent Systematic review of the Content and Effectiveness of Interventions Focusing on Community Participation Post stroke: https://doi.org/10.1016/j.apmr.2019.06.008 	Thank-you for this suggestion. We have added a review of Community Participation Interventions to the scope.
Stroke Association	006	003	 NICE should take into account different forms of evidence when considering the suitability of interventions, including those that are not reliant on randomised control trials (RCT), for example telephone support offers, stroke choirs and peer support. The threshold for accepting evidence for guidelines, such as this one, needs to be considered, especially as many of the services currently provided for stroke rehabilitation are not reliant on traditional forms of accepted evidence. And, there needs to be a balance between patient reported outcomes with clinically reported outcomes. The types of services the third sector deliver, for example, are important to stroke survivors' recoveries and a hugely valuable part of their rehabilitation. We know services such as those 	Thank-you. We agree that there are forms of valid and important evidence other than RCT's. However, it is part of the basic remit of NICE in developing clinical guidelines such as this, to recommend interventions that can be shown to be cost-effective. Activities which are enjoyed by

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				comment
			providing emotional support deliver vital support for stroke survivors once they have left hospital. However, they risk not being included and recognised within the updated guideline.	people with chronic conditions may not necessarily meet this
			Currently, there is lack of direct RCT evidence for the value of community-based interventions such as stroke choirs, art groups, volunteering and community exercise groups. These interventions are greatly valued by participants and their carers and yet RCT evidence is lacking, so they risk not being funded or stipulated in guidance such as NICE's.	criterion. It should also be pointed out that the purpose of an RCT is not to show whether an intervention causes harm:
			While there are some RCTs ongoing that address issues such as music therapy and choirs, the nature of the RCT means that they look at very narrow interventions or outcomes. For example, an ongoing RCT of choirs assesses if attendance at a stroke choir improves language function in aphasia. As useful as this evidence could be, attendance at a stroke choir is beneficial for different people in different ways, so narrowing down to language function in aphasia. While measurable, may not be relevant. Stroke choirs are good for people with and without aphasia. Participants reflect that they help them with their stroke recoveries by enabling people to get out of the house, increasing their confidence, supporting carers and building emotional resilience. The outcomes may be different for everyone, so by narrowing down to a single outcome measure, as done in an RCT, you lose much of the richness and granularity of the value of the intervention. Therefore, the RCT may be negative or neutral and a really valuable intervention will be labelled as not improving outcomes.	harm is important but an RCT is also designed to investigate whether there is benefit, and indeed this is usually the main aim. Having said this, we are pleased to confirm that the scope includes evaluations of music therapy for stroke survivors, and of communit based interventions.
			The purpose of a RCT is to show whether an intervention causes harm. But harms are unlikely from many community-based interventions such as listening to music after stroke, joining a stroke choir, a stroke volunteering programme, a peer support group, a stroke fishing or walking football group.	
			Therefore, evidence should be taken and accepted from stroke survivors about the longer term stroke support that they have or have not received and the benefits of the interventions to the stroke survivor's ongoing needs (loneliness, fatigue, anxiety and depression). Otherwise, NICE risks dismissing interventions that stroke survivors tell us are valuable.	

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			To help combat this, PROMS and PREMs should be considered as key evidence, as well as research on PROMs. ³³ SSNAP are currently working to routinely report on PROMs, whilst we're working on a pilot PREMs project, which can both help inform this guideline as the development process continues over the next two years. The expansion of the SSNAP audit programme will include a more comprehensive data set with the addition of EQ5D. This can be used to drive improvements in rehabilitation and post-acute care. We would be happy to work with NICE to further explain this.	
Society for Research in Rehabilitation	006	003	Table 3; Include visual field defects. Please consider this evidence: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD008388.pub3/full	Thank-you for the information.
Society for Research in Rehabilitation	006	003	Table 3; Include cognitive function. Please consider this evidence: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD002842.pub3/full	Thank-you for the information.
Society for Research in Rehabilitation	006	003	Table 3; Strength and fitness training. Evidence to be considered: (1) Cochrane Systematic review by Saunders et al.(2020): https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD003316.pub7/full (2)Systematic review by Lloyd et al. (2018): https://pubmed.ncbi.nlm.nih.gov/29920979/ .	Thank-you for the information.
Society for Research in Rehabilitation	006	003	Table 3; Repetitive task training. Evidence to be considered: RCT on robot-assisted therapy and enhanced upper limb therapy by Rodgers et al. (2020): https://www.thelancet.com/journals/lancet/article/PIIS0140-67361931055-4/fulltext	Thank-you for the information.
Society for Research in Rehabilitation	006	003	Table 3; Add Interventions to improve arm function. Please consider evidence suggested below: - Mental practice: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD005950.pub5/full - Action observation: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011887.pub2/fu	Thank-you for the information.

³³ Patchick, E., Horne, M., Woodward-Nutt, K., Vail, A., & Bowen, A. (2015). Development of a patient-centred, patient-reported outcome measure (PROM) for post-stroke cognitive rehabilitation: qualitative interviews with stroke survivors to inform design and content. Health Expectations, 18(6), 3213-3224. <u>https://doi.org/10.1111/hex.12311</u>

Comments received in the course of consultations carried out by NICE 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 NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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Society for Research in Rehabilitation	006	003	Table 3; Add Walking therapy - gait training. Please consider evidence suggested below:- Electromechanical -assisted walkingtraining: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006185.pub5/full - Motorimagery: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD013019.pub2/full	Thank-you for the information.
Society for Research in Rehabilitation	006	003	Table 3; transcutaneous electrical nerve stimulation, etc. Comment: this would seem to cover more than one area (depending on the purpose of TENS)	Thank-you. This will be reviewed as part of the spasiticy management section alongside baclofen, botox etc.
Society for Research in Rehabilitation	006	003	- Interventions for sexual dysfunction: Please consider this evidence: <u>https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011189.pub2/full</u>	Thank-you. No evidence review is planned for this topic.
Society for Research in Rehabilitation	006	003	- Telerehabilitation: <u>https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD</u> 010255.pub3/full	Thank-you for the information.
Society for Research in Rehabilitation	006	003	- Falls prevention: <u>https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD008728.pub3/full</u>	Thank-you. No evidence review is planned for this topic.
Society for Research in Rehabilitation	006	003	- Mobilisation: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD006187.pub3/ full	Thank-you for the information.
Society for Research in Rehabilitation	006	003	- Physical activity: <u>https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD012543.pub2/full</u>	Thank-you for the information.
Society for Research in Rehabilitation	006	003	It would also be prudent to refer to latest WHO recommendations on physical activity and sedentary behaviour, which include recommendations for people with long term conditions including stroke: https://www.who.int/publications/i/item/9789240015111	Thank-you for the information.
Society for Research in Rehabilitation	006	003	Table 3; revise to emotional functioning and wellbeing. So this may still refer readers to 'depression in adults' guidance? https://www.nice.org.uk/guidance/cg91 If so, that looks like not	Thank-you for the information.

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			updated since 2009. Emerging third wave CBTs (e.g. mindfulness, Acceptance and Commitment Therapy) that will be missing.	
Society for Research in Rehabilitation	006	003	Table 3; add executive functioning	Thank-you. No evidence review is planned for this topic.
Society for Research in Rehabilitation	006	003	Table 3. the selection of interventions is not complete, for example Neurostimulation (direct) techniques, Constraint, Virtual reality, Mirror, sensory TENS all seem to be absent.	Thank-you. The topics which will be included (Constraint, mirror therapy) are in table 3.
Fresenius Kabi	007	General	Propose to include guidance on nutritional support for stroke patients, including the role of dietitians.	Thank-you. Advice on nutrition is given in NICE guideline CG32: Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition. Cross-reference will be made to this guidance
Royal College of Occupational Therapists	007	General	 Emotional Functioning – new evidence is present in regards to treatment of depressive symptoms, and patient outcomes after stroke e.g. results suggest that cognitive-behavioural therapy augmented with occupational Therapy aimed at improving patients' emotional, behavioural and social functioning positively affects some aspects of caregivers' well-being. Caregivers' effects of augmented cognitive-behavioural therapy for post-stroke depressive symptoms in patients: secondary analyses to a randomized controlled trial https://doi.org/10.1177/0269215519833013 Occupational Therapy Practitioners' Perspectives of Mental Health Practices With Clients in 	Thank-you. Research in this area is important but so far the trials are few and numbers participating are small (around 50 participants in the study quoted here) The data therefore is not sufficient to warrant priority for review this time.
			Stroke Rehabilitation https://doi.org/10.1177/1539449218759627	



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			Association Between Anxiety, Depression, and Post-traumatic Stress Disorder and Outcomes After Ischemic Stroke https://doi.org/10.3389/fneur.2018.00890	
NHS England and NHS Improvement	007	General	The Office of the CAHPO welcome inclusion of the section on music therapy	Thank-you.
Royal College of Speech and Language Therapists	007	general	On page 7, why does it refer to this intervention by professional group: 'Speech and language therapy combined with app-based therapy tools' rather than aphasia/dysarthria therapy? The scope does not do this for the other interventions eg by physio or OT.	Thank-you. The reference to app-based therapy on page 7 has been removed as it was superfluous there.
merapists			The statement 'Speech and language therapy combined with app-based therapy tools for aphasia' needs to be expanded.	The specific question we will address is still given in section 3.5 and the terminology has been
			• App based' is very narrow – many aphasia tools are available using software programmes or web-based access, apps are only one type of possible platform.	altered in line with your suggestion.
			RCSLT recommend that this is changed to: Face to face speech and language therapy augmented by computer-based tools for communication therapy.	
Royal College of Occupational Therapists	008	General	This is a small aspect of occupational therapy practice and results from the inclusion of single RCT in previous guidelines. The inclusion of some therapeutic professions such as 'speech and language therapy' in their own row, whereas others are clearly omitted.	Thank-you. The box in Table 3 to which you refer has been deleted.
			Only including 'Occupational therapy for care home residents' does not reflect the role of occupational therapy in stroke rehabilitation.	

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Royal College of Occupational Therapists	008	General	Vocational rehabilitation - RETAKE study https://www.nottingham.ac.uk/research/groups/longtermconditions/vocational- rehabilitation/retake/index.aspx	Thank-you for the information.
British and Irish Orthoptic Society	008	001	It is surprising that vision is not included for update on rehabilitation options.	Thank-you. Assessment for visual impairment is included in the scope.
Society for Research in Rehabilitation	008	001	It is surprising that vision is not included for update on rehabilitation options.	Thank-you. Assessment for visual impairment is included in the scope.
NHS England and NHS Improvement	009	General	Adopting a strengths based approach and focusing on an individual's strengths is core to the Care Act and reducing dependency on care when not required – a recommendation to include adopting a 'strengths (or asset) based approach when completing the social care assessment would be appropriate to be advocated here. (CH)	Thank-you. The guideline committee will consider this during development.
Royal College of Occupational Therapists	009	024 - 028	The document needs to include recognition of the different phases post-stroke e.g. acute, sub- acute, chronic and how these map onto services HASU, ASU, Rehab. These will all have an impact on assessment.	Thank-you. Service delivery models should reflect evidence and NICE guidelines.
Royal College of Occupational Therapists	009	025 - 026	It is not clear why fatigue and vision have been highlighted as key issues; these are obviously important areas but so are mood and cognition. The assessment of clinical and cost effectiveness of assessment methods vary depending on which screening tool is chosen.	Thank-you. This section sets out the questions for which there will be an evidence review. Other issues, such as mood and cognition, are equally important but do not require an evidence update since it is unlikely that any significant change to existing recommendations would result.

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Society for Research in Rehabilitation	009	027 - 028	Given that national guidelines recommend that every stroke survivor should have specialist orthoptic assessment, it would be more appropriate for question 2.2 to ask 'what are the indications for assessment of stroke survivors by specialist orthoptist assessment?' The question about indications for referral has some merit. However, reliance purely on referral is a dis-service to stroke survivors. Evidence can be provided for the failure to detect visual problems when stroke survivors are screened by non-eye trained clinicians. The missed diagnosis, or mis- diagnosis, leads to health inequalities for stroke survivors which NICE guidelines are expected to avoid.	Thank-you. This has been amended.
Stroke Association	009	016	 2. What issue or issues do you think are most important to address regarding the organisation and planning of stroke rehabilitation services? What are the key questions which you think need to be answered? Key issues and questions that are important to address regarding the organisation and planning of stroke rehabilitation services: 1. 1, 1.1 - as part of this question, we would encourage the evaluation of the longer term impact of changes made to stroke services and pathways as a result of COVID-19, in particular the use of Early Supported Discharge and ensuring this is being delivered in accordance to guidelines. Moreover, for this question we would also highlight the importance of integrated care across the stroke pathway and effective communication 	Thank-you. In relation to Covid-19, the impact has been similar in many chronic conditions and NICE has produced general guidance. If there are stroke-specific issues these will be addressed during guideline development. Early supported discharge has been added as an area
			 across the acute and primary care settings. 2. 3, 3.3 - for this question, we would highlight that rehabilitation should be given for as long as it shows benefit and should be needs rather than time based. For the issues under point 4 on 'specific problems and interventions', we would highlight again that clinical and cost effective outcomes are not the only measurable indicators that should be taken into account. Emotional wellbeing and confidence levels, for example, are others. 	which will be updated. Your comment on the duration of rehabilitation is noted, and will be considered by the guideline committee during development.
Royal College of Occupational Therapists	009	020	Scope of guideline should also incorporate what planning, support and resources are required for community teams to be able to implement - Acute Stroke Team recommendations:	Thank- you. NICE guidelines should help implementation and

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			 e.g. Physical and Occupational Therapy From the Acute to Community Setting After Stroke: Predictors of Use, Continuity of Care, and Timeliness of Care <u>https://doi.org/10.1016/j.apmr.2017.03.007</u> + ICSWP project: <u>https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr07070/#/full-report</u> 	resource allocation as set out in this document.
Different Strokes	009	021	While I agree with what is written in 1.1 here, I would add a 1.2 point to cover 'how best should stroke survivors be communicated with to ensure a successful transition from hospital to home or other care setting'. Too often stroke survivors are given inadequate information. At the very least comprehensive information should be provided in writing to the stroke survivor and their family at point of discharge	Thank-you. CG162 already includes recommendations on hospital to home/care transition (recs 1.1.13 and subsequent) and we do not think a new evidence review is required since this would not produce a substantial change to the guidance.
Association of British Neurologists	009	026	Seems an odd statement, 'what is the effectiveness of measuring something?'	Thank-you. This has been amended.
British and Irish Orthoptic Society	009	027	Given that national guidelines recommend that every stroke survivor should have specialist orthoptic assessment, it would be more appropriate for question 2.2 to ask, "what are the indications for assessment of stroke survivors by specialist orthoptist assessment?". The question about indications for referral has some merit. However, reliance purely on referral is a dis-service to stroke survivors. Evidence can be provided for the failure to detect visual problems when stroke survivors are screened by non-eye trained clinicians. The missed diagnosis, or misdiagnosis, leads to health inequalities for stroke survivors which NICE guidelines are expected to avoid. Visual impairment has been identified as a commonly unmet need at six-month reviews.	Thank-you. This has been amended.
Royal College of Speech and	010	019 - 023	RCSLT is concerned with the question which neglects to compare high intensity SLT with "usual care" alongside no speech therapy or placebo. We recommend that this is broadened to encompass these points.	Thank-you. The question in the scope has been simplified. The detail of the

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Language Therapists			Reference: Godecke E, Armstrong E, Rai T, Ciccone N, Rose ML, Middleton S, Whitworth A, Holland A, Ellery F, Hankey GJ, Cadilhac DA, Bernhardt J; VERSE Collaborative Group. A randomized control trial of intensive aphasia therapy after acute stroke: The Very Early Rehabilitation for SpEech (VERSE) study. Int J Stroke. 2020 Oct 6:1747493020961926. doi: 10.1177/1747493020961926. Epub ahead of print. PMID: 33019888	comparator arms will be finalised by the guideline committee during development, and your comment will be considered at that time.
Royal College of Speech and Language Therapists	010	019 - 023	 RCSLT recommends that the comparison of intensity point needs to reflect the different time points that SLT intervention is provided with respect to intensity. Reference: Godecke E, Armstrong E, Rai T, Ciccone N, Rose ML, Middleton S, Whitworth A, Holland A, Ellery F, Hankey GJ, Cadilhac DA, Bernhardt J; VERSE Collaborative Group. A randomized control trial of intensive aphasia therapy after acute stroke: The Very Early Rehabilitation for SpEech (VERSE) study. Int J Stroke. 2020 Oct 6:1747493020961926. doi: 10.1177/1747493020961926. Epub ahead of print. PMID: 33019888 	Thank-you. The detail of the comparator arms will be agreed by the guideline committee during development and your comment will be considered at that time.
Royal College of Speech and Language Therapists	010	019 - 023	RCSLT is concerned that considering high intensity SLT only with reference to SLT for aphasia continues the focus on providing impairment-based intervention and neglects the value of non-impairment based / combinational intervention impact e.g. on psychological wellbeing. Captured in the provision of Intensive Comprehensive Aphasia Programs (growing evidence base and clinical application), especially in the later stages of rehabilitation.	Thank-you. We agree this is a growing evidence base but as the literature stands specific evidence on these outcomes will not be of sufficient quantity or quality to prioritise for inclusion. There may be scope for research recommendations as part of the guideline process however.
Kent Community Health NHS Foundation Trust	010	015 - 018	The draft scope on the section looking at people after stroke, around the clinical and cost effectiveness of enhanced oral hygiene, please take note of the fact that there is evidence from Japan to show that enhanced mouth care reduces the occurrence of chest infections related to swallowing problems.	Thank-you for the information.

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Kent Community Health NHS Foundation Trust	010	019 - 022	The draft states that in people who have aphasia after a stroke, looking at what is the effectiveness of high-intensity speech and language therapy compared with no speech and language therapy or placebo (social support and stimulation) in improving language, communication abilities and psychological we would want to understand in the guidelines what is meant by the placebo treatments and what is meant by high intensity SLT. Some SLT treatments are being carried out by volunteers locally and the outcomes are much poorer. Communication with people with aphasia is a skill which SLTs are experts at – we need to ensure that these skills are not lost and that 'soft' outcomes such as increased wellbeing are not under estimated as until we address wellbeing we cannot carry out effective impairment based therapy	Thank-you. The detail of the comparator arms will be agreed by the guideline committee during development and your comment will be considered at that time.
Kent Community Health NHS Foundation Trust	010	011 -012	On the interventions for swallowing please consider that dysphagia is very multi-disciplinary not just speech and language therapists (SLTs) – SLT have skills in this area but need to be more proactive in passing the baton on to nursing and dietetic colleagues and empowering them in this.	Thank-you. Swallowing (term changed to oral feeding in updated scope) will be considered as a problem in its own right without confining this to the input of a particular group of health-care professionals.
Royal College of Speech and Language Therapists	010	011 - 012	 RCSLT is concerned that the questions raised relating to communication (SLT role) are not as comprehensive as the question relating to swallow, which is covering all aspects of swallowing intervention. For example, communication intervention for psychological support for people with aphasia is an expanding area of practice with the realisation of the mood / wellbeing post stroke but most significant for those with post-stroke communication problems, and the growing body of evidence reflecting the associated interventions. Please see RCSLT research priorities for dysphagia (swallowing problems here) including a 	Thank-you. The question on swallowing (oral feeding) has been simplified.
			subsection of questions particularly pertaining to stroke-induced dysphagia. These questions would be helpful to consider in this review. https://www.rcslt.org/members/research/research-priorities#section-2	

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Society for Research in Rehabilitation	010	032 - 033	4.10 In people after stroke, what is the clinical and cost effectiveness of music therapy? The term 'music therapy' needs to be clearly defined here ie individual intervention delivered by an HCPC registered music therapist to improve a specific function, or engagement in active music making (e.g. in a group setting) to improve general wellbeing and social participation?	Thank-you. There will be a definition prior to the formal literature search - this will be part of the NICE protocol for this topic.
University Hospitals Birmingham NHS Foundation Trust and Birmingham Community Healthcare	010	001	We are assuming this refers to the AVERT study. The definition and evidence for usual rehabilitation needs to be made clear. Current practice is very variable and measurement of this via SSNAP may be inaccurate due to variance in inclusion and exclusion of rehab, and recording methods.	Thank-you. Early mobilisation (including AVERT) were reviewed as part of the acute stroke clinical guideline (NG128) and so will be cross referenced in this guideline but not formally reviewed again
Sheffield Hallam University	010	004	Specific problems and interventions: The draft scope does not directly address assisted exercise interventions for people with stroke. Assisted exercise interventions enable bilateral movement and are accessible for people with complex motor impairment including people with stroke [Young et al 2018]. Assisted cycling was associated with improved upper limb and lower limb motor coordination [Holzapfel et a 2019, Linder et al 2019], and assisted cycling prior to repetitive upper limb task practice expedited improved upper limb performance [Linder et al 2017]. Participants with stroke randomised to an assisted exercise intervention which comprised 24 sessions of assisted exercise over eight weeks demonstrated a significant improvement in peak VO2 with a mean increase of 2.4mL/kg/min compared to an increase of 1.3mL/kg/min amongst participants assigned to a voluntary exercise intervention [Linder et al 2017]. The addition of assisted exercise machines alongside conventional equipment enhanced uptake and retention of people with stroke recruited to a community-based exercise programme which included nine non-ambulatory participants; analysis of results indicated improvements in self-reported quality of life, activities of daily living and psychosocial functioning [Kerr et al 2019]. This brief summary of recent evidence indicates that assisted exercise represents an accessible solution for people with complex motor	Thank-you. After considering all comments from stakeholders (written, and received at the Stakeholder Workshop) assisted exercise interventions have not been prioritised for inclusion in this update. We appreciate this is an emerging line of post stroke research.

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		impairment following stroke, is associated with improved motor performance and increased cardio-respiratory capacity. The equipment can be installed alongside conventional exercise equipment in rehabilitation and leisure settings, creating an accessible pathway for people with stroke to engage with exercise. References	
		Holzapfel, S. D., Bosch, P. R., Lee, C. D., Pohl, P. S., Szeto, M., Heyer, B., & Ringenbach, S. D. (2019). Acute effects of assisted cycling therapy on post-stroke motor function: A pilot study. <i>Rehabilitation Research & Practice</i> , , 1-10. doi:10.1155/2019/9028714	
		Kerr, A., Cummings, J., Barber, M., McKeown, M., Rowe, P., Mead, G., Grealy, M. (2019). Community cycling exercise for stroke survivors is feasible and acceptable. <i>Topics in Stroke</i> <i>Rehabilitation</i> , 26(7), 485-490. doi:10.1080/10749357.2019.1642653	
		Linder, S. M., Rosenfeldt, A. B., Davidson, S., Zimmerman, N., Penko, A., Lee, J., Alberts, J. L. (2019). Forced, not voluntary, aerobic exercise enhances motor recovery in persons with chronic stroke. <i>Neurorehabilitation & Neural Repair</i> , <i>33</i> (8), 681-690. doi:10.1177/1545968319862557	
		Linder, S. M., Rosenfeldt, A. B., Dey, T., & Alberts, J. L. (2017). Forced aerobic exercise preceding task practice improves motor recovery poststroke. <i>American Journal of Occupational Therapy</i> , 71(2), 1-9. doi:10.5014/ajot.2017.020297	
		Young, R. E., Richards, E., Darji, N., Velpula, S., Goddard, S., Smith, C., & Broom, D. (2018). Power- assisted exercise for people with complex neurological impairment: A feasibility study. <i>International Journal of Therapy & Rehabilitation</i> , <i>25</i> (6), 262-271. doi:10.12968/ijtr.2018.25.6.262	
	Page no.	Page no. Line no.	Please insert each new comment in a new row impairment following stroke, is associated with improved motor performance and increased cardio-respiratory capacity. The equipment can be installed alongside conventional exercise equipment in rehabilitation and leisure settings, creating an accessible pathway for people with stroke to engage with exercise. References Holzapfel, S. D., Bosch, P. R., Lee, C. D., Pohl, P. S., Szeto, M., Heyer, B., & Ringenbach, S. D. (2019). Acute effects of assisted cycling therapy on post-stroke motor function: A pilot study. <i>Rehabilitation Research & Practice</i> , , 1-10. doi:10.1155/2019/9028714 Kerr, A., Cummings, J., Barber, M., McKeown, M., Rowe, P., Mead, G., Grealy, M. (2019). Community cycling exercise for stroke survivors is feasible and acceptable. <i>Topics in Stroke Rehabilitation</i> , 26(7), 485-490. doi:10.1080/10749357.2019.1642653 Linder, S. M., Rosenfeldt, A. B., Davidson, S., Zimmerman, N., Penko, A., Lee, J., Alberts, J. L. (2019). Forced, not voluntary, aerobic exercise enhances motor recovery in persons with chronic stroke. <i>Neurorehabilitation & Neural Repair</i> , 33(8), 681-690. doi:10.1177/1545968319862557 Linder, S. M., Rosenfeldt, A. B., Dey, T., & Alberts, J. L. (2017). Forced aerobic exercise preceding task practice improves motor recovery poststroke. <i>American Journal of Occupational Therapy</i> , 71(2), 1-9. doi:10.5014/ajot.2017.020297 Young, R. E., Richards, E., Darji, N., Velpula, S., Goddard, S., Smith, C., & Broom, D. (2018). Powerassisted exercise for people with complex neurological impairment: A feasibility study. <i>International Journal of Therapy & Rehabilitation</i> , 25(6), 262-271.

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Royal College of Occupational Therapists	010	006	 Scope should consider participation outcomes resulting from High frequency and High intensity therapeutic input in the chronic stage, alongside that provided in acute/sub acute. E.g. Queens Square UL results demonstrated effectiveness of high frequency and high intensiry input on UL recovery at chronic stage of stroke http://dx.doi.org/10.1136/jnnp-2018-319954 Engel-Yeger, B., Tse, T., Josman, N., Baum, C., & Carey, L. M. (2018). Scoping review: The trajectory of recovery of participation outcomes following stroke. <i>Behavioural Neurology</i>, 2018, Article 5472018. https://doi.org/10.1155/2018/5472018 Reduced levels of participation in IADL persist many years after stroke onset and indicate a need to adapt a long-term perspective on stroke rehabilitation. https://doi.org/10.1080/11038128.2017.1329343 	Thank-you. There will be no a priori post stroke time limits for effectiveness of rehab interventions.
Association of Chartered Physiotherapists in Neurology	010	008	ACPIN wishes to raise another question for this section: In people after stroke, what is the clinical and cost effectiveness of interventions to address sensory loss (as a vital part of motor function recovery)?	Thank-you for raising this as a possible area for review. Unfortunately current studies are small and not of sufficient quality to prioritise for review this time. This area did not come up in the NICE surveillance. More research in this area is clearly needed.
Association of British Neurologists	010	015	To achieve what?	Thank-you. The optimal tool would identify poor oral hygiene requiring intervention.

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Royal College of Speech and Language Therapists	010	024	This statement is too narrow in scope: In people with aphasia after stroke, what is the clinical and cost effectiveness of app-based therapy to augment speech and language therapy? This point should be changed to include all computer based therapies.	Thank-you. This question has been amended.
			RCSLT recommends that this is changed to: In people with communication difficulties after stroke, what is the clinical and cost effectiveness of computer-based therapy to augment face to face speech and language therapy?	
Association of British Neurologists	010	029	The terms 'function' and 'disability' are not helpful. Reference should be made to the levels described in the ICF (disorder of body function (impairment), disorder of activity, disorder of participation). Function is often used to mean activity, but actually refers to impairment (see above). Disability crosses all domains of ICF. It is crucial that we start to ask at what level of the ICF a treatment is working, as all are potentially helpful. Using 'disability' and 'function' here is not helpful.	Thank-you. We have added impairment as suggested in conjunction with function. Participation is of course important but is not widely used as an outcome in many trials and so difficult to specify for NICE as a stand alone outcome measure.
Chroma	010	032	In the UK Music Therapy is regulated by the HCPC, and practiced in a range of settings include those that support Stroke rehabilitation with adults. Neurologic Music Therapy (NMT) is an advanced clinical specialism of music therapy that is based on brain research in music and has established itself as a new model for music therapy within medicine. NMT is based at the University of Toronto <u>https://nmtacademy.co/</u> The international training programs of the NMT Academy are endorsed by the World Federation of Neurologic Rehabilitation (WFNR), by the European Federation of Neurorehabilitation Societies (EFNS) and the International Society for Clinical Neuromusicology (CNM).	Thank-you. This is more detail than is required in the scope, but your comments will be considered during development of the guideline.
			In NMT, elements of music such as rhythm, melody, and timing are used as treatment modalities. Standardised clinical interventions are based on clusters of research evidence and established learning principles in motor, speech/language, and cognitive training. The research support for	

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			NMT in stroke rehabilitation has been growing rapidly over the past 20 years. Our comments will highlight research data and clinical applications for Stroke rehabilitation in the sensorimotor, speech/language and cognitive domains. A very comprehensive article covering all aspects of Neurologic Music Therapy in Stroke Rehabilitation is: Thaut, M.H., McIntosh, G.C. Neurologic Music Therapy in Stroke Rehabilitation. Curr Phys Med	
Chroma	010	032	Rehabil Rep 2, 106–113 (2014). https://doi.org/10.1007/s40141-014-0049-y Unlike the traditional socio-cultural model of music therapy, NMT uses the perception of auditory	Thank-you. This is more
Chroma	010	032	structures and patterns in music as cues to retrain brain function. NMT requires advanced certification training and consists of a number of standardized treatment techniques which are based on clusters of research evidence in the areas of motor, speech/language, and cognitive rehabilitation. Our comments will also highlight our own clinical outcomes data from NHS hospitals such as Charing Cross Acute Stroke Unit, where we have worked since 2017.	detail than is required in the scope, but your comments will be considered during development of the guideline.
Chroma	010	032	GAIT Research from many studies over a long period of time show significant entrainment results using auditory rhythm as an external pacemaker. Basic gait parameters such as velocity, step cadence, and swing symmetry all improved with rhythmic cueing. In addition, studies show the EMG variability of the gastrocnemius muscle was reduced significantly in the paretic leg, showing more economical motor unit recruitment patterns as a result of rhythmic auditory cueing Thaut MH, McIntosh GC, Prassas SG, Rice RR. The effect of auditory rhythmic cuing on stride and	Thank-you. This is more detail than is required in the scope, but your comments will be considered during development of the guideline.
-	0.1.0		EMG patterns in hemiparetic gait of stroke patients. J Neurol Rehabil. 1993;7:9-16.	
Chroma	010	032	These studies consisted of patients with right and left hemispheric ischemic and haemorrhagic strokes in the middle cerebral artery and internal capsule distribution. Velocity, stride length, and stride symmetry were significantly higher than for conventional physiotherapeutic based gait therapy.	Thank-you for the information.
			Thaut MH, McIntosh GC, Rice RR. Rhythmic facilitation of gait training in hemiparetic stroke rehabilitation. J Neurol Sci. 1997;151:207–12.	

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Chroma	010	032	A multi-site randomized control trial from 2007 showed significantly higher improvements in gait in hemiparetic stroke rehabilitation than in control groups, accessing conventional gait retraining Thaut MH, Leins AK, Rice RR, Argstatter H, Kenyon GP, McIntosh GC, Bolay V and Fetter M. Rhythmic auditory stimulation improves gait more than NDT/Bobath training in near-ambulatory patients early post stroke: a single blind randomized trial. Neurorehabil Neural Repair. 2007; 21:455–459.	Thank-you for the information.
Chroma	010	032	Data from many studies suggest that the use of a pulsed rhythmic auditory cue has a modulatory effect on motor neuron activity, entraining neural activation patterns into more regular and more synchronized patterns, resulting in more consistent timing and motor unit recruitment. Because these EMG enhancements were always linked with significant kinematic improvements, it os suggested that the rhythmic cues were acting on centrally mediated mechanisms of motor control, possibly via resonance coupling of motor neuron activation patterns to the physiological coding of rhythm in the auditory pathway. In these ways music, and specifically rhythm is able to act as a highly clinically effective treatment modality for Gait training in Stroke rehabilitation.	Thank-you. This is more detail than is required in the scope, but your comments will be considered during development of the guideline.
Chroma	010	032	used during motion. In 2019 Rhythmic Auditory Stimulation (RAS), one of the neurologic music therapy interventions for gait training, was officially included in the Canadian Stroke Best Practice Guidelines and in the Clinical Practice Guidelines for the Management of Stroke Rehabilitation of the U.S. Veterans Administration and the Department of Defence.	Thank-you. This is more detail than is required in the scope, but your comments will be considered during development of the guideline.
Chroma	010	032	Post Stroke Arm & Upper limb rehabilitation In order to extend rhythmic entrainment paradigms to other motor functions, two additional NMT techniques turn functional movements, e.g., in the upper extremities or in full body coordination, into cyclical repetitive movement patterns that can be cued by auditory rhythm.	Thank-you. This is more detail than is required in the scope, but your comments will be considered during

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			 Patterned Sensory Enhancement (PSE) regulates functional movement by translating the temporal, spatial, and force-dynamic components of movement kinematics into sound patterns, similar to sonification patterns in high performance athletic training. PSE is a technique which uses the rhythmic, melodic, harmonic and dynamic-acoustical elements of music to provide temporal, spatial, and force cues for movements which reflect functional exercises and activities of daily living. PSE is applied to movements that are not rhythmical by nature (e.g., most arm and hand movements, functional movement sequences such as dressing or sit-to-stand transfers) and it provides more than just temporal cues. PSE uses musical patterns to assemble single, discrete motions (e.g., arm and hand movements during reaching and grasping), into functional movement patterns and sequences (Thaut et al. 1991). Therapeutic Instrumental Playing (TIMP), maps functional movements unto musical instruments (mostly percussion, keyboard, or digital sound surfaces) and engages the patient in practicing motions repetitively and cyclically via musical instruments. These techniques offer advantages over nonmusical motor training for the following reasons; 	development of the guideline.
			 Priming of the motor system due to the enriched sound environment Auditory feedback for spatial movement control (knowledge of results from sound when the instrument has been struck correctly) Anticipation and timing structure for movement from the external rhythmic cue and from 	
			integrating the external cue (feedforward) with the patient produced sound patterns (feedback)	
Chroma	010	032	In a 2002 study, rhythmic cueing on spatiotemporal control of sequential reaching movements of the paretic arm was studied in 21 hemispheric stroke patients. Reaching movements were studied with and without rhythmic metronome cuing in a counterbalanced design. Metronome	Thank-you. This is more detail than is required in th scope, but your comments will be considered during

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			frequencies were entrained to the naturally selected frequency of the patient. Results indicate statistically significant (P<0.05) improvements of spatiotemporal arm control during rhythmic entrainment. Variability of timing and reaching trajectories were reduced significantly. Time series analysis of sequential movement repetitions showed an immediate reduction in variability of arm kinematics during rhythmic entrainment within the first two to three repetitions of each trial. Rhythm also produced significant increases in angle ranges of elbow motion (P<0.05). Analysis of acceleration and velocity profiles of the wrist joint showed significant kinematic smoothing during rhythmic cuing.	development of the guideline.
			Thaut MH, Kenyon GP, Hurt CP, McIntosh GC, Hoemberg V. Kinematic optimization of spatiotemporal patterns in paretic arm training with stroke patients. Neuropsychologia. 2002;40:1073-81.	
Chroma	010	032	A 2010 study found that improvements during repetitive cyclical bilateral arm training if cued rhythmically by metronome cues (PSE - Patterned Sensory Enhancement) transferred to functional improvements on gross motor tests. Neurologic Music Therapists use this technique in their upper limb treatment plans.	Thank-you for the information.
			Senesac CR, Davis S and Richards L. Generalization of a modified rhythmic bilateral training in stroke. Hum Movem Sci. 2010; 26:137–148	
Chroma	010	032	Whitall J et al found that rhythmic auditory queueing improved motor function in patients with chronic hemiparetic Stroke.	Thank-you for the information.
			Whitall J, McCombe WS, Silver KH, Macko RF. Repetitive bilateral arm training with rhythmic auditory cueing improves motor function in chronic hemiparetic stroke. Stroke. 2000;31:2390–5.	
Chroma	010	032	In a 2009 study, TIMP (Therapeutic instrumental music performance) of the NMT interventions was tested against a control group getting standard care and found that "patients showed significant improvement after treatment with respect to speed, precision and smoothness of movements as shown by 3D movement analysis and clinical motor tests. Furthermore, compared	Thank-you for the information.

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			to the control subjects, motor control in everyday activities improved significantly. In conclusion, this innovative therapeutic strategy is an effective approach for the motor skill neurorehabilitation of stroke patients."	
			Yoo J. The role of therapeutic instrumental music performance in hemiparetic arm rehabilitation. Music Ther Perspect. 2009;27:16–24.	
Chroma	010	032	MIT (Melodic Intonation therapy) one of the NMT interventions is the most frequently used speech/language therapy technique used in stroke rehabilitation.	Thank-you. This is more detail than is required in the scope, but your comments
			There is a significant amount of research starting in the mid-1970s showing the efficacy of MIT with non-fluent expressive aphasia. The following elements in MIT may be considered the main mechanisms engaging preferentially right hemispheric networks for speech production:	will be considered during development of the guideline.
			• In MIT vocal output is slower than when spoken. Singing is characterized by syllables being lengthened, chunked, and patterned, contributing to speed reduction in vocal output. The right hemisphere is better suited to process slowly modulating signals. Thus, translating spoken language into musical prosody prefentially activates right hemispheric language networks (Patel 2005)	
			• Processing of music engages right hemispheric networks, thus, helping to bypass damaged left hemispheric language networks	
			• Rhythmic pacing and entrainment predominantly engages right hemispheric networks in auditory, prefrontal and parietal regions	
			• Patel AD. The relationship of music to the melody of speech and to syntactic processing disorders in aphasia. Ann N Y Acad Sci. 2005;1060:59–70.	



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			• Soto D, Funes MJ, Guzman-Garcia A, Warbick T, Rohhstein P & Humphreys GW. Pleasant music overcomes the loss of awareness in patients with visual neglect. Proc Nat Acad Sci. 2012;106:6011–6016. The study finds support for music stimulation to overcome hemispatial neglect, proposing an additional role for recruitment of attention resources through affective responses to preferred music.	
			Stahl B, Kotz SA Henseler I, Turner R & Geyer S. Rhythm in disguise: why singing may not hold the key to recovery from aphasia. Brain. 2011;134:3083–3093. Data supporting a critical role for rhythm in speech recovery after melodic intonation therapy.	
Chroma	010	032	Cognitive rehabilitation using music as a treatment modality post Stroke Two of the most promising applications of music to cognitive training in stroke rehabilitation may be in the area of musical neglect training (MNT) and music attention control training (MACT), both of which are standardized techniques in NMT.	Thank-you. This is more detail than is required in the scope, but your comments will be considered during development of the guideline.
			 MNT addresses hemispatial neglect and uses active performance exercises on musical instruments (tone bars or drums) that are structured in time, tempo, and rhythm, and are set up in appropriate spatial configurations to focus attention of the neglected or unattended visual field. Frassinetti F, Bolognini N, Ladavos E. Enhancement of visual perception by crossmodal visual-auditory interaction. Exp Brain Res. 2002;147:332-43. 	
			MACT addresses a range of attention-based issues, including sustained and alternate/switched attention by using active patient/music therapist performance exercises on musical instruments (tone bars or drums) that are structured in time, tempo, and rhythm. This enables the patient to focus and develop their capacity to attend and concentrate, via the musical interactions, and then to translate this global change to everyday activities.	

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			Other research points directly to the use of music listening activates a wide-spread bilateral network of brain regions related to attention, semantic processing, memory, motor functions, and emotional processing. In this RCT (n=60) results showed that recovery in the domains of verbal memory and focused attention improved significantly more in the music group than in the language and control groups. MACT is the treatment intervention that brings together music listening and active music playing for the development of cognitive recovery and enhanced attention.	
			• Teppo Särkämö et al, Music listening enhances cognitive recovery and mood after middle cerebral artery stroke, <i>Brain</i> , Volume 131, Issue 3, March 2008, Pages 866–876, https://doi.org/10.1093/brain/awn013	
Chroma	010	032	This feasibility study found "increasing evidence for music-based interventions in neurorehabilitation, improving mood and functional outcomes. In response, there is growing interest from health-care providers in setting up Neurologic Music Therapy (NMT) services. This paper presents some preliminary data on the feasibility and acceptability of NMT in the acute stroke, multidisciplinary team setting, about which little is known."	Thank-you for the information.
			Results: Of 201 patients referred, 177 received treatment and 675 sessions were delivered. Twenty-four patients were discharged before sessions were scheduled and 28 sessions were declined, predominantly due to fatigue. Mean scores (SD) from questionnaire data were: patients (n = 99) 3.34 (0.825), relatives (n = 13) 3.83 (0.372), staff (n = 27) 3.85 (0.388). Mean, post-session VAMS data (n = 52) showed a non-significant reduction in 'Sad' (7.5, p = .007, Cl = 2.1, 12.9) and an increase in 'Happy' (+ 6.2, p = .013, Cl = $-11.0, -1.4$).	

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			Conclusions: Data suggest the service was feasible and helpful, particularly for patient mood, possibly improving engagement in rehabilitation. Research to determine generalizability in different stroke environments and treatment effects within them is warranted. Alexander Street, Jufen Zhang, Susan Pethers, Lydia Wiffen, Katie Bond & Helen Palmer (2020)	
Chroma	010	032	Neurologic music therapy in multidisciplinary acute stroke rehabilitation: Could it be feasible and helpful?, Topics in Stroke Rehabilitation, 27:7, 541-552, DOI: 10.1080/10749357.2020.1729585 Music listening is suggested to have beneficial effects on cognition. In this study seventy-two participants were randomized to mindful music listening (n = 23), music listening (n = 24), or audiobook listening (n = 25). Feasibility and acceptability measures were encouraging: 94% fully consistent with protocol; 68.1% completing $\geq 6/8$ treatment visits; 80-107% listening adherence; 83% retention to six-month endpoint. Treatment effect sizes for cognition at six month follow-up ranged from d = 0.00 ([-0.64,0.64], music alone), d = 0.31, ([0.36,0.97], mindful music) for list learning; to d = 0.58 ([0.06,1.11], music alone), d = 0.51 ([-0.07,1.09], mindful music) for immediate story recall; and d = 0.67 ([0.12,1.22], music alone), d = 0.77 ([0.16,1.38]mindful music) for attentional switching compared to audiobooks. No signal of change was seen for mood. A definitive study would require 306 participants to detect a clinically substantial difference in improvement (z-score difference = 0.66, p = 0.017, 80% power) in verbal memory (delayed story recall).	Thank-you. This is more detail than is required in the scope, but your comments will be considered during development of the guideline.
			 Conclusions: Mindful music listening is feasible and acceptable post-stroke. Music listening interventions appear to be a promising approach to improving recovery from stroke. Baylan S, et al. Measuring the effects of listening for leisure on outcome after stroke (MELLO): A pilot randomized controlled trial of mindful music listening. Int J Stroke. 2020 Feb;15(2):149-158. doi: 10.1177/1747493019841250. Epub 2019 Apr 2. PMID: 30940047; PMCID: PMC7045280. 	

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Chroma	010	032	 A 2020 feasibility study (ACTIVATE) will address an important gap in the evidence base by reporting whether it is feasible to deliver auditory rhythmical cueing in the home and community to improve gait and balance parameters following stroke. The feasibility of the study protocol will be established and results will inform the design of a future multi-centre randomised controlled trial. McCue, P., Del Din, S., Hunter, H. et al. Auditory rhythmical cueing to improve gait and physical activity in community-dwelling stroke survivors (ACTIVATE): study protocol for a pilot randomised controlled trial. Pilot Feasibility Stud 6, 68 (2020). https://doi.org/10.1186/s40814-020-00605-1 	Thank-you for the information.
Chroma	010	032	The effect of music-supported therapy (MST) as a tool to restore hemiparesis of the upper extremity after a stroke has not been appropriately contrasted with conventional therapy. The aim of this trial was to test the effectiveness of adding MST to a standard rehabilitation program in subacute stroke patients. A randomized controlled trial was conducted in which patients were randomized to MST or conventional therapy in addition to the rehabilitation program. The intensity and duration of the interventions were equated in both groups. Before and after 4 weeks of treatment, motor and cognitive functions, mood, and quality of life (QoL) of participants were evaluated. A follow- up at 3 months was conducted to examine the retention of motor gains. Both groups significantly improved their motor function, and no differences between groups were found. The only difference between groups was observed in the language domain for QoL. Importantly, an association was encountered between the capacity to experience pleasure from music activities and the motor improvement in the MST group. MST as an add-on treatment showed no superiority to conventional therapies for motor recovery. Importantly, patient's intrinsic motivation to engage in musical activities was associated with better motor improvement. Grau-Sanchez, Jennifer, et al. "Music-supported therapy in the rehabilitation of subacute stroke patients: A randomized controlled trial." Annals of the New York Academy of Sciences (2018).	Thank-you. This is more detail than is required in the scope, but your comments will be considered during development of the guideline.
Chroma	010	032	Since 2017, Chroma has been working at Charing Cross Acute Stroke Unit. A 3-phase improvement methodology was implemented, and it involved collaboration between Imperial	Thank-you. This is more detail than is required in the

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			College Healthcare NHS Trust, Chroma Therapies Ltd, and Imperial Health Charity. Feasibility of NMT in the acute setting and cost effectiveness were primary considerations, along with improving patient experience and psychosocial outcomes.	scope, but your comments will be considered during development of the guideline.
			 Clinical data from Chroma's NMT service at Charing Cross Acute Stroke Unit (ASU) shows that between January 2019 - August 2019 outcomes data from NMT sessions showed outcomes across the three main domains of Cognitive, Speech & Language and Sensorimotor improved in the following ways Cognitive (Sample size 17 patients) 88.2% of patients receiving NMT for cognitive impairments were able to achieve one of their MDT goals in under two NMT sessions. 70.5% of patients receiving NMT for cognitive impairments were able to achieve two or more of their MDT goals in under four NMT sessions. 	
			 Speech and Language (Sample size 19 patients) Aphasia: (Sample size - 12 patients) 100% of patients receiving NMT for aphasia achieved their target language in one . 	
			 by session. Dysarthria: (Sample size 7 patients) 100% of patients receiving NMT for dysarthria were able to increase their decibel output by 72%. 66.7% of patients receiving NMT for dysarthria were able to increase their phonation duration by 40%. 	



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			Sensorimotor (sample size 30 patients)	
			 85.7% of patients receiving NMT for gait irregularities (RAS) improved on average by over 40% in a single session. Mean cadence and velocity of patients receiving RAS over the duration of the project increased from 75% to 86.54%. 	
			From September 2019 - December 2020 patietn outcomes data showed that;	
			 148 patients (59%) who received NMT achieved their MDT goals on average 5.5 days sooner than expected. This improvement occurred within one to two sessions of NMT. The data suggests, although does not prove, that early goal achievement in NMT leads to earlier discharge than predicted. This in turn leads to more available beds. 	
			• Using the MYOP (Paterson, 1996), patients receiving NMT reported a <u>17% decrease</u> in primary symptom severity over the course of 13 days (6 NMT sessions) on average. Patients receiving NMT reported a <u>33% decrease</u> in secondary symptom severity over the course of 13 days (6 sessions) on average. Augmenting the therapeutic intervention, NMT, appears to accelerate the rehab pathway for ASU patients.	
			• PROMS data shows the significance of NMT for patients' recovery:	
			 5% said NMT was not important 24% said NMT was slightly important 71% said NMT was very important or essential 	



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			 100% of patients said they would recommend NMT to patients with similar symptoms to theirs 	
			 Measuring patient <u>in-session</u> change using ratified outcome measures, the following improvements were seen in <u>one NMT session</u>: 	
			 10m walk GAIT, velocity, and stride length improved by 43% 5m walk GAIT, velocity, and stride length improved by 48% Average number of repetitions increased by 67% Average decibel output increased by 23% (essentially returning to normal decibel range) Average time taken to produce first word decreased by 73% Average attempts at successful phonation increased by 90% We believe these clinical outcomes make a very strong case for the inclusion of Neurologic Music Therapy within the updated Stroke guidelines, especially when viewed alongside the consistent research into all aspects of Stroke rehabilitation using music as a treatment modality. 	
			Paterson, C. (1996). Measuring Outcome In Primary Care: A Patient-generated Measure, MYMOP, Compared to The SF-36 Health Survey. British Medical Journal 1996;312:1016-20.	
Royal College of Speech and Language Therapists	011	014 - 020	RCSLT recommends that 'participation' based on the ICF, and 'wellbeing' could be included as a main outcome.	Thank-you. It is unlikely that these will be reported in studies reviewed for most of the proposed questions, but the committee will

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				consider adding them for specific questions.
Society for Research in Rehabilitation	011	001 - 004	 4.11 In people with shoulder pain after stroke, what is the clinical and cost effectiveness of transcutaneous electrical nerve stimulation, acupuncture, functional electrical stimulation and intra-articular steroid injection in reducing pain? Why limit this to non-routine physical /occupational therapy interventions, which are part of conventional / routine practice aimed at resolving the cause of the shoulder pain (e.g. subluxation and /or impingement) rather than treating the symptoms of pain? 	Thank-you. Current trials use these specific interventions as add ons to 'usual therapy' so the effects of the former are very difficult to tease out precisely. Trials on specific physio interventions are too small and not of sufficient quality to be prioristised for review.
Society for Research in Rehabilitation	011	005 - 008	4.12 In people after stroke, what is the clinical and cost effectiveness of interventions (transcutaneous electrical nerve stimulation, intrathecal 7 baclofen, oral baclofen, botulinum toxin and acupuncture) in reducing spasticity? Same as above - what about conventional physical / occupational therapy interventions to reduce spasticity?	Thank-you. The guideline committee will agree the appropriate comparators for the named interventions, but it is likely that this will include using the interventions as adjuncts to conventional therapies.
Society for Research in Rehabilitation	011	017 - 020	3.6 Main outcomes - should also include participation and social engagement.	Thank-you. It is unlikely that these will be reported in studies reviewed for most of the proposed questions, but the committee will consider adding them for specific questions.
Society for Research in Rehabilitation	011	011 - 013	4.14 In people after stroke, what is the clinical and cost effectiveness of interventions (including bladder retraining and botulinum toxin) on improving urinary incontinence after a stroke? - also	Thank-you. These interventions are covered in the NICE guideline CG148:

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			needs to include other interventions that improve continence (urinary and faecal). Not sure why the focus is just on bladder training and botulinum toxin	Urinary incontinence in neurological disease: assessment and management, and will be cross referenced in our guidelines. We have removed urinary incontinence from the list of areas for which a new review will be performed.
Society for Research in Rehabilitation	011	009 - 010	4.13 In people after stroke, what is the clinical and cost effectiveness of mirror therapy?, - to achieve what outcome?	Thank-you. Mirror therapy is designed to improve movement (impairment) of an affected limb, hemisensory inattention, activities of daily living and reduce pain. We will review evidence for these outcomes.
Association of Chartered Physiotherapists in Neurology	011	04	Please include the use of orthoses here	Thank-you. Use of orthotics is included in the current guideline CG162. Neither our surveillance report nor feedback from stakeholders has suggested that there is significant new evidence which would change current recommendations, and this topic has therefore not been prioritised for review.



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Association of Chartered Physiotherapists in Neurology	011	014	ACPIN suggests that the inclusion of PROMS in this section will be beneficial	Thank-you. This has been added as main outcome

Registered stakeholders