Appendix B: Stakeholder consultation comments table

2019 surveillance of Stroke rehabilitation in adults (2013) NICE guideline CG162

Consultation dates: 31 January 2019 to 13 February 2019

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Overall response</th>
<th>Comments</th>
<th>NICE response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chroma Therapies Ltd t/a Chroma</td>
<td>Yes</td>
<td>Chroma provides Rhythmic Auditory Stimulation (RAS) via our team of Neurologic Music Therapists to NHS and private healthcare organisations across the UK. This proposal to update the guidance to include music therapy and RAS will make a significant difference to Stroke survivors and healthcare organisations. The Cochrane Review is referring specifically to Rhythmic Auditory Stimulation (RAS), which is a Neurologic Music Therapy (NMT) technique, and not standard across music therapy. I would suggest using the terminology Neurologic Music Therapy vs Music Therapy to make the distinction. Not all Music Therapists can do RAS, but all NMTs have been trained to do it. Information about NMT</td>
<td>Thank you for your comment. The scope of the Cochrane review included all music interventions, and we therefore used the term ‘music therapy’ in the evidence summary section heading, and in the impact statement, to reflect the scope of the Cochrane review. Of the 29 studies identified by the Cochrane review, 14 used Rhythmic Auditory Stimulation or Rhythmic Auditory Cueing. We make specific reference in Appendix A: evidence summary to Rhythmic Auditory Stimulation and its benefits, but we will also reflect this in the impact statement, and ensure that developers who will perform the guideline update are aware of the distinction between Neurologic Music Therapy and Music Therapy. Regarding the references you have provided, books are not a valid evidence type for inclusion in surveillance reviews. However we</td>
</tr>
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training and certification can be found here: https://nmtacademy.co

In the book ‘Re-Engineering the Spinal Cord – Evidence-Based Neurehabilitation’ (2005, Springer, von Wild Editor) in the chapter ‘Evidence Based Medicine in Neurologic Rehabilitation: A Critical Review (Hoemberg, 1-14pp), RAS is listed as one of only 3 gait training techniques with high levels of evidence (level I or II). The other 2 are FES and treadmill with partial body support.

In the “Handbook of Clinical Neurology – Neurologic Rehabilitation” (Elsevier, Barnes & Good Eds) in the chapter ‘Neurorehabilitation Approaches to Facilitate Motor Recovery (Hoemberg, 161-174pp) again RAS is listed among only 4 evidence based gait training techniques (Robot-assisted methods were added).

Note that the positive findings on Rhythmic Auditory Stimulation in these books agree with the conclusions of the Cochrane review examined by the surveillance review.

<table>
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<tr>
<th>Neurocare Europe Limited</th>
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</table>
| Stroke Association       | Yes | We welcome NICE’s proposal to update the existing guidelines for stroke rehabilitation in adults. 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, most recently as set out in the NHS Long-Term Plan.
   We are pleased to see that the guideline has been reviewed and compared to the Royal College of Physicians’ 2016 Stroke guidelines. We also welcome the aspiration to |
|                          |     | Thank you for your comment.
   During the surveillance review, we considered both the NHS long term plan (reference 1 in your comment), and the Royal College of Physicians 2016 Stroke guidelines. They are referred to at relevant points in Appendix A: evidence summary. As you note, we are planning to explore engaging with the Royal College of Physicians on any update. We are pleased that you agree with the areas proposed for update.  |
|                          |     | To address your comments on specific aspects of and sections of the guideline: |

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rehabilitation for people recovering from stroke. 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.

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.

We are disappointed that section 1.3 on providing support and information is not recommended for update. Provision of accessible information for those affected by stroke continues to be lacking - 1 in 3 respondents to our 'New Era for Stroke' survey in 2016 disagreed or strongly disagreed with the statement that they received enough information about what was happening to them. During the development of the National Stroke Programme stroke survivors continually called for better, more systematic rehabilitation', we did identify evidence for circuit class (i.e. group) walking therapy to improve mobility.

You note that your services 'pick up the often significant social, practical and emotional issues faced by stroke survivors and their families ... (which) should be reflected in any guidance.' These issues are referred to in recommendation 1.3.2 'Provide information about local resources (for example, leisure, housing, social services and the voluntary sector) that can help to support the needs and priorities of the person with stroke and their family or carer.'

**Providing support and information**

Surveys are not a suitable evidence type for inclusion in a surveillance review. However, we acknowledge your concerns that many respondents to your survey felt they did not receive enough information. The guideline does recommend identifying information needs and how to deliver them, taking into account specific impairments, pacing the information to the person's emotional adjustment, providing information about local resources to support needs and priorities, and regularly reviewing information needs. This may therefore be an implementation issue and we will pass on this information to the relevant NICE team.

Although the guideline does not refer to specific information sources, the recommendations are designed to encompass a broad range of information because the guideline committee who made
provision of information, which is why we’re leading on the development of the ‘stroke passport’ as part of the National Stroke Programme. We also provide support through our local groups, information sheets and My Stroke Guide. We would like to see the guidelines outline more clearly the kinds of support available to those affected by stroke, including online support to ensure this is flagged to every stroke survivor who could benefit.

We welcome the acknowledged need to update the section on emotional functioning to include sex, relationships and emotions. In a 2015 Stroke Association survey of over 1000 stroke survivors, 1 in 5 told us the emotional impact of stroke was hard to deal with, while 42% of people report a negative change in their relationship with their partner after a stroke. We are pleased to see this section of the guidance be brought into line with RCP guidelines.

We echo comments made by consulted topic experts around longer term stroke care regarding the importance of peer support, community involvement and the crucial role of the third sector in providing support, advice and information. We would like to see the guideline’s recommendation 116 to include mention of peer support groups and voluntary sector involvement, to reinforce the important role of this sector in this part of the pathway.

References

the recommendations noted that ‘information provided is likely to vary from patient to patient, and needs to reflect patients’ needs and priorities’ family expectations, and the local resources’.

**Sex, relationships and emotions**

We are pleased that the decision to update this area of the guideline is aligned with the findings of your survey about the impact of stroke on emotions and relationships. However reference 3 by McKevitt (2011) reporting these results is prior to the search dates of the surveillance review and so cannot formally be included in the evidence summary.

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1.6.2 All patients who fail a vision screen should have a full orthoptic assessment and management and should not be limited to patients with diplopia. All visual impairments will impact on the patient’s psychosocial well being and their ability to undertake effective rehabilitation.

1.6.3 This should not be limited to patients with awareness of hemianopia. Those without awareness should also be offered therapy and support to undertake that therapy. It should also not be limited to hemianopia but patients with field loss.

### Appendix B: stakeholder consultation comments table for 2019 surveillance of Stroke rehabilitation in adults

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<td>Royal College of Speech and Language Therapists</td>
<td>Not answered</td>
<td>No comments provided</td>
<td>Thank you.</td>
</tr>
<tr>
<td>British Acupuncture Council</td>
<td>Yes</td>
<td>No comments provided</td>
<td>Thank you for your answer.</td>
</tr>
<tr>
<td>Medtronic Ltd</td>
<td>Yes</td>
<td>No comments provided</td>
<td>Thank you for your answer.</td>
</tr>
<tr>
<td>NHS England</td>
<td>Not answered</td>
<td>No comments provided</td>
<td>Thank you.</td>
</tr>
<tr>
<td>Association of British Neurologists</td>
<td>Yes</td>
<td>Areas identified for consideration in the update all seem sensible areas to look at again in light of new evidence. An update to the stroke rehabilitation guideline seems sensible, particularly given the problems around the first iteration.</td>
<td>Thank you for your comment. We are pleased that you agree with the need to update the guideline, and our plan to explore engaging with the Intercollegiate Stroke Working Party.</td>
</tr>
</tbody>
</table>
The suggestion of engagement with the ICSWP is encouraging if somewhat surprising (perhaps taking on board some of the criticisms of the first NICE guideline). There will be a much greater chance of a pragmatic and relevant set of guidelines with this approach.

I would like to add a vote for the assessment and management of disorders of oral feeding, given the new classification of food consistencies (https://iddsi.org/).

There is always an emphasis on swallowing, but not on the other components of successful oral feeding, in particular cough, posture, vigilance, and food consistency.

Difficult to disagree with the suggestions for areas to review. The robot assisted arm therapy section was suggested for updating on the basis of RATULS which has not yet been presented, but perhaps they know more about the timing of this.

Assessment and management of disorders of oral feeding in stroke is of relevance to NICE guidelines CG32 Nutrition support for adults and CG68 Stroke and transient ischaemic attack in over 16s. The issues you raised in this area will be added to the issue log for these guidelines for consideration at their next surveillance review.

The basis for identifying a trigger for updating recommendations on robot-assisted arm training was based on a Cochrane review and 2 additional randomised controlled trials. We noted the RATULS trial (Robot Assisted Training for the Upper Limb after Stroke) is underway and that it may provide additional useful data in this area once findings have been published. If this trial publishes its findings during development of the guideline update it may be possible to incorporate it into the update.

### NICE guideline CG76 Medicines adherence covers:
- Patient involvement in decisions about medicines; Supporting adherence; Reviewing medicines; and Communication between healthcare professionals.

### NICE guideline NG5 Medicines optimisation covers:
- Patient safety incidents; Communication when patients move between care settings; Medicines reconciliation; Medication review; Self-management plans; Patient decision aids; Clinical decision support; and Organisational and cross-sector working.

2a) Are medicines management issues that may arise in stroke rehabilitation suitably covered by other NICE guidance such as NICE CG76 and NICE NG5?

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<tbody>
<tr>
<td>Neurocare Europe Limited</td>
<td>No comments</td>
<td>No comments provided</td>
<td>Thank you.</td>
</tr>
<tr>
<td>Stroke Association</td>
<td>Yes</td>
<td>No comments provided</td>
<td>Thank you for your answer.</td>
</tr>
<tr>
<td>British and Irish Orthoptic Society</td>
<td>Not able to comments</td>
<td>No comments provided</td>
<td>Thank you.</td>
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<tr>
<td>Royal College of Speech and Language Therapists</td>
<td>Not answered</td>
<td>No comments provided</td>
<td>Thank you.</td>
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<tr>
<td>British Acupuncture Council</td>
<td>Not answered</td>
<td>No comments provided</td>
<td>Thank you.</td>
</tr>
<tr>
<td>Medtronic Ltd</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your answer.</td>
</tr>
<tr>
<td>NHS England</td>
<td>Partially</td>
<td>It's not uncommon for patients to be discharged after a stroke with a variety of medications some of which are new and some pre-existing – patients and their carers are often confused about these and especially in regard to anticoagulant drugs and anti hypertensives. Very clear guidance on what has been stopped and started should be given – patients for example may have been on warfarin previously and then are commenced on a new oral anti coagulant. On discharge they do not appreciate the fact that the oral anti coagulant is different from that previously commenced. We acknowledge your concerns about patients with stroke and their carers being confused about medicines. This is an issue for various conditions, and so NICE guideline CG76 Medicines adherence (which is linked to by NICE guideline CG162) makes recommendations to cover similar scenarios common to many patients, such as:</td>
<td>Thank you for your comment.</td>
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Thank you.
that these must not be taken together. Similar confusion about aspirin in individual cases occurs. A clear written plan should be given to all patients and GPs at discharge with specific reference to high risk medications.

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|   | • 1.1.18 Encourage and support patients, families and carers to keep an up-to-date list of all medicines the patient is taking.  
• 1.1.25 Offer patients information that is relevant to their condition, possible treatments and personal circumstances, and that is easy to understand and free from jargon.  
• 1.1.29 Patients differ in the type and amount of information they need and want. Therefore the provision of information should be individualised.  

Regarding your concerns about written plans for patients and GPs at discharge, NICE guideline NG5 Medicines optimisation makes several recommendations in this area, including:  
• 1.2.1 Organisations should ensure that robust and transparent processes are in place, so that when a person is transferred from one care setting to another: the current care provider shares complete and accurate information about the person’s medicines with the new care provider and the new care provider receives and documents this information, and acts on it.  
• 1.2.3 Health and social care practitioners should share relevant information about the person and their medicines when a person transfers from one care setting to another. This should include, but is not limited to, all of the following: […] details of the medicines the person is currently taking – name, strength, form, dose, timing, frequency and duration, how the medicines are taken and what they are being taken for.  

We therefore believe that the issues you raise are covered by NICE guidelines CG76 Medicines adherence and NG5 Medicines.  

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<th>No comments provided</th>
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</table>
| Medtronic Ltd               | The guideline makes no recommendation on intrathecal baclofen for the treatment of post stroke spasticity. We suggest that intrathecal baclofen should be considered for addition to this guideline and would like to draw your attention to two 2018 publications detailing results of the SISTERS RCT which investigated the effects of intrathecal baclofen therapy on post stroke spasticity, pain and quality of life.  

Thank you for alerting us to these 2 publications (which were not identified in the searches performed for the surveillance review) reporting results of a randomised controlled trial in 60 people with severe poststroke spasticity. We have added these to the surveillance evidence summary.  
We acknowledge that the results show that intrathecal baclofen therapy versus conventional medical management appears to improve spasticity, pain and quality of life versus conventional management.  
The Royal College of Physicians Intercollegiate Stroke Working Party does make the following recommendation ‘People with generalised or diffuse spasticity after stroke should be offered treatment with skeletal muscle relaxants (e.g. baclofen, tizanidine)…’ We are proposing this is considered as an area for update in the guideline and have amended Appendix A: Evidence summary with this new evidence and conclusion of impact. |

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<td>See above</td>
<td>Thank you for your comment. Please see our response to your comments above for question 2a.</td>
<td></td>
</tr>
<tr>
<td>Association of British Neurologists</td>
<td></td>
<td>Thank you for your comment. The guideline makes a specific mention of education in recommendation 1.4.2 ‘Provide education and support for people with stroke and their families and carers to help them understand the extent and impact of cognitive deficits after stroke, recognising that these may vary over time and in different settings.’ Additionally, several recommendations are made regarding information provision, including: identifying information needs and how to deliver them, taking into account specific impairments, pacing the information to the person’s emotional adjustment, providing information about local resources to support needs and priorities, and regularly reviewing information needs. We therefore believe that the issues you raise are covered by the guideline.</td>
<td></td>
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<tr>
<td>A Cochrane overview of interventions for upper limb function</td>
<td></td>
<td>Found benefits of: mental practice, interventions for sensory impairment, and unilateral (vs. bilateral) arm training. The evidence base for these was systematic reviews from 2009 to 2013, and the current surveillance review found no more recent evidence. [Note: the Cochrane overview covered other interventions which have more recent evidence bases – see individual sections in Appendix A for details].</td>
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<tr>
<td>a) Should any of these 3 interventions be considered in an update of CG162?</td>
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b) If so, are you aware of more recent evidence since 2013?

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<tr>
<td>Association of British Neurologists</td>
<td>Yes, all</td>
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The evidence searches performed for the surveillance review identified several studies of electrical stimulation, including neuromuscular electrical stimulation (NMES) for various aspects of stroke rehabilitation. The findings are presented in detail in Appendix A: evidence summary. An overview of the findings is given below:

**Swallowing therapy**

Evidence was found from a Cochrane review and 2 RCTs. This evidence is covered by NICE interventional procedures guidance IPG634 [Transcutaneous neuromuscular electrical stimulation for oropharyngeal dysphagia in adults](https://www.nice.org.uk/guidance/ipg634), which states: ‘For adults with dysphagia after a stroke, the evidence on efficacy suggests a potential benefit, but is limited in quality and quantity. Therefore, this procedure should only be used with special arrangements for clinical governance, consent, and audit or research.’

**Electrical stimulation for the upper limb**

Mixed results from 8 heterogeneous RCTs are unlikely to impact the guideline recommendation not to routinely offer electrical stimulation for the hand and arm, but to consider a trial of electrical stimulation in people who have evidence of muscle contraction after stroke but cannot move their arm against resistance.

**Shoulder pain**

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A single RCT found that electrical stimulation applied to the supraspinatus and deltoids significantly reduced shoulder pain, but evidence from other studies confirming effects are needed.

**Electrical stimulation for the lower limb**

Of 5 RCTs, only 1 found any significant positive effects (of bilateral over unilateral electrical stimulation for results on the Timed Up and Go test). In 5 reports of the other 4 RCTs, no benefit was found of electrical lower limb stimulation on walking. This evidence is unlikely to affect the guideline which makes no recommendations on electrical stimulation for the lower limb.

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</table>
| Royal College of Speech and Language Therapists | Yes | **1.8 Communication**

**Speech and language therapy for aphasia**

We would also encourage inclusion of emerging large-scale trials of digital interventions from to be reviewed and potential be made into recommendations.

Furthermore there should be a recommendation included that does not limit the 6 month/annual review stages as the point of referrals to be made to SLT. Evidence supports that SLT is helpful for improving people with aphasia years after their stroke (Bretenstien et al., 2017) and so it should be easy for people to make self-referrals through their GP at any instance post-stroke, as there is always potential for

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Northcott et al. (2018): This study was identified by the surveillance review searches. However, due to the large number of studies identified in the initial evidence search, several strategies were used to select studies for inclusion in the evidence summary. One of the strategies was to include only systematic reviews from Cochrane, therefore as a non-Cochrane review, this study was excluded. The study concluded that: ‘Following a stroke, non-kin contact is vulnerable, strain is observed within the family unit, and poor social support is associated with depressive symptoms.’ This study has now been added to Appendix A: Summary of evidence.

One of the areas of the guideline we have identified for consideration in the update is sex, relationships and emotions. The results of this study support our decision to examine this area.

It should also be noted that the guideline already includes some recommendations relevant to this aspect of post-stroke issues such as 1.11.3 ‘Encourage people to focus on life after stroke and help them to achieve their goals. This may include: facilitating their participation in community activities, such as shopping, civic engagement, sports and leisure pursuits, visiting their place of worship and stroke support groups; supporting their social roles, for example, work, education, volunteering, leisure, family and sexual relationships’.

British Acupuncture Council

Yes

You have excluded acupuncture based on the findings of one systematic review (Yang 2016). It is arguable whether that is the correct decision, given that this review found positive indications for acupuncture in a number of stroke areas: it comes down to considerations of methodological

Thank you for your comment.

When the guideline was originally developed, no evidence was examined for acupuncture or any other complementary and alternative medicine, and no review questions were included specifically about complementary and alternative medicine. As the

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Appendix B: stakeholder consultation comments table for 2019 surveillance of Stroke rehabilitation in adults (2013)
quality of the trials and of course the usual contentious acupuncture issue over sham/placebo and hence interpretations of the evidence. Given that this is not a clear-cut decision we are surprised that you have restricted your review just to this one review. On a quick count with pubmed I came across at least 20 systematic reviews published in English (including more Cochrane ones) since the last stroke guideline. We would urge you to have look more closely at the whole body of acupuncture evidence. Examples of some of the issues are given below, but we have not looked into this thoroughly ourselves. Consider also that stroke is the inpatient condition in Chinese hospitals that provides more acupuncture referrals than anything else. It is almost always delivered in conjunction with orthodox rehabilitation treatment.

**Insomnia**

The Yang Cochrane review only identifies one study relating to sleep in people who have had a stroke (Zhang 2013, published in a Chinese journal), so I think the the systematic review by Lee (BMC Complementary Alternative Med 2016) should be considered.

**Dysphagia**

Bath 2018 Cochrane Review for Dysphagia includes studies published in 2016, including Chen et al. BMC Complement Alternat Med 2016 and Xia Clin Rehabil 2016, so these could be considered in the update. However in Chen, stroke onset was 2-7 days onset. Li Chin J Integrat Med 2018 is a meta-analysis of dysphagia so this could be considered too (doesn't include Xia or Chen).

surveillance review takes its lead from the protocols used by the original guideline developers, studies of complementary and alternative medicine were excluded from the surveillance review. However we included the Cochrane review (Yang 2016) in the surveillance review as an overview of the best available current evidence on acupuncture for stroke rehabilitation. The authors concluded that 'most included trials were of inadequate quality and size. There is, therefore, inadequate evidence to draw any conclusions about its routine use'. This therefore remains an area where not enough evidence of good quality is available to consider making recommendations. However, as we are proposing to fully update the guideline this may be an area considered further through the scoping process.

We also included in the surveillance review the Cochrane review of dysphagia (Bath 2018) that you refer to in which several acupuncture studies were included. The authors noted that 'Acupuncture resulted in significant results for reducing the proportion of participants with dysphagia at end of trial. However, these findings may be due to chance, given that testing for subgroup differences did not yield significant results. Acupuncture did not reduce swallowing ability.' The authors further stated that 'data from three studies may have been confounded due to use of 'routine' acupuncture or a different type of acupuncture as control, variation in delivery of therapy, and risk of language bias, in that some of the acupuncture literature is available in full only in Chinese language journals'. We therefore believe that there is not enough evidence of good quality to consider making recommendations on acupuncture for dysphagia.
**Analysis of studies with various times post stroke onset**

There are some good studies such as Zhang 2015 but the patients were in the acute stage of <1 month onset so are rejected by the Yang Cochrane review and are in the Xu Cochrane review instead. Some include studies in the acute and chronic phase of stroke:

- **Lui et al. J Altern Complement Med 2014**, a meta-analysis of acupuncture on cognitive function in stroke is good but the period after stroke is mixed (The time interval between stroke onset and treatment varied. In 10 trials the time interval ranged from 48 hours to 1 month, and in nine trials, the time interval was 3 to 36 months.)
- **Yue J, et al. Acupunct Med 2017;35:2–8.** Looks at whether acupuncture improves stroke but includes studies with duration of symptoms from 1 day to 6 months but it isn't clear whether this is the stroke onset or hiccup onset.
- **Fang Sci Rep 2016** is an RCT in patients who had a recent stroke (30-40 days since onset) so falls between acute and chronic and may also include herbs. Include for consideration? (It isn't in the Xu Cochrane report)
- **Jiang C, et al. JAMDA 17 (2016) 1114e1122** is interesting but the time since stroke is unclear from the baseline demographics.
- **Cai Arch Physical Med Rehabil 2017** is a good meta-analysis but the post-stroke period ranged from one day to four years.
- **Wang et al. BMC Complementary and Alternative Medicine 2016** is a decent RCT related to improvements in cognitive impairment but the inclusion criteria require a recent episode of...
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**Nationwide cohort studies**


The fact that most of the studies are carried out in China is presented as a criticism in the Cochrane review. There must be an argument here considering the heritage of acupuncture, its incorporation in the treatment of stroke at the hospital level thus giving access to the funding, facilities and patients that are denied acupuncture researchers in the UK.

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<table>
<thead>
<tr>
<th>Medtronic Ltd</th>
<th>Yes</th>
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<tr>
<td>The guideline makes no recommendation on intrathecal baclofen for the treatment of post stroke spasticity. We suggest that intrathecal baclofen should be considered for addition to this guideline and would like to draw your attention to two 2018 publications detailing results of the SISTERS RCT which investigated the effects of intrathecal baclofen therapy on post stroke spasticity, pain and quality of life.</td>
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Thank you for your comment. Regarding the 2 publications you have identified, please see our response to your previous comment about this under question 2b) above.

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Orthoptics, pharmacy and dietetics to the core multidisciplinary stroke team (page 5 and 11 of the surveillance review): In reality, it is unlikely there will be additional evidence on the make-up on MDT stroke teams. However, in practice the skill mix of effective, integrated stroke teams needs to be based on anticipated demand at population level, according to local admissions for adults diagnosed with strokes and according to recommended care by NICE.

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<tr>
<th>Stakeholder</th>
<th>Overall response</th>
<th>Comments</th>
<th>NICE response</th>
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<tbody>
<tr>
<td>Association of British Neurologists</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your answer.</td>
</tr>
<tr>
<td>Chroma Therapies Ltd t/a Chroma</td>
<td>Not answered</td>
<td>No comments provided</td>
<td>Thank you.</td>
</tr>
<tr>
<td>Neurocare Europe Limited</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your answer.</td>
</tr>
<tr>
<td>Stroke Association</td>
<td>Yes</td>
<td>Although it is not a protected category under the Equality Act, people from the most economically deprived areas of the UK are around twice as likely to have a stroke than those from the least deprived areas. A study of stroke audit data found that the most deprived patients had an average age of onset 5 years lower than the least deprived patients. They also had greater co-morbidities and were less likely to have been independent before their stroke.</td>
<td>Thank you for your comment. Regarding economic deprivation: We suspect the link you supplied in reference 1 may be incorrect and that this page may be what you intended to notify us of. It is a large data set with no accompanying narrative analysis and therefore cannot be included in the surveillance review. Reference 2 is an analysis of a national registry and is not a suitable evidence type to include in the surveillance review as it presents associative links without examining any possible causal relationships.</td>
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suggesting that there is overlap with the equality issues around age and disability. We therefore strongly recommend that the guideline considers socioeconomic deprivation to help reduce the health inequalities relating to stroke.

Similarly, studies have found that ethnic minorities were not only at greater risk of having a stroke, but more likely to report a greater number of unmet needs following a stroke. We strongly consider the guidelines to reflect these findings, and make recommendations to address them, specifically addressing any barriers around access, understanding or culture that prevent ethnic minority stroke survivors from accessing the support they need.

We know through our Life After Stroke Services – which support over 60,000 stroke survivors each year – that younger stroke survivors, specifically those under 55, often report problems accessing appropriate post-stroke support which we do not see as acutely in stroke survivors closer to the average age of onset. Further, age of onset data published by the Stroke Audit team in 2017 shows that strokes in men in this age group are growing faster than the trend in overall incidence. Nearly double the number of working age strokes now occur in men than in women. A new study looking at suicide after stroke shows than men are also more likely to die from suicide following a stroke than women. We therefore strongly suggest that younger stroke survivors and particularly younger men are considered as a group requiring specific consideration to address these issues when updating the guidance around emotional support and mental health.

management strategies. We acknowledge your concerns about the association of deprivation with increased risk of stroke, lower age of onset, more comorbidities and less pre-stroke independence. However these are issues mainly related to stroke prevention and the scope of NICE guideline CG162 specifically excludes primary and secondary prevention of stroke. The issues are more relevant to other NICE guidelines, such as NICE guidelines PH15 Identifying and supporting people most at risk of dying early from cardiovascular disease and PH25 Cardiovascular disease prevention. We also note that reference 2 also includes a statement that ‘there is no strong evidence that 30 day mortality is linked with deprivation’ which is of greater relevance to NICE CG162, and is unlikely to affect recommendations.

Regarding ethnic minorities: Risk of stroke is out of scope for the guideline (see above). Reference 3 is from 2011 and therefore outside the search dates of the surveillance review and cannot be included in the surveillance review. We note that the study abstract lists examples of unmet needs as being stroke information; reduction in or loss of work activities, loss in income and increase in expenses. We acknowledge your concern that ethnicity was significantly associated with unmet needs. The unmet needs quoted in the study are largely covered by the guideline which makes specific recommendations on information provision (including identifying the patient’s information needs and how to deliver them, and a link to NICE guideline CG138 Patient experience in adult NHS services). NICE guideline CG138 is focussed on tailoring care to the specific needs of individual patients and identifying and managing issues around returning to work.

Regarding younger stroke survivors: This population is within the scope of the guideline (which covers adults and young people aged

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Other professional groups have been given clear guidelines for their roles within stroke however none are provided for orthoptists.
There are no guidelines to discuss provision of information, education and training in visual problems to MDT, patients, carers and family
Visual impairment is not discussed in return to work sections. There needs to be consideration of the visual demands of the job and the effects of visual impairment on work performance and any adaptations that need to be made

| Royal College of Speech and Language Therapists | Yes | People with lower levels of health literacy should be added. Over one third of people will have communication needs after a stroke. As such, the RCSLT recommends that people with communication needs and cognitive difficulties are added. It is also important to always refer people undergoing stroke rehabilitation to speech and language therapists should there be concerns or issues on mental capacity – SLTs are key professionals involved in this and there is considerable evidence to support their inclusion as demonstrated by the amendment to the Mental Capacity Act. | Thank you for your comment. All NICE guidelines that undergo surveillance are updated with the following wording at the start of the recommendations:  
- People have the right to be involved in discussions and make informed decisions about their care, as described in your care.  
Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.  
The above wording contains links to pages on the NICE website that cover issues related to health literacy including mental capacity and involving all patients in decisions about care as far as possible. |

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<th>Comment Provided</th>
<th>Comments Provided</th>
<th>Response</th>
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<tbody>
<tr>
<td>British Acupuncture Council</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your answer.</td>
</tr>
<tr>
<td>Medtronic Ltd</td>
<td>No</td>
<td>No comments provided</td>
<td>Thank you for your answer.</td>
</tr>
<tr>
<td>NHS England</td>
<td>Yes</td>
<td>In common with most long term conditions people from deprived and marginalised communities find it more difficult to engage with and maintain rehabilitation. Considerable effort should be made to support these individuals to access rehabilitation and to facilitate the understanding of the benefits it can bring. I would strongly support the recommendation to move to be in line with other guidance, however it is important to note that many stroke units have significant workforce challenges and even if commissioned the service may not be able to deliver sufficient staff to provide 7 days services. This may be mitigated by reconfiguration but the public perception of this is often poor. I would strongly support the inclusion of specific advice on discussion of additional issues including sex. It is often an area that both clinicians and patients shy away from discussing due to embarrassment or assumptions that it cannot be discussed. It however is really important for well being. I would suggest that a specific section in a guideline would act as useful prompt to de-stigmatise it. The variety of visual impairments post stroke are often ignored or forgotten in the broader scope of disability.</td>
<td>Thank you for your comment. Engagement with the guideline by deprived and marginalised communities is an implementation issue and we will pass this information on to the relevant NICE team. NICE guidance recommendations reflect best practice that services should aspire to (such as a 7-day stroke service). The final decision on new recommendation wording lies with the guideline committee who will develop the update. Developing NICE guidelines: the manual chapter 7: 'Incorporating economic evaluation' states that the committee may require more robust evidence on the effectiveness and cost effectiveness of recommendations that are expected to have a substantial impact on resources (defined as implementing a single guideline recommendation in England costing more than £1 million per year, or implementing the whole guideline in England costing more than £5 million per year.) We will ensure your concerns about the availability of specialist staff are passed on to the developers.</td>
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Specialist advice on managing a visual disability can have a profound impact on recovery and well being. If occurring in isolation we would seek specialist advice on visual impairments and it should not be any different in stroke care.

The ability to engage with all forms of rehabilitation and to return to as normal a life as possible is highly dependent on visual ability.

Oral health is important in stroke as changes both in swallowing and saliva production can have a profound effect on the ability to maintain oral hygiene and health. Patients need support and advice to understand their oral health needs and how they can be met.

Guidance would be helpful to commissioners in light of conflicting evidence, as previously noted specialist staff in rehabilitation are often in short supply and commissioning decisions and the ability to deliver the service needs defined guidance to ensure maximum benefit in all services.

I would support the review to be clear on what is and is not appropriate to commission, however sufficient regard to the availability of specialist staff should be specifically included in the review. It would seem very sensible to define who would and would not benefit from shoulder injection as it’s not appropriate to undertake an intervention such as joint injection without appropriate cause.

I am puzzled by the suggestion that care home residents could be classed as a single group. I would suggest a more appropriate means of assessment would be in relation to frailty etc.

We welcome a review of occupational therapy provision to care home residents, however are unclear why this relates only to occupational therapy and no other rehabilitation/therapy. People living in care homes often receive inequitable access to NHS care compared to people

We are pleased you agree with our proposal for the update to consider issues concerning sex, vision, mouth care, and shoulder pain.

NICE recommendations in the context of stroke rehabilitation relate to best management practice, not how to achieve this such as staffing requirements and workforce planning. As noted above - the final decision on making new recommendations lies with the guideline committee. Developing NICE guidelines: the manual chapter 7: "Incorporating economic evaluation" states that the committee may require more robust evidence on the effectiveness and cost effectiveness of recommendations that are expected to have a substantial impact on resources.

The proposed consideration for update in relation to occupational therapy was based on a large randomised controlled trial specifically in care homes, therefore the impact statement was based around this intervention and population. However we did additionally state that expert comments within an NIHR signal about this trial noted that patients in the study were very frail and cognitively impaired. Therefore, the message may not necessarily be that people in care homes should not be encouraged to be independent or participate in activities, but that a rehabilitation approach may not work for people with significant comorbidities and impairments. Therefore, it may be that any changes to recommendations in this area could be centred on physical attributes such as frailty rather than place of residence. Any final decisions on new recommendation wording rest with the guideline committee who will develop the update and we will ensure they are aware of your comments.

We acknowledge your concerns about people living in care homes receiving inequitable access to NHS care. Recommendation 1.1.14 states ‘Ensure that people with stroke who are transferred from...
living in their own homes, as recognised by NHS England's framework for enhanced health in care homes (EHCH), and this includes people discharged to care homes from hospital after a stroke. We would therefore welcome consideration of a widened scope according to patient/population need rather than solely individual profession(s).

hospital to care homes receive assessment and treatment from stroke rehabilitation and social care services to the same standards as they would receive in their own homes.’ NICE has also developed a guideline focusing on transition between inpatient hospital settings and community or care homes for adults with social care needs. This guideline aims to improve people’s experience of admission to, and discharge from, hospital by better coordination of health and social care services.

Your comment about inequitable access to NHS care in care homes therefore relates to an implementation issue and we will pass this information on to the relevant NICE team.

| Association of British Neurologists | No | No comments provided | Thank you for your answer. |

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