Stroke rehabilitation scope stakeholder workshop breakout group discussions
Date: 12 October 2020 Time: 10:00 – 12:30
Notes

3.1 Population: **Groups that will be covered:** The guideline will cover stroke survivors aged 16 and older who have continuing impairment and / or limitation of activities. No specific subgroups of people have been identified as needing specific consideration. **Groups that will not be covered:** • Children and young people (under 16). • People who have had a transient ischaemic attack. • People who have had a stroke and have full recovered.	Is the population appropriate? o Are there any specific subgroups that have not been mentioned? Stakeholders discussed the phrase 'fully recovered', as listed under 'groups that will not be covered' in the draft scope. It was suggested that 'fully recovered' should be defined. It was highlighted that some people make a full physical recovery after stroke, but have other deficits, for example, with fatigue and emotional aspects. There was a view that no person fully recovers from a stroke. It was noted that some stroke survivors may not seek help until a later stage in their recovery. Rehabilitation should be inclusive for younger stroke survivors, who may have different needs and seek help at a later stage in their recovery. Transient ischaemic attack may also be redundant, because rehabilitation depends on needs. Stakeholders asked where subarachnoid haemorrhage fits in to the scope. It was noted that rehabilitation isn't included in the NICE subarachnoid haemorrhage guideline. Stakeholders asked where transient ischaemic attack is covered, if it is not to be covered by this guideline.
3.3 Key areas that will be covered in the update: 1. Organising health and social care for people needing rehabilitation after stroke. - Medicines management. 2. Planning and delivering stroke rehabilitation. - Intensity and frequency of stroke rehabilitation, including 7-day	These are the key areas of clinical management that we propose covering in the guideline. Do you think this is appropriate, acknowledging we must prioritise areas for inclusion? 1. Organising health and social care for people needing rehabilitation after a stroke

services. 3. Emotional functioning. - Sex, relationships and emotions. 4. Vision. - Vision assessment. 5. Swallowing. 6. Mouth care. 7. Communication. - Speech and language therapy for aphasia. - Therapy apps. 8. Movement. - Shoulder pain. - Walking therapy (circuit class therapy). - Electromechanical and robot-assisted arm training. 9. Self-care. - Occupational therapy for care home residents. 10. Spasticity - Transcutaneous electrical nerve stimulation. - Intrathecal baclofen. 11. Music therapy. 12. Mirror therapy. **Key clinical issues that will not be covered:** None specified in scope	Stakeholders requested that these issues be addressed: • Organisation, including community management • Role of a pharmacist in medicines management, education, information provision, dietetics. 2. Planning and delivering stroke rehabilitation • Frequency should be clarified • Intensity – this is different in the community setting; teams delivering it may need help interpreting the evidence • This section is missing models of rehabilitation, service structure. Long term plan is rehab for longer, this is where the guidance has a gap. After early supported discharge, what happens? NHS England rehab pilots may give some evidence. It was queried whether this evidence can be included for community rehab services • Stakeholders asked if non-RCT evidence can be considered. Noted that there are some areas in the scope that do not have RCT evidence. • Stakeholder experience is that those with best recovery of motor and communication function are those people who have been encouraged to be goal-orientated. Professionals should set goal-orientated outcomes and give encouragement to follow them and use positive language. It was requested to capture this in the guideline. 3. Emotional functioning • Stakeholders wanted more detail about what would be covered under this heading, and fed back that emotion and cognition should be separate topics. Self-care, self-management and telerehabilitation are separate topics. • It was queried whether a specific section on pain

	management is needed, instead of referencing other NICE guidance • It was suggested that a holistic approach could be taken to cover all aspects of this topic • Stakeholders highlighted mind body interventions, meditation, guided imagery, mindfulness, bio feedback, and hypnosis; stakeholders reported that there is evidence in this area. 4. Vision • Stakeholders suggested that it is important to include identification of people needing a referral for orthoptist assessment. 5. Swallowing • Dietary modification (from RCTs) – new international dietary texture descriptors were mentioned. • It was highlighted that there is some evidence of a benefit of acupuncture for dysphagia. • Stakeholders suggested that neuromuscular electrical stimulation/ neurotransmission for swallowing exercises could be included. 6. Mouth care • It was suggested that dental professionals are currently under-utilised in mouth care • It was queried whether the question is about assessment or interventions. Stakeholders were aware of some assessment tools. • Aspiration pneumonia can occur due to poor mouth care; health economics impact of this is large. 7. Communication • Stakeholders suggested covering intensity.

	• Provision of communication aids was highlighted as an issue; important to specify where the responsibility lies. • Inclusion of communication aids, technologies, different technology evidence. • Technology alongside therapy. • App based therapies to be included. • Observational evidence around multi-disciplinary team working. 8. Movement • Shoulder pain - Identification of people who would benefit from steroid injections to treat shoulder pain. - Some people are more susceptible, should there be pre-emptive treatment? - Subluxation is common following a stroke. - There is evidence for acupuncture to treat shoulder pain. - The possibility of broadening this to cover neurogenic pain and neuropathic pain was raised. It was suggestion to add a separate section on pain. • Walking therapy - There were contrasting views about circuit class therapy. Some stakeholders expressed a view that it is not suitable for the majority of patients, whereas some stakeholders reported that some units use it a lot. The correct term needs to be used in the guideline. • Electromechanical and robot arm training - Stakeholders reported that this is not yet in mainstream use. There is some evidence available. They were aware of a centre that uses robot arm training.

	9. Self-care • Stakeholders commented that community stroke teams visit care homes. The Enhanced Health in Care Homes guidance was mentioned as important and relevant. • Stakeholders were aware of a study in this area which reports improvement in quality of life as an outcome. • Self-care has potential benefit on costs, if patients can manage their own care. 10. Spasticity • Stakeholders suggested inclusion of oral baclofen, botulinum toxin and acupuncture. Stakeholders highlighted RCT evidence for acupuncture to treat spasticity and shoulder pain. • Stakeholders mentioned handheld TENS machines that can be used for self-care. • Stakeholders flagged the absence of guidance for identification of spasticity (NICE or otherwise). It was noted that spasticity can be recognised years down the line, thus delaying treatment and worsening outcomes. 11. Music therapy • Improves gait, upper limb function and communication • Can be unit based or community based. • Supports psychological, emotional and physical aspects of stroke rehabilitation • Stakeholders highlighted that this is a specific profession and needs to be delivered by a trained person; the guidance should reflect this • There may not be RCT evidence in this area but the topic should be included.

	12. Mirror therapy • It was queried whether this should be included in the movement section. • It is a relatively inexpensive treatment. It could be delivered as part of a package. Stakeholders highlighted the evidence for mirror therapy to treat the upper limb
Specific probes for key clinical issues:	No comments
Any comments on guideline committee membership? • Chair (already appointed) • Topic adviser (already appointed) • Stroke physician x 2 • Neuropsychologist • Secondary care neurophysiotherapist • Community neurophysiotherapist • Occupational therapist • General practitioner • Speech and language therapist • Stroke specialist nurse • Third sector representative • Lay member x 2 Co-opted members	Stakeholder comments: • Neurorehabilitation should be included on the committee (currently listed as co-opted member) • There was a request for more speech therapy representation on the committee. • There should be a Dietetic co-opted member • There should be a Music Therapist co-opted member • OT is specialised, so it should state Neurorehabilitation OT or Stroke specialist OT • More OT representation, 2 of both OTs and Physio • Questioned whether we need 2 stroke physicians and a GP • Should include Stroke specialist SLT • Include Rehabilitation consultant for post-acute care • Include Neuropsychiatrist for more severe end of spectrum • Include a Vocational rehab co-opted member

• Orthoptist • Speech and language therapist – aphasia • Orthotist • Social worker • Neurorehabilitation doctor	

Further Questions:

Draft review questions

A question about dietetic intervention was proposed. There are benefits of optimising nutrition in terms of reductions in bed days (and therefore could be cost saving). It was noted that if there are no clinical data, it will be difficult to build a model to investigate this.

1. Are there any critical **clinical** issues that have been missed from the Scope that will make a difference to patient care?

The following areas were suggested by stakeholders:

- Continence: many stakeholders emphasised this as an important area. Continence affects 40-50% of stroke patients in hospital, and is a barrier to people being discharged. It affects mood and motivation. There was a view that this could be a research question. Noted there is already NICE guidance on continence, but it is not Stroke specific.
- Fatigue: many stakeholders emphasised the importance of fatigue to stroke survivors
- Nutrition and hydration: issues with dysphagia, tube feeding, pre-existing malnutrition, low mood, mobility issues can be key for stroke survivors.
- Remote rehab: may need to be handled by its own question, or the committee to consider how remote delivery applies to each intervention
- Ongoing physiotherapy (long-term)
- Green care therapy (includes outdoor horticultural, etc.) for improvement of well being
- Tai Chi

Stakeholders asked whether timeframes for providing interventions would be included.

2. Are there any areas currently in the Scope that are **irrelevant** and should be deleted?
None identified
3. Are there areas of **diverse or unsafe practice** or uncertainty that requires addressing?
A stakeholder raised the issue of provision of funding for communication systems. There is currently regional variation in how this is funded . There is a need for a clear commissioning framework, which is not in place at the moment. Stakeholders mentioned standardisation of the intensity and frequency of therapy , since regional variation exists Stakeholders reported that younger patients can be missed from rehab while the cause of their stroke is being investigated and this becomes the main focus. Stakeholders mentioned vocational rehabilitation, there is variation in provision.
4. Which area of the scope is likely to have the most marked or biggest health implications for patients?
Swallowing and mouth care could have an impact on nutrition, reducing length of stay, infection
5. Which practices will have the most marked/**biggest cost** implications for the NHS?
No comments
6. Are there any **new practices** that might **save the NHS money** compared to existing practice?
Remote rehab could be cost saving and allow more efficient working in the community. Improved mouth care could reduce infection and hospital stay. Early awareness and referral to support organisations via early signposting to local and third sector services and telehealth support.

7. If you had to delete (or de prioritise) two areas from the Scope what would they be?
None identified
8. As a group, if you had to rank the issues in the Scope in order of importance what would be your areas be?
Top priorities: • Organisation and planning • Swallowing and mouth care • Communication • Intensity and frequency of physiotherapy
9. What are the top 5 outcomes?
Additional outcomes mentioned: • Comment about outcomes around remote rehab – because digital inequality is an issue • Mood suggested as an outcome; mood could be covered by the emotional functioning question • Motivation / ability to self-manage were suggested • Cognition outcomes
10. Are there any areas that you think should be included for the purposes of the quality standard? Are there any service delivery or service configuration issues that you think are important?
Accessibility of services
11. Other issues raised during subgroup discussion for noting:
Equalities issues to take into account:

- Groups not represented in research – those who struggle with communication, cognitive problems
- Carer support and impact on carers (e.g. time off work, travelling) – could include as part of population and / or outcomes

Aligning with national policy is important.

Nurse representation in previous guideline was low – Stroke nursing could be included as part of community rehab services.