Supplementary material 6: Stakeholder Activity 5: *Clinical implications*

1. Aim	
Task aim	To agree implications arising from the review findings for (a) stroke survivors and carers, (b) clinicians and (c) policy makers.
2. Methods	
Who was involved?	Lived Experience Group n=2, Clinical Expert Group n=2, Research team n=8
When was the involvement?	A meeting was held in November 2021. This occurred after completion of data synthesis and analysis for both the scoping and Cochrane review. This is considered as involvement during Stage 10-11, interpretation of findings.
What happened?	A 2-hour videoconference meeting. Prior to the meeting, stakeholders were sent a written summary of the results of the scoping and Cochrane review. At the start of the meeting a presentation was delivered providing a summary of the results from both the Scoping Review and Cochrane Review. The meeting then split into 2 breakout groups: 1. Lived Experience Group members (discussion facilitated by DJN). People in this group discussed what they considered the key implications for stroke survivors and carers arising from the review results. 2. Clinical experts and researchers (discussion facilitated by AP). People in this group discussed what they considered the implications for clinicians were. These discussions were structured around each individual sense. The meeting participants then came together, and the group facilitator gave a brief overview of the group discussions and key implications raised. The full group then discussed the implications for policymakers. Note-takers recorded each of the discussed implications during the meeting. The meeting discussions were audio-recorded and a member of the research team listened back through to ensure that no points were missed from the final list of implications.
Level of involvement?	The aim was that stakeholders contributing to this task would have influence over the final review, having generated statements of implications which would be incorporated into the review findings / discussion of findings.
3. Results	
Outcomes—Report the results of stakeholder involvement in the study, including both positive and negative outcomes	Key points raised in the discussion are summarised below. **Implications for stroke survivors and carers** Overall the group felt disappointed that there is no evidence to improve treatment. The group highlighted that the post-stroke period is scary and that information about perceptual disorders is needed. Information provision should not be given in isolation but with someone alongside who can provide support and remember details. Increased awareness is also needed to highlight that perceptual disorders

	and stroke can occur in young people. Care for people with perceptual disorders is a complicated process and individual support (with opportunities to talk) is required. Stroke survivors can continue to make progress over a long period of time. **Implications for clinicians** The group discussed implications related to each sense but felt that there was a common set of points that could be applied to all areas. These included that: • clinician should have awareness that stroke survivors' perception (such as vision, hearing, touch, somatosensation, taste and smell) can change following stroke • clinician should ask questions about potential disorders within assessments • If a stroke survivor has a perceptual disorder, ask how it impacts on their life • clinician should be honest that there is no strong evidence to support interventions but that this doesn't mean that nothing works • clinician shouldn't discount routine or simple interventions e.g. writing things down • clinician should consider what the purpose of an intervention is – think holistically. E.g. if the aim is to enhance quality of life then the intervention may differ from an aim to improve perception • there is a need for increased knowledge about how to help stroke survivors with perceptual disorders In addition, points for specific perceptual disorders were discussed. For disorders of **hearing, taste and smell perception** Appropriate members of the stroke care team should: • Ask if a stroke survivor's hearing, taste or smell has changed since their stroke • Ask specific questions about areas of difficulty e.g. for hearing, ask if it is more difficult to hear multiple people (compared to a single person) • Take stroke survivor's disorder into account when providing care e.g. information may need to be in written format if there is a hearing perceptual disorder (if appropriate) • Consider a stroke survivor's overall abilities and what might be causing difficulties e.g. is it hearing or inattention? For disorders of **tactile/touch perception** Appropriate members of the stroke care team should: • Ask specific questions about areas of difficulty e.g. have you noticed a difference in your touch? • Have awareness of the theoretical underpinnings of touch

	perception. • Consider incorporating strategies to enhance touch into other interventions (e.g., Activities of Daily Living training) • Be aware that the research relating to tactile/touch perception does not currently reflect standard/routine care For **somatosensory disorders** • Therapists should continue with standard therapy for pusher syndrome (i.e. no change to current standard clinical practice) • Standard therapy could be combined with additional robotic training if it is available For **vision perception disorders** Appropriate members of the stroke care team should: • Assess and, where appropriate, make changes to the stroke survivor's environment. For example, this could include removing clutter, or items which pose trip risks. • Encourage stroke survivors to use alternative strategies to compensate for visual perceptual disorders • Be holistic. Treatment might not be about specific interventions for the perceptual disorder. For example, health professionals may introduce compensation strategies to help stroke survivors finds ways to live with their disorder or may make adaptations to both home & hospital environments. • Consider that both restitutive (recovery) and compensatory approaches may enable stroke survivors to experience success, and can be combined The full group then discussed **Implications for Policy makers:** • A need for person-centred care that considers perceptual disorders • Increased awareness of all perceptual disorders post stroke is required • Education for all clinicians is needed (not just stroke specialists) • Interventions for perceptual disorders are a specialist area requiring adequate numbers of trained staff • There are economic implications if stroke survivors are not supported • An absence of evidence is not evidence of absence. • Perceptual disorders should feature within clinical guideline regardless of whether evidence is sufficient, other evidence such as patient stories should be considered • There are benefits to enabling stroke survivors to be independent but this shouldn't be the only focus of care

	• Stroke survivors may still need care and support despite being independent • Information provision on perceptual disorders is important for stroke survivors. Information should be provided in a variety of formats • Information provision is not an alternative to care and support • Further work is needed so interventions for perceptual disorders can be evidence based • Perceptual disorders (such as hearing assessments) should be an integral part of post stroke assessments and involve a range of healthcare professionals
4. Discussion & conclusions	
Outcomes—Comment on the extent to which stakeholder involvement influenced the study overall. Describe positive and negative effects	Participants from the lived experience contributed to and informed discussion on the overall project findings. These included implications for clinicians in relation to the different sensory areas, implications for research and policy. We consider that the level of stakeholder involvement contribution for this event was at the *influencing* level.
5. Reflections / critical perspective	
Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	Although evaluation forms were used for this event no forms were returned. The lack of response from stakeholder involvement members may reflect that several project meetings were taking place within a short period of time. Information to inform discussion was also sent out in advance of meetings which added to the stakeholder involvement workload. Where possible future events would be more evenly spread out to avoid stakeholder involvement fatigue. The wording of some of the agreed implications was amended prior to presentation in the final report, in response to feedback which highlighted the need for further clarification. This was done whilst attempting not to change the meaning of the originally stated implications. Had we had additional time, it would have been good to involve all the stakeholders in agreeing the updated wording.