Supplementary material 5: Stakeholder Activity 3: Organisation and interpretation of scoping review results

1. Aim	
Task aim	To discuss the meaning of the Cochrane review results, including: • What are the key findings? • What do these mean to people with lived experience or clinical expertise? • What gaps in the evidence are there?
2. Methods	
Who was involved?	Lived experience group n=4, Clinical expert group n=1, Research team n=11
When was the involvement?	There was a meeting in November 2021. This was within Stages 9 and 10 of the review process (analysing data and interpretation of findings).
What happened?	The meeting was held by videoconference and lasted 2 hours. There was an introductory presentation on 'what is a Cochrane review', an overview of the evidence included in the Cochrane review, followed by a presentation of the Cochrane review results for the senses of hearing, taste, smell, touch, somatosensation and vision. It was explained that there were no data relating to the senses of hearing, taste and smell. For the senses, stakeholders were asked: • What are your thoughts on this finding? • What does this mean to you / for you? The meeting ended with an overview of the results and stakeholders were asked to discuss what the overall result of the review was.
Level of involvement?	The aim was that stakeholders would contribute to the Cochrane review, by providing their views, thoughts and experiences.
3. Results	
Outcomes—Report the results of stakeholder involvement in the study, including both positive and negative outcomes	The main results of the discussion were: **Results for Hearing, Taste & Smell** There were no studies found that addressed interventions for hearing, taste or smell. Overall the group were not surprised at the low amount of evidence but felt that there was a clear need for studies in this area. The group highlighted the huge impact that these perceptual problems can have on quality of life and wondered how prevalent these perceptual problems were and if assessment tools were sensitive enough to pick up changes following stroke. As this Cochrane review only includes randomised controlled trials the group acknowledged that there were other study designs included within the scoping review (although none were identified specifically for taste and smell). It was also highlighted that with one of the main COVID symptoms being loss of taste and smell there might be future studies emerging that might be of interest.

	Results for Touch There were three studies presented for touch. Two of the studies improved perception (pressure). No difference was found for activities of daily living, mobility or adverse events. The studies were small with extremely limited data. The group felt that the interventions were novel (such as robotics or vibrating gloves) and didn't really reflect practice when trying to retrain touch. Interventions can often seem simple or straightforward and aren't taken forward for research trials. It was felt that services are so under resourced that there is only the capacity to provide services and not to undertake research. There is a real appetite however for sharing practice on perceptual disorders and a future need for collaboration with researchers. The group discussed that this review has only addressed perception rather than sensory issues too and was this a limitation. We were reminded that this review only includes adults as participants and therefore wouldn't necessarily capture literature on sensory integration interventions. The way that perception has been defined within the project doesn't include literature around mood or communication either. **Results for Somatosensation** Seven studies were presented for somatosensation. These were divided into two groups, studies that looked a Pushers syndrome and those that looked at other somatosensation disorders. Three of the studies using conventional physiotherapy improved ability in activities of daily living. Four studies using robotic or games based training improved ability in Pushers syndrome presentation. No difference was found for perception, mobility and navigation or adverse events. The studies were small with extremely limited data. The group identified that some of the interventions within the RCTs were quite similar (e.g. sensory discrimination training vs table top games) and wondered if the interventions had moved too soon to testing by RCT when further intervention development was needed (as per Society for Rehabilitation Research guidelines). It may be that both interventions were effective so the RCT is not showing any difference between the two groups. Standard therapy often includes a lot of contact including reassurance and the group wondered if this was missing from some of the experimental interventions. It was highlighted that none of the studies measured psychological impact. An emphasis on dosage is also needed to identify if resources are available to deliver the intervention in an effective way. Like the studies on touch there was an emphasis on novel interventions which might be more likely to gain funding for research rather than everyday practice. Not everyone however will be willing to take part in studies involving brain stimulation for example. It was felt that we need to look at the participants included within the studies as those with communication difficulties may have been excluded. The majority of studies were in hospitals and we should look at the stage post stroke too.

	Results for Vision Seven studies were presented for vision. Interventions were all very different for vision studies so data couldn't be combined. No effect was found for activities of daily living, mobility and navigation or perception. The studies were small with extremely limited data. The fact that none of the studies showed any difference was disappointing. It was highlighted that there are a number of new interventions such as apps but these interventions have been classified as interventions for visual field loss rather than a perceptual problem. There are other Cochrane reviews on visual field loss and neglect so we purposefully excluded studies on these. The group was reminded that perception includes recognising and interpreting sensory information. The studies included have a small number of participants so it's important to look at confidence intervals too. Even if results are not statistically significant there might be clinical significance. This data has been extracted for the Cochrane review. Often people with visual perceptual disorders will frequently have multiple issues and this must be a challenge for trial recruitment. Some group members highlighted that they have been involved in multiple groups identifying recommendations, but these don't seem to be making a difference in practice. It can be frustrating trying to make changes to service delivery, it can take a long time for changes to be implemented. There have been some changes to practice, but these changes are uneven across the country. We need standards to be more specific in relation to what we should actually assess or offer people with visual impairment post stroke. There are lots of people who aren't diagnosed with a visual impairment, and it's missed. A key issue seems to be training and a lack of easily available assessment tools that don't take much time to complete. Perhaps we can learn from studies from aphasia where there is research conducted to train healthcare professional behaviour. Service user and involvement can be very powerful and make more impact than scientific studies, so we need both to push for change. We need a lot more recognition and funding for this area. Overall data is limited so what we can draw from the data is limited. There should however be an emphasis on quality of life. CH highlighted that there are a further two meetings to discuss implications for practice and research. We haven't presented any information on quality of the studies included and the confidence that we have in the evidence. **Key findings in relation to aims of the day** • No studies found for hearing, taste and smell • Perceptual interventions are complex and have a big impact on quality of life post stroke

	• There is an absence of evidence, the data is limited and no one intervention seems to be more effective than another • Not surprised at the low amount of evidence and disappointed that studies for some studies (such as vision) didn't show any effect • Interventions in the studies don't reflect real world practice where the role of the therapist is important, instead there is a focus on novel interventions • Sample sizes are small and may not pick up clinically important differences • Further discussion needed on whether we should continue with interventions in practice that haven't shown any effect **<u>Implications for Care</u>** • Perceptual interventions are complex and have a big impact on quality-of-life post stroke • We need to consider how research findings are implemented in practice, there is still a need to increase awareness of perceptual problems post stroke <u>Implications for Research</u> • Clear need for research on interventions for hearing, taste and smell perceptual disorders • Research should address interventions that are used in clinical practice (including the supporting role of the therapist) rather than focus on novel interventions. An emphasis on dosage is also needed • There is a lack of capacity for clinical rehabilitation groups to undertake research and a need to collaborate with researchers
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 group contributed to the discussion of the Cochrane systematic review findings in relation to each of the senses. They considered the implications for rehabilitation as well as future research and highlighted what they felt to be the key findings. Participants felt that their level of contribution was at the *influencing* level within this task. As for Activity 3, this was a greater perceived level of involvement than we had planned for, suggesting that the people involved felt that their contribution was having an impact on the review.
5. Reflections / critical perspective	
Comment critically on the study, reflecting on the things that went well and those that did	Although evaluation forms were used for this event only one form was returned with minimal information included. The lack of response from stakeholder involvement members may reflect that a number of project meetings were taking place within a short period of time, with attendance at meetings prioritised over requested paperwork.

not, so others can learn from this experience	