

## Supplementary material 4: Stakeholder Activity 3: Organisation and interpretation of scoping review results

1. Aim	
Task aim	To discuss the meaning of the scoping review results, including: <ul style="list-style-type: none"> <li>• What are the key findings?</li> <li>• What do these mean to people with lived experience or clinical expertise?</li> <li>• What gaps in the evidence are there?</li> </ul>
2. Methods	
Who was involved?	Meeting 1 Lived Experience Group n= 4, Clinical Expert Group n=4, Research team n=7 Meeting 2 Lived Experience Group n=5, Clinical Expert Group n=3, Research team n=6
When was the involvement?	There were two meetings: one in September 2020 to discuss the preliminary findings, and one in May 2021 to discuss the final scoping review findings. Both were classed as being within Stage 9 and 10 of the review process (analysing data and interpretation of findings).
What happened?	Both meetings were held by videoconference and lasted 2 hours. At meeting 1 there were two short presentations summarising the preliminary findings from the scoping review. Stakeholders were asked what their thoughts were on the preliminary findings, whether the results were clear, what they wanted to know more about, and what their key findings were, and meant, to them. There was also a presentation about ways that the data could be mapped, and discussions around the best way to map the data, whether we should have one, or more, map, and the relationships which interested people most. At meeting 2 there were short presentations covering (i) an overview of the scoping review results, (ii) the interventions covered by the scoping review, (iii) the outcomes covered by the scoping review. Stakeholders were asked: <ul style="list-style-type: none"> <li>• What are the key findings?</li> <li>• What does this mean to you?</li> <li>• What questions are you left with? (what's missing/any gaps)</li> </ul>
Level of involvement?	The aim was that stakeholders would contribute to the scoping review, by providing their views, thoughts and experiences.
3. Results	
Outcomes— Report the results of stakeholder involvement in the study, including both	The key points raised in <b>Meeting 1</b> discussion were:  <u>Lived Experience Group key points:</u> 1. The studies included had outcome measures that were typically less than three months. The Lived Experience Group members did not feel like this represented their or their loved ones recover post stroke. LEG1*: My daughter's evolution post stroke can be tracked over years

<p>positive and negative outcomes</p>	<p>not months.</p> <p>2. The things that matter to people after their stroke (outcomes) can be very different. LEG2: I was surprised that the way I perceive things in terms of the outcome measures is very different from what a lot of other people's concerns were.</p> <p>3. Rehabilitation stops three months after stroke. LEG2: I felt abandoned three months after stroke</p> <p>4. Rehabilitation can be very focused on physiotherapy with not much input from neuropsychology. LEG3: What I didn't know was how I was progressing from a neurological point of view.</p> <p>5. Rehabilitation needs to consider the full effects of the stroke (including mental health). LEG4: it is important to consider the full knock-on effect of a stroke on a person's life.</p> <p>6. The information provided to a stroke survivor about timeframes of rehabilitation can affect how they view their own recovery: LEG2: I was told that if I hadn't made any improvements within 12 weeks then the way that I was after 12 weeks was the way that I would be for the rest of her life</p> <p>7. There was a clear lack of interventions delivered in a community setting: LEG1: so many of the interventions are hospital based. The risk here is that many issues may not present until the person is back at home. LEG2: But it really is not representative of a person's life when they get back home</p> <p>8. Going forward there needs to be more research that explores the possibilities for tele-rehabilitation. LEG1: I am excited by the possibility for ongoing online interaction rather than just those very few precision hours that happen in an isolated setting out with the environment with which you are living.</p> <p><u>Clinical Expert Group key points:</u></p> <p>1. Taste and smell have only been addressed in one study out of 49. CEG1*: taste and smell are underrepresented and isn't focused on, despite it being an important part of rehabilitation, particularly for people struggling with swallowing issues.</p> <p>2. There was a clear lack of studies that were delivered remotely. CEG2: No studies were delivered remotely. All studies reviewed were delivered face to face.</p> <p>3. There doesn't seem to have been much work done in the area of visual perception since 2010. CEG3 I was surprised that it seems like not much work has been done since 2010</p> <p>4. Currently rehabilitation may be too focused on the physical aspects of recovery. LD: People would actually really benefit from seeing a neuropsychologist for extended periods because they will work on identifying cognitive deficits but also emotion-based therapies and family based therapies.</p> <p>5. Audiology doesn't test people for perceptual hearing difficulties which may explain some of the lack of research in this area. CEG4: It isn't even really part of standard audiological clinical practice that they would be accessing perception.</p> <p>6. There is a lack of evidence for interventions addressing visual</p>
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perception post stroke. LD: I'm not surprised that there is a clear lack of a developed evidence base on visual perceptual difficulties despite their importance for people after stroke.

7. Perceptual interventions need to look at long term outcomes. SH: Recovery doesn't stop at three months I think that is a really important point to recognize.

Mapping discussion key points:

1. The ability to focus on the parts of the evidence that is most important to you in the maps is useful. SH: I like the way you can selected or zoom in on aspects of the data that you may be particularly interested in.

2. Visually it could be useful if the maps were pictures of people and you could then selected the area you were interested in (e.g. eyes = vision). SH: Could you do a map of the body or parts of the body?

3. It is very important to get the maps sense specific. CEG4: I would be interested between the senses. Because my question will be about a sense specifically

4. The maps could be used to create profiles of the interventions that stroke survivors with specific perceptual disorders require. LEG1: I think this has tremendous potential for profiling the individual

5. The maps should focus on the evidence gaps to direct future research. CEG1: It helps to highlight for other researchers where can we focus going forward. It is nice to be able to point people towards those gaps

The key points raised in **Meeting 2** discussion were:

Overall views: Overall it was felt that there hasn't been much research conducted especially when compared to other areas of stroke research. This is important because stroke is still the third leading cause of disability in the world and we now have more stroke survivors living with a greater severity of disability. It's important that the review highlights that there has been little research and suggests what needs to be done.

Awareness and understanding: Not everyone in the group was familiar with some of the terms used, for example Pusher syndrome (where someone pushes towards the affected side) or somatosensation (pressure, temperature & body position). The group felt that there was a lack of ongoing support and information and a sense of not knowing all the perceptual problems that can occur following a stroke. This is important because issues can sometimes be hidden and stroke survivors or carers can be unaware of what to look out for or what to ask for help with. Not knowing what you should be working towards can make you feel quite isolated and depressed.

Long term recovery: The group pointed out that improvements to senses such as vision can continue for many years after stroke. This is particularly the case with childhood stroke as the brain continues to develop but that these changes to perception aren't recorded over long

periods of time. This information might be helpful in developing our understanding of how people recover following stroke.

Study designs: It was noted that there are lots of case reports included in the scoping review (more than any other study design) and this might be because the interventions are difficult to research, they need to be carefully described which is a difficult thing to do. This might be one of the reasons that this area is at an early stage of research and not well funded. Interventions delivered within a case report might be tailored to the individual person and could be difficult to standardise to test with a larger group, but this is something that needs to be looked at moving forward.

Unpublished work: The group felt that there must be lots of information that hasn't been published and perhaps a way forward is to look at how you can bring together all the case reports. Lots of the information that we want about interventions hasn't been reported within studies so if we are going to look at how we can learn from individual case reports then we need to look at how they can be better reported.

Study settings: Many of the studies delivered their interventions in hospital settings but the group highlighted that so much is done for you in hospital, so it's only when stroke survivors return home do they find out what areas of everyday life they have difficulty with. Some people are still discovering things that have been affected years later so it's important to include people who are at later stages post stroke. It can put a lot of pressure on stroke survivors to be told that most of your recovery will take place in the first six months as years down the line you can still improve. Knowing this can help you to adjust and accept your situation. You end up finding ways of doing things and it might not be as bleak as you felt early on.

Outcomes: The outcomes that were reported by the studies included those that were measured by tests as well as those self-reported by stroke survivors using a rating scale for example. The group felt it was important to look at both what you could measure but also what people experience themselves. It was highlighted that no qualitative studies that aimed to explore experiences were found. It was also highlighted that none of the studies reported information on any stroke survivor or carer involvement in the research conducted or in the choice of outcomes measured. The group felt that stroke survivors or parents/carers could be given definitions of perceptual problems and a grid to chart difficulties that they had and whether interventions delivered had an impact. This would help to highlight issues that a person might have but they might not be aware of. It can be quite small things, but these can have an impact on quality of life and can be overlooked. There are also tips that you can share that can make quite a difference to someone and prevent them having to struggle with something for years because they didn't know.

Senses: It was noted that there are more studies that have looked at vision

	or somatosensation than other senses such as hearing, tactile, taste or smell. Group members felt
<b>4. Discussion &amp; conclusions</b>	
Outcomes— Comment on the extent to which stakeholder involvement influenced the study overall. Describe positive and negative effects	<p>Participants from the lived experience group contributed to the discussion of the scoping review findings. They considered what the findings meant to them as stroke survivors and highlighted what areas they felt were of importance.</p> <p>Participants felt that their level of contribution was at the <i>influencing</i> level within this task. 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.</p>
<b>5. Reflections / critical perspective</b>	
Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	<p>The flow of the meeting worked well at a speed that everyone could follow. The meeting was well prepared, and information was sent out in advance. There was good, collaborative discussion with all opinions welcomed.</p> <p>The meeting was conducted online, and some participants struggled with their internet connection which impacted on their ability to engage.</p>

\* Details of individual commenters from the Lived Experience Group (LEG) and Clinical Expert Group (CEG) have been anonymised and are replaced using the abbreviation of the group the person belonged to, and a number e.g. LEG1

