

## Supplementary material 1: Stakeholder activity 1 - definition of key terms

1. Aims	
	<p>A) To agree definitions and terminology and decide how these should be applied in the review process,</p> <p>C) To create a comprehensive set of search terms and determine how the definition of perception can be used when selecting papers for inclusion,</p> <p>B) To create a taxonomy of perceptual defects to inform the review structure.</p>
2. Methods	
Who was involved?	Lived Experience Group n=2, Clinical Expert Group n=3, Research team n=9, plus Cochrane Stroke information specialist
When were they involved?	In month 1 of the review (meeting held on 22 <sup>nd</sup> January 2020) and at the stage of developing the review questions, methods and protocol.
What happened?	<p>A full-day face-to-face meeting, covering:</p> <ul style="list-style-type: none"> <li>• Welcome &amp; introductions</li> <li>• Presentation of project background &amp; aims</li> <li>• Role of stakeholder involvement, discussed &amp; agreed meeting rules and methods of voting to reach consensus</li> <li>• Discussion &amp; consensus activities around definitions &amp; terminology: the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) definition of perception, to be used in the project was presented ("specific mental functions of recognizing and interpreting sensory stimuli"), followed by description of what this did and did not include. It was noted that the group cannot change this definition but could suggest additions to maximise the clarity and ease of understanding, perhaps considering the need for further explanation, clarification of terms, or a lay description.</li> <li>• Discussion and agreement on which senses should be included in the review, and associated definitions. The WHO ICF definitions for perception in vision, visuospatial, hearing, taste, smell, and touch were discussed. Disorders whose inclusion was not clear (hallucination, balance, proprioception and somatosensory) were discussed.</li> <li>• Identification of search terms. Paper and flip charts were set up around the room. Taste and smell were combined but all other sensory area were addressed in isolation. Participants moved freely round the room and added to each sheet/chart the names or description of perceptual disorders relating to sense.</li> <li>• Classification of perceptual disorders. Pre-prepared slips containing definitions/descriptions of visual and visuospatial perceptual disorders were set out on one large table and participants were encouraged to discuss and arrange these into a meaningful classification system. Specialists in other senses were encouraged to identify a classification system for their field.</li> </ul> <p>CONSENSUS VOTES included:  VOTE 1 (on methods of voting): to discount all "neither agree nor disagree" votes, and that 2/3 of the remainder must be "agree" or "strongly agree" to be considered</p>

	<p>as agreement on a decision.</p> <p>VOTE 2 (on definition of perception): to accept the WHO ICF definition of perception as “specific mental functions of recognizing and interpreting sensory stimuli” with no modifications.</p> <p>VOTE 3 (on lay definition of perception, which was generated through discussion): to accept a lay definition of perception as “processing and understanding information from the senses”</p> <p>VOTE 4 (on definitions of the senses, which were generated through discussion): to accept these definitions of the senses included in this review:</p> <table border="1" data-bbox="323 633 1401 1529"> <tr> <td data-bbox="323 633 592 779">Vision (Visual)</td> <td data-bbox="592 633 1401 779">Processing and understanding visual (vision) information. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret visual information.</td> </tr> <tr> <td data-bbox="323 779 592 965">Hearing (auditory)</td> <td data-bbox="592 779 1401 965">Processing and understanding auditory (hearing) information. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret auditory information.</td> </tr> <tr> <td data-bbox="323 965 592 1115">Taste (gustatory)</td> <td data-bbox="592 965 1401 1115">Processing and understanding gustatory (taste) information. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret gustatory information.</td> </tr> <tr> <td data-bbox="323 1115 592 1265">Smell (olfactory)</td> <td data-bbox="592 1115 1401 1265">Processing and understanding olfactory (smell) information. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret olfactory information</td> </tr> <tr> <td data-bbox="323 1265 592 1379">Tactile</td> <td data-bbox="592 1265 1401 1379">Processing and understanding information from the skin. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret tactile information.</td> </tr> <tr> <td data-bbox="323 1379 592 1529">Somatosensation (including proprioception)</td> <td data-bbox="592 1379 1401 1529">Processing and understanding somatosensory (or proprioceptual) information which may include the mental functions of being able to distinguish, discriminate, recognise, and interpret somatosensory information.</td> </tr> </table>	Vision (Visual)	Processing and understanding visual (vision) information. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret visual information.	Hearing (auditory)	Processing and understanding auditory (hearing) information. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret auditory information.	Taste (gustatory)	Processing and understanding gustatory (taste) information. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret gustatory information.	Smell (olfactory)	Processing and understanding olfactory (smell) information. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret olfactory information	Tactile	Processing and understanding information from the skin. This may include the mental functions of being able to distinguish, discriminate, recognise and interpret tactile information.	Somatosensation (including proprioception)	Processing and understanding somatosensory (or proprioceptual) information which may include the mental functions of being able to distinguish, discriminate, recognise, and interpret somatosensory information.
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Level of involvement?	We gave the stakeholder involvement Group members control over the operationalisation of the definitions used and the senses included in the review. We achieved this through facilitated discussion, supported by voting to capture level of agreement with developed definitions.												
<b>3. Results</b>													
Outcomes—Report the results of stakeholder	<p>During the meeting four statements were generated and voted on.. Results of these votes are as follows:</p> <p>VOTE 1: agreement on this definition of consensus for meeting decisions.</p> <table border="1" data-bbox="323 1973 1401 2009"> <thead> <tr> <th data-bbox="323 1973 639 2009">Option</th> <th data-bbox="639 1973 751 2009">Count</th> <th data-bbox="751 1973 1002 2009">% of counted</th> <th data-bbox="1002 1973 1401 2009">Comments</th> </tr> </thead> </table>	Option	Count	% of counted	Comments								
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involvement in the study, including both positive and negative outcomes			votes	
	1. strongly agree	9	100	<ul style="list-style-type: none"> <li>Fair way to move forward</li> <li>I in part suggested it!</li> </ul>
	2. agree	3		
	3. neither agree or disagree	1	discounted	
	4. disagree	0		
	5. strongly disagree	0		

VOTE 2: agreement on the definition of perception.

Option	Count	% of counted votes	Comments
1. strongly agree	5	90.9	<ul style="list-style-type: none"> <li>Good to keep the WHO ICF-acknowledged definition and add lay definition in which we add our interpretation, with including the explanation of mental functions from the ICF</li> </ul>
2. agree	5		<ul style="list-style-type: none"> <li>Still query mental functions</li> <li>Broad enough</li> </ul>
3. neither agree or disagree	3	Not counted	<ul style="list-style-type: none"> <li>Being practical because lay is better</li> </ul>
4. disagree	1	9.1	<ul style="list-style-type: none"> <li>Not happy with “recognising and interpreting”. Unclear what meaning is of these words. Does it include discrimination, detection etc</li> </ul>
5. strongly disagree	0		

VOTE 3: agreement on a lay definition of perception

Option	Count	% of counted votes	Comments
1. strongly agree	9	100	<ul style="list-style-type: none"> <li>It is meaningful, sensible, captures the life of the person – after all, our research is focussing on impact on people’s lives</li> <li>succinct</li> </ul>
2. agree	4		<ul style="list-style-type: none"> <li>I understand what this means</li> </ul>
3. neither agree or disagree	0	Not counted	
4. disagree	0		

5. strongly disagree	0		
VOTE 4: agreement on definitions of the included senses			
Option	Count	% counted	Comments
1. strongly agree	8	100	<ul style="list-style-type: none"> <li>• Clear and easy to follow</li> <li>• Specific application of generic perception definition to each sense</li> </ul>
2. agree	6		<ul style="list-style-type: none"> <li>• Consistent definition agreed by experts</li> <li>• Same template works well, consistency, might be a bit vague</li> <li>• Uniform and follows on from agreed-on lay decision</li> </ul>
3. neither agree or disagree	1	Not counted	
4. disagree	0		
5. strongly disagree	0		
A detailed list of perceptual disorders relating to each sense was generated.			
Classification systems for visual perceptual disorders and for taste and smell disorders were created.			

#### 4. Discussion & conclusions

Outcomes  
—  
Comment on the extent to which stakeholder involvement influenced the study overall. Describe positive and negative effects

The detailed list of perceptual disorders relating to each sense directly informed the terms used in search strategy.

We expected it would be difficult to apply the agreed definition of perception and we planned that stakeholder groups would pilot the decided inclusion criteria to a selection of screened search results. Meeting time constraints meant that this activity was not completed.

#### 5. Reflections / critical perspective

Comment critically on the study,

Overall, the day worked well, it was well structured, organised and had a sense of purpose. A clear introduction to the study was provided which increased participants' understanding. They felt that there was an open environment which meant that they could share their opinions and felt listened to. There was sufficient

<p>reflecting on the things that went well and those that did not, so others can learn from this experience</p>	<p>time allocated for discussion.</p> <p>Participants found the day challenging (although enjoyable), particularly the technical jargon used and requested a terminology brief. There wasn't enough time to work through all items on the agenda and if information had been sent in advance this might have helped. It was a lot to cover by including six senses, but this was needed for the project. A larger voice for those with a lived experience was required.</p>
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#### 4. Discussion & conclusions

<p>Outcomes— Comment on the extent to which</p>	<p>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.</p>
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<p>stakeholder involvement influenced the study overall. Describe positive and negative effects</p>	<p>Participants felt that their level of contribution was at the <i>influencing</i> 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.</p>
<p><b>5. Reflections / critical perspective</b></p>	
<p>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>	<p>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.</p>

4. Discussion & conclusions	
Outcomes— Comment on the extent to which stakeholder involvement influenced the study overall. Describe positive and negative effects	<p>The research team and stakeholder groups were able to create a clear list of research priorities, via an email-based ranking process. This is a key output of this project</p> <p>We estimate that the level of stakeholder involvement contribution for this meeting was at the <i>controlling</i> level.</p>
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	<p>The email ranking process appeared to work well, with a good rate of return. One stroke survivor struggled to understand how to prioritise – what things she should consider to be able to assign a rank – and advice was given via email. Further advice could have been added to support Clinical Expert Group members in this exercise.</p> <p>Some researchers did not take part, as they felt their role was primarily methodological, and their input was not relevant to the very clinical nature of the questions.</p>