

### Supplementary material 3: Stakeholder Activity 2b. Outcome measure identification and prioritisation - Ranking the priority of different outcome domains

1. Aim	
Task aim	To generate a shared ranking / prioritisation of outcome domains (to report data in the scoping review and select primary and secondary outcomes for the Cochrane review).
2. Methods	
Who was involved?	Lived Experience Group n=4, Clinical Expert Group n=3, Research team=8
When was the involvement?	Month 8 of the project (August 2020). This was within Review Stage 2-3 – developing the methods and protocol.
What happened?	The results of Activity 2a were used to inform a list of ‘categories’ of outcome measures, which included examples of how these may impact on the life of a stroke survivor with perceptual difficulties. These were tabulated and sent to everyone involved, who individually ranked each of the categories from 1 (most important) to 17 (least important) (see Ranking sheet below, Annex 1). Individual rankings were summed to provide combined rankings for stakeholders (lived experience and clinical expert group), researchers (research team) and whole group combined. The results were used to inform the decision on the order of how to present data in both reviews, and the specific (6) outcomes to include within the Cochrane review.
Level of involvement?	The aim was for the lived experience and clinical experts to have control over the outcome measures that were included in the Cochrane review.
3. Results	
Outcomes— Report the results of stakeholder involvement in the study, including both positive and negative outcomes	The combined (whole group) rankings, from most to least importance, were: <ol style="list-style-type: none"> <li>1. activities of Daily living (ADL)</li> <li>2. extended ADL (eADL)</li> <li>3. social activities and participation</li> <li>4. psychological and mental health</li> <li>5. quality of life (QoL)</li> <li>6. mobility navigation and safety</li> <li>7. sensation, cognition, motor ability, attention</li> <li>8. impact on rehabilitation</li> <li>9. perceptual function</li> <li>10. impact on family friends and carers</li> <li>11. paediatric specific – measure of development, education etc</li> <li>12. discharge destination</li> <li>13. feasibility, acceptability etc</li> <li>14. adverse events</li> <li>15. ability to compensate using other skills</li> <li>16. neurological function</li> <li>17. economic outcomes</li> </ol>

	<p>The rankings for researchers only were</p> <ol style="list-style-type: none"> <li>1. ADL</li> <li>2. EADL</li> <li>3. QoL</li> <li>4. social activities and participation</li> <li>5. psychological and mental health</li> <li>6. mobility navigation and safety</li> <li>7. discharge destination</li> <li>8. sensation, cognition, motor ability, attention</li> <li>9. impact on rehabilitation</li> <li>10. perceptual function</li> <li>11. impact on family friends and carers</li> <li>12. paediatric – measures of development, education</li> <li>13. adverse events</li> <li>14. feasibility, acceptability etc</li> <li>15. economic outcomes</li> <li>16. ability to compensate using other skills</li> <li>17. neurological function</li> </ol> <p>The rankings for the stakeholders only were</p> <ol style="list-style-type: none"> <li>1. social activities and participation</li> <li>2. mobility navigation and safety</li> <li>3. EADL</li> <li>4. Psych and mental health</li> <li>5. ADL</li> <li>6. QoL</li> <li>7. sensation, cognition, motor ability, attention</li> <li>8. perceptual function</li> <li>9. impact on rehabilitation</li> <li>10. impact on family friends and carers</li> <li>11. paediatric – measures of development, education</li> <li>12. feasibility, acceptability etc</li> <li>13. ability to compensate using other skills</li> <li>14. discharge destination</li> <li>15. adverse events</li> <li>16. neurological function</li> <li>17. economic outcomes</li> </ol>
<b>4. Discussion &amp; conclusions</b>	
<p>Outcomes— Comment on the extent to which stakeholder involvement influenced the study overall.</p>	<p>The list of outcomes was ranked by both the lived experience group and co-applicants resulting in an overall list of prioritised outcomes. The outcomes were mapped to the list of impacts (generated by the lived experience group) to ensure that all areas were covered.</p> <p>We considered that the level of involvement of the Lived Experience Group was controlling this stage of the review.</p>

Describe positive and negative effects	
<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	This was an ongoing process rather than a set event, as a result evaluation forms were not used. On reflection, this was a missed opportunity to capture feedback on this task.

Annex 1: Ranking Sheet (sent by email and completed individually)

<b>Categories</b>	<b>Examples</b>	<b>Rank (1-17) 1= most important 17 = least important</b>
<b>Ability in core activities of daily living</b> <i>Definition: People's daily self-care activities</i>	<ul style="list-style-type: none"> <li>• Struggling to clean teeth</li> <li>• Having to start water on unaffected side of body to determine temperature</li> <li>• Limited ability to dress</li> </ul>	
<b>Measures of perceptual ability</b>	<ul style="list-style-type: none"> <li>• Difficulty recognising objects</li> <li>• Poor texture discrimination</li> <li>• Impaired sense of taste</li> </ul>	
<b>Compensating for perceptual deficits by using other skills</b>	<ul style="list-style-type: none"> <li>• The use of braille</li> <li>• Reliance on touch/tactile sense</li> <li>• Increased reliance on memory</li> </ul>	
<b>Ability in extended activities of daily living</b> <i>Definition: Activities and tasks beyond basic self-care that may be necessary for living independently</i>	<ul style="list-style-type: none"> <li>• Struggling to read</li> <li>• Giving up driving</li> <li>• difficulty leaving home (alone)</li> <li>• difficulty with travel</li> </ul>	
<b>Quality of life</b> <i>Definition: the standard of health, comfort, and happiness experienced by an individual or group</i>	<ul style="list-style-type: none"> <li>• Enjoyment of food is reduced</li> <li>• General wellbeing and happiness</li> <li>• Social wellbeing</li> <li>• Physical wellbeing</li> </ul>	
<b>Social activities and skills, participation</b> <i>Participation definition: the act of taking part in something</i>	<ul style="list-style-type: none"> <li>• Impaired interaction with other people</li> <li>• Difficulty having a conversation with a loved one</li> <li>• inability to fulfil a caring role</li> <li>• unable to go to church or do a hobby</li> </ul>	

<b>Mobility, navigation, and safety</b>	<ul style="list-style-type: none"> <li>• Getting into danger, or being unsafe</li> <li>• Bumping into things and accidents around the house causing injuries</li> </ul>	
<b>Measures of sensation, cognition, motor ability, attention</b>	<ul style="list-style-type: none"> <li>• Hard to concentrate on any other task while holding something</li> <li>• loss of balance</li> <li>• change of sense of self in space</li> </ul>	
<b>Paediatric specific: development and education</b>	<ul style="list-style-type: none"> <li>• Impact on learning</li> <li>• Impact on cognitive development</li> <li>• Perceptual impairments can lead to behavioural issues</li> </ul>	
<b>Psychological effects and mental health</b>	<ul style="list-style-type: none"> <li>• Mental wellbeing affected</li> <li>• Effects on happiness and contentment</li> <li>• Frustration</li> <li>• Depression and anxiety</li> <li>• loss of confidence</li> </ul>	
<b>Brain (neurological) function</b>	<ul style="list-style-type: none"> <li>• brain scans e.g.MRI</li> </ul>	
<b>Discharge destination or residence after stroke</b>	<ul style="list-style-type: none"> <li>• Returning home</li> <li>• Going to live in residential care</li> </ul>	
<b>Impact on rehabilitation</b>	<ul style="list-style-type: none"> <li>• ability to achieve rehabilitation goals</li> </ul>	
<b>Adverse events caused by the intervention</b>	<ul style="list-style-type: none"> <li>• Falls</li> <li>• Pain</li> <li>• Allergic reaction</li> </ul>	
<b>Economic outcomes</b>	<ul style="list-style-type: none"> <li>• cost of the treatment / staff delivering the treatment</li> <li>• changes in long-term health care costs</li> </ul>	
<b>Feasibility, acceptability, and implementation</b> <i>Definition: measures of how well something has worked and how well it is likely to work in practice</i>	<ul style="list-style-type: none"> <li>• difficulty using hearing aids</li> <li>• inability for staff to deliver rehabilitation as planned</li> </ul>	
<b>Impact on the family, friends and carers</b>	<ul style="list-style-type: none"> <li>• Burden of providing support</li> <li>• Needing to help when someone cannot read</li> <li>• Difficulty having a conversation with a loved one</li> </ul>	