

Supplementary material 2: Stakeholder Activity 2a: Outcome measure identification and prioritisation - explore impact of perceptual problems on life after stroke

1. Aim	
Task aim	To identify the ways that perceptual impairments can impact people’s lives (to inform future selection of outcome measures).
2. Methods	
Who was involved?	Lived Experience Group n=5, Research team n=2
When was the involvement?	Month 5 of the project (14 th May 2020). This was within Review Stage 2– planning the methods
What happened?	Group members met by videoconference. They discussed how perceptual issues affect stroke survivors which was used to develop a list of the impacts of perceptual impairments.
Level of involvement?	The aim was that people involved would <u>influence</u> decisions around selection and prioritisation of outcome measures.
3. Results	
Outcomes— Report the results of stakeholder involvement in the study, including both positive and negative outcomes	<p>The members of the group suggested that perceptual issues following stroke can impact people’s lives in the following ways:</p> <ul style="list-style-type: none"> Every area of life Reading Reading facial expressions Having to use the ‘auditory environment’ to compensate for visual perceptual issues getting into danger, or being unsafe affecting the way people can understand the world around them Impact on learning and cognitive development Disconnections between the word for an item, and the item itself The use of books, reading, stories for learning (including braille skills) Cognitive impairment caused by the impact of perceptual issues on learning/development The need to declutter the home environment Needing to develop-strategies to help compensate for and deal with perceptual issues making a mental map of a new environment, to allow the person to move around The use of braille Reliance on touch/tactile sense Increased reliance on memory Difficulty reading visual cues Impaired interaction with other people - Mental wellbeing affected Effects on happiness and contentment Guilt about preserving self as a burden on loved ones Impact on family members

	<p> Burden of providing support Needing to help when someone cannot read The impact of a stroke survivors depression on family/carers The impact of personality changes Diminished sight and hearing Lack of assessment Lack of support Understanding the nature and severity/extent of perceptual changes Understanding what the long-term impact of sight loss will be Understanding how perceptual issues will impact dependents /children Developing strategies to deal with sight issues Impact on ability to achieve goals Bumping into things and accidents around the house- causing injuries Struggling to clean teeth Textures of food can be unpleasant, even horrible eg sandwiches with lettuce and cold meat is disturbing Enjoyment of food is reduced Having to give up driving General impact on life overall Huge shock Struggle to pick things up Avoidance of tasks that require lifting of good sense of touch eg shopping, cooking Inability to determine the weight of objects Cannot identify what an item is by touch Forgetting an object is being held Texture discrimination impaired Sense of touch doesn't start until half-way up arm recognition of temperature impaired Having to start water on unaffected side of body to determine temperature Impact on having hair washed at the hairdressers Lack of control of hand muscles means you can drop things Hard to concentrate on any other task while holding something missing out the left hand side of the keyboard when texting Difficulty communicating Impaired sense of taste Can't hear so well Can't taste more subtle flavours – so when cooking flavours now need to be much stronger Food textures are difficult to discriminate Cannot swallow certain foods Terrified of choking on small things or anything slippery Any-slippery food is perceived as horrible Psychological impact of stroke Impact on carer when personality changes Hearing loss Not using / difficulty using hearing aids Frustration when you cannot hear someone </p>
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	<p>Difficulty having a conversation with a loved one Having to find new ways to communicate e.g. writing notes, lip-reading Very frustrated by impairments Acceptance of impairments Children and young people can have autistic like traits (like temper tantrums) Perceptual impairments can lead to behavioural issues Struggle to understand and make yourself understood Reduced ability to control your own life Concern about how you now look to others</p>
4. Discussion & conclusions	
<p>Outcomes— Comment on the extent to which stakeholder involvement influenced the study overall. Describe positive and negative effects</p>	<p>The generated list of impacts highlights the wide-ranging impact of perceptual impairment on stroke survivors and their family members, friends and carers.</p> <p>This list was grouped together by the research team into a series of categories, which were used for Activity 2b. This ensured that the outcome measures considered for prioritisation in Activity 2b comprehensively covered what the Lived Experience Group described as the impact of perceptual problems.</p> <p>We considered that the level of involvement of the Lived Experience Group was <i>influencing</i> this stage of the review.</p>
5. Reflections / critical perspective	
<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>This was an ongoing process rather than one set event, as a result evaluation forms were not used. On reflection, this was a missed opportunity to capture feedback on this task.</p>

