

Supplementary material 7: Stakeholder Activity 6a: Research recommendations

TASK 6: Research recommendations	
Activity 6a: Research gaps relating to perceptual problems after stroke.	
1. Aim	
Task aim	To agree the research gaps relating to perceptual problems after stroke.
2. Methods	
Who was involved?	Lived Experience Group n=2, Clinical Expert Group n=2, Research team n=98
When was the involvement?	A meeting was held in December 2021. This occurred after completion of data synthesis and analysis for both the scoping and Cochrane review. This is considered as involvement during Stage 10-11, interpretation of findings.
What happened?	<p>A 2-hour meeting was held via videoconference. Prior to the meeting, the stakeholders were contacted by email and asked to submit research questions / gaps, based on their consideration of the review findings. In addition, the research team went through notes and transcripts from previous stakeholder meetings and extracted any proposed research gaps / questions / recommendations.</p> <p>During the meeting, previously submitted and identified research gaps were presented, grouped into research questions which addressed the whole / general topic of post stroke perceptual impairment, and research questions which addressed a specific sense. With the presentation of each group of research questions, stakeholders were asked if any important questions / research gaps were missing. These were written down as they were discussed, so that stakeholders could clarify or comment on wording of the questions.</p> <p>Following the meeting, the research questions were collated. Where research questions were addressing similar topics, these were brought together into a stated research gap which may reflect more than one research question, however the original research questions were linked to these stated research gaps in order to ensure transparency. The collated research gaps / questions were then circulated by email to all stakeholders, asking them if these were comprehensive or whether they could identify any further research gaps / questions. Any additional submissions were added to the collated list.</p>
Level of involvement?	The aim was that stakeholders contributing to this task would control the final review, having generated statements of research gaps which would directly inform Activity 6b, and the generation of research recommendations.
3. Results	
Outcomes — Report the results of stakeholder	<p>The collated list of research gaps (and summed score) was as follows:</p> <p>1. RESEARCH PRIORITIES RELATING TO PERCEPTUAL PROBLEMS IN GENERAL</p> <p>We need:</p>

involvement in the study, including both positive and negative outcomes	<p>Research to enhance robust assessment of perceptual problems following stroke</p> <p>This includes (1) finding the best way to assess perception, including in those who have other impairments, such cognitive (thinking) impairments or other illnesses (2) finding the best way of telling the difference between perceptual problems and other problems (e.g. sensory, cognitive) (3) Assessing how perceptual problems affect function (such as everyday skills) (4) Assessments done as part of clinical practice, and outcome measures assessed for research studies.</p>
	<p>Research to establish the prevalence of perceptual problems following stroke</p> <p>This includes (1) finding the frequency (prevalence) of perceptual problems after a 1st stroke (2) finding the frequency of perceptual problems after a 2nd or subsequent stroke (3) exploring patterns of natural recovery, including long term recovery (4) exploring the relationship between perceptual problems and other stroke-related impairments</p>
	<p>Research to determine interventions currently delivered for perceptual disorders</p> <p>This includes exploring (1) what is ‘usual care’ provided to stroke survivors with perceptual problems? (2) what interventions are currently delivered in the ‘real world’, and what is the nature of these interventions? (3) what is the nature of current long-term care for people with perceptual problems?</p>
	<p>Research to explore the lived experiences of stroke survivors and carers</p> <p>This includes (1) Exploring their experiences and the impact of perceptual problems on daily lives (2) exploring their awareness and understanding of their perceptual problem (3) finding what is most important to stroke survivors and carers (4) identifying what support services they need (5) exploring long term impact</p>
	<p>Research to establish best ways of providing teaching / ensuring adequate knowledge and understanding of professionals (including those working in health and social care, and in charity/3rd sector organisations)</p>
	<p>Research to explore current care delivery and pathways, across NHS, social care and charities</p> <p>This includes (1) who is providing care (2) what care/services are provided (3) when and where are care/services provided (4) when and how are referrals to specialists made (6) are there clear pathways and plans for care for perceptual problems (7) acceptability to stroke survivors and carers</p>
	<p>Research that explores interventions in a way that reflects real world needs (for stroke survivors and clinicians)</p> <p>This includes (1) using or creating outcome measures that reflect stroke survivors’ priorities (2) exploring interventions currently in use, or readily accessible to clinicians (3) exploring intervention / service costs (4) explore feasibility, acceptability and sustainability (5) includes all relevant populations, and considers co-morbidities</p>

Research to establish a clear definition of perception

Research to explore the impact of perceptual impairment on the family and carers

This includes

1) what is the impact on children of stroke survivors (2) What do family members provide by way of support for individuals with perceptual problems? (3) What is the impact on family members and carers of providing support to individuals with perceptual problems e.g. caregiver strain, depression, quality of life

2. RESEARCH PRIORITIES RELATING TO VISUAL PERCEPTION

There are a lack of studies relating to visual perception and a lack of evidence about effective interventions.

Future research should address the following questions:

How well is the whole visual system (or hierarchy) assessed?
How effective are current interventions?
Amongst GPs and other health and social care practitioners, what is their knowledge of, and attitude about, visual perceptual disorders? What are their training needs?
Who are the professionals involved in providing care of people with visual perceptual disorders and what are their roles and referral pathways? Are current pathways they working/effective?
Within current clinical practice, when are visual perceptual problems being assessed/addressed? How does this vary in different geographical areas? What is best practice?
How 'acceptable' are different interventions (types, intensities, etc)?
What are the experiences of stroke survivors? (How does a stroke patient cope with visual disorders? Does what they see impact on their perceptual meaning?)

3. RESEARCH PRIORITIES RELATING TO SOMATOSENSATION

There are a lack of studies relating to somatosensation and a lack of evidence about effective interventions.

Future research should address the following questions:

How well is somatosensation assessed, in current clinical practice?
How can understanding and awareness of somatosensation be improved, amongst stroke survivors, their families and carers, and the wider health and social care team?
What are, and how effective are, current interventions?
Amongst GPs and other health and social care practitioners, what is the importance of knowledge of / education about somatosensation post stroke, and who and when to refer to specialist services / other professionals?
What are current pathways (across different service providers)? Are they working/effective?
Within current clinical practice, when are somatosensory problems being assessed/addressed, and who by?

<p>How 'acceptable' are different interventions (types, intensities, etc)?</p>
<p>What are the experiences of stroke survivors? (How does a stroke patient cope with these disorders? What is the impact on their lives, and that of their carers?)</p>
<p>How does somatosensation impact on balance and mobility? (How best can the role of somatosensation be identified, and how can this be differentiated from other factors that affect balance and mobility?)</p>
<p>How is temperature perception, and tolerance to temperature changes, affected by stroke?</p>
<p>4. RESEARCH PRIORITIES RELATING TO TOUCH / TACTILE PERCEPTION</p>
<p>There are a lack of studies relating to touch / tactile perception and a lack of evidence about current interventions.</p>
<p>Future research should address the following questions:</p>
<p>How can understanding and awareness of touch / tactile perception be improved, amongst stroke survivors, their families and carers, and the wider health and social care team?</p>
<p>What are, and how effective are, current interventions?</p>
<p>Amongst GPs and other health and social care practitioners, what is the importance of knowledge of / education about touch / tactile perception post stroke, and who and when to refer to specialist services / other professionals?</p>
<p>What are current pathways (across different service providers)? Are they working/effective?</p>
<p>Within current clinical practice, when are touch / tactile perception problems being assessed/addressed? Who is assessing for touch / tactile perception problems, and how well are they doing this?</p>
<p>How 'acceptable' are different interventions (types, intensities, etc)?</p>
<p>What are the experiences of stroke survivors? (How does a stroke patient cope with these disorders? What is the impact on their lives, and that of their carers?)</p>
<p>What education is required by stroke survivors, carers and health and social care professionals relating to touch / tactile perception, and how effective is this?</p>
<p>How does stroke affect hypersensitivity (e.g. pain caused by water when showering)?</p>
<p>5. RESEARCH PRIORITIES RELATING TO TASTE AND SMELL PERCEPTION</p>
<p>There are a lack of studies relating to taste and smell perception and a lack of evidence about current interventions. This includes <i>loss of, and distortion of,</i> taste and smell.</p>
<p>Future research should address the following questions:</p>
<p>What is the prevalence of taste and smell perception problems following stroke?</p>
<p>How can taste and smell perceptual problems be identified during the acute post-stroke phase?</p>
<p>Do stroke survivors who experience taste and/or smell problems have</p>

	prolonged rehabilitation/nutritional problems?
	How do taste and/or smell perceptual problems relate to social activities and participation, including enjoyment of food?
	What are the risks associated with disordered taste and smell and how can these risks be reduced/minimized? (e.g. hazards associated with eating dangerous food, or smelling gas).
	How does the perception of texture impact on palatability and enjoyment of food?
	Are there any interventions for taste and/or smell which may help with rehabilitation?
	Amongst GPs and other health and social care practitioners, what is the importance of knowledge of / education about taste and smell perception post stroke, and who and when to refer to specialist services / other professionals?
	Within current clinical practice, when are taste / smell perception problems being assessed/addressed? Who is assessing for taste / smell perception problems, and how well are they doing this?
	What are the experiences of stroke survivors? (How does a stroke patient cope with these disorders? What is the impact on their lives, and that of their carers?)
	What education/training is required by stroke survivors, carers and health and social care professionals relating to taste / smell perception?
	6. RESEARCH PRIORITIES RELATING TO HEARING PERCEPTION
	There are a lack of studies relating to hearing perception and a lack of evidence about effective interventions.
	Future research should address the following questions:
	How effective are current tools for assessing hearing perception impairments? Are they suitable / effective for stroke survivors with other impairments, including cognitive impairment?
	What, and how effective, are current interventions?
	Amongst GPs and other health and social care practitioners, what is the importance of knowledge of / education about hearing perceptual problems post stroke, and who and when to refer to specialist services / other professionals?
	What are current pathways (across different service providers)? Are they working/effective?
	Within current clinical practice, when are hearing perceptual problems being assessed/addressed? How does this vary in different geographical areas? What is best practice?
	How 'acceptable' are different interventions (types, intensities, etc)?
	What are the experiences of stroke survivors? (How does a stroke patient cope with hearing disorders? Does what they hear impact on their perceptual meaning? Does the hearing disorder impact on how others perceive them? How does the hearing disorder impact on their communication, and ability to participate in daily and social activities?)
	What is the understanding of the stroke survivor's communication partners about their hearing problem, and how does this impact on communication?

	<p>7. Overall recommendations about research</p> <p>In addition to the above priorities for future research relating to perceptual problems after stroke, it is important that future research:</p> <ul style="list-style-type: none"> • Has consistent reporting of results • Involves stroke survivors and carers • Assesses outcomes that are of importance to stroke survivors and carers • Has a sufficiently long follow-up period • (For randomised controlled trials – is adequately powered) • Assesses and documents whether participants have concurrent impairments, including more than one perceptual impairment and/or other stroke and non-stroke relating impairments • Is pragmatic in relation to the clinical populations eligible for inclusion • Clearly documents participant groups who are included / excluded from a study • Considers sustainability
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 lived experience group were able to contribute by identifying research gaps both in advance of the meeting, during discussion and post-meeting for the different senses. This information informed the development of research recommendations.</p> <p>We consider that the level of stakeholder involvement contribution for this meeting was at the influencing level. This was a lower level of involvement than we had planned for; the level of control the lived experience group had within this activity was limited by technical challenges which arose due to the meeting format.</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>Members of the lived experience group were able to actively contribute to the development of research priorities. This meant that areas of research that were of importance to them were included in the overall report.</p> <p>Formulation of research priorities took place in a “live format” during the meeting. This meant switching between presentation slides during an online meeting, which proved to be challenging for stroke survivors with a visual impairment to follow. In future an alternative method of data capture should be considered during online meetings.</p>

