Supplementary material 8: Stakeholder Activity 6b: Research recommendations

1. Aim	
Task aim	To reach consensus on the top priorities for future research relating to perceptual problems after stroke.
2. Methods	
Who was involved?	Lived Experience Group n=3, Clinical Expert Group n=4, Research team n=~~8~~9 (two research team members chose not to take part in this activity)
When was the involvement?	A consensus activity was carried out by email in February 2022. This occurred after the generation of research gaps (Activity 6s). This is considered as involvement during Stage 10-11, interpretation of findings.
What happened?	An email was sent to all stakeholders. The stakeholders were presented with the list of key research gaps relating to perceptual impairment in stroke (from Activity 6a). Each of the general research gaps were listed, with a written description of what that topic covers. The research gaps circulated were only those relating broadly to perceptual problems, and not those which relating to specific senses. There were a total of 9 general research gaps. Stakeholders were asked to rank these from 1-9, where 1 is the most important area for more research, and 9 least important. As a prompt, stakeholders were given the introductory statement: "A good way to think of it is to imagine you had £500,000 for a project – what would you want to spend it on?" These were reworded slightly to ensure clarity of meaning (see chapter 8)
Level of involvement?	The aim was that stakeholders contributing to this task would control the final review, having reached a shared consensus on the prioritisation of research gaps.
3. Results	
Outcomes—Report the results of stakeholder involvement in the study, including both positive and negative outcomes	The original prioritised list of research gaps and summed scores:

Rank (summed score)	Research Gap
1 (45)	**Research to explore the lived experiences of stroke survivors and carers** This includes • Exploring their experiences and the impact of perceptual problems on daily lives • exploring their awareness and understanding of their perceptual problem • finding what is most important to stroke survivors and carers • identifying what support services they need

			• exploring long term impact
	2 (53)		**Research to enhance robust assessment of perceptual problems following stroke** This includes • what is the best way to assess perception, including amongst subpopulations who have other impairments, such cognitive (thinking) or communication impairments or other illnesses? • what is the best way of distinguishing between perceptual problems and other problems (e.g. sensory, cognitive)? • do perceptual problems impact on function (such as everyday skills)? If so, how do they impact on function and to what extend do they impact on function? • exploring the assessments done as part of clinical practice and outcome measures assessed for research studies, including their relevance, validity and reliability
	3 (57)		**Research that explores interventions in a way that reflects real world needs (for stroke survivors and clinicians)** This includes • using or creating outcome measures (of effectiveness) that reflect stroke survivors' priorities • exploring interventions currently in use, or readily accessible to clinicians • exploring intervention / service costs • explore feasibility, acceptability and sustainability • includes all relevant populations, and considers co-morbidities
	4 (73)		**Research to determine interventions currently delivered for perceptual disorders** This includes exploring • what is 'usual care' provided to stroke survivors with perceptual problems?

		• what interventions are currently delivered in the 'real world', and what is the nature of these interventions? • what is the nature of current long-term care for people with perceptual problems?	
	5 (79)	**Research to establish the prevalence of perceptual problems following stroke** This includes • finding the frequency (prevalence) of perceptual problems after a 1ˢᵗ stroke • finding the frequency of perceptual problems after a 2ⁿᵈ or subsequent stroke • exploring patterns of natural recovery, including long term recovery • exploring the relationship between perceptual problems and other stroke-related impairments	
	6 (81)	**Research to explore current care delivery and pathways, across NHS, social care and charities** This includes • who is providing care? • what care/services are provided? • when and where are care/services provided? • when and how are referrals to specialists made? • are there clear pathways and plans for care for perceptual problems? • what is the acceptability of care delivery to stroke survivors and carers?	
	7 (86)	**Research to explore the impact of perceptual impairment on the family and carers** This includes • what is the impact on children of stroke survivors • What do family members provide by way of support for individuals with perceptual problems? • 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	
	8 (97)	**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)
	9 **(101)**	**Research to establish a clear definition of perception** This may include work to determine clear definitions and names (terms) for perceptual disorders

4. Discussion & conclusions

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

We estimate that the level of stakeholder involvement contribution for this meeting was at the *controlling* level. |

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	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.

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. |

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