

# Interventions for people with perceptual disorders after stroke: the PIONEER scoping review, Cochrane systematic review and priority setting project

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## Scientific summary

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# Scientific summary

## Background

Perception is the synthesis and interpretation of information gathered through the senses: hearing, taste, touch, smell, visual and information on temperature, pressure, vibration and body position, known as somatosensation. Up to a fifth of stroke survivors experience perceptual disorders after stroke, limiting their ability to perceive and process sensory information and reducing their ability to take part in daily activities. To date, the effectiveness of perceptual disorder interventions after stroke is unclear. Clinical guidelines offer limited recommendations. Stroke survivors, carers and healthcare professionals have stated that improving research into perception is important to them. Further, it is important to systematically identify evidence gaps and future research priorities.

## Objectives

We aimed to:

- Identify all published and unpublished research evaluating interventions for perceptual disorders after stroke, providing a comprehensive report on the scope and nature of the evidence to date and highlighting the research gaps identified.
- Synthesise and appraise the quality of randomised controlled trial (RCT) evidence of the effectiveness of perceptual disorder interventions after stroke.
- Understand the implications of our findings for stroke survivors and HCPs working in this area and to determine future research priorities.

## Methods

Our project included a scoping review, the revision and expansion of a Cochrane systematic review and we worked with a Lived Experience Group and a Clinical Expert Group to co-create research recommendations and identify research priorities.

Our scoping review of the literature was based on a systematic search of several electronic databases including MEDLINE, EMBASE and CINAHL (inception to August 2021), as well as searches of grey literature, contacting experts and forward citation tracking. We included studies of any design which explored interventions for stroke survivors with hearing, smell, somatosensation, taste, touch or visual perception disorders. Eligible abstracts and full texts were independently reviewed by two reviewers; data were extracted, tabulated and narratively synthesised. Data availability and outcome measures used were mapped. In keeping with scoping review methodology, we did not formally assess research quality.

We updated a Cochrane systematic review, including RCTs of adult stroke survivors with perceptual disorders. We assessed the risk of bias, conducted meta-analyses to explore effectiveness of interventions and judged our confidence in the findings using grading quality of evidence and strength of recommendations (GRADE). Outcomes were measured using activities of daily living (ADLs) with extended activities of daily living (EADLs), quality of life, mental health, perceptual function and adverse events data also collated.

Using structured involvement and priority setting approaches we worked in partnership with our Lived Experience and Clinical Expert Groups to agree clinical implications and to future research priorities.

## Results

This project was coproduced with people with lived experience of stroke and perceptual disorders ( $n = 5$ ) and relevant multidisciplinary clinical expertise ( $n = 4$ ). Working in partnership with the core research team, these groups informed the project throughout, agreeing definitions of perception, relevant outcome measures, clinical implications and priorities for future research.

### Scoping review

Of 91,869 records screened, we included 80 studies (including 36 case reports; 22 RCTs) in the scoping review, most (64%) of which were published in the previous decade. Participants ( $n = 893$ ) were predominately adults and male; five children were included. Studies generally had small sample sizes, with RCTs accounting for most participants (70.5%; 630/893). The perceptual disorders represented included visual (43%), somatosensory (35%), auditory (9%), tactile (8%) or 'mixed' disorders (5%) which included one study on taste–smell disorders. We identified 93 interventions including rehabilitation (84%), pharmacological (6.5%) and non-invasive brain stimulation (NIBS) interventions (7.5%); no surgical or assessment-based interventions were identified. Intervention details were limited. Outcome measures commonly included perceptual function (75%), motor/sensorimotor (40%), ADLs (23%) or sensation (15%). No data on discharge destination, health economic, feasibility, educational (children), psychological well-being and mental health, quality of life, or activity and participation were reported. Time points were typically immediately after the intervention (39%) or within 3 months follow-up with just 15% of studies capturing outcomes beyond that time point.

### Cochrane systematic review

Drawing on the scoping review results, the trials identified in a previous Cochrane Review and an updated search of bibliographic databases, 2575 records were identified. From these, 114 full texts were considered and 18 RCTs ( $n = 541$ ) were included. All but six were stroke survivors, between 19 days and 4.3 years from onset.

The interventions included targeted visual (seven RCTs;  $n = 225$ ), tactile (three RCTs;  $n = 70$ ), somatosensory (seven RCTs;  $n = 196$ ) and one mixed tactile-somatosensory disorders (one RCT;  $n = 50$ ). No RCT evaluated interventions for stroke-related hearing, taste or smell disorders. Interventions included 1 NIBS, 1 compensatory, 25 restitution, 4 mixed and 1 unclear intervention approach. Seven included RCTs (39%) measured participants' ADLs though others captured perception (11 RCTs), adverse events (6 RCTs), mobility (4 RCTs) and EADLs (1 RCT). None measured activity and participation, quality of life or psychological well-being and mental health outcomes. We identified 11 ongoing RCTs.

The risk of bias of the included RCTs varied, with 72% describing adequate generate of the randomisation sequence and outcome assessor blinding, but concealment of allocation was considered adequate for only a third. Most trials adequately reported participant attrition (78%) and the outcome data gathered (89%). Other sources of bias were noted including an imbalance between the groups at baseline and altered eligibility criteria mid-RCT.

With limited data there was insufficient evidence to determine the effectiveness of any one intervention compared to no intervention or an alternative intervention. Based on the small number of RCTs, the small sample sizes and the limited comparisons available, our confidence in the evidence was, using GRADE, judged to be low–very low.

## Strengths

Throughout this project, a Lived Experience and Clinical Expert Group were centrally involved in the development of definitions, categorisation, outcome measurement selection, interpretation of data and

research prioritisation, supporting clinical relevance and validity. The consensus working definitions and categorisations developed may support future research on this topic area. Our scoping and systematic reviews were conducted to the highest research conduct and reporting standards.

## Limitations

Despite large numbers of people experiencing one or more perceptual disorder after stroke, there is a striking lack of relevant research to inform interventions. What little has been reported is often based on a single participant or small sample sizes. There is limited description of the perceptual disorder, the intervention(s) evaluated and a focus on perception outcomes rather than measures that reflect the functional impacts described by the Lived Experience Group, for example ADLs. We also found evidence of under-researched subpopulations including children and people with hearing, taste and smell perceptual disorders. The project team, Lived Experience and Clinical Expert Groups are UK-based, and it is unclear whether our priorities (outlined below) capture the wider international picture.

## Priority setting

Our clinical expert ( $n = 4$ ) and lived experience ( $n = 5$ ) stakeholders' input was pivotal throughout the project. Together with the core research team, these groups agreed the clinical implications and research priorities emerging from the findings.

## Implications for health care

Clinical recommendations include the facilitation of improved awareness of stroke-related perceptual disorders, assessment and information provision and holistic intervention approaches and support. While the research evidence was insufficient to support clinical decision-making relating to the choice of intervention approach, the scoping review provides an important information resource for clinicians developing best practice until sufficient evidence becomes available.

## Recommendations for research

The evidence informing interventions for perceptual disorders after stroke is limited, and absent for smell, taste and tactile disorders. Future research should prioritise (1) exploration of the lived experience of people with stroke-related perceptual disorders, (2) improving assessments of stroke-related perceptual disorders, (3) exploring interventions in a way that reflects real-world needs, (4) exploring current clinical practices that address perceptual disorders following stroke and (5) establishing the prevalence of perceptual disorders after stroke.

## Conclusions

Healthcare professionals lack high-quality evidence of effective interventions to inform their provision of advice, treatment and education of stroke survivors with perceptual disorders and their families. Evidence informing these research priority topic areas is urgently required.

## Study registration

This study is registered as PROSPERO CRD42019160270.

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