Perceptual disorders after stroke InterventiON EvidencE Review (PIONEER): a scoping review and Cochrane Review revision and expansion

Study Protocol

Version 1 26th February 2020

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This project is financially supported by National Institute of Health Research Health Technology Assessment (HTA) (NIHR128829). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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Funder

Name:	NIHR Health Technology Assessment
Funder Number:	NIHR128829
Funder start date:	01.01.2020
Funder end date:	31.03.2021

VERSION HISTORY

Version Number	Date	Date superseded	Changes Made	Reasons for Change
1	26/2/20			

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1. Background and Rationale

1.1. What is the problem: perception and stroke

1.1.1. What is perception?

Perception is the ability of the brain to interpret and integrate information detected by the different sensory systems. It is an umbrella term, that includes perceptual abilities in all senses: visual, hearing (auditory), taste (gustatory), smell (olfactory) and tactile systems. Perception involves multiple steps in the processing of sensory information: to organise it, assign meaning and create an understandable representation of the sensory landscape[1].

1.1.2 Perceptual disorders in stroke

The nature and frequency of perceptual disorders in stroke research is unclear, but using current data we estimate that up to 880,000 stroke survivors in the UK are affected[2]. Visual perceptual disorders may affect up to 69% of individuals at one month post stroke and in 74% at two years post stroke[2]. Deficits can affect a broad range of visual skills including recognition, location judgement, depth perception, perception of motion, image differentiation and integration of sensory information[1,3,4].

Auditory perception deficits can include difficulty with localisation and lateralisation; discrimination of speech from non-speech sounds; recognition of auditory patterns; and difficulty with competing acoustic signals[5]. A recent case-control study reported an auditory processing deficit prevalence of 40% in stroke survivors aged between 18 and 60 years[6].

Stroke is associated with both olfactory dysfunction[7,8] and taste impairment[9]. Almost a third of stroke survivors may have a total loss of taste and 6% have lateralised impairment of taste function a week after stroke[10]. Olfactory dysfunction persists a year after onset in 43% of stroke survivors, with 29.7% having a reduced ability to perceive odours, and 10.8% with no ability to detect odour[11].

Tactile perceptual skills may be reduced by up to 85% on the affected side after stroke[12–14]. Deficits can impair tactile recognition, including discrimination of texture, shape, and length, and object recognition[15].

1.1.3 Impact of perceptual disorders in stroke

Perceptual disorders reduce an individual's ability to understand their environment and thus respond appropriately to it. Our recent qualitative work has shown that visual impairment limits practical abilities, social activities and relationships, and reduces self-confidence, leading to social isolation[16]. Quantitative studies have shown that visual perceptual dysfunction is associated with reduced ability in activities of daily living[17], greater disability, poorer quality of life[18] and can predict poor self-care[19]. Auditory perceptual disorders impact on listening and linguistic skills, reducing communication ability, which may impact on diagnosis and restrict

participation in rehabilitation[6]. Taste dysfunction can lead to subjective unpleasantness when eating, impaired appetite and in turn dietary changes, malnutrition and weight loss, known to impact on rehabilitation outcomes[20]. The inability to smell negatively impacts on eating, social communication and safety. Altered perception of touch can lead to poorer performance of motor tasks, accidents and injuries (such as scalds and burns), learned non-use of limbs[21] and is linked with poor recovery of motor function[12] and reduced ability in activities of daily living[22].

1.2. Why this research is needed now

1.2.1 Interventions for perceptual disorders

Treatment approaches for perceptual disorders are primarily rehabilitative, aiming to compensate for the loss in function, but these vary depending on the sense affected and the nature of the dysfunction. Therapeutic approaches to visual disorders may include sensory stimulation, (practising tasks that require visuo-perceptual skills)[23,24], functional training (practicing everyday tasks)[25] and strategy training (finding alternate strategies to achieve goals) including the use of other senses. Olfactory and gustatory disorders due to stroke receive less attention in rehabilitation [26] and pharmacological approaches have been suggested [27], as has referral to a dietitian for advice[28]**.** For impaired touch perception, interventions typically focus on the upper limb, and include retraining sensory recognition and discrimination using specialist equipment[29].

1.2.2 Current care is poorly documented and variable

As perceptual impairments can affect all five senses, care typically involves a range of healthcare professions. The limited information available on services suggests that current management is restricted and variable[30]. Healthcare professionals may be unfamiliar with perceptual impairments in hearing, taste, smell and touch, so stroke survivors affected may not be assessed or diagnosed, nor be provided with treatment [20,31,32]. This is compounded by stroke survivors' and their families' poor awareness and understanding of different perceptual losses, resulting in under reporting of these disorders [32,33].

1.2 3 Clinical guidance is limited by lack of research

Guidelines clearly note the paucity of research on which to base clinical recommendations for perceptual disorder interventions[34–36]. Withing UK stroke guidelines for adults, most recommendations are based on best practice consensus. Current UK guidelines do not provide clinicians with much-needed up-to-date treatment guidance: the focus is on visual impairments; no specific assessment methods are recommended; treatment suggestions are extremely limited and no specific guidance is given on how to choose or deliver these treatments.

1.2.4 Why this research is needed now:

Identifying effective interventions for perceptual impairments is a shared top ten research priority for stroke survivors, carers and healthcare professionals[37]. Clinicians have highlighted the limitations imposed on clinical practice in relation to some perceptual disorders by a lack of research into effective interventions[38], and have called for research to support both assessment methods and treatment approaches[39]. NICE guidelines have also called for further research[34].

2 Aims and objectives

We aim to identify, review and synthesise the existing evidence for interventions in the management of perceptual disorders following stroke. Our specific objectives are:

1: To identify published and unpublished research relating to interventions for perceptual disorders after stroke and provide an overview of the scope and nature of that evidence, highlighting evidence gaps.

2: To synthesise and appraise randomised controlled trial evidence of the clinical effectiveness and cost of interventions.

3: To share our findings with stroke survivors, carers and healthcare professionals, using their perspectives and expertise to determine future research priorities.

3. Conceptual framework: defining perception

Perception is extremely difficult to define. There is no one accepted definition and huge variation in the potential scope and components included. Further, there is no agreement on the delineation between perception and other skills – sensation and perception are frequently grouped together, and perception can be considered one of a range of cognitive abilities[1,3]. Conceptual differences are linked to variations in professional background, theoretical approach, research methodology, geographic location and these also vary with time. Difficulty in establishing and applying a definition of perception has been an issue for previous reviews of interventions for perceptual impairment in stroke[40].

We plan to use the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) definition of perceptual disorders which include "specific mental functions of recognizing and interpreting sensory stimuli"[41] (ICF code b156). This definition is most suitable as; (i) it provides a very clear distinction between the functions of sensation and perception; (ii) whilst placing perception within the field of cognitive activity, it has a clear distinction from other cognitive functions; (iii) the definition is applicable to all five senses and not just to vision (as often occurs) and (iv) the WHO ICF is widely accepted, understood and used world-wide.

We propose to exclude sensory disorders (ICF code b2) and disorders of attention (ICF code b140 encompassing visual neglect), as these topic areas have a separate evidence base[42,43] to support clinical care and inform future research. We will fully explore and agree our definition and delineation of perception, and the practical implications of this in work with our PPI groups at the start of the project (section 3.3.2).

4. Research Plan / Methods

4.1 Design Summary and Rationale

We will conduct a 3-stage project to address the requirements of this call (in bold) and our project objectives.

Stage 1. Systematic Scoping Review with Evidence Gap Mapping (objective 1)**.** We will undertake a scoping review of the literature to identify all evidence relating to interventions for perceptual disorders after stroke. Scoping reviews aim to map a broad field of literature, rather than address a very focussed question, thus this approach is appropriate given the numerous, diverse perceptual problems occurring post-stroke and the wide range of potential interventions. Our scoping review will employ systematic, transparent methods to analyse all the relevant research[44].

Our approach will follow a six-stage framework, including thorough searching and use of broad study design inclusion criteria (see 4.2 below)[45]. We will examine the relevant research, using iterative methods, to create, test and refine our search strategy, to develop a rigorous search of the existing literature[46]. We will provide a full overview of the volume, nature, and characteristics of the primary research conducted to date[45,47]. We will include **all interventions, all participant age groups, settings, study designs** (including quantitative and qualitative methods) and **all outcomes** relating to interventions for perceptual disorders. Results will be summarised narratively and diagrammatically, providing **evidence maps** and clear assessment of **evidence gaps**[48].

Stage 2. Cochrane Review Expansion and Revision (objective 2)**.** We will review the RCT evidence of the clinical effectiveness and cost of interventions for perceptual disorders after stroke. Cochrane Reviews provide the highest quality evidence synthesis[49]: we will revise and expand the Cochrane Review "Non-pharmacological interventions for perceptual disorders following stroke and other adult-acquired, non-progressive brain injury"[40]. We will identify, assess and synthesise the evidence from RCTs to determine where **sufficient evidence already exists** to support a specific intervention. Where possible, we will consider participant subgroups (e.g. age, sex, stroke severity) to identify where an intervention or approach might be **beneficial to one or more subgroup**, vital in informing clinical recommendations.

Cochrane review methodologies provide the highest quality approach for synthesis of evidence intervention effectiveness[50]. However, the Cochrane review on perceptual disorders in stroke has several limitations; it included data from non-stroke individuals (i.e. with other adult acquired, non-progressive brain injury), explored only non-pharmacological interventions, focused mainly on visual disorders and is now dated (last search August 2009). A further Cochrane review focuses on a small subset of perceptual disorders (sensory impairment in the upper limb)[21]. We will revise the Cochrane Review of perception to focus specifically on evidence that relates to the stroke population, to include all perceptual impairments and all treatment approaches, and use TiDieR checklist to maximise clarity of intervention descriptions[51], providing an up-to-date, comprehensive and clinically meaningful evidence synthesis.

Stage 3. Integration of project findings (objective 3). We will work in partnership with our Clinical Expert and Lived Experience Group (see below), so our review findings will be interpreted in the context of current clinical practice and stroke survivor experiences[52]. Using structured methods of involvement[53] and priority setting[54] we will agree research priorities and provide r**ecommendations for future research**.

4.2 Stage 1: Scoping Review with Evidence Gap Mapping

We will conduct a systematic scoping review to map the main sources and types of evidence available [55] and provide a clear overview of the number, range, scope, and design of studies, allowing assessment of evidence gaps.

We will employ the refined 6-stage systematic scoping review framework devised by Arksey and O'Malley [45,56,57] to ensure rigour and transparency, and include an evidence gap mapping process (stage 5) [58]. This involves;

(1) identifying the research question

(2) identifying the relevant studies

(3) study selection

(4) charting the data (data extraction)

(5) collating summarising and reporting (with evidence gap mapping)

(6) consultation (which for PIONEER will take place throughout the review process).

Current best practice scoping review reporting guidance will be used[59]. We have published our protocol via PROSPERO (CRD42019160270).

4.2.1 Information Sources and Search

We will perform a systematic and comprehensive search of the literature to identify all relevant studies. Our search strategy has been drafted (see example in Appendix 1), and peer-reviewed in accordance with PEER guidelines[60]. It will be further refined following discussion with PPI group (see below) to specifically target interventions for the five different sensory areas, a broad stroke survivor age range, the full range of perceptual disorders and encompassing the wide range of terminology used.

We will search a wide range of sources including:

Electronic sources

i. Bibliographic databases
    a. MEDLINE
    b. EMBASE
    c. ERIC
    d. CINAHL
    e. AMED
    f. PsycINFO
    g. ASSIA
    h. PsycLIT
    i. LILACS (Latin American and Caribbean Health Sciences Literature)
    j. Epistemonikos
    k. Cochrane library databases (CENTRAL, CDSR)
    i. Web of Science Core Collection
ii. DARE, NHSEED and HTA databases (archived at CRD) (https://www.crd.york.ac.uk/CRDWeb/)
iii. registers of ongoing trials (Clinicaltrials.gov, WHO international Clinical Trials Registry Platform, EU Clinical Trials Register)

Other sources

iv. grey literature including OpenGrey, Grey Matters, Google scholar and NIHR Clinical Research Network
v. contact research and professional associations or foundations, and specialist physiotherapy database PEDro (http://www.pedro.org.au/) and occupational therapy database OTseeker (www.otseeker.com)
vi. PROSPERO, Conference Proceedings Citations Index (Science), ProQuest Dissertations and Theses
vii. websites of relevant charities and patient support organisations
viii. contacting experts in the field
ix. searching national / international guidelines, government websites, relevant HCP professional websites
x. citation tracking using Science Citation index, and searching the reference lists of included studies

4.2.2 Agreeing and operationalising "perception"

Operationalising the term 'perception' will be challenging due to the many different definitions and descriptions used within studies. Following a decision-making meeting with the research team, Cochrane Stroke Group information specialist, Clinical Expert Group and Lived Experience Groups we will agree our definitions and terminology and decide on our application of these definitions to the review process.

(i) Agreeing our definitions: Agreeing a robust set of definitions and vocabulary is an essential step for the team, in order to support a shared understanding of the conditions and interventions under consideration.

In advance of this meeting, all participants will be sent a meeting pack with the WHO ICF definition (section 4.2) and our draft definitions of key terms (such as visual, auditory, tactile, olfactory etc). Participants will discuss each of the proposed definitions in turn and reach consensus on a definition[53]. This will be achieved using a structured, facilitated discussion[61], supported by voting techniques to confirm consensus has been reached. A practical activity, involving moving cards containing key terms to create a taxonomy, will be carried out and captured (by photograph).

(ii) Applying our definitions: To ensure our search identifies as many of the relevant perceptual disorders as possible, the research team, Cochrane Stroke Group information specialist, Clinical Expert Group and Lived Experience Groups will identify all relevant terms to include in our literature search. This will be based on our agreed definitions (above) and core terms elicited from key psychology texts[3,4]. The draft search strategy and identified titles and example abstracts (from running the draft search in Medline) will be considered, and discussion facilitated around whether the results are perceived to be comprehensive, or whether additional search terms are required[62]. As the terminology may be more extensive for visual disorders, we will use a list of visual disorders as a template to search for analogous disorders in other senses. Such iterative development is a recognised component of scoping reviews, given the uncertainty relating to concepts and terms[46].

Attendees will apply the current inclusion criteria to the screened draft search results. Any problems arising will be discussed and used to refine screening decision-making. This meeting will be recorded, and the decisions and their impact on the review process will be reported.

4.2.3 Developing the search strategy

We have developed a preliminary search strategy in conjunction with the Cochrane Stroke Group information specialist (Appendix 1). It updates the original Cochrane Review strategy, combining 'stroke' terms (lines 1-4) with broad terminology relating to 'perception' and 'perceptual disorders' (lines 6-10).

We will add terms for specific perceptual disorders in all five sensory areas following (i) discussion with research team and our PPI groups (see 4.2.2) and (ii) integrating

these new key terms (using free text and MeSH) with our current draft strategy. We will test the searches in Medline and refine the search terms further prior to searching other databases.

4.2.4.Screening and Eligibility.

A two-step process will be used to determine study inclusion in accordance with current scoping review guidance[56].

1. All titles will be assessed for eligibility by one reviewer (KM). Any obviously irrelevant titles and duplicates will be excluded. All other titles will be assigned a code to denote the sensory area it likely relates to, to note if more than one sensory system is involved, or if it is unclear. Study identification processes will be managed using Endnote.

2. The remaining abstracts will be screened by two reviewers (KM, CH). Based on the inclusion criteria (see Table 1) the reviewers will independently class abstracts as relevant, irrelevant or unsure. Titles will be assigned a code to denote the sensory area it likely relates to, to note if more than one sensory system is involved, or if it is unclear. Potentially relevant studies will be sent for further review by an expert relating to the sense addressed: they will class the abstracts as relevant or irrelevant. We will exclude all studies ranked as irrelevant and will retrieve the full text of the remaining studies. Two reviewers will then independently assess the full text articles against the predefined selection criteria shown in Table 1. Any disagreements will be resolved following discussion with an additional member of the research team or Clinical Expert Group. Reason(s) for each exclusion will be recorded

Table 1: Inclusion criteria for the scoping review

Aspect	Criteria
PARTICIPANTS	of any age (adults and children) with stroke-related disorders affecting the "functions of auditory, visual, olfactory, gustatory, tactile and visuospatial perception" [41] Studies which combine stroke and non-stroke populations will be included in this Stage 1 scoping review and coded to indicate whether they are a stroke-only or mixed population. To assist with distinguishing between sensory, perceptual and cognitive disorders reviewers will use relevant details, such as lesion location, classification systems used or reported theories of neural function. Studies that combine perceptual disorders with sensory or cognitive disorders, or where the precise nature of the disorder cannot be determined will be included and coded to clearly indicate this (as perceptual, perceptual-sensory, perceptual-cognitive, mixed, unclear).
HEALTH TECHNOLOGY	all interventions that expressly address a perceptual disorder. We envision these may include rehabilitation, pharmacological, screening/ assessment

	interventions and possibly surgical. We will include and code all interventions that address perceptual disorders across more than one sense.
STUDY DESIGN	all quantitative, qualitative and mixed-methods primary research studies, exploring clinical effectiveness, economic outcomes or implementation of interventions
SETTING	all settings, including hospital, community and out-patients, and any geographical location
DATA COLLECTED	all quantitative outcomes or qualitative data. The primary quantitative outcome of interest, and the ranking of secondary outcomes will be agreed with our co-production groups but may include; activities of daily living, quality of life, perceptual tests, depression and discharge destination
DATE AND LANGUAGE	All published and unpublished studies in any language, with no date limitations

We will exclude:

- studies of participants with perceptual disorders arising from other (non-stroke) neurological conditions
- studies addressing cognitive, sensory or attentional disorders.
- studies where the aim of the intervention is not clear
- secondary research, such as literature reviews

4.2.5 Data extraction and charting

Data extraction forms (using Windows Excel) using a series of free text and dropdown menus will be drafted by the co-applicant team, using existing in-house templates that have been successfully employed in other complex evidence syntheses. The data extraction sheets will be adapted and independently piloted by two reviewers using 5-10 studies selected to reflect the diversity of study designs, populations and interventions included. Reviewers will compare extraction, discuss and potentially amend the forms for further extraction. Extraction will be conducted by one reviewer and cross-checked by a second. Any disagreement will be resolved by discussion or referral to an independent reviewer. The data extraction form will include the following:

- Study: country, setting, design, year
- Participant: age, gender, time since stroke, hemisphere affected, stroke severity, perceptual disorder and method of diagnosis, presence of other stroke-related impairment
- Intervention for perceptual disorder: description using TIDieR checklist [51]
- Outcomes: all quantitative outcomes used, time point of data collection (post stroke or study specific) and results. From qualitative studies, we will record all descriptive themes relating to intervention effect/impact, costs or implementation, including the name and description of the content and meaning[63] and the time point post stroke of data collection.

Study and evidence quality will not be appraised, following current reporting guidlines[59] as our aim is to map the scope of literature available, rather than grade its quality[59].

4.2.6 Evidence Gap Mapping

Interactive Evidence Gap Maps will be created using Tableau visual analytic software and a systematic, transparent process, guided by recent recommendations[48,58]. Map organisation will be decided in consultation with our PPI groups[64], but may reflect perceptual disorders, intervention approaches, and outcome measures. They may use cells ("bubble") to denote relevant studies, with bubble colour showing the different types of evidence and size denoting the number of studies. Cells with no bubbles clearly show research gaps, where there is no evidence available on a given intervention and outcome.

4.2.7 Data collation, summarising and reporting

Along with Evidence Gap Maps, review results will be collated and presented in structured tables of identified evidence. We will divide the results into two sections: one for interventions for children (<18 years old) and one for adults (≥ 18 years old). Narrative reports will be used to summarise the evidence[45]. They will firstly provide a numerical summary describing the scope of studies identified; the perceptual disorders addressed; interventions explored, and quantitative outcomes and qualitative themes reported. The report will then provide a descriptive thematic summary of the findings, related clearly back to the review aim[46].

The organisation and interpretation of the review findings will be shared and discussed in detail with our PPI groups.

4.2.8 Outputs

- Evidence Gap Maps: presented using Tableau will provide a very clear, detailed and interactive visual summary of the existing evidence.
- Structured tables of identified evidence
- Narrative summary of the volume, range and nature of evidence in this field reported to PRISMA-ScR[59]

4.3 Stage 2: Cochrane Review Expansion and Revision

In Stage 2 we will synthesise and appraise the high-quality evidence of intervention effectiveness and cost, identifying which interventions are shown to be effective, for which perceptual impairments

We will expand and revise an existing Cochrane Systematic Review "Non-pharmacological interventions for perceptual disorders following stroke and other adult-acquired, non-progressive brain injury"[40]. The revision will update the review (searching from inception to current date), enhance the review's specificity to stroke

to ensure it meets the requirements of this call (by excluding perceptual disorders from other causes of non-progressive brain injury), and reflect the latest review methodology advances (including the use of GRADE and TIDieR described below). The authors of the original review have given their permission, and our review revision and expansion has been registered with the Cochrane Stroke Group.

The Cochrane Review will remain focussed on adults. We have explored the appropriateness of incorporating studies involving children. Our preliminary searches identified a recent comprehensive review of evidence for a child population, which identified no RCTs relevant to our research question[65]. A further review of RCT evidence relating to children would be a duplication of effort and will thus not be carried out.

Our expanded and revised review will consider three questions:

1. Are interventions for perceptual deficits after stroke more effective than control, placebo, standard care or no intervention?

2. Is one intervention for perceptual deficits after stroke more effective than another intervention?

3. Are interventions more effective at improving outcomes in stroke survivors with specific demographic variables (including age, stroke severity, time since stroke).

4.3.1 Inclusion Criteria

The intervention inclusion criteria are given in table 2

Table 1: Inclusion criteria for the Cochrane Review

Aspect	Criteria
PARTICIPANTS	adults (18 years or over)) with stroke-related disorders affecting the "functions of auditory, visual, olfactory, gustatory, tactile and visuospatial perception" [41]). Where studies have a mixed stroke and non-stroke population, we will make every effort to extract the stroke-specific data (e.g. by contacting original researchers or through individual participant data (IPD) data extraction where possible). Where this is not possible we will only include a mixed population where at least 80% of the participants are specified as having a perceptual disorder due to stroke[40].
HEALTH TECHNOLOGY	all interventions that expressly address a perceptual disorder. We envision these may include rehabilitation, pharmacological, screening/ assessment interventions and possibly surgical. We will include and code all interventions that address perceptual disorders across more than one sense.
STUDY DESIGN	RCTs and randomised cross-over studies.
COMPARISONS	between an active intervention and either no treatment, control, placebo or standard care, or an alternative intervention

SETTING	all settings, including hospital, community and out-patients, and any geographical location
DATA COLLECTED	• Primary outcome: any validated standardised measure of ability in activities of daily living (ADL). We propose to include the following standardised measures: Barthel Index, Functional Independence Measure, Modified Rankin Scale, Katz Index of Activities of Daily Living, Assessment of Motor and Process Skills (AMPS), and Rehabilitation Activities Profile. If a trial provides data on more than one of these, we will extract them in the order given above. • Secondary outcomes: ○ Standardised measures of perceptual function e.g. Rivermead Perceptual Assessment Battery, Motor Free Visual Perception, Birmingham Object Recognition Battery, Chessington Occupational Therapy Neurological Assessment Battery. ○ Ability in extended activities of daily living e.g. Frenchay Activities Index, Nottingham Extended Activities of Daily Living scale, Lawton Instrumental Activities of Daily Living, Rivermead Activities of Daily Living score. ○ Quality of life and social isolation: EQ5D, Health-related quality of life scale, Quality of Well Being scale, SF36, Stroke Impact Scale. ○ Depression and anxiety: Hospital Anxiety and Depression scale, Beck Depressive Inventory, General Health Questionnaire, Geriatric Depression Scale discharge destination. ○ Discharge destination or residence after stroke. ○ Adverse events: falls, death, fatigue, accident rates. ○ Economic outcomes: intervention costs, resource use. ○ Carer burden: Sense of Competence Questionnaire. We will present this list, supplemented by additional outcomes identified during the scoping review, to our PPI groups by email. The groups will consider these and reach consensus on any additions or modifications via teleconference. They will also discuss and agree the order of importance of the secondary outcomes.
DATE AND LANGUAGE	any language, with no date limitations

We will exclude:

- Studies that do not use an RCT or randomised cross-over design
- Studies addressing cognitive, sensory or attentional disorders.
- Studies where the aim of the intervention is not clear

4.3.2 Information sources, search and selection

RCTs and randomised cross-over studies will be identified during the scoping review as described above (4.2.1-4.2.3); our search will be updated prior to review completion. Two independent reviewers will then apply the Cochrane review inclusion criteria (4.3.1). Any disagreements will be resolved by use of a third independent reviewer, with consultation with a member of the research team or Clinical Expert Group if agreement cannot be reached.

4.3.3 Data extraction

Data extraction forms will be drafted, independently piloted by 2 reviewers and refined (see 4.2.5). Extraction will be conducted by one reviewer and independently checked by a second[66]. Any disagreements will be resolved by use of a third independent reviewer, with consultation with a member of the research team or Clinical Expert Group if required. The data extraction form will include the following:

- Study: country, setting, design, year
- Study design: randomisation method, prospective power calculation and use of intention-to-treat analysis. We will also record dropout rate and adherence
- Participant: age, gender, time since stroke, hemisphere affected, stroke severity, perceptual disorder and method of diagnosis, presence of other stroke-related impairment
- Intervention for perceptual disorder: description using TIDieR checklist [51]
- Outcomes: time point of data collection (post stroke or study specific) and results. We will create a table of outcome measures in each trial, and into this extract the assessment instrument, measurement timepoint, sample size and summary data for each intervention group. For dichotomous data we will extract the numbers who specifically did, and specifically did not, experience the outcome in each group, i.e. the 2x2 table. For continuous data we will extract means and standard deviations for each intervention group: if these are not available we will we contact authors and request them or calculate using Cochrane methods[66]. For all outcomes we will record any significance test, t, f, P values and directions of findings. If a trial provides data on more than one of the primary outcomes, we will extract them in the order given above. For cross-over RCT designs only data up to the point of crossover will be extracted.

4.3.4 Quality appraisal of the primary datasets

The risk of bias of included studies will be independently categorised as high, low or some concerns[67] by two authors. Following discussion with the Cochrane Stroke Group Editor we will use the Cochrane 'Risk of bias 1.0' tool to assess the risk of bias from selection bias, performance bias, detection bias, attrition bias, reporting bias and other bias. Any disagreements between independent reviewers will be discussed with a third reviewer and consensus reached. Reasons for judgements will be transparently reported. Where reporting is unclear, we will attempt to contact the

trial authors for necessary information. Where possible, the effect of including studies which are judged to be at 'high' risk or to have 'some concerns' within statistical analyses will be systematically explored using sensitivity analyses.

4.3.5 Data synthesis and meta-analysis

Review Manager software (RevMan 5.3)[68] will be used to carry out statistical analyses to determine treatment effects. We will use data from studies involving stroke survivors and from studies with a mixed population where stroke-specific data can be extracted.

Meta-analysis will use a random-effects model, in order to adjust for differences due to intra-study variability. Fixed effects models assume a consistent estimate between each study, a random effects study allows the estimate to vary within a normal distribution. For dichotomous variables we will calculate Peto odds ratios with 95% confidence intervals (CI), for continuous data will calculate standardised mean differences and 95% CI. Within analyses we will group the studies based on the taxonomy agreed with the co-production groups and will prospectively discuss and agree the organisation of data syntheses with the co-production groups to ensure their relevance. These may be organised by the perceptual disorder (visual/auditory/gustatory/olfactory/tactile) and treatment approach (surgery, pharmacology, rehabilitation)[40]. Comparisons will explore active intervention versus no treatment, control, placebo, standard care (review question 1) or alternate intervention (review question 2).

Statistical heterogeneity will be calculated and discussed using the I^2 statistic. I^2> 75% will be deemed considerable[69], and we will explore the individual trial characteristics to identify potential sources of heterogeneity. We will use pre-planned subgroup analyses (see below). We will consider sensitivity analyses based on characteristics arising during data extraction. Where stroke specific data is unavailable, findings will be tabulated and synthesised narratively, but will not inform our meta-analyses.

Where possible we will conduct sub-group analyses to explore the effect of pre-defined groups (review question 3). These groups will include the age, gender, and the type, side, severity of, time since stroke or for additional subgroups identified as a priority by the PPI groups. We will carry out sensitivity analysis on the primary outcome, to explore the risk of bias categories noted above and publication type.

The certainty of evidence in each synthesis will be judged using GRADE methodology. Two reviewers will independently grade the inconsistency, indirectness, imprecision, publication bias and other factors that may impact on the quality of evidence. Using Cochrane specific GRADE guidance, and considering the risk of bias assessment, down-grades and upgrades will be applied and final gradings of evidence quality for each comparison (very low/ low/ moderate/ high) will be reached through discussion[70,71].

We will also explore the feasibility of conducting network meta-analysis (NMA) by considering the number of trials, outcome measures and comparisons made[72]. NMA can combine the data from studies which directly compare interventions (direct comparisons) to calculate an estimate of effect between interventions which have not been directly compared within studies (indirect comparisons). If feasible, we will perform NMA in SAS (using PROC MIXED), with fixed demographic and treatment effects, and study as a random effect[73]. The variance structure will be unstructured with study homogeneity assessed via covariance parameters. Each comparison will be illustrated by a network graph, showing the number of studies (and participants), treatment node and comparisons.

4.3.6 Reporting

We will use GRADEpro to generate a summary of findings table that will clearly show the synthesised effectiveness of interventions, via calculated effect sizes, and the quality of that evidence. Detailed tables of included studies, interventions, comparisons and subgroup analyses as well as narrative summaries of the findings will be presented. We will use TIDieR[51] checklist and PRISMA[74] reporting guidelines and relevant extensions.

4.3.7 Outputs

1. Clear systematic review and summary of the RCT **evidence of the effectiveness of interventions for perceptual disorders,** including results of analyses, and **summary of evidence relating to key participant subgroups in the context of the evidence quality.**
2. **Implications for clinical practice**
3. **Publication of the full review via the Cochrane Library**

4.4 Stage 3 – Integration and Priority setting

We will explore the clinical implications of stage 1 and 2 findings and agree the most important areas for future research. Working in partnership with the Clinical Expert and Lived Experience Groups we will consider the findings in relation to the lived experiences of stakeholders, potential applications of research findings, challenges related to service delivery, and internal political dynamics[75–78]. In this way we will (i) maximise the real-world usefulness of the synthesised evidence from stage 1 and 2 to both clinical practice and future research, and (ii) identify and minimise any barriers to the uptake of that evidence[75]. We will use our previous evidence and experience of involving stroke survivors in review projects[53,79], and priority setting processes[37,80,81] to ensure active co-production of recommendations.

4.4.1 Methods

Integration of project findings will be conducted at a final face-to-face meeting of the review team and our Lived Experience and Clinical Expert PPI groups. Prior to the meeting participants will receive the key stage 1 and 2 findings, and the Evidence Gap Maps, presented using accessible language and formats. Our meeting will be conducted in two stages:

4.4.2 Facilitated discussion: The impact of findings on clinical care

The findings relevant to clinical practice will be reviewed, and the group asked to discuss and agree the implications for (a) stroke survivors and carers, (b) clinicians and (c) policy makers in the NHS, social care and charity-based service providers e.g. RNIB.

Led by our stroke-survivor co-applicant (DJN) and evidence synthesis PPI expert (AP), facilitated discussion[61] informed by Participatory Methods[82] will be used to ensure all opinions are heard and represented. The key implications for each of the three groups will be decided by reaching consensus through discussion, ensuring there is agreement on all points.

4.4.3 Nominal Group Technique: The impact of findings on future research

The findings relevant to future research will be reviewed: this will begin by considering the Evidence Gap Maps, and the areas where there is a clear lack of research and move to consider the limitations of the high-quality RCT evidence as determined by the Cochrane review. Using the facilitated discussion methods noted above, the groups will discuss the implications for (d) researchers and (e) funders

We recognise it is likely there will be many perceptual disorders and interventions for which there is a paucity of evidence, and that there are a wide range of potential research approaches to address these. Therefore, we will determine specific priority areas for future research studies, and grant funding. This process will (i) determine what the important questions are that research must answer (where relevant generating PICO questions[83]) (ii) prioritise these questions using Nominal Group Technique[84], and where possible (iii) suggest appropriate methods to answer these questions (via group discussion).

Nominal Group Technique (NGT) is most appropriate for (i) and (ii) as it provides a structured format to identify and achieve prioritisation of research questions in this topic – which can be difficult to achieve using more discursive approaches[54]. Additionally, this method is democratic, fosters equal participation and tends to generate a greater number of new ideas[85]. It will build on our knowledge of James Lind Alliance consensus methods, be facilitated by AP/DJN and use 4 stages[86]

Generation of ideas: where participants are asked to write down all research questions of importance, based on the evidence they have been provided with and the previous discussions. Participants will not discuss their ideas with others.

Methodological co-applicants will not take part, to adhere to recommendations on maximum numbers and maximise clinical relevance

Sharing ideas: participants will be asked to share their ideas in turn, which are recorded on a whiteboard/flipchart. Participants are encouraged to write down any new ideas that arise[85].

Group discussion: Participants are invited to discuss and ask question about other's ideas, with the facilitator ensuring each person contributes and all ideas are covered, whilst avoiding overt criticism. The group may suggest new items for discussion and combine items into categories, but none are removed.

Voting and ranking: with participants assigning a rank to each potential question, in relation to the original aim

4.4.4 Outputs

1. **Identification of main clinical implications from stages 1 and 2**
2. **Agreed priorities for future research**, including the perceptual disorders, interventions and study designs required where possible

5. Dissemination, Outputs and anticipated Impact

We have two main impact goals:

1. Academic Impact[87]: to direct research funds and activities to priority areas where evidence gaps exist, impacting on future research by advising on the topics, questions and methods to address these priorities and informing funders on the need to support this work.
2. Economic and Societal Impact[87] : to improve the care provided to stroke survivors with perceptual impairments by the identification of any clinical and cost effective interventions, which can be immediately highlighted to clinicians and clinical guideline groups.

Our impact pathways have been developed with our Impact Officer, considering who we want to reach, why, and how best to do so. It includes a comprehensive dissemination matrix (Appendix 2).

5.1 What we will produce

To reach researchers and funders our outputs will include: open access, high impact, peer-reviewed publications (x3); a briefing paper for commissioning groups; a succinct, accessible list of research priorities. To reach stroke survivors, carers, and care providers (in the NHS, Social care and charitable sector) we will produce: a concise summary of implications for those delivering care; associated online training for clinicians (webinars/ YouTube videos); a leaflet describing what the findings

mean for stroke survivors and carers (using appropriate print sizes); podcast of findings and a project blog.

5.2 How we will engage and influence

The key to adoption and implementation of our findings is ensuring our outputs are accessible and our dissemination plan is tailored to our target groups. We will work with our Lived Experience Group and Clinical Expert Group to (i) ensure we have clear messages regarding the research priorities and clinical implications of our work (see 4.4) (ii) these are presented in an accessible and engaging way (iii) identify who we should engage with to maximise our reach and impact (iv) identify how best to access these groups.

To reach academics and funders we plan to present at local and national international conferences (including European Stroke Organisation Conference, International Conference on Low Vision Research and Rehabilitation (costed), UK Stroke Forum), cascade our research summaries through established networks and collaborators, promote our papers on social media e.g. @GCU Stroke and directly communicate our list of research priorities to funders e.g. NIHR and the Stroke Association.

To impact on healthcare, we plan to engage with clinical guideline groups (we have links to guideline development groups in the UK, US, Canada, Sweden and Norway). To directly inform clinical practice we will advertise our training resources and blogs via clinical networks (e.g. Scottish Stroke AHP Forum), social media and professional newsletters e.g. RCOT bulletin, and attend relevant professional conferences.

To reach stroke survivors and carers we plan to send our leaflet to relevant charities (e.g. the Stroke Association, Fifth Sense) for inclusion in their magazines, attend local support groups and information events and engage via targeted social media use. To reach a more general readership we shall also submit an article to The Conversation http://theconversation.com/uk

5.3 Authorship

The PIONEER study will adhere to the International Committee of Medical Journal Editors (ICMJE)[88] recommendations on authorship which recommend that authorship should be based on

1. “Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND

2. Drafting the work or revising it critically for important intellectual content; AND

3. Final approval of the version to be published; AND

4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved."

A publication and dissemination policy document, which fully describes authorship requirements for co-applicants and members of the PPI groups, will be provided to all members of the research team.

6. Project management & Ethics

The project will be undertaken within the Chief Scientist's Office (CSO) core-funded Nursing, Midwifery and Allied Health Professions Research Unit (NMAHP RU) at Glasgow Caledonian University. Christine Hazelton will lead the project, managing and conducting research activities including supervision of the project Research Assistant, with clerical support. Prof Marian Brady will support CH in co-leading the project.

The full co-applicant team will hold monthly teleconferences, designed to monitor study progress and address any questions or issues. Each meeting will determine a list of tasks, deadlines and responsibilities required to ensure milestones are met. Additional email communication will be used to address smaller queries with individual co-applicants throughout the project life.

The project will adhere to all NMAHP Research Unit and Glasgow Caledonian University research governance and data protection policies. As the project does not involve any stroke survivor research participants NHS ethical approval is not required. PPI, while being carried out with consideration of ethical issues, will not require ethical approval[89]. However, as data will be collected from the PPI groups members, including audio-recording of meetings and collection of opinions on their role and input, then ethical approval is advised[90] and this has been sought and provided by Glasgow Caledonian University (HLS/NCH/19/021; 16/1/20).

7. Patient and Public Involvement: Research Co-production

7.1 Approach

We have planned for meaningful involvement and co-production with stroke survivors and carers (Lived Experience Group) and clinicians working in this field (Clinical Expert Group) throughout our research, which will maximise the quality, relevance and accessibility of our work. We will structure our approach based on the

ACTIVE framework[79] and the related Cochrane Training resources on Involving People[91]. We will use an approach which combines involvement that:

- Is continuous (throughout the review) AND one-time (at key stages)
- uses direct interaction for one-time events, by bringing our Lived Experience and Clinical Expert Groups together for face-to-face meetings at the initial stages (month 1) and final stages (month 14). It also uses indirect interaction for the continuous involvement, via email, post and teleconference.
- "control" aspects of the process and its outputs[79].

PPI involvement will be reported with reference to the GRIPP2 tool.

7.2 Aspects of PPI

7.2.1 Co-Production

To support co-production we are working with a Co-applicant DJN (with lived experience of a stroke-related perceptual problem), who has a shared responsibility for this research. His main role is to contribute his knowledge, perspective and expertise as a stroke survivor and will contribute to decisions around the design, conduct, interpretation and reporting of this research.

7.2.2 Lived Experience Group

This group will comprise 5 individuals, (including those with perceptual problems, or parents of children affected). This group will be involved in:

(i) Two face-to-face meetings. one at the start of the project, and one following completion of evidence synthesis.

(ii) Four virtual meetings (tele- or video-conference) to update members on project progress, to gain feedback on relevant issues (e.g. outcome measures, inclusion of specific papers) and to provide opportunities for discussion, questions and answers.

(iii) Feedback on written materials (email or post). Group members will be invited to input on draft versions of abstracts and lay summaries of the review protocol, scoping review results, evidence maps, the Cochrane Review, final project reports, manuscripts and conference abstracts.

We will work with group members to identify their personal training and support needs and plans. Essential training (e.g. introduction to evidence-based practice and systematic reviews) will be provided by the research team and online training, such as Cochrane's 'Understanding evidence-based healthcare' and modules on systematic reviews.

7.2.3 Clinical Expert Group

Given the number and diversity of perceptual impairments that may occur post-stroke we have involved a range of multidisciplinary healthcare professionals in our Clinical Expert Group. It includes consisting of Dr Gera de Haan (Clinical Visual

Neuropsychologist), Prof Carl Philpott (Consultant ENT surgeon), Dr Christine Johnson (Lecturer in audiology), Dr Kathleen Vancleef (Neuropsychologist with specialism in paediatric visual perceptual dysfunction), was formed. The specialisms complement the expertise of the applicant team, and ensure input relating to all sensory areas, adult and paediatric services, range of care settings and geographic locations.

(i) Two Face-to-face meetings

(ii) Members will be consulted for their specialist input during the scoping and Cochrane reviews which may include, for example, input on choice of search terms, study inclusion decisions, data extraction and categorisation. Records will be maintained, detailing impact on project decisions.

(iii) Feedback on written materials. Group members will be invited to input on draft versions of abstracts and lay summaries of the review protocol, scoping review results, evidence maps, the Cochrane Review, final project reports, manuscripts and conference abstracts.

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9. Appendices

1. Draft Search Strategy (Medline)

1. cerebrovascular disorders/ or basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp cerebral small vessel diseases/ or exp intracranial arterial diseases/ or exp "intracranial embolism and thrombosis"/ or exp intracranial hemorrhages/ or stroke/ or exp brain infarction/ or stroke, lacunar/ or vasospasm, intracranial/ or vertebral artery dissection/
2. (stroke$ or poststroke or apoplex$ or cerebral vasc$ or brain vasc$ or cerebrovasc$ or cva$ or SAH).tw.
3. ((brain$ or cerebr$ or cerebell$ or vertebrobasil$ or hemispher$ or intracran$ or intracerebral or infratentorial or supratentorial or middle cerebral artery or MCA$ or anterior circulation or posterior circulation or basilar artery or vertebral artery or space-occupying) adj5 (isch?emi$ or infarct$ or thrombo$ or emboli$ or occlus$ or hypoxi$)).tw.
4. ((brain$ or cerebr$ or cerebell$ or intracerebral or intracran$ or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli$ or putaminal or putamen or posterior fossa or hemispher$ or subarachnoid) adj5 (h?emorrhag$ or h?ematoma$ or bleed$)).tw
5. or/1-4
6. exp perceptual disorders/ or exp perception
7. sensation/ or hearing/ or smell/ or taste/ or touch/ or vision, ocular/ or color vision/ or exp mesopic vision/ or night vision/
8. sensation disorders/ or hearing disorders/ or hearing loss/ or deafness/ or deaf-blind disorders/ or hearing loss, bilateral/ or hearing loss, central/ or hearing loss, sudden/ or hearing loss, unilateral/ or hyperacusis/ or tinnitus/ or olfaction disorders/ or somatosensory disorders/ or exp taste disorders/ or vision disorders/ or alice in wonderland syndrome/ or color vision defects/
9. ((percept$ or visuo?percept$ or visual?percept$ or visuo?spatial or visual?spatial or visuo?construct$ or visual?construct$) adj5 (disorder$ or impairment$ or problem$ or abilit$ or difficult$ or deficit$ or training or re?training or remediation or rehabilitation or intervention or therapy)).tw.
10. (aural$ or auditory or audiospatial or hearing or taste or olfactory or olfaction or smell or vision or visual$ or sight$).tw.
11. or/6-10
12. 5 and 11

2: Dissemination Matrix

Stakeholder Group	A. Distribution through networks	B. Online sources	C. Professional magazines and journals	D. Conference presentations	E. Peer review publications	F. Social Media
1. Stroke survivors and carers	NMAHP RU stroke rehabilitation research advisory group NMAHP RU newsletter.	Stroke News (Stroke Association) RNIB Connect The Conversation Evidently- Cochrane blog Carers.uk.org Stroke4carers.org		To support groups e.g. Different Strokes Patient-centred stroke information days Co-produced presentation – UK Stroke Forum	Co-production of journal publication (Research Involvement and Engagement)	@marianBrady @CRHazelton @PCampbell48 @GCUstroke @NMAHPRu @RNIB @RNIB Scotland @TheStrokeAssoc @FifthSenseUK @WeAreVisibility @chsscotland @BPSOfficial @OPSYRIS1 GCU Stroke facebook page
2. Third sector • Fifth Sense • CHSS • RNIB • Stroke Assoc. • Visibility	Scottish Stroke Vision and Hearing Network Scottish Council on Visual Impairment • Scottish Council on Deafness • Action on Hearing Loss, UK	Podcasts on gcu.ac.uk				
3. Clinicians • OT • Optometry • Physiotherapy • Psychology	NMAHP RU newsletter Scottish Stroke Vision and Hearing Network Opsyris SSAHP Forum CSP	training video on youtube.com BPS.org.uk Blog on gcu.ac.uk	e.g. The Psychologist Optometry Today Frontline BSA News (Audiology)	UK Stroke Forum Training Day Scottish Stroke AHP Forum Opsyris conference Lectures at GCU, GU, QMU		
4. Commissioners	Briefing paper to commissioning groups Parliamentary Cross-Party groups	VisionUK.org.uk				
5. Researchers & International Collaborators	EFRR, ESO, WSO SRR members Stroke Research Network Personal Networks	Blog on gcu.ac.uk		ESO, ESOC, WSO SRR NNR UK Stroke Forum	Cochrane Library HTA CRD High impact open access journals x3	
6. Funders	Stroke Association NIHR –submission of future research suggestions			UK Stroke Forum		