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# Non-pharmacological interventions for longer-term stroke survivors or their carers: an overview of Cochrane Reviews (Protocol)

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**[Overview of Reviews Protocol]**

# Non-pharmacological interventions for longer-term stroke survivors or their carers: an overview of Cochrane Reviews

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## ABSTRACT

This is a protocol for a Cochrane Review (Overview). The objectives are as follows:

To produce an overview of Cochrane Reviews of non-pharmacological interventions with evidence relevant to community-based longer-term stroke survivors or their carers, focusing on person-centred outcomes.

This will include:

- identifying types of non-pharmacological interventions that have been evaluated in the longer-term after stroke (included intervention types), where such a trial has been included in a Cochrane Review;
- identify types of non-pharmacological intervention that may be applicable to the longer-term after stroke but have only been evaluated in the shorter-term after stroke, where such a trial has been included in a Cochrane Review;
- categorise these intervention types according to the poststroke problems they are directly intended to address, as defined by Cochrane Review authors;
- identifying the outcomes considered most important (primary outcomes) for included intervention types, as defined by Cochrane Review authors;
- examining evidence of the effects of included intervention types specific to the longer-term after stroke;
- signposting readers to evidence of effective interventions;
- identifying opportunities for merging or splitting existing Cochrane Reviews.

# BACKGROUND

Stroke is the second greatest cause of death and disability worldwide after ischaemic heart disease (Feigin 2015; WHO 2018). Annually, there are 10.3 million new strokes (Feigin 2017), with around 795,000 people in the USA (Benjamin 2018), and more than 100,000 people in the UK (Stroke Association 2018), experiencing a stroke. The burden of stroke is particularly high in low- and middle-income countries, where stroke incidence levels now exceed those of high-income countries by approximately 29% (Feigin 2014; Thrift 2012). In high-income countries, improvements in care immediately following a stroke over recent decades mean a greater proportion of people are surviving beyond the first few months (henceforth 'stroke survivors') (Carter 2007; Lee 2011). Globally, in 2013 there were 25.7 million stroke survivors alive (Feigin 2017). Almost two-thirds of UK stroke survivors leave hospital with a disability (Stroke Association 2018). As such, stroke generates considerable health and social care costs. In the UK, costs are estimated at GBP 8 billion a year, including GBP 3 billion direct costs to the National Health Service, as well as other wider economic costs such as informal care costs, benefits payments, and lost economic productivity (National Audit Office 2010). Moreover, 30% of UK stroke survivors receive care informally from family and friends (henceforth 'carers') (Royal College of Physicians 2018). Carers are thrust into a role that is often physically, emotionally, and time intensive (Greenwood 2010; Ski 2015).

## Description of life in the longer-term after stroke

While there have been substantial improvements in the acute stroke care pathway, longer-term outcomes remain poor for many stroke survivors and their carers (Crichton 2016; Hawkins 2017; Jaracz 2015; Meyer 2015; Murray 2007). In this review, we will define 'longer-term' as six months or more after stroke. This time point, while inevitably somewhat arbitrary, is beyond the current scope of typical rehabilitation services, when people have had time in the community living with their new circumstances. The longer-term after stroke follows the initial disruption to life, relationships, and expectations experienced by many stroke survivors, and is a period when stroke survivors may experience recovery, continuing disruption, turbulent recovery and decline, or enduring decline (Hawkins 2017). Similarly, while some carers of stroke survivors adapt to successfully manage their new role, others experience burden at varied times in the care trajectory up to at least five years (Hung 2012; Greenwood 2009; Jaracz 2015; Quinn 2014; Tooth 2005; Visser-Meily 2008).

For many stroke survivors, longer-term outcome is poor; approximately one-third are left with some physical impairment (Feigin 2010; McKevitt 2011), depression and fatigue are prevalent (Hackett 2014; van de Port 2006), inactivity common (Mayo 2002; Patel 2006), and quality of life often deteriorates (Kwok 2011). Many stroke survivors have comorbidities (94% in Scotland; Gallacher 2014), which need managing in addition to stroke consequences. Data from the South London Stroke Register indicated that 20% to 30% of stroke survivors have a poor outcome over a range of domains up to 10 years after the incident event (Wolfe 2011). Problems in the longer-term after stroke include the physiological effects of the stroke as well as how those effects, the event of the stroke, and the care received interact with the person, their loved ones, and the wider social setting (Algurén 2012). For example, a stroke may cause problems with motor control, cognition, vision, energy, and speech and language functions, any of which can make daily activities difficult (Sarre 2014). For another stroke survivor, the shock of the stroke may cause a complete loss of confidence, which makes their economic, social, and civic life difficult (Peoples 2011; Salter 2008). For a family, loss of income, changes in roles, the new support needs of the stroke survivor, and changes in personality may place tremendous strain on the individuals and the functioning of the family (Hesamzadeh 2015; Sarre 2014).

Many stroke survivors require assistance from informal carers, often family members, for activities of daily living (Anderson 1995; Guidetti 2010). This burden of care has an important effect on carers' physical and psychosocial wellbeing (Greenwood 2008; Parag 2008; Rigby 2009), with up to 48% of carers reporting health problems and two-thirds a decline in social life (Murray 2003). Carers also continue to have instrumental, informational, and emotional needs in the longer term, for which they value support from family members, healthcare professionals, friends, and peers (Cameron 2013; Jaracz 2015).

## Description of non-pharmacological interventions for longer-term stroke survivors or their carers

In the longer term, the care environment for stroke survivors changes to one of living at home unassisted or assisted, or as a resident of long-term care. These different circumstances provide different opportunities and challenges to living that are likely to result in different needs. They also provide different opportunities and challenges to providing interventions.

We have not specified particular intervention types; however, for pragmatic reasons of scale and based on our expertise, we have limited our scope to non-pharmacological interventions following an established approach for Cochrane Reviews (e.g. Legg 2011; MacKay-Lyons 2013). We define 'non-pharmacological' to exclude invasive interventions such as surgery or minimally invasive interventions such as acupuncture, and to exclude pharmaceutical substances and forms, but not advice about them as part of a larger intervention.

Examples of broad groups of relevant interventions specifically for stroke survivors include physical, cognitive, visual, speech and

language training, and practice of daily activities. Relevant interventions that may be given to either stroke survivors or their carers include provision of devices, information, advice, education, lifestyle interventions, support for self-management, talking therapies, and social and recreational activity. Interventions at the family level may include social work, while interventions at the health service level may include care co-ordination, care navigators, and interdisciplinary management.

Because the problems people face in the longer-term after stroke are so varied, interventions are likely to either be applicable only to certain people, or to include a component of tailoring or calibration such as an assessment with protocolised responses, or a discussion of needs with goal setting and action planning.

### How the intervention might work

Because this overview will not be limited to specific interventions, those included might work in a variety of ways. This is particularly true given the broad range of effects a stroke can have. Overall, interventions may seek to reverse the negative effects of the stroke, to help people to accommodate their current circumstances successfully, or both. They may also seek to prevent future problems such as recurrent stroke. Interventions may, for example, be designed to work by changing the person's body functioning, their knowledge, beliefs, or skills. They may seek to change thought processes, emotions, intentions, goals, or behaviour. They may seek to provide support to an individual (e.g. practical, emotional, financial) or to identify or organise other sources of support.

### Why it is important to do this overview

Despite policy recommendations for greater emphasis on longer-term stroke care (Department of Health 2007; National Audit Office 2010), and being a key component of the World Stroke Organization campaign, strategies for longer-term care are not well developed. The provision of ineffective interventions has considerable resource implications and potential to add to patient and carer stress. As such, identifying the most effective interventions to improve longer-term stroke outcomes is a recognised priority for stroke research. In the UK, this was demonstrated during the James Lind Alliance priority setting project, where "What are the best ways to help people come to terms with the long-term consequences of stroke?" was the second-highest priority research question identified (Pollock 2012). This overview will help to address this consumer priority.

This overview will examine the evidence for a wide range of interventions for longer-term stroke survivors or their carers that have been systematically reviewed by Cochrane. There is a substantial body of potentially relevant analyses to be synthesised, which would be difficult for practitioners, policy makers, and consumers to assimilate. Moreover, we plan to isolate the evidence that applies specifically to the longer-term after stroke. This overview will provide a comprehensive, accessible summary of the current published evidence, as well as identify gaps for future research in longer-term stroke care.

## OBJECTIVES

To produce an overview of Cochrane Reviews of non-pharmacological interventions with evidence relevant to community-based longer-term stroke survivors or their carers, focusing on person-centred outcomes.

This will include:

- identifying types of non-pharmacological interventions that have been evaluated in the longer-term after stroke (included intervention types), where such a trial has been included in a Cochrane Review;
- identify types of non-pharmacological intervention that may be applicable to the longer-term after stroke but have only been evaluated in the shorter-term after stroke, where such a trial has been included in a Cochrane Review;
- categorise these intervention types according to the poststroke problems they are directly intended to address, as defined by Cochrane Review authors;
- identifying the outcomes considered most important (primary outcomes) for included intervention types, as defined by Cochrane Review authors;
- examining evidence of the effects of included intervention types specific to the longer-term after stroke;
- signposting readers to evidence of effective interventions;
- identifying opportunities for merging or splitting existing Cochrane Reviews.

## METHODS

This overview of Cochrane Reviews will include reviews that are broadly relevant to community-based, longer-term stroke survivors or their carers, but only those comparisons with directly applicable evidence. We will reanalyse these comparisons using only data from the relevant studies. Therefore, we will apply different criteria at the level of the review and per comparison for included reviews. The overview will delineate intervention types as they are presented in the reviews and will not seek to reclassify these or otherwise combine effect estimates from different reviews.

## Criteria for considering reviews for inclusion

For clarity, the following criteria will apply to reviews as a whole.

### Types of reviews

- **Current Cochrane Intervention reviews:** the latest published version of systematic reviews on the effects of healthcare interventions produced by Cochrane review groups that have not been withdrawn, without restriction by publication date.

### Types of interventions

Any of the interventions as grouped in the review meet the following criterion.

- **Non-pharmaceutical and non-invasive** (examples of inclusions are dietary advice, exercise, self-management support, transcutaneous electrical nerve stimulation; examples of exclusions are medicines, nutritional supplements, surgery, acupuncture).

### Types of participants

At least one study included in the review has participants who meet all of the following.

- **Stroke survivors or their carers:** at least 80% of participants are stroke survivors or their carers, as defined in the study. If the study includes people who have had a transient ischaemic attack (TIA) in addition to people who have had a stroke it will satisfy this criterion, but if the study only includes people who have had a TIA it will not.
- **At least six months after stroke:** mean time since most recent stroke (the participant's or the person they care for) at the start of intervention delivery is at least six months.
- **Living in the community:** more than 50% of participants are not inpatients.

## Criteria for considering comparisons for inclusion

The following criteria will apply to comparisons within reviews that meet the criteria above.

### Types of comparisons

- Intervention versus no additional intervention (e.g. usual care) or placebo interventions (e.g. attention control interventions) or
- comparisons of interventions which both meet the inclusion criteria.

Where multiple time points are reported, we will select those closest to intervention end and last available follow-up, where data permit. Where a review conducts subgroup analyses but also reports pooled totals across the subgroups, we will use the totals across subgroups and ignore the subgrouping.

### Types of interventions

All of the interventions in the comparison must be non-pharmaceutical and non-invasive.

### Types of participants

At least one study in the comparison has participants who meet all of the following.

- **Stroke survivors or their carers:** at least 80% of participants are stroke survivors or their carers, as defined in the study. If the study groups people who have had a stroke with those who have had a TIA it will satisfy this criterion, but if the study only includes people who have had a TIA it will not.
- **At least six months after stroke:** mean time since most recent stroke (the participant's or the person they care for) at the start of intervention delivery is at least six months.
- **Living in the community:** more than 50% of participants are not inpatients.

### Types of outcomes

Because we will be using existing comparisons, the following are inclusion criteria for comparisons rather than a schema for quantitative pooling of data.

### Primary outcomes

We have selected primary outcomes with the aim of covering patient-relevant outcomes that may be relevant to a broad range of stroke survivors and carers. In doing so, we have consulted with our Consumer Research Advisory Group and drawn upon recent prioritisation work (Davis 2017; Duncan Millar 2019), and a core outcome set in aphasia (Wallace 2019), the only core outcome set for effectiveness trials developed in conjunction with consumers in the field of stroke that we are aware of.

Our primary outcomes for stroke survivors will include:

- **quality of life:** "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL Group 1993; e.g. World Health Organization Quality of Life assessment short-form (WHOQOL-BREF)). We will not include subscales where an instrument produces higher-order scales;
- **self-perceived health status:** self-perception of health overall or dimensions thereof. Assessments typically incorporate functioning, mood, and pain, for example Medical Outcomes Study 36-item Short-Form health survey (SF-36), EuroQol 5-Dimension health questionnaire (EQ-5D). We will not include subscales where an instrument produces higher-order scales;
- **emotional well-being:** positive and negative emotional states including pleasure, eudaimonia, depression, and anxiety, for example Warwick-Edinburgh Mental Well-Being Scale (WEMWBS), General Health Questionnaire (GHQ);

- **participation and extended activities of daily living:** involvement in society such as education, work, community life, religion, politics, recreation/leisure, interpersonal interactions, and other complex tasks/activities required to live in the community, for example London Handicap Scale (LHS), Reintegration to Normal Living Index (RNLI), Nottingham Extended Activities of Daily Living Scale (NEADL).

For carers, the same outcomes are of interest, with the addition of:

- **carer strain and related concepts:** such as burden or coping, for example Caregiver Burden Scale.

#### Secondary outcomes

Secondary outcomes will be the primary outcomes of included reviews, excluding body functioning and structure (impairment) outcomes. We will group outcomes according to the International Classification of Functioning, Disability and Health (ICF; WHO 2001), or other frameworks if the ICF is not applicable. This approach to secondary outcomes uses the expertise of review authors to capture specific outcomes of relevance, given the variety of sequelae of stroke. We have chosen to exclude body functioning and structure outcomes in consultation with our consumer group, to make the review more manageable, as these can be considered mediators of patient-relevant outcomes and are likely to be relevant only to particular interventions. Similarly, we will not specify particular adverse events, but will summarise which (if any) are considered by each review and their findings.

## Search methods for identification of reviews

We will handsearch the complete list of reviews and protocols prepared by the Cochrane Stroke Group (CSG). In addition, we will search the Cochrane Database of Systematic Reviews (CDSR) using a search strategy that the CSG Information Specialist has helped us to develop (see Appendix 1).

## Data collection and analysis

We will use Covidence software for data management throughout the process of selecting reviews and extracting data. Should this prove to be infeasible, we will develop an inhouse database for this purpose.

### Selection of reviews

Two overview authors will independently screen titles and abstracts of records identified from the electronic searches and retain any that are potentially relevant. We will obtain the full-text of those reviews and, where necessary to assess the time since most recent stroke, their included studies. We will include the reviews that meet our criteria. We will retain protocols that appear likely to meet the criteria as ongoing reviews. Where inclusion is unclear, the overview authors will discuss the issues at a consensus meeting.

#### Selection of non-pharmacological interventions trialled in stroke but not longer-term stroke

To address our second objective, during the review selection process we will identify current Cochrane intervention reviews that meet our intervention criteria and the first of our participant criteria (a study where at least 80% are stroke survivors or their carers). Reviews which we later exclude because the other participant criteria are not met (i.e. living in the community at least six months after stroke) will form our selection of non-pharmacological interventions trialled in stroke but not longer-term stroke.

#### Selection of reviews where several reviews assess the same intervention

Because we are only including Cochrane Reviews, we do not anticipate identifying reviews that address identical topics. However, we may identify several reviews assessing the same intervention. Where several reviews assess the same intervention with regard to different outcomes, or different types of poststroke problems, we will retain each review. Where several reviews assess the same intervention in different populations that each include a poststroke population (e.g. stroke survivors, people with acquired brain injury, adults), we will select the review with the most participants in studies that meet our criteria and exclude the others. Where no one review can be selected through this method, we will select the review that has the most similar inclusion criteria to our populations of interest.

### Selection of comparisons

We will examine the comparisons reported in the included reviews and include those that meet our criteria. Where inclusion is unclear, the overview authors will discuss that comparison at a consensus meeting.

### Data extraction and management

Two overview authors will extract data independently using a form that has been specifically designed and piloted by the overview author team. The overview authors will discuss any disagreements that arise at a consensus meeting.
Data extracted will include the following.

#### Review

- Aims and rationale.
- Types of studies.
- Types of participants and how defined.
- Interventions.
- Outcomes assessed and those that were primary.

- Adverse events.
- Date of last search.
- Method of assessing quality of studies.
- Number of included studies and their references.
- Number of included participants.

#### Studies included in reviews

- References.
- Whether the study meets the inclusion criteria (participant).

#### For studies which meet the inclusion criteria

- Types of participants (stroke survivors or carers, or both, and how defined).
- Time since most recent stroke of participants at start of intervention.
- Risk of bias as assessed by the authors of the included review.

#### Comparisons/analyses

We will download forest plot data from the CDSR for included reviews. In addition, we will extract the following for each included comparison.

- Compared conditions (e.g. intervention type versus usual care).
- Outcome that it maps to in our scheme and details of the measures used.
- Specifics of time points, if any (e.g. end of intervention).
- Specifics of participants, if only a subset of those included in the review are specified (e.g. outpatients only).
- GRADE rating, including reasons.

We will contact the authors of included reviews to confirm or obtain data if we are uncertain about the reported data or when relevant data are mentioned but not reported. If the review is more than two years old or if the date that the next stage was expected has expired, we will contact authors to ask about the status of any update.

### Assessment of methodological quality of included reviews

We will assess the methodological quality of individual reviews using AMSTAR 2 (Shea 2017). Two overview authors will independently conduct ratings, in duplicate, on piloted forms. The overview authors will resolve disagreements by consensus. We will present judgements per item with a supporting statement and will rate overall confidence in the results of the review in line with the advice of the AMSTAR 2 authors (Shea 2017).

### Assessment of methodological quality of individual studies

We will report Cochrane 'Risk of bias' assessments where they were conducted by the original Cochrane review authors. We will not reassess risk of bias.

### Assessment of overlap

We will include overlapping reviews (where primary studies are included in multiple reviews) as we will not pool effect estimates of reviews. To assess the overlap between reviews with respect to the studies they included, we will present a citation matrix, calculate the corrected covered area (CCA) and interpret it as slight (0 to 5), moderate (6 to 10), high (11 to 15) or very high (greater than 15) overlap as recommended by Pieper 2014. Additionally, we will conduct a network analysis with reviews linked to the studies that they include in a directed network. We will use visual inspection based on a Force Atlas layout (Gephi 2017), and a cluster analysis using the Girvan-Newman method (Girvan 2002), to identify 'communities' of reviews and studies.

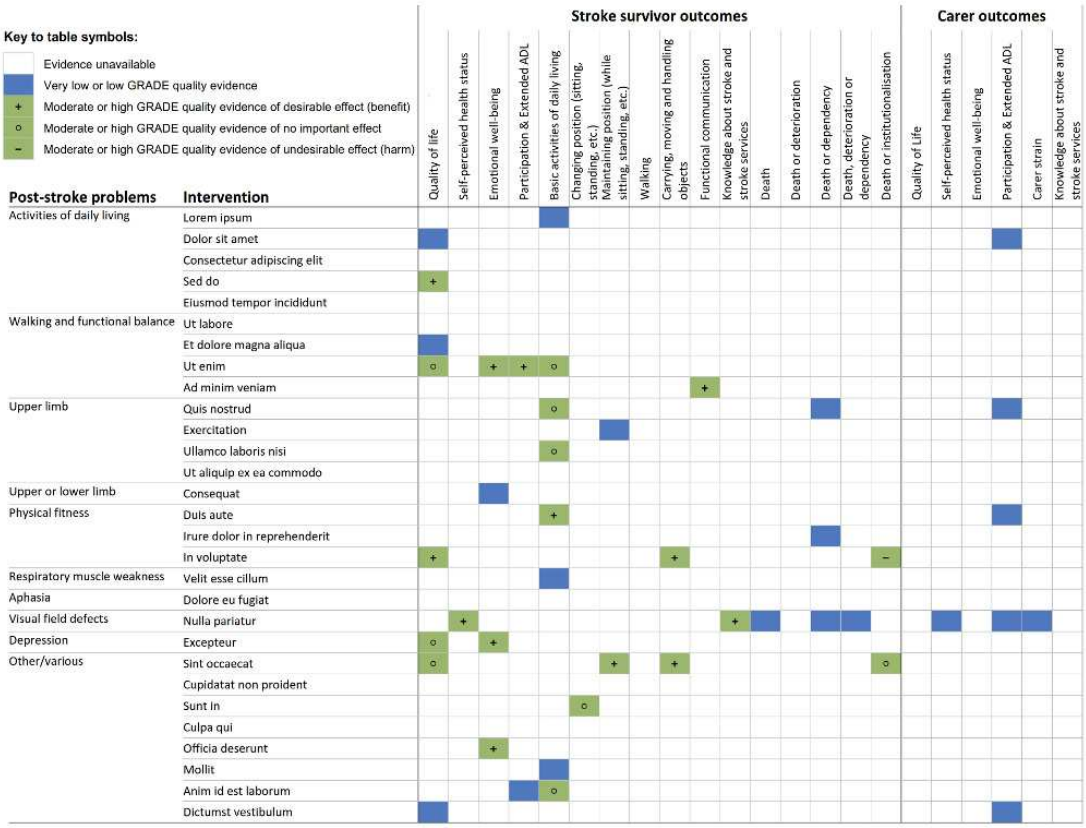
### Data synthesis

We will reanalyse included comparisons using only studies meeting the participant criteria. We will conduct a narrative synthesis of these results and the results from the included reviews for the whole population, grouped by outcomes, the problems addressed, and the interventions evaluated.

### Assessment of quality of evidence

We will use GRADE to rate the quality of evidence for each reanalysed comparison based on the methods described in Chapter 11 of the *Cochrane Handbook for Systematic Reviews of Interventions*, using GRADEprofiler (GRADEpro GDT) software (Guyatt 2011; Schünemann 2017), and then for each intervention-outcome (i.e. across comparisons addressing the same outcome type for the same intervention type). Two overview authors will independently conduct ratings in duplicate. The overview authors will resolve disagreements by consensus. In the narrative synthesis, we will present detailed results for moderate- or high-quality evidence; where evidence is low quality, very low quality, or unavailable this will be summarised. We will present a summary of quality and direction of evidence in a table following a similar style to that of Pollock 2014 (a mock-up example is presented in Figure 1).

**Figure 1. Example of table summarising quality and direction of evidence of intervention effects for particular problems.**




We will prepare a 'Summary of findings' table for each included intervention type to present the results of meta-analysis and narrative synthesis for the comparisons with no additional intervention or placebo interventions. We will present results from the end of the intervention for each of this overview's primary outcomes, including potential harms, as well as the primary outcome(s) of the Cochrane Review for that intervention (the source of the comparison), which are included in this overview as secondary outcomes, as outlined in the 'Types of outcomes section.

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* *Indicates the major publication for the study*

# APPENDICES

## Appendix 1. Cochrane Library search strategy

1. MeSH descriptor: [Cerebrovascular Disorders] this term only
2. MeSH descriptor: [Basal Ganglia Cerebrovascular Disease] this term only
3. MeSH descriptor: [Brain Ischemia] explode all trees
4. MeSH descriptor: [Carotid Artery Diseases] explode all trees
5. MeSH descriptor: [Cerebral Small Vessel Diseases] explode all trees
6. MeSH descriptor: [Intracranial Arterial Diseases] explode all trees
7. MeSH descriptor: [Intracranial Embolism and Thrombosis] explode all trees
8. MeSH descriptor: [Intracranial Hemorrhages] explode all trees
9. MeSH descriptor: [Stroke] explode all trees
10. MeSH descriptor: [Vasospasm, Intracranial] this term only
11. MeSH descriptor: [Vertebral Artery Dissection] this term only
12. (*stroke* or apoplex* or cerebral vasc* or brain vasc* or cerebrovasc* or cva* or SAH):ti,ab,kw (Word variations have been searched)
13. ((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) near/5 (isch?emi* or infarct* or thrombo* or emboli* or occlus* or hypoxi*)):ti,ab,kw (Word variations have been searched)
14. ((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) near/5 (h?emorrhag* or h?ematoma* or bleed*)):ti,ab,kw (Word variations have been searched)
15. MeSH descriptor: [Brain Injuries] this term only
16. MeSH descriptor: [Brain Injury, Chronic] this term only
17. MeSH descriptor: [Brain Damage, Chronic] this term only
18. (acquired near/5 brain injur*):ti,ab,kw (Word variations have been searched)
19. {or #1-#18} in Cochrane Reviews, Cochrane Protocols

## CONTRIBUTIONS OF AUTHORS

TC conceived the overview, designed the protocol, and is the guarantor.

AF conceived the overview and designed the protocol.

SO, LB, and JH designed the protocol.

SO additionally co-ordinated the development of the protocol.

## DECLARATIONS OF INTEREST

The overview authors include authors of studies that are included in reviews, and authors of Cochrane Reviews, that will be included in the overview. The host institution (Bradford Teaching Hospitals NHS Foundation Trust) holds intellectual property for interventions that would be eligible for inclusion in included reviews. The authors have received government and charity funding to develop and test interventions that would be eligible for inclusion in included reviews and are likely to apply for funding for such studies in the future. No funders have or will have any involvement in the design, conduct, or decision to publish related to this overview.

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