



STUDY PROTOCOL

REVISED

Patient and public involvement in stroke research: a scoping review protocol [version 2; peer review: 2 approved]

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Abstract

Background: Growing consensus supports public and patient involvement (PPI) in research as the lived experience of patients, family carers and users of health and social care services bring unique insights to healthcare research. The impact and burden of stroke present ongoing challenges for those living with its consequences and could potentially limit PPI activity. This review aims to explore PPI in published stroke research to identify and describe the extent, nature and design of PPI activities, the type/s of studies involved and the profile of PPI participants engaged in stroke research.

Methods: This systematic scoping review, guided by the Arksey & O'Malley five step framework, will be reported according to the PRISMA-ScR reporting guidelines. PPI is embedded at each stage of this proposed scoping review from conceptualisation, participation, contribution and collaboration. The Population, Concept, Context (PCC) structure defines the research question which asks - How is PPI in stroke research currently being conducted and how do the study authors report their PPI activities and its impact? A comprehensive range of electronic databases including PubMed, CINAHL, EMBASE, PsychINFO and the Cochrane Database of Systematic Reviews will generate a broad range of studies. Grey literature (e.g. OpenGrey, Lenus) and internationally recognised stroke organisation websites will be searched for additional research reports. Data extraction will adhere to the Joanna Briggs Institute guidelines, with results collated and mapped to the research cycle stage/s.

Conclusions: The outlined scoping review protocol will

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version 2		
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Any reports and responses or comments on the article can be found at the end of the article.

comprehensively identify and map the existing scientific literature that reports PPI in stroke research. Findings will be presented in relation to PPI conceptualisation, participant profiles and activities in stroke research, volume, type and range of approaches. Knowledge gaps may be identified thereby offering opportunities and recommendations for future priorities for PPI in stroke research.

Keywords

patient and public involvement, patient engagement, patient participation, stakeholder involvement, stroke research

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REVISED Amendments from Version 1

The protocol has been revised following invaluable feedback from two reviewers. In the introduction further clarity has been provided relating to Irish and European data on the burden of stroke and predicted rise in stroke cases. We have reformatted our aims and objectives and further referenced our methodological framework as suggested. We have clarified the inclusion criteria in anticipation of our inclusive approach and the potentially onerous task of identifying PPI activity in stroke research. The PubMed search strategy string and a PRISMA_ScR checklist has been included as Extended data. Further information is provided on hand searches and the use of a grey literature checklist. Reasons for exclusion will be included in a PRISMA flow diagram. We updated Stage 5 to explain our data extraction process, how we propose to evaluate/report the impact of PPI, and the diversity of the experience-based stroke research partners. We added further information on our stakeholder engagement, identifying a co-author as someone with lived experience of stroke contributing to the research process. In the discussion section we clarified our intention to map the concept of PPI in current stroke research practices and in so doing identify any gaps which may emerge thus providing some key opportunities and recommendations for future research.

Any further responses from the reviewers can be found at the end of the article

Introduction

Stroke is a major cause of death and disability worldwide and many survivors live with significant disability¹. Globally over 15 million people have a stroke each year making it the second leading cause of death worldwide and leading cause of adult disability, accounting for almost 5% of disability-adjusted life years^{2,3}. According to the latest National Audit of Stroke in Ireland (NOCA), almost 6,000 people were admitted to hospital in 2019 and 71% of those with ischaemic stroke had disabilities on discharge⁴.

Despite advances in prevention, early recognition/diagnosis and treatment, projections indicate a significant increase in stroke events worldwide in the coming years⁵. Whilst death rates have reduced, the burden of stroke for those living with the consequences, both survivors and their loved ones, present ongoing daily challenges. Communication difficulties, cognitive impairment, perception issues, emotional factors and general fatigue, although less obvious than physical disabilities can be equally as devastating. This burden of stroke reveals a vulnerability for people to become marginalised, limiting their ability to actively engage in their own care and/or fully participate in life after stroke^{6,7}. The Stroke Action Plan for Europe identifies and aims to address the challenges facing stroke survivors and families, associated with life after stroke⁵.

In healthcare research specifically, patients with a lived experience of disease, family carers and users of health and social care services bring unique insights. Over the past 20 – 30 years patient and public involvement (PPI) in health and social

research has evolved and gained widespread support. The UK has been at the forefront of establishing policy support through the National Institute for Health Research (NIHR) advisory group, INVOLVE, and defines PPI as “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”⁸. The term ‘public’ is used to include patients, potential patients, carers, and anyone who uses health and social care services or represents service users. In Ireland, since 2017 the Health Research Board (HRB) and the Irish Research Council (IRC) have committed to develop and support PPI with the establishment of the PPI Ignite network⁹. PPI in research is considered to occur when “individuals meaningfully and actively collaborate” at one or more stages of the research process¹⁰. The conceptual model often used to describe this collaboration is drawn from Arnstein’s ladder of citizen participation¹¹. In this model three approaches to involvement are described – consultation, collaboration, and user-control along a spectrum of involvement which can vary at different stages.

A number of arguments have been postulated for actively involving patients and the public in research. These generally relate to the political mandate for inclusion from research funders; the moral argument that supports the rationale that people affected by the outcomes of research should be included in the decision making; and the consequentialist argument that asserts the benefits to the quality of research as a result of involving service users. This latter argument has a growing consensus as the positive impact on improving research quality and strengthening relevance is acknowledged¹². However, there remains ambiguity in the literature on the concept and understanding of what is and what is not PPI in research¹³. This can lead to misunderstanding and misinterpretation of the extent of public involvement in research and potential tokenistic representation especially in relation to seldom heard voice groups including individuals with stroke and their carers/family.

Adopting the four values of respect, openness, reciprocity and flexibility, and working collaboratively across all stages of involvement is recommended to support inclusivity, particularly with diverse, seldom heard groups¹⁴. The impact and burden of stroke on the individual and family could potentially limit PPI activity but consideration of these barriers and facilitators has been found to benefit stroke survivors, carers and the research process¹⁵. Working with people affected by stroke and health care professionals, the UK Stroke Association has identified priority areas for research across the two main stroke care pathways - Stroke prevention, diagnosis, pre-hospital and hospital care; and Stroke rehabilitation and long-term care¹⁶. Stroke survivors/carers represented over 50% of contributors suggesting an interest and eagerness to be involved in the research process despite limitations.

As PPI gains recognition and importance in stroke research in principle, it is critical to understand what is happening in parallel in stroke research practice. This paper describes the protocol for a scoping review collating and commenting on current PPI practices described and reported in stroke research.

To our knowledge no current scoping review has examined the published literature to explore PPI in stroke research as we outline here.

Protocol

Aims and objectives

The overarching aim of this review is to identify and describe current practices of PPI in stroke research. Specifically, this review will focus on the nature, design and type/s of studies that involve patients and/or members of the public in the planning, conduct and/or dissemination of stroke research, and explore how PPI has been conceptualised in stroke research.

Objectives:

1. map the volume, type and range of PPI approaches in stroke research
2. profile PPI participants and examine representativeness of participants from an equality, diversity and inclusion (EDI) perspective
3. map PPI research activities against the stroke research cycle
4. collate reported enablers and barriers to PPI application in stroke research
5. explore the impact of PPI on stroke research, clinical practice and health policy

Design

A scoping review will be conducted as it is considered the most appropriate methodology to broadly map the key sources and types of evidence available when the extent and nature of the research is largely unknown¹⁷. The review will conform to the 5 stages of the Arksey & O'Malley framework for scoping studies¹⁸ refined by Levac¹⁹ and the methodological framework described by Peters *et al.* in the JBI Manual for Evidence Synthesis (Chapter 11)²⁰. The review will be reported according to the PRISMA-ScR reporting guidelines²¹.

Stage 1: Identify the research question

Stage 2: Identify the relevant studies

Stage 3: Study selection

Stage 4: Charting the data

Stage 5: Collating, summarising and reporting the results

Stage 6: Stakeholder consultation (optional)

Data will be extracted and mapped to the published stages of PPI engagement across the research cycle (Figure 1)^{9,22}.

Stage 1: Identify the research question

The first stage of the protocol clearly identifies the research question based on the overall aim of the scoping review; namely to examine the extent, range, and nature of stroke research that actively involves patients and the public across any or multiple stages of the research process.

The Population, Concept, Context (PCC) structure proposed by the Joanna Briggs Institute (JBI)²³, outlined below, was used to define the research question which asks: How is PPI in stroke research currently being conducted and how do the study authors report the details of their PPI activities and its impact?

Population: individuals who have experienced stroke. This includes stroke survivors, carers and family who can all be affected by stroke. The lived experience of each can bring unique insights to stroke research.

Concept: PPI (as defined by NIHR⁸ as “research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” and where “an active partnership between patients and the public and researcher” is present). This will include all initiatives or activities irrespective of the terminology used, where there is explicit involvement of PPI partners across any of the phases of stroke research (Figure 1).

Context: Stroke research – relating to aspects including but not limited to stroke recognition, primary or secondary prevention, acute care, treatment/management, rehabilitation, survival, long-term outcomes/care, community support.

Based on the review question, aims and objectives and PCC framework the following Inclusion/exclusion criteria was developed (Table 1):

Stage 2: Identify the relevant studies

As the research question is broad, a comprehensive range of electronic databases has been identified by the authors to assist in a systematic and targeted search strategy. All publications that meet the inclusion criteria identified will be selected. No date, location or language limitations will be applied with respect to the manuscripts selected. The search will involve the electronic databases PubMed, CINAHL, EMBASE, PsycINFO and the Cochrane Database of Systematic Reviews (Extended data²³). These libraries were chosen as they will yield a broad, cross disciplinary range of studies. In addition, reference lists of included studies will be checked. To target relevant grey literature, a systematic search will be conducted in the key databases, e.g. OpenGrey and Lenus. A grey literature checklist e.g. Cadth (Canada's drug and health technology agency)²⁴, will help to ensure a comprehensive search is completed. Websites relating to internationally recognised stroke organisations (e.g. World Stroke Organisation, European Stroke Organisation, UK Stroke Association, American Heart Association/ American Stroke Association and Stroke Foundation-Australia) and other charitable/non-governmental organisations (e.g. James Lind Alliance) will be searched for additional, non-indexed published research reports and policy documents which include empirical data.

The targeted search strategy, developed in consultation with the information scientist (librarian), will be adapted for each database. The key search concepts resulting from the PCC framework are ‘individuals with experience of stroke’ (population), ‘PPI’ (concept) and ‘stroke research’ (context). Closely

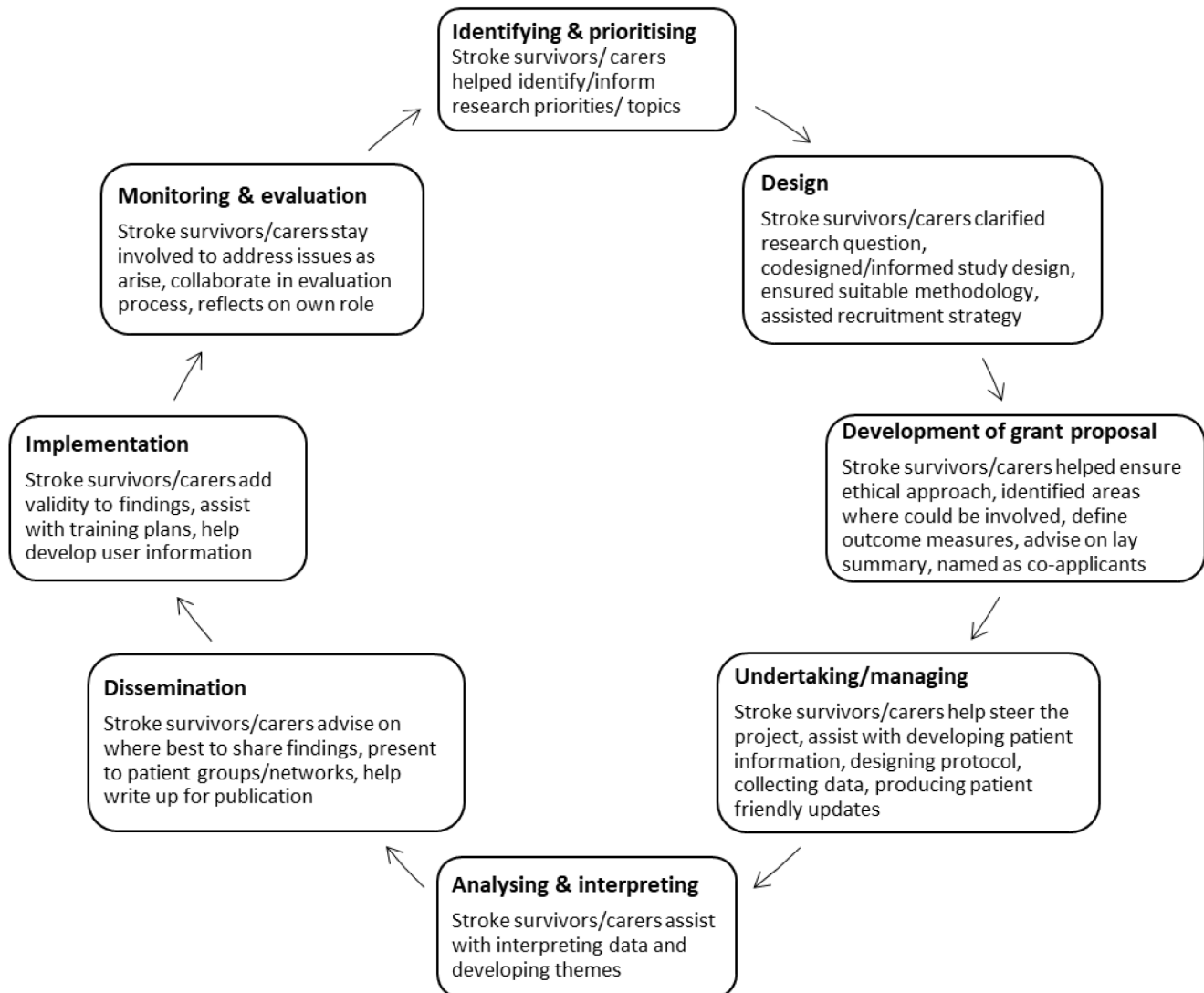


Figure 1. Research cycle framework^{9,22}.

examining these concepts and using thesaurus terms where appropriate generates a comprehensive list of search terms including stroke survivor, stroke carer, patient and public involvement, patient participation, patient engagement, consumer involvement, stakeholder participation and stroke research.

A sample of an indicative search strategy for the PubMed database is provided below (Table 2).

Stage 3: Study selection

Studies retrieved by the targeted search strategy will be collated and uploaded to Covidence for screening and final selection. Duplicates will be removed. Two reviewers will independently screen each record by title and abstract using the specified inclusion/exclusion criteria. Included studies following review of titles and abstract, will be retrieved in full text and again will be assessed independently by two reviewers. Disagreements

will be resolved by discussion and where consensus is not achieved a third researcher will be consulted before final inclusion/exclusion.

Stage 4: Charting the data

A data charting form will be devised to determine the relevant information to extract from the included sources using Microsoft EXCEL spreadsheet software. This will be developed in accordance with the JBI guidelines²⁰ for charting and extracting data and in conjunction with the purpose specific research cycle framework developed for this review. It is anticipated that this form will require review and modification as the process advances and familiarity with selected studies dictates a need to capture further information.

- Author(s)
- Year of publication
- Title

Table 1. Inclusion/exclusion criteria.

Inclusion	Exclusion
Empirical stroke research studies of any study design, including qualitative, quantitative and mixed methods and where relevant, published pre-trial consultation processes	
Studies with a clear statement in relation to PPI activities/initiatives which fit the principles of PPI in stroke research, irrespective of terminology An inclusive approach to screening will be taken whereby if PPI is not mentioned in the title or abstract, the full text manuscript will be reviewed with particular focus on the methods and acknowledgements sections	Studies, including those where the focus is on participation or engagement in trials or other research, that do not explicitly state involvement of PPI partners in one or more stages of the stroke research cycle identified in Figure 1 .
Title and abstract in English language	
A publication date cut off of 2014 will be applied to include studies published after the first handbook for health researchers was published ²²	
Publications which include empirical data (e.g. qualitative, quantitative, meta-analyses, review papers)	Publications that do not report original empirical data (e.g. editorials, commentary pieces) and conference abstracts

Table 2. Sample search strategy.

Population – individuals with experience of stroke	
#1	(patient OR survivor OR adult OR family OR carer OR parent)
#2	(stroke OR poststroke OR post-stroke OR cerebrovascular disease OR cerebrovascular disorders OR CVD OR CVA OR brain infarction OR intracranial arterial diseases)
#3	#1 AND #2
Concept – PPI (patient and public involvement)	
#4	("patient and public involvement" OR "patient involvement" OR "patient partnership" OR "patient collaboration" OR "patient engagement" OR "patient advocacy" OR "patient participation" OR "consumer participation" OR "consumer involvement" OR "consumer engagement" OR "stakeholder participation" OR "stakeholder engagement" OR "patient driven" OR "survivor participation" OR patient participation [MeSH] OR patient advocacy [MeSH] OR stakeholder participation" [MeSH] OR survivor participation)
Context – stroke research	
#5	(stroke OR poststroke OR post-stroke OR cerebrovascular disease OR cerebrovascular disorders OR CVD OR CVA OR brain infarction OR intracranial arterial diseases)
#6	(research OR review OR investigat* OR study OR project OR evaluation)
#7	#5 AND #6
#8	#3 AND #4 AND #7

- Origin/country of origin
- Study aims/purpose
- Study type
- PPI concept description, approach, stages of inclusion
- PPI representation: population, profile, and underrepresentation of groups, where present
- PPI research activities, contributions
- Facilitators and barriers identified in incorporating PPI
- PPI in research evaluation, benefits, impact

Stage 5: Collating, summarising and reporting the results

Data extraction will be completed independently by at least 2 reviewers and any discrepancies will be resolved by discussion to reach consensus. In accordance with scoping review

guidelines, the quality of any study included in this review will not be assessed for risk of bias.

The review findings will be reported using the PRISMA-ScR guidelines²¹. A PRISMA flow diagram will be produced to present an overview of the identification screening, eligibility and inclusion phases, with the reasons for exclusion of studies in the screening process provided.

The extracted data will be presented in tabular format, providing a brief summary of each individual study included in the review and documenting barriers/facilitators and impact of participation, where reported in individual studies. Data from the studies included in the review will be collated and mapped to the stage/s of the research cycle. Summary tables will be utilised to present the current volume, publication year, origin, study characteristics, and methodological design. The benefit of PPI in stroke research will be recorded where the study details changes (added value) in the research methods/activities; interpretation of results, dissemination activities or in policy/practice that was attributed to experience-based involvement. Impact of PPI in stroke research will be recorded where the individual study details changes in the research activity; interpretation of results, dissemination activities or in policy/practice that was attributed to PPI in stroke research. Evaluation of impact will be guided by appraisal criteria²⁵ which considers whether the paper discusses the difference PPI has made to the research activities and the impact of user involvement on the research project (e.g. length of study, financial implications of involvement activities, cost-benefit analyses), and whether benefits claimed are supported by examples from the research project.

PPI participants in current stroke research will be profiled and examined as representative of the stroke population and family/carer network. The diversity of the experience-based stroke research partners will be examined for sex, ethnicity, stroke type, disability level and will consider issues that may marginalise specific stroke groups from PPI activities including notable mobility and/or communication issues.

A compendium of approaches taken to PPI in stroke research will be developed including the involvement as described e.g. consultation, collaboration, and user-control across the different stages of the research cycle. A narrative synthesis will be conducted for findings that focus on the contribution made by PPI in stroke research and the methods used to report this in the scientific literature. Consistent with scoping review guidance, no appraisal of the quality of the studies will be conducted.

Stage 6: Stakeholder consultation

Strong PPI engagement will be embedded in this scoping review methodology. A stroke research advisory panel including multiple stakeholders (people affected by stroke – survivors/carers/advocates, clinicians, research team) has been developed to guide both the design and the conduct of this review and further stroke research activities. A co-author on this study protocol has personal experience of stroke (JH) and acts as our

stroke champion on all PPI issues, contributing to the research development. As an integral member of the review team our champion will collaborate in constructing the questions to drive data extraction, and / or reporting and disseminating the findings.

Study status

Electronic database searches are in progress and will be completed by 1st December 2021. No study selection process, formal screening or data extraction has commenced at time of submission.

Discussion/conclusion

There is a growing consensus on the importance of PPI in health and social care research, although current practices in stroke research remain uncharted. A scoping review is indicated where the objective of the review is to generate a clear picture of a concept and its gaps in existing research²⁶. Gaps in current stroke research practices may be identified thereby providing some key opportunities and recommendations for future research. These broad objectives dictated our approach, as presented, to identifying and mapping the existing scientific literature that reports PPI in current stroke research.

While a scoping review can take a broader approach and search for opinion pieces, editorials and guideline documents, we opted in this review to keep a narrower focus to only stroke research with empirical outputs to capture current practices, as opposed to including and summarising best practice recommendations. Where present, PPI activity in stroke research may not always be explicitly reported in scientific papers and appropriately indexed and we acknowledge this potential barrier in searching the stroke research literature. We further acknowledge that while we chose to focus solely on research with empirical output/s, the quality of individual research studies included in the review and primary results unrelated to PPI are not commented on directly.

The findings from this scoping review will help identify what is currently reported in terms of the profile of PPI participants in stroke research, the strategies employed for collaboration and the PPI contributions across the phases of the research cycle. Knowledge gaps will be identified and future priorities for PPI in stroke research identified as a result of this scoping review. Dissemination of the findings will contribute to enhanced awareness and understanding of the need for PPI in stroke research as well as highlighting the current impact of PPI in stroke research, where reported.

Data availability

Underlying data

No data are associated with this article.

Extended data

Open Science Framework: Patient and public involvement in stroke research: a scoping review protocol. <https://doi.org/10.17605/OSF.IO/FP65E23>

This project contains the following extended data:

- PubMedSearchStrategy.docx
- PRISMA-ScR-Fillable-Checklist_11Sept2019.pdf

Data are available under the terms of the [Creative Commons Zero “No rights reserved” data waiver](#) (CC0 1.0 Public domain dedication).

Acknowledgements

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Open Peer Review

Current Peer Review Status:  

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Reviewer Report 01 August 2022

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Elizabeth A Lynch 

Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, Adelaide, SA, Australia

Great work - authors have responded and addressed all queries in full

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Stroke, rehabilitation

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 30 May 2022

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Julie Broderick 

Discipline of Physiotherapy, School of Medicine, Trinity College Dublin, University of Dublin, Dublin, Ireland

The authors need to be commended for a protocol in this valuable topic area of PPI applied to stroke. This emerging area very much lends itself to the scoping review methodology. I

particularly liked how PPI was the topic of this protocol and how it was integrated into Stage 6 of the Arksey and O Malley framework. I have some relatively minor points which are mainly around providing more detail around the scoping review protocol methodology.

Some points for your consideration:

1. I would suggest that the aim is reframed as a single overarching protocol aim, rather than how it is numbered currently
2. This is more a formatting issue - but could the objectives be numbered
3. It is useful to refer to seminar papers in the area of scoping review methodology - Arksey and O' Malley and Levac which are included but I would also suggest referring to Chapter 11 of the JBI Manual for Evidence Synthesis as a methodological framework for this scoping review. I see the JBI data extraction tool was listed but this Chapter is worth reading in detail, also using it as a framework and referring to it in the context of scoping review methodology.
4. In stage 2: 'Leanus' (grey literature) is mentioned in the abstract and methodology - I think this should be spelt 'Lenus', Will reference list of included studies/sources of evidence be checked for possible inclusions. An indicative search strategy is included but could a full search strategy for one of the electronic databases be included as extended data. Could more detail of the grey literature search be included - eg Cadth grey matters tool/others.
5. in Stage 3: Could it be stated that reasons for exclusions will be recorded and charted in the PRISMA flow diagram
6. In Stage 4: Clarify if data will be extracted by one author and verified by another. Following the JBI convention, risk of bias assessment is not a necessity. Clarify whether a risk of bias assessment will take place or not.
7. In Stage 5: Specify how impact will be evaluated/charted and how representativeness of participants will be assessed from an EDI perspective.
8. Discussion: It is mentioned that a scoping review objective is to generate gaps in existing research - but gaps will not be explored in this review so this point may need revision in the context of this protocol.
9. Final point - Could PRISMA-P checklist with location of reporting elements be uploaded as extended data.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Yes

Are the datasets clearly presented in a useable and accessible format?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Research in physical functioning across chronic diseases with a focus on socially excluded populations. Evidence synthesis.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 18 Jul 2022

Patricia Hall, RCSI Division of Population Health Sciences, RCSI University of Medicine and Health Sciences, Dublin 2, Ireland

Thank you for your positive comments and detailed points for consideration.

Please see below detailed responses:

Point 1: I would suggest that the aim is reframed as a single overarching protocol aim, rather than how it is numbered currently

In response to Point 1 – Thank you, numbering has been removed as suggested.

This now reads as below:

The overarching aim of this review is to identify and describe current practices of PPI in stroke research. Specifically, this review will focus on the nature, design and type/s of studies that involve patients and/or members of the public in the planning, conduct and/or dissemination of stroke research, and explore how PPI has been conceptualised in stroke research.

Point 2: This is more a formatting issue - but could the objectives be numbered

In response to Point 2 – I have reformatted the objectives in a numbered sequence.

This now reads as:

Objectives:

- 1. map the volume, type and range of PPI approaches in stroke research*
- 2. profile PPI participants and examine representativeness of participants from an equality, diversity and inclusion (EDI) perspective*
- 3. map PPI research activities against the stroke research cycle*
- 4. collate reported enablers and barriers to PPI application in stroke research*
- 5. explore the impact of PPI on stroke research, clinical practice and health policy*

Point 3 : It is useful to refer to seminar papers in the area of scoping review methodology - Arksey and O' Malley and Levac which are included but I would also suggest referring to Chapter 11 of the JBI Manual for Evidence Synthesis as a methodological framework for this scoping review. I see the JBI data extraction tool was listed but this Chapter is worth reading in detail, also using it as a framework and referring to it in the context of scoping review methodology.

In response to Point 3 – thank you I have read this chapter in the JBI manual in detail and with great interest.

This now reads in the manuscript:

The review will conform to the 5 stages of the Arksey & O'Malley framework for scoping studies¹⁸ refined by Levac¹⁹ and the methodological framework described by Peters in the JBI Manual for Evidence Synthesis (Chapter 11).²⁰

Point 4: In stage 2: 'Leanus' (grey literature) is mentioned in the abstract and methodology - I think this should be spelt 'Lenus', Will reference list of included studies/sources of evidence be checked for possible inclusions. An indicative search strategy is included but could a full search strategy for one of the electronic databases be included as extended data. Could more detail of the grey literature search be included - eg Cadth grey matters tool/others.

In response to Point 4 - (i) apologies for the spelling error; this has now been corrected in the manuscript. (ii) Reference lists will be checked and sample PubMed search strategy is included as supplementary information. (iii) Thank you I was not familiar with Cadth but will now explore this grey literature checklist tool when searching the grey literature.

The manuscript now reads:

The search will involve the electronic databases PubMed, CINAHL, EMBASE, PsychINFO and the Cochrane Database of Systematic Reviews (Supplementary file). These libraries were chosen as they will yield a broad, cross disciplinary range of studies. In addition, reference lists of included studies will be checked. To target relevant grey literature, a systematic search will be conducted in the key databases, e.g. OpenGrey and Lenus. A grey literature checklist e.g. Cadth (Canada's drug and health technology agency), will help ensure a comprehensive search is completed.

Point 5: in Stage 3: Could it be stated that reasons for exclusions will be recorded and charted in the PRISMA flow diagram

In response to Point 5 - Thank you, I have included this detail in the manuscript which now reads:

A PRISMA flow diagram will be produced to present an overview of the identification, screening, eligibility and inclusion phases, with the reasons for exclusion of studies in the screening process provided.

Point 6: In Stage 4: Clarify if data will be extracted by one author and verified by another. Following the JBI convention, risk of bias assessment is not a necessity. Clarify whether a risk of bias assessment will take place or not.

In response to Point 6 - Thank you, I have clarified the extraction process and the manuscript now includes:

Data extraction will be completed independently by at least 2 reviewers and any discrepancies will be resolved by discussion to reach consensus. In accordance with scoping review guidelines, the quality of any study included in this review will not be assessed for risk of bias.

Point 7: In Stage 5: Specify how impact will be evaluated/charted and how representativeness of participants will be assessed from and EDI perspective.

In response to Point 7 - it is expected the process of summarising and reporting results will be an iterative process. Where individual studies provide detail, the impact will be recorded and the diversity of PPI partners will be examined. The manuscript now reads:

The extracted data will be presented in tabular format, providing a brief summary of each individual study included in the review and documenting barriers/facilitators and impact of

participation, where reported in individual studies. The benefit of PPI in stroke research will be recorded where the study details changes (added value) in research methods/activities; interpretation of results, dissemination activities or in policy/practice that was attributed to experience-based involvement. Evaluation of impact will be guided by appraisal criteria²⁵ which considers whether the paper discusses the difference PPI has made to the research activities and the impact of user involvement on the research project (e.g. length of study, financial implications of involvement activities, cost-benefit analyses), and whether benefits claimed are supported by examples from the research project.

The diversity of the experience-based stroke research partners will be examined for sex, ethnicity, stroke type, disability level and will consider issues that may marginalise specific stroke groups from PPI activities including notable mobility and/or communication issues.

Point 8: Discussion: It is mentioned that a scoping review objective is to generate gaps in existing research - but gaps will not be explored in this review so this point may need revision in the context of this protocol.

In response to Point 8 – apologies it was not the intention to suggest gaps will be explored but rather by comprehensively mapping current stroke research practice, gaps may be identified thereby providing some key opportunities for future research.

This is now included in the manuscript as:

Gaps in current stroke research practices may be identified thereby providing some key opportunities and recommendations for future research.

Point 9: Final point - Could PRISMA-P checklist with location of reporting elements be uploaded as extended data.

In response to Point 9 - A checklist is now included in a supplemental information file

Competing Interests: No competing interests were disclosed.

Reviewer Report 22 November 2021

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Elizabeth A Lynch

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This scoping review will present the state of play regarding PPI in stroke research, which is an exciting concept.

- In introduction, I would be tempted to provide more hard data/numbers in statements in

the first paragraph - e.g. "many survivors" (give a number or proportion), "significant increase" (from what level) etc.

- With regard to the inclusion criteria, I think there needs more detail re "Studies with a clear statement in relation to PPI activities/ initiatives which fit the principles of PPI in stroke research, irrespective of terminology" - does this need to be presented in the title? Or abstract? Or paper? Do the authors envisage reading every abstract from the initial search (which is likely to be huge) to look for PPI? Or look for this in titles which might be more feasible but more likely to miss relevant publications.
- "Strong PPI engagement will be embedded in this scoping review methodology... A PPI Champion / stroke survivor contributed to the research objectives and the refining of the search strategy described in this protocol" - can you be explicit whether there is someone with lived experience of stroke in the authorship team? I think there is someone but I'm not quite sure (and if there isn't, should there be, to ensure/demonstrate strong PPI engagement?)

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Partly

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Stroke, rehabilitation,

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 18 Jul 2022

Patricia Hall, RCSI Division of Population Health Sciences, RCSI University of Medicine and Health Sciences, Dublin 2, Ireland

Thank you for your positive comments and detailed feedback.
Please see detailed responses below:

Point 1: In introduction, I would be tempted to provide more hard data/numbers in statements in the first paragraph - e.g. "many survivors" (give a number or proportion),

"significant increase" (from what level) etc.

In response to Point 1 – in the introduction I have provided further data on specific numbers relating to Ireland and Europe.

This now reads:

Stroke is a major cause of death and disability worldwide¹. Globally stroke is the second leading cause of death and third leading cause of disease burden accounting for almost 5% of disability-adjusted life years According to the latest National Audit of Stroke in Ireland (NOCA), almost 6,000 people were admitted to hospital in 2019 and 71% of those with ischaemic stroke had disabilities on discharge.

Despite advances in prevention, early recognition/diagnosis and treatment, projections indicate a significant increase in stroke events worldwide in the coming years.⁵ An ageing population contributes strongly to this increase with European predictions estimating a 34% rise in stroke cases by 2035.

Point 2. With regard to the inclusion criteria, I think there needs more detail re "Studies with a clear statement in relation to PPI activities/ initiatives which fit the principles of PPI in stroke research, irrespective of terminology" - does this need to be presented in the title? Or abstract? Or paper? Do the authors envisage reading every abstract from the initial search (which is likely to be huge) to look for PPI? Or look for this in titles which might be more feasible but more likely to miss relevant publications.

In response to Point 2 – I have clarified the inclusion criteria to make the anticipated screening process more explicit. We do not think it will be possible to identify PPI activity in stroke research only in the title and abstract. We now detail that an inclusive approach will be taken whereby if not identified by title and abstract, full manuscript review will be undertaken with a primary focus on the methodology and acknowledgement sections. This will indeed be potentially onerous but in order to be as comprehensive as possible, since PPI is often not called out in the title/abstract, we feel it is a necessary undertaking to fully address the question. However as this approach will likely generate a high volume of manuscripts to review, a publication date cut-off of 2014 will now be applied to include only studies published after the first handbook of PPI was developed for health researchers. The inclusion criteria now states:

Studies with a clear statement in relation to PPI activities/initiatives which fit the principles of PPI in stroke research, irrespective of terminology. An inclusive approach to screening will be taken whereby if PPI is not mentioned in the title or abstract, the full text manuscript will be reviewed with particular focus on the methods and acknowledgements sections. As PPI is a relatively new concept a publication date cut-off of 2014 will be applied to include only studies published after the first handbook was developed for health researchers was published²²

Competing Interests: No competing interests were disclosed.

Author Response 18 Jul 2022

Patricia Hall, RCSI Division of Population Health Sciences, RCSI University of Medicine and Health Sciences, Dublin 2, Ireland

Point 3 : "Strong PPI engagement will be embedded in this scoping review methodology... A PPI Champion / stroke survivor contributed to the research objectives and the refining of

the search strategy described in this protocol" - can you be explicit whether there is someone with lived experience of stroke in the authorship team? I think there is someone but I'm not quite sure (and if there isn't, should there be, to ensure/demonstrate strong PPI engagement?)

In response to Point 3 – apologies I did not make it clear that one of the authors has indeed the lived experience of stroke. I have corrected this omission as it is very important to us to demonstrate our strongly embedded PPI.

This now reads in the manuscript:

A co-author on this study protocol has personal experience of stroke (JH) and acts as our stroke champion on all PPI issues, contributing to the research development.

Competing Interests: No competing interests were disclosed.
