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Stroke patient and stakeholder engagement (SPSE): concepts, definitions, models, implementation strategies, indicators, and frameworks—a systematic scoping review

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Abstract

Background Involving stroke patients in clinical research through patient engagement aims to ensure that studies are patient-centered, and may help ensure they are feasible, ethical, and credible, ultimately leading to enhanced trust and communication between researchers and the patient community. In this study, we have conducted a scoping review to identify existing evidence and gaps in SPSE.

Methods The five-step approach outlined by Arksey and O'Malley, in conjunction with the Preferred Reporting Items for Scoping Reviews (PRISMA-ScR) guidelines, provided the structure for this review. To find relevant articles, we searched PubMed, Web of Science, and Embase databases up to February 2024. Additionally, the review team conducted a hand search using Google Scholar, key journals, and references of highly relevant articles. Reviewers screened articles, selecting eligible English-language ones with available full texts, and extracted data from them into a pre-designed table tested by the research team.

Result Of the 1002 articles initially identified, 21 proved eligible. Stakeholder engagement primarily occurred during the design phase of studies and within the studies using qualitative methodologies. Although the engagement of stakeholders in the research process is increasing, practice regarding terminology and principles of implementation remains variable. Researchers have recognized the benefits of stakeholder engagement, but have also faced numerous challenges that often arise during the research process.

Conclusion The current study identifies stakeholder groups and the benefits and challenges researchers face in implementing their engagement. Given existing challenges and limited specific models or frameworks, it is suggested to explore applied recommendations for stakeholder engagement in future studies, that may enhance stakeholder engagement, overcome obstacles, and unify researchers' understanding of engagement and implementation.

Keywords Cerebrovascular disorders, Patient advocacy, Stakeholder participation, Stakeholder engagement, Stroke

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Introduction

Involving stroke patients in clinical research through Patient and Stakeholder Engagement (PSE), also known as Patient and Public Involvement (PPI), helps ensure that studies are patient-centered, and can enhance feasibility, credibility, and ethical conduct [1–3]. This approach can ultimately lead to more relevant and effective outcomes, as well as improved trust and communication between researchers and the patient community. Additionally, it is expected to enhance the overall quality of studies [4–7].

High-level organizations (e.g., UNESCO, EU) and well-known funders (Bill and Melinda Gates Foundation, Wellcome Trust, etc.) are increasingly mandating PSE for the clinical studies they fund. Despite the numerous papers addressing PSE activities and various recommendations of differing quality and focus, there remains a lack of consensus among authors regarding the most effective methods for developing and nurturing PSE [3, 5, 8–10]. There is no well-established framework or model, the terminology is often unclear, and ultimately, more evidence is needed to define the conditions and approaches under which PSE is most effective [5, 8–10]. The unclear definitions and diverse terminology can exacerbate the special challenges that individuals with disabilities such as communication and cognitive impairments seen in stroke patients face in research engagement [3, 11–13].

Due to its status as the world's second leading cause of death and long-term disability and its increasing frequency as populations age [14–16], we have therefore conducted a scoping review focusing on stroke as an index indication. Our ability to prevent and manage stroke, and thus decrease its burden, also influenced our choice. Optimal stroke prevention and management requires collaboration among governments, scientific organizations, healthcare professionals, researchers, patients, and families [14, 16–18]. The European Stroke Action Plan (2018–2030) emphasizes improving the linkage between research results and patient populations [19]. As in other indications, patient and stakeholder engagement in stroke research is not clear, necessitating comprehensive studies to identify barriers, gaps, needs, and opportunities regarding PSE. Although we focus on stroke, the findings will also be relevant to other diseases.

The primary objectives of this study are to gather evidence on Stroke Patient and Stakeholder Engagement (SPSE), derive insights from past experiences and recommendations, and clarify key concepts, definitions, models, strategies, indicators, and frameworks for establishing SPSE. Based on our findings we propose a comprehensive framework that integrates patient and stakeholder perspectives into stroke research, potentially advancing both theoretical understanding and practical

applications for more effective, inclusive, and patient-centered stroke management and rehabilitation.

Methods

The study protocol entitled “Systematic scoping review protocol of Stroke Patient and Stakeholder Engagement (SPSE)” was published in 2023, in the *Journal of Systematic Reviews* [20]. The planning, conducting, and reporting of the findings of this scoping review were guided by 5 steps described by Arksey and O'Malley. These steps included (1) identifying the initial research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collecting, summarizing, and reporting the results- as well as the Preferred Reporting Items for Scoping reviews (PRISMA-ScR) [21–23].

Systematic scoping reviews are fundamentally undertaken to map certain knowledge fields, identify key concepts and knowledge gaps, as well as address thorough inquiries, which may involve a variety of approaches but do not evaluate the quality of studies [21–23].

Step 1: Identifying the initial research question

A scoping review was employed to achieve the following objectives:

- (1) Characteristics of the studies conducted in terms of the central concern, the temporal and spatial process of conducting and publishing the studies;
- (2) Identifying the sorts of existing recommendations, challenges, process of engagement, guidelines, and models;
- (3) Determining the current SPSE evidence related to groups of stakeholders and Phase of engagement for establishing SPSE;
- (4) Compiling the related terms/concepts to stakeholder engagement and definitions;
- (5) Understanding how stakeholders participate in different stages of the study;
- (6) Determination Principles of Patient and Stakeholder Engagement (PSE) in the Research Process;
- (7) Identifying challenges and benefits regarding Patient and Stakeholder Engagement (PSE) in the research process;

We addressed the following questions concerning research related to stroke:

- (1) What are the characteristics of the studies, including their central concern and the chronological and geographical aspects of conducting and publishing them?

- (2) What recommendations, challenges, engagement processes, guidelines, and models for establishing SPSE are mentioned in existing studies?
- (3) What current SPSE evidence is related to various stakeholder groups and stages of engagement for SPSE in the research process?
- (4) What are the related terms and concepts of stakeholder engagement, and how are they defined?
- (5) How do stakeholders engage in different phases of the study?
- (6) What are the principles of Patient and Stakeholder Engagement (PSE) in the research process?
- (7) What challenges and benefits are associated with Patient and Stakeholder Engagement (PSE) in the research process?

The findings of this scoping review will be utilized to shape the development of principles, models, or tools that will offer guidance to researchers in the field of SPSE.

Step 2: Identifying relevant studies

Based on past studies, there are no clear and uniform terms in the field of stakeholder engagement in the research process [11, 24]. To find relevant studies, a brief review of the existing studies and MeSH and Emtree terms was conducted to select the best keywords to search. Then, the search strategy was set with keywords “research,” “Cerebrovascular Disorders,” “stroke,” “Patient Advocacy,” “Caregivers,” and “Stakeholder Participation.”

Three health databases including PubMed, Web of Sciences, Embase, and Google Scholar search engine were searched until February 2024 to find related literature. Also, to complete the review, a hand search of studies and a review of resources of highly relevant articles and key

journals were done. You can find the search strategy of the PubMed database in Supplemental File 1.

Results from the search strategies were exported and managed using Endnote X.7.5.3 and Microsoft Word. The de-duplication process was completed using the steps outlined by Bramer et al. [25]. Two team members (ShSh and HKh) independently used a Word screening tool and the abstract-level eligibility criteria to screen titles and abstracts.

Based on inclusion criteria, English articles related to stroke patients or rehabilitated patients with research competence in PSE are considered for reporting in this scoping review study.

Step 3: Study selection

The final studies were selected after secondary screening by reading the full text of the articles, which was based on the inclusion and exclusion criteria. The inclusion and exclusion criteria are presented in Table 1. The selection of inclusion criteria was meticulously designed to ensure comprehensive inclusion of all relevant evidence about the research topic. Standard definitions, such as those for stroke, were utilized to maintain consistency and clarity. This approach guarantees that the final report encompasses all pertinent studies, thereby enhancing the transparency and robustness of the review process. The full-text screening process was conducted independently by the same screening pairs. Consensus discussions were conducted to resolve any disagreements between screeners. If disagreements persisted despite these discussions, a third team member (JR or TR) was consulted to provide a resolution. Additionally, challenging issues were deliberated in meetings by the entire research team to ensure thorough and balanced decision-making.

Table 1 The inclusion and exclusion criteria of the study

Criterion	Definition
General	The article describes, reflects, and/or evaluates a type of research engagement approach in the area of health research about Stroke, in which research users were engaged in the research process
Population	The study included past or present stroke patients (of any age, gender, or health status, as well as their family carers) their formal and informal caregivers, patient representatives, researchers, and participants from various nations
Engagement	Stakeholder engagement is a collaborative approach to research that values the unique perspectives and strengths of non-traditional research partners [3]
Screening procedure	This scoping review defined important ideas, definitions, and components and identifies models, implementation techniques, indicators, and frameworks for the establishment of SPSE
Disease definitions	The American Heart Association/American Stroke Association defines a stroke as one that includes silent infarctions (including cerebral, spinal, and retinal) and silent hemorrhages [26]
Setting	Our aim was worldwide, encompassing all nations
Study design	We considered observational and interventional investigations, including experimental, quasi-experimental, analytical, descriptive, qualitative, systematic reviews, randomized controlled trials, non-randomized controlled trials, before-and-after studies, and interrupted time-series studies
Result and conclusion	By presenting the various definitions of engagement, models, protocols, implementation strategies, indicators, and frameworks for stroke patients, we synthesized existing knowledge to address gaps in the literature on SPSE research

Step 4: Charting data and data extraction

For data extraction and presentation of the review results, the authors designed and tested several tables and figures, which can be found in the results section. Two researchers (ShSh and HKh) independently extracted the data and afterward integrated their findings. Data extraction and analysis followed the directed qualitative content analysis method suggested by Hsieh and Shannon, utilizing previously established definitions, principles, terminologies, and a comprehensive list of related information from published papers [27].

The study characteristics extracted utilizing an Excel form and exported to Word included the first author, year of publication, country of study, title, study design, and study aims. The engagement characteristics extracted were the definition of stakeholder engagement, group of engaged stakeholders, phase of stakeholder engagement, challenges and benefits of stakeholder engagement, and principles and strategies to implement SPSE in the research process.

The first author (HKh) reviewed the extracted information and resolved any uncertainties (e.g., engagement definitions or study design) through discussions with two team members (JR or TR). Subsequently, two team members (HKh and ShSh) who contributed to data extraction reviewed the findings and provided feedback. The first author (HKh) then finalized the results based on this feedback. Finally, each category of extracted data was referenced to the corresponding publications from which they were extracted.

Step 5: Collecting, summarizing, and reporting the results

A summary and report of findings are provided below in the results part.

Results

A systematic search resulted in 1440 articles, of which 438 were removed due to duplication. In the first screening, the title and abstract of the remaining 1002 articles were reviewed. Based on inclusion and exclusion criteria, 63 articles were selected for full-text reviewing and secondary screening. Ultimately, 21 articles met the inclusion criteria and were reported in this scoping review study (Fig. 1).

European countries have been at the forefront of SPSE studies, with the UK leading with five papers, followed by the USA and China with three each. Other studies have been conducted in Italy, Australia, Canada, Germany, Norway, Sierra Leone, India, Nigeria, and Scotland (Fig. 2).

Studies on SPSE are categorized based on their goals. 43% of the articles specifically focus on SPSE (first category), while 57% of studies address aims such as identity

reconstruction, stroke recovery, or rehabilitation, all involving stakeholders in the research process (second category).

Research on SPSE has garnered attention from researchers since 2005. The number of published articles has steadily increased, with 61% of articles published after 2021, averaging three studies per year (Fig. 3). In recent years, the number of articles that have engaged stakeholders (second category) has proved greater than those that have discussed SPSE (first category). The number of articles published in 2024 may increase by the end of the year.

The first category of studies that specifically focused on SPSE is shown in Table 2. A significant number of studies did not have a clearly defined methodological approach. None of the studies that referenced the SPSE model presented a comprehensive and transparent outline of how stroke patients and their stakeholders could participate in the research. Additionally, none of the studies outlined any guidelines about engagement. Although the involvement of patients and stakeholders in different phases of the research was mentioned in 67% of the articles, less than half of the studies acknowledged the complications associated with engagement. Intriguingly, more than 77% of the studies proposed recommendations for enhancing SPSE, as shown in Table 2.

The second category of articles includes studies that engage patients and stakeholders in the study process or have been planned for SPSE (study protocol). These protocols utilized a combination of qualitative (75%) and quantitative (25%) research methodologies. Various stakeholders, such as patients, caregivers/relatives, health professionals, and policymakers, were planned to be involved in the research process, including designing studies (2 articles), conducting studies (analyzing data, 1 article), and disseminating findings (1 article), as outlined in Table 3. For instance, Faccio et al. involved three stroke survivors and their families in the research design, based on their expressed needs, with the goal of identifying strategies and devices to be implemented in public services to improve the care pathway [33]. In Farre et al.'s study, six stroke patients and three spouses engaged in the process of drafting a funding proposal. Also, the views of these stakeholders were considered in the design of the interventions [34].

Completed studies have employed different research paradigms, including quantitative (3 articles), qualitative (4 articles), and mixed methods (1 article), to involve patients and stakeholders in the research process. These stakeholders included patients, caregivers/relatives, health professionals, and research users. One qualitative study specifically addressed the inclusion of SPSE in proposal writing. Engagement with stroke patients and their

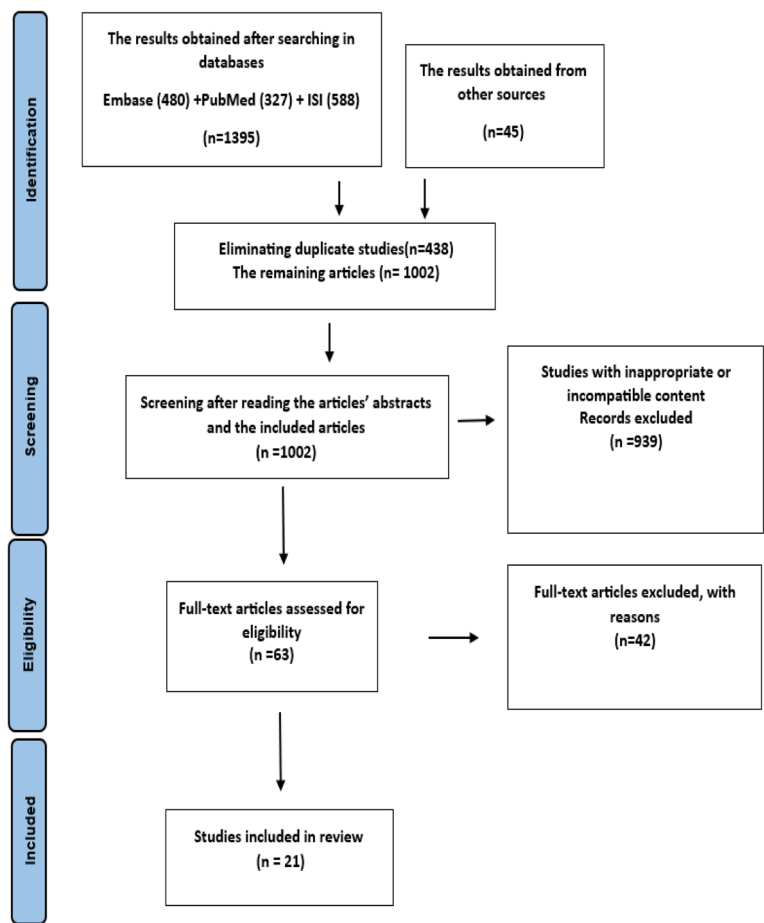


Fig. 1 The PRISMA flowchart

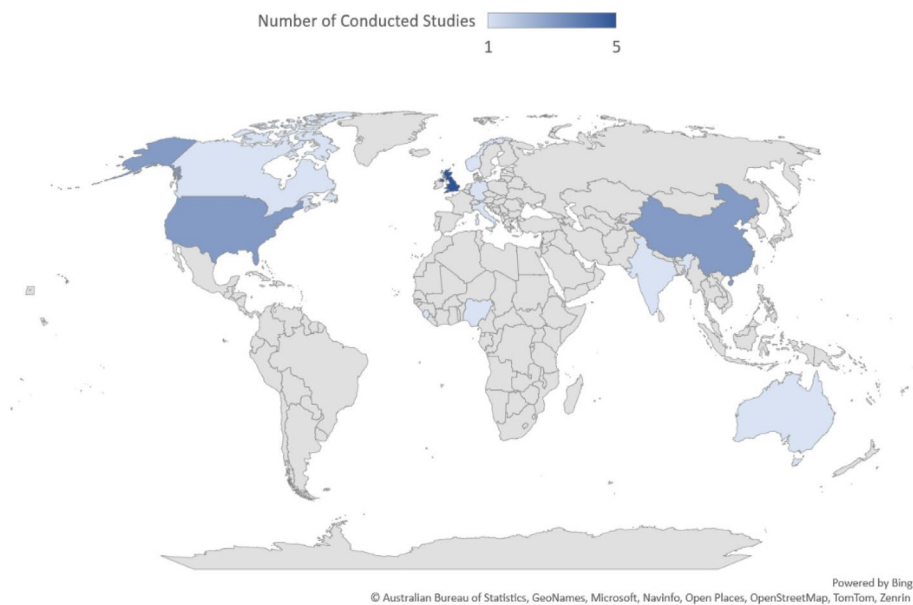


Fig. 2 Spatial distribution of published studies

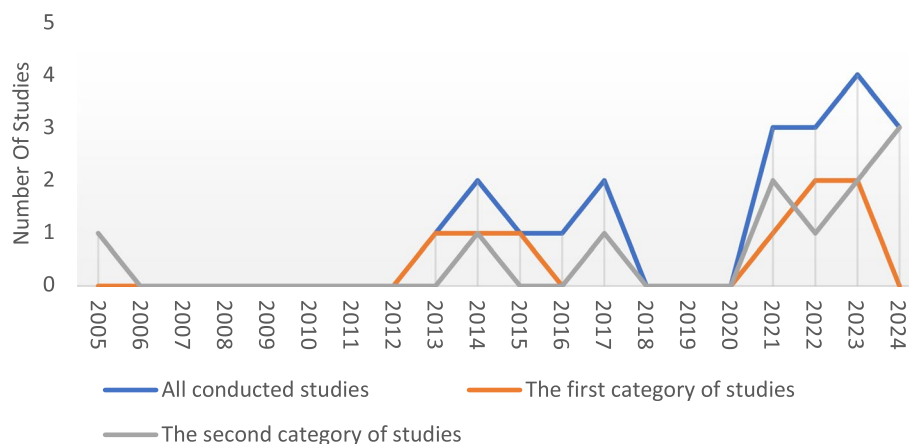


Fig. 3 Temporal trends in published SPSE studies

stakeholders occurred during the design phase in 62% of the articles, during data analysis in 25%, and in the dissemination of findings in 12% (Table 3).

The concept of Patient and Stakeholder Engagement (PSE) within the research process has been considered by various terms and phrases, including collaborative research approach, working together in a partnership, involvement of individuals who have an interest in the research, carrying out research with or by members of the public, an active partnership between patients, carers, and members of the public with researchers, engaging in collaborative research activities, the inclusion of users not as participants but as co-researchers, cooperation in decision-making and research activities which can be taken as co-production, codesigning, stakeholder involvement, and research partnerships (Table 4).

Throughout phases of the research process, such as study design, implementation, and dissemination of results, diverse methodologies have been employed for engaging stakeholders, as outlined in Table 5. Among the 21 studies examined, only 6 (28%) provided detailed descriptions of the specific methods of stakeholder engagement utilized. These studies belong to the first category, which focuses on SPSE. Articles that engaged stakeholders in the research process did not elaborate on the methods of engagement.

SPSE is considered from the early stages of research (e.g., topic/title selection) to the final stages (e.g., dissemination of findings). However, the majority of the articles did not provide comprehensive information on the mechanisms employed for engaging stakeholders in the planning, conducting, or communication of study findings.

The findings presented in Table 5 are applicable for conducting research within both quantitative and qualitative paradigms at different stages of the study.

However, stakeholder engagement requires adherence to several principles, which can complicate the employment of SPSE at each stage of the research process. These principles are outlined in Table 6.

This review highlights the limited integration of SPSE principles in previous studies, with only 33% of the articles reviewed demonstrating some aspects of SPSE. The analysis reveals a lack of consistency in the implementation of SPSE principles, with researchers often relying on their interpretations to guide their methodology of SPSE. The principles identified in the literature incorporate various aspects of the research process, including general principles (e.g., ethical consideration, flexibility, and openness) and specific guidelines, as summarized in Table 6. Based on the findings, researchers should prepare for stakeholder engagement in multiple ways, such as developing a protocol or roadmap, allocating adequate resources in terms of cost and time, and providing continuous training to stakeholders. During the research process, it is crucial to ensure the active participation of stakeholders through measures such as soliciting feedback and holding informal meetings.

Articles discussing stakeholder engagement challenges accounted for only 14% of the total studies reported in Table 7. Our findings indicate that stakeholder engagement in the research process is associated with several challenges related to the research process, researchers, and stakeholders. Some challenges are inherent to the nature of engagement, such as being time-consuming and costly, which cannot be altered but can be managed. Other challenges, which pertain to all three areas, align with the principles mentioned in the previous table. Adhering to these principles, such as detailed and operational planning, appears to mitigate these challenges and can be further explored in future studies.

Table 2 Studies that specifically focused on SPSE (first category)

	Author(s)	Title	Type of study	Key findings				
				Model	Guideline	Process of engagement	Challenges	Recommendation
1	Hoekstra et al. [11]	Systematic overviews of partnership principles and strategies identified from health research about spinal cord injury and related health conditions: A scoping review	Scoping review			*		*
2	Brown et al. [13]	Stakeholder involvement in a Cochrane review of physical rehabilitation after stroke: Description and reflections	Not clear			*	*	*
3	Arnold et al. [28]	"What Do You Need? What Are You Experiencing?" Relationship Building and Power Dynamics in Participatory Research Projects: Critical Self-Reflections of Researchers	Not clear				*	*
4	McShan et al. [7]	Better Together: Evolution of Patient Stakeholder Engagement in Healthy Lifestyle Research After Acquired Brain Injury	Not clear			*		
5	Roach et al. [29]	Lay Stakeholders in Science and Research Initiative	Not clear			*	*	*
6	Gesell et al. [3]	Methods guiding stakeholder engagement in planning a pragmatic study on changing stroke systems of care	Not clear	*		*		*
7	Boote et al. [30]	Stroke survivor and carer involvement in, and engagement with, studies adopted onto the NIHR Stroke Research Network portfolio: questionnaire survey	Letter to the editor			*		
8	Pollock et al. [31]	Development of a new model to engage patients and clinicians in setting research priorities	Priorities setting research	*				*
9	Sims et al. [32]	How to develop a patient and carer advisory group in stroke care research	Not clear				*	*

Numerous articles have broadly examined the advantages of stakeholder engagement compared to studies focusing on challenges. Specifically, five studies have highlighted the benefits, while only three studies have addressed the challenges. Additionally, Table 8 illustrates that the anticipated benefits of stakeholder engagement outweigh the identified challenges. The proposed benefits of stakeholder engagement extend beyond stakeholders, researchers, and the research process, benefiting a wide range of groups.

Discussion

This scoping review study identified types of evidence related to SPSE, summarized experiences and recommendations, clarified key concepts, definitions, and components, and identified models, implementation strategies, indicators, or frameworks for establishing SPSE.

The results of our study reveal a higher frequency of SPSE in qualitative research methodologies compared to quantitative and mixed methods, which aligns with the findings of Peniche et al. [45]. Many of the studies

Table 3 (continued)[illegible]

Table 4 Related terms/concepts to stakeholder engagement and definitions

Study	Stakeholder engagement and related concepts	Definition
Gesell et al. [3]	Stakeholder Engagement	Stakeholder engagement is a collaborative research approach that values nontraditional research partners' unique perspectives and strengths
Brown et al. [13]	Coproduction	Working together in a "partnership" to produce research, and considered this one form of stakeholder involvement, in which specific criteria are met concerning partnership working
Brown et al. [13]	Stakeholder Involvement	The involvement in research of any people who have an interest in the research, in partnership with the (traditional) research team Research being carried out "with" or "by" members of the public rather than "to," "about," or "for" them. It is an active partnership between patients, carers, and members of the public with researchers that influences and shapes research
Hoekstra et al. [11]	Research Partnerships	Individuals, groups, or organizations that are engaged in collaborative research activities involving at least one researcher and any stakeholder
Morgan et al. [42]	User Involvement	The inclusion of users not as participants but as co-researchers with a key position in the research design, data collection, interpretation, and dissemination processes
Arnold et al. [28]	Participation	Participation refers to the cooperation in decision-making and research activities of those persons who are directly affected by the problems that are the subject of the respective research projects

Table 5 Different stages of Patient and Stakeholder Engagement (PSE)

Stage of study	Stakeholders' engagement	Resources
Study design	<ul style="list-style-type: none"> ■ Selection of the research topic ■ Identifying or prioritizing topics for research ■ Checking the applicability of the research ■ Developing and revising the research question ■ Elaboration or approval of the research proposal or protocol ■ Compilation of the grant proposal ■ Designing interventions ■ Design questions and interview guide ■ Designing study inclusion criteria ■ Develop, evaluate, or revise data collection tools ■ Elaboration of informed consent form and details of participants 	Boote et al. [30] Gesell et al. [3] Roach et al. [29] McShan et al. [7] Brown et al. [13] Hoekstra et al. [11]
Study conduct	<ul style="list-style-type: none"> ■ Literature review ■ Selecting participants for the study ■ Expressing opinions in various contexts such as forms of data collection and informed consent study applications ■ Conducting a pilot study and providing feedback ■ Data collection ■ Planning interviews ■ Data analysis and interpretation ■ Conducting interviews or managing focus group discussions ■ Training participants in the field of interventions ■ Supervision of study implementation 	Boote et al. [30] Gesell et al. [3] Roach et al. [29] McShan et al. [7] Brown et al. [13] Hoekstra et al. [11]
Dissemination of findings	<ul style="list-style-type: none"> ■ Feedback on the comprehensibility and fluency of the published findings ■ Feedback on the best strategies for disseminating findings (timeliness and effectiveness) ■ Participating in preparing the manuscript of the article or reviewing and providing feedback ■ Knowledge translation activities ■ Translation of scientific data into comprehensive and understandable language ■ Presentation of study results in conferences ■ Providing clinical recommendations and policy briefs ■ Planning on how to publish findings ■ Developing key messages 	Boote et al. [30] Gesell et al. [3] McShan et al. [7] Brown et al. [13] Hoekstra et al. [11]

that specifically focused on SPSE (first category) lacked a defined methodological approach, and none provided a comprehensive or transparent framework for including stroke patients and their stakeholders in the

research process. We believe this unclear methodology in the first category could be a barrier to understanding the SPSE process and may reduce the transparency and reproducibility of the reported studies. Furthermore,

Table 6 Principles of Patient and Stakeholder Engagement (PSE) in the research process

Study	Eara	Principals
Sims et al. [32] Pollock et al. [31] Gesell et al. [3] Roach et al. [29] Brown et al. [13] Arnold et al. [28] Hoekstra et al. [11]	Principals related to research process	<ul style="list-style-type: none"> ■ Ethical considerations ■ Development of a suitable protocol (road map) for the stakeholders and Explanation of the role and responsibility of stakeholders ■ Detailed and operational planning for the engagement of stakeholders ■ Use the targeted strategy and select a diverse group of stakeholders with good experience through local and national professionals or community networks and spend proper time and consideration to recruit stakeholders ■ Predetermined planning to manage disagreements between stakeholders and researchers ■ Maintaining transparency and trust in communication with stakeholders ■ Active participation of all co-researchers in all parts of the research process on an equal basis ■ Determine level and type of stakeholder engagement according to their interest, skill, time, health status and project needs and budget constraints ■ Develop an engagement database ■ Engage groups that are marginalized or disadvantaged in society ■ Choosing the appropriate time and place to hold consultation meetings for stakeholders (e.g., patients with mobility restrictions) ■ Have informal meetings (to get to know each other) and structured meetings (face-to-face, phone, conference calls) ■ Ensuring that IT support is available before and during meetings ■ More frequent, shorter, meetings (rather than less frequent, longer meetings) ■ Permanent reflection on relationships and power dynamics in the field of engagement in research processes ■ Consideration the experience of the research team about stakeholder engagement at the planning stage ■ Include a knowledge broker or other facilitator to support the collaborative process (e.g., facilitate conversations) ■ Funding for the collaborative research activities
	Principals related to stakeholders	<ul style="list-style-type: none"> ■ Orientation and ongoing training of stakeholders ■ Pay the engagement costs of patients and caregivers (such as travel expenses) ■ Attention to the needs and values of stakeholders and issues that may provoke emotional responses from stakeholders ■ Getting feedback from the stakeholders about their engagement in the research process continuously ■ Evaluating the level of satisfaction of the stakeholders from the engagement and the feeling of the value of their perspective ■ Providing Regular “check-ins” and feedback opportunities for stakeholders to share their viewpoints and ask questions ■ Careful attention to potential burnout, overcommitment ■ The benefits of being engaged in research should be clearly defined ■ Cooperation in the research project should depart from these familiar role patterns and allow for more liberal cooperation, for example, without entering into a therapy contract
	Principals related to researchers	<ul style="list-style-type: none"> ■ Using simple and understandable language in communication with patients and caregivers (e.g., aphasia-friendly information sheet) ■ Listening carefully to the opinions and views of stakeholders ■ Considering the appropriate and different communication methods for engagement of stakeholders and informing them about the research process (face-to-face interview, email, phone, etc.) ■ Flexibility and openness in stakeholder engagement ■ Educate and/or train researchers about stakeholder engagement ■ Use different tools to ensure that research users understand and/or participate in everything (e.g., flipcharts, communication tools)

specific guidelines or protocols for engagement were not offered in any of the studies. While only a minority of the studies acknowledged the challenges related to engagement, most did provide general suggestions for SPSE. The majority of SPSE occurred during the design phase, followed by data analysis, and the dissemination of findings in completed studies.

SPSE has been described using various terms/concepts and phrases, all emphasizing a collaborative approach. Despite the importance of SPSE, the majority of articles reviewed did not carefully detail the strategies used to involve stakeholders in the research process. While a range of methodologies were utilized through the research process, only a limited number provided

Table 7 Challenges regarding Patient and Stakeholder Engagement (PSE) in the research process

Related area	Challenges	Resource
Challenges related to stakeholders	<ul style="list-style-type: none"> ■ Physical disabilities and communication disorders of patients (aphasia) ■ Fear of not being able to participate actively and being ineffective as a researcher ■ Feeling unable to balance their clinical responsibilities and duties in the research process 	Sims et al. [32] Arnold et al. [28]
Challenges related to researchers	<ul style="list-style-type: none"> ■ Insufficient knowledge about how to engage stakeholders ■ Lack of enough time ■ Inadequate simplification and accessibility of stakeholder engagement in the research process 	Sims et al. [32] Brown et al. [13] Arnold et al. [28]
Challenges related to the research process	<ul style="list-style-type: none"> ■ The limitation of published studies that have experienced the engagement of stakeholders ■ Time-consuming and costly and limited resources for the engagement of stakeholders ■ Difference of opinions of researchers and stakeholders in the process of data analysis ■ Communication challenges between researchers and stakeholders (such as power relations) ■ Selection of the research topic ■ Determination of the level and stages of engagement ■ Organizational rules ■ Multiplicity of stakeholders 	Sims et al. [32] Gesell et al. [3] Arnold et al. [28]

Table 8 Benefits of Patient and Stakeholder Engagement (PSE) in the research process

Study	Benefits
Sims et al. [32] Roach et al. [29] McShan et al. [7] Brown et al. [13] Arnold et al. [28]	<ul style="list-style-type: none"> ■ Improving the quality of study ■ Simplifying interview questions ■ Providing an alternative way of data analysis ■ Improving decision-making in the field of the study process (receiving funds, choosing scientific guides) ■ Improving the credibility of the study ■ Promoting the use of study results for the general public, policymakers, and other stakeholders ■ Providing a realistic, unique, and diverse view in the process of research design and implementation ■ Helping researchers to better understand the views and opinions of the study audience ■ Helping to develop programs with higher health literacy ■ Changing the knowledge and views of stakeholders, which led to their roles and scope of engagement evolving over time ■ Achieving more relevant and meaningful studies ■ Create space for sharing views and better mutual understanding of stakeholders and researchers ■ Hearing the voices and opinions of people whose voices are less heard in society ■ Democratic design of the study process and reduction of discrimination ■ Improving the study design and associated outcomes, and ensuring cultural appropriateness of materials ■ Increasing recruitment and retention of research subjects ■ Injecting transparency, and accountability into the research process ■ Reduced length of surveys administered to study participants ■ Ensuring study goals and project activities are meaningful and patient-centered ■ Grown research team's understanding of the scope, value, and importance of partnering with patients in research

detailed descriptions of the SPSE methods employed. The literature defines principles of SPSE that cover various aspects of the research process, both general and specific, yet there is limited discussion on strategies specifically tailored to stroke patients and their stakeholders.

One of the strengths of our systematic scoping review is our comprehensive search and specific focus on stroke patients and their stakeholders, unlike previous reviews which had a more generalized approach to patient stakeholder engagements. Our use of clear eligibility criteria and rigorous methods for systematic data analysis

and extraction ensures that we have not overlooked any essential information regarding characteristics, concepts, definitions, components, models, implementation strategies, indicators, challenges, benefits, or frameworks related to establishing stroke patient stakeholder engagements. We believe our study is comprehensive due to its inclusive exploration of recommendations and key concepts for establishing SPSE, distinguishing it from similar reviews. Our study involves all aspects of engagements, including PPI, without time constraints up to 2024. Following Arksey and O'Malley's five steps and utilizing

directed qualitative content analysis, we included all relevant papers, including protocols, categorizing them into those discussing or implementing engagement. Our study uniquely addresses the challenges and benefits related to researchers, stakeholders, and the research process in implementing SPSE.

This study was limited by the high number of conference papers and the restricted access to their full texts. Additionally, the diversity of terminology in the field of stakeholder engagement required the authors to formulate a search strategy based on MeSH Headings, Emtree terms, and synonyms. To address this limitation, hand searches were conducted to identify relevant studies and key journals, thereby planning to improve study accuracy. It is recommended that the terminology introduced in this study be integrated into the search strategies of future researchers.

Furthermore, the study was also constrained by the extensive studies utilizing co-design and priority-setting methods, which prevented their comprehensive inclusion in this scoping review. These methods warrant further investigation in future studies.

Based on this review, there has been a noticeable increase in the publication rate of articles, particularly since 2021 [7, 11–13, 28, 29, 33–37, 40, 41, 44]. This trend aligns with a growing emphasis on stakeholder engagement in the research process, reflecting broader efforts towards knowledge translation, responsible research, and open science [46–48].

European countries, especially the United Kingdom have taken the lead in conducting SPSE studies. The increasing interest from other developed countries like the United States and China, as well as less developed countries such as Sierra Leone and Nigeria, suggests a growing interest in SPSE within the research community [3, 7, 35–37, 39, 40, 43]. Despite concerns over the cost of SPSE, many suggested principles, such as prioritizing stakeholder needs and values, and maintaining flexibility and openness, appear to be achievable for researchers irrespective of financial constraints [13, 28, 32]. Hence, it appears that implementing SPSE strategies is feasible across countries with varying economic and developmental statuses. Consequently, future research endeavors should focus on further exploring the advantages and impacts of engagement, including the economic and social repercussions of SPSE.

The findings of this review suggest that the articles can be categorized into two distinct groups based on the study's objective; those that focused on discussing engagement (first category) and those that implemented this approach (second category) which is not considered in a recently published review [45].

The majority of the first group of studies that discussed SPSE lacked a defined methodological approach [3, 7, 13, 28, 29, 32]. Additionally, none of the studies provided a comprehensive and transparent framework for including stroke patients and their stakeholders in the research process. Furthermore, none of the studies offered specific practical guidelines for engagement [3, 7, 11, 13, 28–32]. Only a minority of the studies acknowledged the challenges related to engagement, but most of them did offer suggestions for SPSE [3, 11, 13, 28, 29, 31, 32].

The second group of studies on SPSE in Health Research had differing research paradigms, including qualitative, quantitative, or mixed methods, with some studies also following a protocol [33–36]. Among these, articles with a qualitative paradigm were more commonly found. The authors of these studies suggest that the flexibility offered by qualitative research methods has contributed to the growing interest in stakeholder engagement in this area. Stakeholders have been involved in multiple stages of the research process, such as designing interview guides, collecting and analyzing data, and disseminating research findings [3, 7, 11, 13, 29, 30]. However, challenges have been identified in the form of struggling perspectives and disagreements between researchers and stakeholders during the data analysis process [3, 13, 28, 32].

In quantitative research, stakeholders play a key role in the design and dissemination of research findings, as demonstrated by studies conducted by Zhang and Morgan [40, 42]. Other studies also support the engagement of stakeholders in various stages of quantitative research, including selecting research topics and titles, formulating research questions, choosing appropriate measurement tools, designing interventions, and sharing research findings [40, 42–44].

Opposite to previous research in the field of SPSE, which primarily utilized quantitative and qualitative methodologies, only one mixed-methods study was identified. This study employed a co-design methodology [44].

In general, in the second category of studies, several stakeholders were involved in the research process, with the largest group being patients with stroke [37, 38, 43]. Other stakeholders identified included caregivers and/or families of patients, professional teams, and policymakers. The terms “research users” and “consumers” were also used in Morgan and Hostetler’s study with a similar meaning of stakeholders, including a wide range of individuals within this group [11, 42]. Wu et al.’s study on identifying stakeholders in healthcare introduced 12 groups as stakeholders in the healthcare system, including individuals from universities, hospitals, nursing homes, monitoring systems, and insurance institutions.

The classification presented in this article appears to encompass all relevant people in healthcare and offers a comprehensive definition of stakeholders, which may be valuable for future researchers [49].

Regardless of the study paradigm in which the stakeholders engaged, the highest level of SPSE has been in the study design phase which is in line with the study by Peniche, de Moraes Faria et al. followed by other stages including the formulation of a research proposal, data collection, and analysis, drafting of the manuscript, and dissemination of research findings [33–36, 40, 41, 45].

Based on the results of this study, the terms “involvement” and “partnerships” have been identified as interchangeable with stakeholders’ engagement in the research process [3, 11, 13, 28, 42, 50]. The use of various terms may present a challenge for researchers seeking to approach relevant studies on stakeholder engagement [24]. Therefore, there is a serious need to establish a clear and comprehensive definition of stakeholder engagement in research to support future investigations [3, 24]. Conducting concept analysis studies can help elucidate the nuances of this crucial concept and establish a comprehensive, widely accepted definition to facilitate coherence and consistency within the research community.

The methods of stakeholder engagement in the research process, from initial question formulation to dissemination of findings have been discussed in a few articles, which are in the first category. The dispersed and unstructured presentation of these steps in different studies makes it difficult to follow the SPSE step-by-step. Also, some steps are less discussed and remain unclear, further explanation of the process of engagement is needed [3, 7, 11, 13, 28–32].

In contrast to the inadequate methods mentioned for stakeholder engagement, several principles are considered in the articles. Key principles highlighted in these studies, such as ethical considerations, flexibility, and building trust, align with the guidelines for conducting research in the biomedical sciences. The unique characteristics of stroke patients and the diverse stakeholders involved necessitate the development of tailored protocols to effectively engage all parties involved [3, 13, 28, 29, 31, 32, 50].

However, given the diversity of research methodologies, the complex nature of the stroke patient’s complicated situation, and the numerous obstacles encountered during the research procedure, mere acquaintance with the principles and recommendations for designing and executing studies involving stakeholder engagement proves insufficient [3, 11, 51].

Also, the relationship between these principles and the methods of participation is not mentioned in the articles, and the prioritization of the implementation of these

principles is not clear. It should also be noted that due to the different nature of studies in different paradigms, the importance and prioritization of these principles will be different [3, 11, 13, 28, 29, 31, 32].

Based on the findings of the study, challenges related to researchers, stakeholders, and the research process have been identified. Researchers may struggle with issues such as unfamiliarity with patient engagement and patients’ physical limitations [3, 13, 28, 32]. Recommendations from various studies include allocating more resources and time for these types of studies, educating stakeholders, and increasing awareness before initiating research involving engagement [3, 11, 13, 28, 29, 31, 32]. Differences between quantitative and qualitative paradigms, ethical concerns regarding stakeholders’ rights, potential compromises in study criteria, and the lack of evaluation standards for studies involving stakeholder engagement further complicate the issue [3, 7, 11, 13, 28–32].

In addition to the challenges associated with engaging stakeholders in the research process, several studies have highlighted the numerous advantages of this practice [46–48, 52]. Many of these benefits, such as enhancing study quality, improving study credibility, and incorporating the perspectives of marginalized voices, align with principles of responsible research practices. The promotion of democracy, transparency, and patient-centeredness in research has garnered significant attention in recent years. The benefits of stakeholder engagement extend beyond just stakeholders, researchers, and the research process, benefiting various other groups of the community as well [46–48, 52]. Further study is needed to explore the latent benefits of SPSE.

Based on the findings of existing studies, which indicate a lack of a specific framework or model, limited details on the steps and methods of stakeholder engagement, the need to observe several principles during the research process, and the presence of various challenges, it is evident that SPSE should be a focus of future research. Studies in this area should aim to provide a specific definition of stakeholder engagement, clarifying its antecedents, attributes, and consequences. Additionally, the development of specific models or frameworks and applied strategies for conducting studies in different paradigms should be followed.

One of the limitations of this study was the selection of studies in English, which can lead to language bias. Considering the importance of stakeholder participation in the research process and the results obtained regarding the tendency of different countries towards this issue, it is suggested to conduct multicenter studies in various languages in the future.

Conclusions

The research on Stroke Patient and stakeholder engagement (SPSE) has shown a global increase in recent years, with countries worldwide, including those in Europe, adopting this approach irrespective of their developmental stage. Although the reviewed literature often references related terms and definitions, there is a lack of substantial elaboration on them, indicating the need for more empirical studies to strengthen the concept and definitions. Stakeholder engagement has been detected across quantitative, qualitative, and mixed methods paradigms, predominantly occurring during the design phase. However, the research process using SPSE is often vague and controversial, underscoring the necessity for more qualitative studies to understand its nature and process. It is recommended that the methodology in the study be clarified by applying SPSE principles to enhance transparency and reproducibility. The existing principles in the literature address various aspects of research, providing effective guidance for both quantitative and qualitative studies. This includes several strategies like developing a suitable protocol (roadmap) for stakeholders and clearly explaining their roles and responsibilities. Still, further research is required to explore hidden strategies and clarify their application. There is inconsistency in implementing SPSE principles, with researchers relying on personal interpretations. To enhance stakeholder engagement, researchers should plan for engagement diversely, allocate resources effectively, provide continuous training, and ensure active stakeholder participation. Challenges such as time and cost limitations are inherent in SPSE but can be managed with targeted strategies. Developing and implementing specific applied strategies tailored for SPSE can address challenges and pave the way for future research in this area. Establishing consistent terms and definitions for SPSE using a concept analysis study, can further advance research efforts.

Abbreviations

SPSE	Patient and Stakeholder Engagement
PPI	Patient and Public Involvement
SPSE	Stroke Patient and Stakeholder Engagement

Supplementary Information

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Additional file 1. PubMed search strategy.

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Authors' contributions

HKh: conceptualization, data curation, investigation, formal analysis, funding acquisition, methodology, project administration, writing—original draft, writing—review and editing. ShSh: investigation, data curation, formal analysis, writing—review and editing. JR: investigation, writing—review and editing.

TR: investigation, writing—review and editing. UD: conceptualization, funding acquisition, methodology, writing—review and editing, and supervision. GG: writing—review and editing. All authors gave final approval for publication and agreed to be held accountable for the work performed therein.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

Et Board at the School of Public Health, Shandong University. All study participants provided informed consent prior to participation in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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References

- Drude N, Martinez-Gamboa L, Haven T, Holman C, Holst M, Kniffert S, et al. Finding the best fit for improving reproducibility: reflections from the QUEST Center for Responsible Research. *BMC Res Notes*. 2022;15(1):270.
- Skovlund PC, Nielsen BK, Thaysen HV, Schmidt H, Finset A, Hansen KA, et al. The impact of patient involvement in research: a case study of the planning, conduct and dissemination of a clinical, controlled trial. *Research involvement and engagement*. 2020;6:1–16.
- Gesell SB, Klein KP, Halladay J, Bettger JP, Freburger J, Cummings DM, et al. Methods guiding stakeholder engagement in planning a pragmatic study on changing stroke systems of care. *J Clin Transl Sci*. 2017;1(2):121–8.
- Cottrell EK, Whitlock EP, Kato E, Uhl S, Belinson S, Chang C, Hoomans T, Meltzer DO, Noorani H, Robinson KA. Defining the benefits and challenges of stakeholder engagement in systematic reviews. *J Comp Eff Res*. 2015;5:13–19.
- Russell J, Fudge N, Greenhalgh T. The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? *Research involvement and engagement*. 2020;6:1–8.
- Martinez J, Wong C, Piersol CV, Bieber DC, Perry BL, Leland NE. Stakeholder engagement in research: a scoping review of current evaluation methods. *Journal of Comparative Effectiveness Research*. 2019;8(15):1327–41.
- McShan E, Self A, Nalepa E, Driver S. Better Together: Evolution of Patient Stakeholder Engagement in Healthy Lifestyle Research After Acquired Brain Injury. *Arch Phys Med Rehabil*. 2022;103(12):e102–3.
- Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. *Health Expect*. 2019;22(4):785–801.

9. Fergusson D, Monfaredi Z, Pussegoda K, Garritty C, Lyddiatt A, Shea B, et al. The prevalence of patient engagement in published trials: a systematic review. *Research Involvement and Engagement*. 2018;4:1–9.
10. Price A, Schroter S, Snow R, Hicks M, Harmston R, Staniszevska S, et al. Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study. *BMJ Open*. 2018;8(3): e020452.
11. Hoekstra F, Trigo F, Sibley KM, Graham ID, Kennefick M, Mrklas KJ, et al. Systematic overviews of partnership principles and strategies identified from health research about spinal cord injury and related health conditions: A scoping review. *J Spinal Cord Med*. 2023;46(4):614–31.
12. Lim MJR, Tan J, Neo AYY, Ng BCJ, Asano M. Acceptance of disability in stroke: a systematic review. *Ann Phys Rehabil Med*. 2024;67(2): 101790.
13. Brown J, Baer G, Cameron S, Jackson K, Lamouline C, Morley R, et al. Stakeholder involvement in a Cochrane review of physical rehabilitation after stroke: Description and reflections. *Cochrane Evidence Synthesis and Methods*. 2023;1(10): e12032.
14. Katan M, Luft A. Global burden of stroke. *Semin Neurol*. New York: Thieme Medical Publishers; 2018.
15. Department of Economic and Social Affairs. *World Population Ageing*. Oxford Univ Press Inc. New York: United Nations; 2017.
16. Wafa HA, Wolfe CD, Emmett E, Roth GA, Johnson CO, Wang Y. Burden of stroke in Europe: thirty-year projections of incidence, prevalence, deaths, and disability-adjusted life years. *Stroke*. 2020;51(8):2418–27.
17. Krishnamurthi RV, Ikeda T, Feigin VL. Global, regional and country-specific burden of ischaemic stroke, intracerebral haemorrhage and subarachnoid haemorrhage: a systematic analysis of the global burden of disease study 2017. *Neuroepidemiology*. 2020;54(2):171–9.
18. Li L, Scott CA, Rothwell PM. Stroke. "Trends in stroke incidence in high-income countries in the 21st century: population-based study and systematic review." 2020;51(5):1372–80.
19. Norrving B, Barrick J, Davalos A, Dichgans M, Cordonnier C, Guekht A, et al. Action plan for stroke in Europe 2018–2030. *Eur Stroke J*. 2018;3(4):309–36.
20. Roudini J, Weschke S, Rackoll T, Dirnagl U, Guyatt G, Khankeh H. Systematic scoping review protocol of Stroke Patient and Stakeholder Engagement (SPSE). *Syst Rev*. 2023;12(1):180.
21. Arksey H, O'Malley LJ. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19–32.
22. Colquhoun HL, Levac D, O'Brien KK, Straus S, Tricco AC, Perrier L, et al. Scoping reviews: time for clarity in definition, methods, and reporting. *J Clin Epidemiol*. 2014;67(12):1291–4.
23. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *JBI Evidence Implementation*. 2015;13(3):141–6.
24. Kujala J, Sachs S, Leinonen H, Heikkinen A, Laude D. Stakeholder engagement: Past, present, and future. *Bus Soc*. 2022;61(5):1136–96.
25. Bramer WM, Giustini D, de Jonge GB, Holland L, Bekhuis T. De-duplication of database search results for systematic reviews in EndNote. *Journal of the Medical Library Association: JMLA*. 2016;104(3):240.
26. Sacco RL, Kasner SE, Broderick JP, Caplan LR, Connors J, Culebras A, et al. An updated definition of stroke for the 21st century: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2013;44(7):2064–89.
27. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–88.
28. Arnold D, Glassel A, Bottger T, Sarma N, Bethmann A, Narimani P. "What Do You Need? What Are You Experiencing?" Relationship Building and Power Dynamics in Participatory Research Projects: Critical Self-Reflections of Researchers. *Int J Environ Res Public Health*. 2022;19(15).
29. Roach WH Jr, Bischoff JM, Dennis B, Donalson M, Dunbar SB, Hill D, et al. Lay Stakeholders in Science and Research Initiative: A Science Advisory From the American Heart Association. *Circulation*. 2021;144(5):e96–106.
30. Boote J, Jones Z, McKevitt CJ, Wallace-Watson C, Rodgers H. Stroke survivor and carer involvement in, and engagement with, studies adopted onto the NIHR Stroke Research Network portfolio: questionnaire survey. *International journal of stroke : official journal of the International Stroke Society*. 2015;10(1):E6–7.
31. Pollock A, St George B, Fenton M, Crowe S, Firkins L. Development of a new model to engage patients and clinicians in setting research priorities. *J Health Serv Res Policy*. 2014;19(1):12–8.
32. Sims S, Brearley S, Hewitt G, Greenwood N, Jones F, Ross F, et al. How to develop a patient and carer advisory group in stroke care research. *Nurse Res*. 2013;20(3):6–11.
33. Faccio E, Fonte C, Smania N, Neri J. (Re) constructing identity following acquired brain injury: The complex journey of recovery after stroke. *Health Expect*. 2024;27(1): e13874.
34. Farre A, Morris JH, Irvine L, Dombrowski SU, Breckenridge JP, Ozakinci G, et al. Exploring the views and experiences of people recovering from a stroke about a new text message intervention to promote physical activity after rehabilitation—Keeping Active with Texting After Stroke: A qualitative study. *Health Expect*. 2023;26(5):2013–22.
35. Wang W, Pucciarelli G, Mei Y, Zhang Z, Vellone E. The dyadic self-care experience of stroke survivors and their caregivers: A qualitative descriptive study. *Health Expect*. 2023;26(6):2325–39.
36. Lin B, Zhang Z, Guo Y, Wang W, Mei Y, Wang S, et al. Perceptions of recurrence risk and behavioural changes among first-ever and recurrent stroke survivors: A qualitative analysis. *Health Expect*. 2021;24(6):1962–70.
37. O'Hara J, Baldeh M, Parmar D, Williams J. Exploring the experiences of stroke survivors, informal caregivers and healthcare providers in Sierra Leone: a qualitative study protocol. *Int J Stroke*. 2021;16(2_SUPPL):94–5.
38. Liu H, Lindley R, Alim M, Felix C, Gandhi DB, Verma SJ, et al. Protocol for process evaluation of a randomised controlled trial of family-led rehabilitation post stroke (ATTEND) in India. *BMJ Open*. 2016;6(9): e012027.
39. Owolabi MO, Akinyemi RO, Hurst S, Arulogun O, Olaniyan O, Gebregziabher M, et al. Tailored Hospital-based Risk Reduction to Impede Vascular Events After Stroke (THRIVES) study: qualitative phase protocol. *Crit Pathw Cardiol*. 2014;13(1):29–35.
40. Zhang W, Ye M, Zhou W, Gao Y, Zhou L. Trajectory and predictors of family function in caregivers of stroke survivors: A longitudinal study of the first 6 months after stroke. *J Adv Nurs*. 2024;80(1):264–74.
41. Solbakken LM, Langhammer B, Sundseth A, Brovold T. Transitional care for patients with acute stroke-A priority-setting project. *Health Expect*. 2022;25(4):1741–52.
42. Morgan LJ, Chambers R, Banerji J, Gater J, Jordan J. Consumers leading public consultation: the general public's knowledge of stroke. *Fam Pract*. 2005;22(1):8–14.
43. Duncan PW, Bushnell CD, Rosamond WD, Jones Berkeley SB, Gesell SB, D'Agostino RB Jr, et al. The Comprehensive Post-Acute Stroke Services (COMPASS) study: design and methods for a cluster-randomized pragmatic trial. *BMC Neurol*. 2017;17(1):133.
44. Lynch EA, Bulto LN, West M, Cadilhac DA, Cooper F, Harvey G. Code-signing implementation strategies to improve evidence-based stroke rehabilitation: A feasibility study. *Health Expect*. 2024;27(1): e13904.
45. Peniche P, de Moraes Faria CDC, Hall P, Fingleton C, McPhillips L, Gaetz R, et al. A scoping review of patient and public involvement (PPI) in empirical stroke research. *Syst Rev*. 2024;19:17474930241262638.
46. Vicente-Saez R, Martinez-Fuentes C. Open Science now: A systematic literature review for an integrated definition. *J Bus Res*. 2018;88:428–36.
47. Boon W, Duisterwinkel C, Strick M, Thunnissen M. Open science & stakeholder engagement: why, how, and what could be improved? *Utrecht University*; 2021:1–22.
48. Lakomý M, Hlavová R, Machackova H. Open science and the science-society relationship. *Society*. 2019;56:246–55.
49. Wu J, Wang Y, Tao L, Peng J. Stakeholders in the healthcare service ecosystem. *Procedia CIRP*. 2019;83:375–9.
50. Ali-Khan SE, Jean A, Gold ER. Identifying the challenges in implementing open science [version 1; peer review: 2 approved]. *MNI Open Res*. 2018;2:5.
51. Boaz A, Hannev S, Borst R, O'Shea A, Kok M. How to engage stakeholders in research: design principles to support improvement. *Health research policy and systems*. 2018;16:1–9.
52. Rising KL, Kemp M, Leader AE, Chang AM, Monick AJ, Guth A, et al. A Prioritized Patient-Centered Research Agenda to Reduce Disparities in Telehealth Uptake: Results from a National Consensus Conference. *Telemedicine Reports*. 2023;4(1):387–95.

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