

Reporting Patient and Public Involvement (PPI) Partner Characteristics in Stroke Research: A Systematic Review

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Abstract

Background

Patient and Public Involvement (PPI) is standard practice in participatory stroke research. A fundamental principle of PPI is that meaningful involvement transitions stroke survivors from research participants to active PPI partners (co-researchers) in the research process. Although existing reporting tools, such as the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist, standardize PPI process-level reporting, they lack mechanisms to capture PPI partner-level sociodemographic and clinical characteristics, creating a reporting gap that limits the assessment of equity, inclusivity, and representation.

Aim

To systematically review the reporting of PPI partner characteristics in stroke research.

Method

Three independent researchers conducted a systematic review using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. The study protocol was registered on the PROSPERO website. A comprehensive electronic search was conducted across seven databases: CINAHL, Embase, Medline, PsycINFO, PubMed, Scopus, and Web of Science. The search strategy targeted 3 primary concepts: stroke, patient and public involvement, and demographic and clinical characteristics. The review was conducted using the Covidence software.

Results

Out of 4,668 screened citations, 85 published studies met the inclusion criteria. While PPI process-oriented reporting quality was high, PPI partner characteristics were poorly reported, including ethnicity (9%), socioeconomic status (13%), primary language (13%), and stroke type (27%).

Conclusion

The review concluded that while PPI process-oriented reporting has matured, the limited reporting on PPI partners' demographic and clinical characteristics highlights an ongoing challenge in stroke participatory research. Systematically describing who was involved enables greater transparency and meaningful evaluation of the inclusivity and representativeness of PPI partners in stroke research. Future work should focus on the development and validation of a PPI partner-level companion reporting tool to complement existing process-oriented guidance, such as GRIPP2, and improve the reporting of the characteristics of those involved. Greater representation in PPI can help ensure that research priorities, processes, and outcomes reflect the needs and experiences of the wider stroke population.

Plain English Summary

Patient and Public Involvement (PPI) means doing research with people affected by a condition, rather than only studying them. In stroke research, people who have experienced a stroke can help shape research questions, plan studies and explain findings. Their involvement helps researchers focus on what matters to people living with stroke. To understand whose experiences are represented, researchers need to describe the people involved. Existing guidance helps researchers explain how people contributed, but provides less guidance on reporting their backgrounds and stroke-related characteristics.

We reviewed 85 published studies to examine what researchers reported about their PPI partners in stroke research. Three researchers searched seven research databases and assessed the studies. Most studies described the involvement process well. However, few reported partners' ethnicity, financial or social circumstances, main language, or type of stroke. This makes it difficult to assess whether those involved reflect the wider population affected by stroke. Missing information does not necessarily mean that people from different backgrounds were excluded; it means we cannot judge how broadly different experiences were represented.

We recommend developing and testing an additional reporting tool to help researchers describe who is involved, alongside existing guidance on how involvement takes place. Clearer reporting would help researchers, patient partners and organisations identify gaps in representation and consider how to involve people with a wider range of backgrounds and experiences. Broader involvement could help ensure that stroke research addresses the needs and priorities of the people it aims to benefit.

Background

Patient and Public Involvement (PPI), defined as research carried out 'with' or 'by' members of the public rather than 'to', 'about', or 'for' them, has become a cornerstone of ethical, relevant, and high-quality health research¹. Involvement can occur at different levels, from consulting with members of the public to collaborative partnerships between researchers and service users, and ultimately to research that is led by users themselves². A fundamental principle of PPI is that meaningful involvement shifts individuals from being research participants to becoming active partners or co-researchers in the research team³.

In stroke research, involving people with stroke, carers, and family members, namely PPI partners, ensures the research priorities align with lived experiences, intervention designs account for post-stroke disabilities, and study outcomes reflect what matters most to the stroke survivors⁴. When meaningfully embedded across the research cycle, PPI enhances feasibility, improves participant recruitment and retention, and facilitates translating findings into clinical practice⁵. Yet, despite the widespread endorsement of PPI, evaluating its quality, impact, and equity relies heavily on transparent and complete reporting. The Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist represents a transformative milestone in standardizing PPI reporting by providing researchers with structured guidance on reporting aims, methods, outcomes, stages of involvement, and critical

reflections⁶. However, while GRIPP2 establishes *how* PPI should be reported in terms of process and impact⁶, it offers minimal guidance regarding *who* is involved. Specifically, it lacks a dedicated section to describe the demographics, socioeconomic, and clinical characteristics of PPI partners.

Stroke, as the leading cause of acquired adult disability worldwide, often results in a complex combination of neurological, cognitive, physical, and communication impairments⁷. Furthermore, stroke disproportionately affects individuals from lower socioeconomic backgrounds and ethnic minority populations⁸. Without transparent and detailed reporting of PPI partner characteristics, it is impossible to determine whether their involvement is genuinely representative, equitable, and inclusive or whether cohorts of PPI partners systematically exclude those with communication impairments, cognitive deficits, or social disadvantage⁹. To ensure that PPI in stroke is both inclusive and reproducible, researchers require dedicated guidance on describing the clinical and social context, communication profiles, accessibility adaptations, and background experiences of the PPI partners.

Aim

The aim of this review was to systematically review the reporting of PPI partner characteristics in stroke research.

Methods

A systematic review was conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement¹⁰ (see Appendix 1 for PRISMA 2020 checklist). This systematic review was registered on the International Prospective Register of Systematic Reviews (PROSPERO) website (Registration Number: CRD420251068920).

Framework of Study Design

The review was structured on the PICO framework¹¹:

Population (P): Adults (aged ≥ 18 years) with a history of ischemic stroke or intracerebral hemorrhage (ICH), and/or next of kin (NOK), family members, friends, or informal carers engaged as PPI partners across health and service contexts.

Intervention (I): PPI embedded in ischemic stroke or ICH research across any level or form of involvement (e.g. consultation, collaboration, coproduction, codesign or patient advisory partners).

Comparator (C): Not applicable (descriptive systematic review).

Outcomes (O): (a) Sociodemographic characteristics reported for PPI partners (e.g. age, gender, ethnicity, socioeconomic status, geographic location, primary language, communication profile, disability

profile). (b) Clinical characteristics reported for PPI partners (e.g., stroke type, time since stroke, comorbidities). (c) PPI reporting practices and quality (e.g. use of GRIPP2, PPI type and level of involvement, PPI cohort roles, reflection).

Search strategy and selection criteria

A comprehensive electronic search was conducted across 7 bibliographic databases from inception to 10th of June 2026: CINAHL, Embase, Medline, PsycINFO, PubMed, Scopus and Web of Science. The search strategy targeted 3 primary concepts: stroke, patient and public involvement, and demographic and clinical characteristics. The full adapted search string included MESH terms and definitions as follows: (stroke[Mesh] OR ischemic stroke[tiab] OR ischaemic stroke[tiab] OR intracerebral hemorrhage[tiab] OR intracerebral haemorrhage[tiab]) AND (sociodemographic[tiab] OR demographic[tiab] OR age[tiab] OR gender[tiab] OR ethnicity[tiab] OR socioeconomic[tiab] OR comorbidity[tiab] OR clinical characteristics[tiab] OR stroke severity[tiab] OR NIHSS[tiab] OR disability[tiab]) AND ("Patient Participation"[Mesh] OR PPI[tiab] OR "patient and public involvement"[tiab] OR "public involvement"[tiab] OR "patient involvement"[tiab] OR "patient engagement"[tiab] OR "co-production"[tiab] OR "co-design"[tiab]). Secondary search articles, opinion pieces, editorials, conference abstracts lacking reporting methods, and non-peer-reviewed grey literature were not included in this review.

Studies were eligible for inclusion if they met the following predefined criteria: (a) search involving adults with ischemic stroke or ICH and/or the next of kin (NOK), family, or carers engaged as PPI partners, (b) primary empirical studies of any design, including randomized and non-randomized studies, where PPI is explicitly reported in the context of stroke research, (c) studies published in English or non-English studies where translation was feasible. No search date restrictions were applied. Studies involving adolescents or individuals under 18 years of age, where stroke survivors or carers acted solely as participants in data collection rather than serving in a PPI role, were excluded.

Data Extraction

All retrieved records were imported into Covidence systematic review¹² for duplicate identification and management. Duplicates were identified by Covidence and verified manually. Two independent reviewers (Reviewer 1 MC and Reviewer 2 HO) screened titles and abstracts against the predefined eligibility criteria. Full-text copies of potentially eligible articles were retrieved and independently assessed for inclusion by both reviewers. Any disagreements were resolved through consensus or by consulting a third reviewer (Reviewer 3 SB). The reasons for full-text exclusion were categorized and documented directly within Covidence.

Data extraction was conducted independently in duplicate using a standardized extraction form developed in Microsoft Excel. The extracted variables included:

- Study data: Author(s), Date, Country, Study Design, Research Context
- PPI Characteristics: PPI Cohort (numbers and roles), PPI type/level, and the research stage(s) PPI partners were involved in
- PPI Partner Reporting Data: sociodemographic parameters (age, gender, ethnicity, socio-economic status (SES), location, languages) and clinical details (stroke type, time since onset, severity, aphasia/communication impairment, physical disability, comorbidities).
- Inclusion Adaptations and Guidelines: use of reporting guidelines and inclusion and/or accessibility adaptations (e.g. use of accessible materials and venues, flexible meetings).

PPI reporting and Quality Assessment

The methodological quality of the included studies was assessed using the criteria outlined in the Cochrane Handbook for Systematic Reviews¹³. Given the focus of this review on evaluating how PPI is reported in stroke literature, quality and reporting assessment were performed using the GRIPP2 Short Form (SF) reporting checklist⁶. The GRIPP2-SF checklist was utilized as the standard tool to systematically evaluate the completeness and quality of PPI reporting, specifically examining how studies reported aims, methods, stages of involvement, outcomes, PPI impact, and reflections. Two reviewers, MC and HO, conducted the assessment independently. Discrepancies were resolved through discussion and consensus between the reviewers, MC and HO.

Results

The database search identified 5,409 citations. Following the removal of 741 duplicates, 4,668 titles and abstracts were screened, of which 4,453 were excluded. Of the 198 full-text sources assessed for eligibility, 113 were excluded for not meeting the inclusion criteria. In total, 85 published studies were included^{14–97}. Please see Fig. 1 for the flowchart of the process following the PRISMA guidelines.

Figure 1. The PRISMA flow diagram for the review process

Study Characteristics

Geographically, the literature was heavily clustered in high-income English-speaking countries. The United Kingdom contributed the largest proportion (n = 33), followed by Australia (n = 21), Ireland and Canada with five studies each, and Sweden and New Zealand with three studies respectively. The remaining 16 studies (19%) originated from other European, Asian, or multi-country research consortia. To map the data, we developed five comprehensive tables to characterize the PPI literature in stroke research. Specifically, Table 1 (see below) provides an overview and outlines a summary of the reporting rates for the demographic and clinical characteristics of the PPI partners across the mapped studies. Table 2 summarizes the research topic/focus area and sub-field (e.g., examples of interventions or

services evaluated) within stroke PPI research, while Table 3 summarizes the PPI methodology and the study design categories across the included literature. Table 4 reports the rates of Operational Practices and Supports for PPI partners, and Table 5 presents the stages of the research cycle involving PPI partners.

Demographic and Clinical Characteristics of PPI partners

Across the 85 included studies, reporting of PPI partner characteristics was highly inconsistent. While roughly half of the studies reported basic demographic information such as gender (43%), age (41%), and geographic locations (44%), critical SES indicators (education, income, employment) were reported only in 11/85 studies, and ethnicity/race in just 8 out of the 85 published studies. Reporting stroke type (ischemic vs ICH) among the PPI partners was sparse across the 85 included studies. Three-quarters of all studies omitted stroke subtype, describing PPI partners using broad terms such as “stroke survivors” or “people with lived experience”. Explicit reporting of stroke subtype was provided in only 15 studies, with an additional 8 studies providing indirect or implicit details (e.g., specifying post-stroke aphasia cohorts). When subtypes were detailed, ischemic stroke predominated, with minimal transparent representation of individuals recovering from ICH. Severe reporting deficits were similarly observed across other clinical and stroke-specific parameters. Although aphasia and communication profiles were described in 47 studies, post-stroke cognitive status was reported in only 18 studies, and physical disability profiles in 35 studies. Furthermore, key neurological contextual data were frequently omitted, including the time since stroke ($n = 27$), stroke severity measures ($n = 15$), and medical comorbidities ($n = 14$). Finally, several studies conflated the clinical characteristics of trial participants with those of their PPI partners or failed to report PPI partner demographics separately from general study samples. See Table 1 for a summary of the above reporting information.

Table 1
Reporting and characteristics of PPI partners across the included studies (n = 85)

Domain	PPI partner characteristic	Reported, n (%)	Characteristics reported
<i>Sociodemographic</i>	Age	41 (48.2)	Working-age and older adults
	Gender/sex	43 (50.6)	Women and men represented
	Geographic location	44 (51.8)	Mostly UK and Australian cohorts
	Socioeconomic status	11 (12.9)	Education and employment as the main socioeconomic indicators
	Language(s) spoken	11 (12.9)	Limited information; mainly English
	Ethnicity/race	8 (9.4)	Limited information on ethnic/racial background
<i>Communication & cognition</i>	Communication profile/aphasia	47 (55.3)	Mainly aphasia
	Cognitive impairment	18 (21.2)	Cognitive status poorly documented
<i>Functional & clinical</i>	Disability/physical function	35 (41.2)	Physical disability, mobility limitations and hemiparesis
	Time since stroke	27 (31.8)	Varied; most partners were several years post-stroke
	Stroke type	23 (27.1)	Ischaemic/haemorrhagic status where unspecified
	Stroke severity	15 (17.6)	Including measures/indicators of stroke severity
	Comorbidities	14 (16.5)	Other health conditions
Note: Detailed characteristics of individual studies are presented in Supplementary Table 1.			

Research Context of Included Studies

The 85 included studies represented a broad spectrum of stroke research contexts. The most frequent research areas were health services delivery and care pathway redesign, aphasia and physical rehabilitation, and digital health and self-management interventions. See Table 2 for a summary of the research contexts and sub-fields of the included studies.

Table 2
Summary of the Research Context and Sub-fields in the included studies (n = 85)

Research Context / Focus Area	Reported, n (%)	Examples of Interventions & Services Evaluated
<i>Health Services & Care Delivery</i>	26 (30.6%)	Service delivery redesign, post-discharge care pathways, community rehabilitation service
<i>Aphasia & Communication Disability</i>	22 (25.9%)	Communication partner training, aphasia service co-design, accessible materials
<i>Physical Rehabilitation & Technology</i>	20 (23.5%)	Upper/lower limb devices, robotics, mirror therapy, mobility & exercise tools
<i>Self-Management & Digital Health</i>	14 (16.5%)	Mobile apps, digital health tools, secondary prevention tutorials
<i>Psychological, Cognitive & Fatigue</i>	2 (2.4%)	Post-stroke fatigue interventions, cognitive rehabilitation, mood management
<i>Research Priorities & Capacity Building</i>	1 (1.2%)	Research priority setting, training co-researchers

In terms of methodology, active co-design and co-production frameworks dominated the PPI stroke literature, including Experience-Based Co-Design (EBCD), co-creation workshops, and Integrated Knowledge Translation (IKT). Other study designs included standalone qualitative studies with embedded PPI groups, mixed-methods evaluations, priority-setting partnerships, and feasibility trials. See Table 3 for details.

Table 3
PPI Methodology and Study Design Categories of the 85 included studies

Methodology / Study Design Category	Reported, n (%)	Examples
<i>Co-design / Co-production / Participatory Research</i>	59 (69.4%)	Experience-Based Co-Design (EBCD), co-creation workshops, iterative prototyping, Integrated Knowledge Translation (iKT)
<i>Qualitative Studies with Embedded PPI</i>	9 (10.6%)	Embedded advisory groups, stakeholder consultations
<i>Mixed-Methods Evaluation Studies</i>	6 (7.1%)	Process evaluations, mixed feasibility studies
<i>Other Empirical / Methodological Studies</i>	5 (5.9%)	Conceptual frameworks, reflexive critiques
<i>Feasibility, Pilot & Trial Studies</i>	3 (3.5%)	Cluster RCTs, pilot feasibility studies
<i>Priority Setting & Delphi Studies</i>	3 (3.5%)	James Lind Alliance partnerships, survey consensus

Operational Practices and Accessibility Supports

Evaluation of PPI operational practices across the 85 included studies revealed substantial variation in reporting transparency. The impact of PPI on study protocols, materials, or intervention design was reported in 78 studies. Regarding accessibility and inclusion adaptations, 55 studies documented physical and environmental support (e.g., flexible scheduling, venue accessibility), while 54 studies reported communication adaptations (e.g., aphasia-friendly formatting, supported communication techniques, or speech therapy involvement). Training or orientation was provided to PPI partners in 52 studies, and 29 studies formally recognized PPI partners as co-authors in scientific publications. However, significant reporting gaps were observed regarding eligibility and financial remuneration. Inclusion criteria for PPI partners were stated in only 43 studies, while exclusion criteria were reported in just 15 studies. Most notably, details regarding financial compensation, travel reimbursement, or honoraria were omitted in 77 studies. See Table 4 for details.

Table 4
Reporting Rates of Operational Practices and Supports for PPI Partners

Operational / Support Variable	Reported, n (%)	Key Findings & Context
<i>Impact of PPI Reported</i>	78 (91.8%)	Over 90% of studies reported how PPI input shaped study protocols, intervention content, or materials.
<i>Accessibility Supports Provided</i>	55 (64.7%)	Included flexible scheduling, transport assistance, accessible venues, and online platform adaptations.
<i>Communication Supports Provided</i>	54 (63.5%)	Included aphasia-friendly materials, supported communication techniques, extra processing time, and speech therapy input.
<i>Training / Orientation Provided</i>	52 (61.2%)	Included orientation to research processes, online meeting tools (e.g., Zoom), and qualitative analysis co-training.
<i>PPI Inclusion Criteria Stated</i>	43 (50.6%)	Half of the studies provided no explicit inclusion criteria for selecting public partners.
<i>PPI Process Evaluation Conducted</i>	38 (44.7%)	Less than half evaluated the PPI process (e.g., via surveys, qualitative interviews, or reflective feedback).
<i>PPI Co-Authorship Recognized</i>	29 (34.1%)	Roughly one-third of studies formally included PPI partners as co-authors on the publication.
<i>PPI Exclusion Criteria Stated</i>	15 (17.6%)	Over 80% provided no explicit exclusion criteria (e.g., excluding severe cognitive impairment or non-English speakers).
<i>Financial Payment / Honoraria</i>	8 (9.4%)	Over 90% of studies omitted details regarding financial compensation, travel reimbursement, or honoraria.

Finally, across the research cycle, PPI engagement was heavily concentrated in initial study design and intervention co-development. While 88% (n = 75) of studies involved PPI partners in intervention co-design, only 7% (n = 6) embedded PPI partners in project governance or steering boards, and only 8% (n = 7) involved them in recruitment planning. Involvement in other stages was substantially lower, including dissemination, data collection, qualitative data co-analysis, priority setting, etc. Please see Table 5 for details.

Table 5
Stages of Research Cycle Involving PPI Partners

Research Lifecycle Stage	Reported, n (%)	Context / Observations
<i>Study Design / Intervention Development</i>	75 (88.2%)	Dominant stage; co-designing interventions, protocol refinement, and study materials.
<i>Dissemination & Knowledge Translation</i>	25 (29.4%)	Co-authoring, co-presenting at conferences, drafting lay summaries.
<i>Data Collection & Study Conduct</i>	24 (28.2%)	Co-facilitating workshops, conducting participant interviews, assisting usability testing.
<i>Data Analysis & Interpretation</i>	24 (28.2%)	Qualitative co-analysis, thematic verification, member checking.
<i>Priority Setting & Research Questions</i>	23 (27.1%)	Identifying research gaps, framing aims, James Lind Alliance partnerships.
<i>Materials Development & Refinement</i>	14 (16.5%)	Designing participant information sheets, consent forms, and surveys.
<i>Recruitment Strategy</i>	7 (8.2%)	Advising on participant recruitment channels and strategies.
<i>Governance / Steering Committee</i>	6 (7.1%)	Sustained representation on project advisory or steering boards.

Quality Assessment

Quality and completeness of PPI reporting across the 85 included studies were evaluated using the GRIPP2 Short Form (GRIPP2-SF). Independent dual evaluation by the two reviewers (MC and HO) demonstrated high inter-rater reliability (ICC = 0.91). Overall, compliance with GRIPP2-SF process-oriented standards was high. The mean overall GRIPP2-SF total score was 9.19/10 (median 9.0, range 4–10). Based on standard GRIPP2-SF rating thresholds, 77 studies (90%) were rated as High reporting quality, 7 studies (9%) as Moderate to Moderate-High, and only 1 study was Low Quality. High reporting completion was observed for process-related domains, including PPI aims, PPI methods, and PPI-specific results. The most frequent reporting limitation concerned reflections and critical perspectives on the PPI process, which were fully reported in 37 studies and only partially reported in 42 studies. However, studies that achieved high GRIPP2 scores routinely omitted basic demographic and clinical details regarding their PPI partners. Over 90% of the studies failed to report ethnicity, 87% omitted SES status, 82% did not report stroke severity, and 78% did not document cognitive profile data.

Discussion

The synthesis of the 85 included studies showed inconsistency in reporting demographic, clinical, socioeconomic, and inclusion-related PPI partner information. This limits the assessment of

representativeness and inclusivity of PPI in stroke participatory research.

A central finding of this review is that comprehensive reporting of PPI processes in the published studies does not equate to reporting of inclusivity. Numerous studies demonstrated well-structured, iterative co-design workflows^{36,62}, yet omitted demographic and clinical characteristics of their PPI partners. Critical variables, such as ethnicity, socioeconomic background, stroke severity, time post-stroke, and communication and cognitive impairments, were under-reported. Even in focused co-production studies involving people with aphasia^{29,88}, systematic reporting of core PPI partners' characteristics remained inconsistent. This widespread omission prevents the research community from evaluating whether PPI partners genuinely reflect the broader spectrum of stroke pathology or if marginalized subgroups are excluded. Furthermore, reporting of compensation and eligibility criteria was also limited, reducing transparency around potential socioeconomic barriers and PPI partner selection.

Across the reviewed evidence, approaches ranged from consultation to co-production, with some studies involving stroke survivors across multiple stages of the research cycle, including study design, analysis, intervention development, and dissemination^{53,56,67,68}. Collaborative approaches included Experience-Based Co-Design (EBCD), which facilitated meaningful partnerships between patients, caregivers, and healthcare professionals in service development^{31,51,59,93}. Integrated co-design was also implemented through Integrated Knowledge Translation (IKT) in intervention studies^{39,83,86,89,96,97}. However, the use of PPI methodologies did not necessarily indicate equivalent levels of shared decision-making or active involvement across the studies, highlighting an important distinction between adopting a co-design methodology and achieving true co-production⁹⁸. Despite high GRIPP2 reporting completeness scores, several studies had omitted essential demographic and clinical PPI characteristics^{33,73}. Taken together, these findings indicate that while PPI is embedded in stroke research, PPI partner recruitment remains heterogeneous, and reporting transparency is incomplete.

The review also demonstrated that PPI in stroke research remains heavily front-loaded in the early intervention design and development phases^{84,86}. While many studies actively involve PPI partners in shaping materials, prototypes, or clinical priorities^{16,17,79}, sustained involvement across the research cycle was less evident. This suggests that PPI partners are more commonly involved in shaping existing research products than in contributing to project inception, governance, or later stages of the research cycle.

Limitations

Several limitations of this review warrant acknowledgment. First, the analysis was dependent on information explicitly reported in the included studies; therefore, non-reporting of a PPI partner characteristic cannot be interpreted as evidence that the characteristic was not considered during recruitment or involvement. Similarly, GRIPP2-SF scores reflect completeness of PPI reporting rather than the quality, inclusivity, or effectiveness of PPI itself. Differences in terminology and reporting

practices across studies, particularly those published before the introduction of GRIPP2, may also have affected study identification, data extraction, and comparison across the evidence base.

Future Directions

A key next step is the development and validation of a PPI partner-level companion tool that could complement process-oriented guidance such as GRIPP2, bridging the gap between PPI process reporting and transparency regarding who is involved. The development of such a tool could draw on established equity frameworks such as PROGRESS⁹⁹, while incorporating stroke-specific clinical and communication characteristics relevant to meaningful and inclusive involvement. Following validation, future studies should examine whether PPI partners reflect the diversity of the wider stroke population, particularly people with communication or cognitive difficulties and other underserved groups, whose lived experiences are essential to informing research that addresses their needs and priorities.

Conclusion

The synthesis of the stroke PPI literature highlights that, while PPI methodologies and process-oriented reporting have advanced, substantial gaps remain in reporting who is involved, particularly regarding PPI partners' demographic and clinical characteristics. Without transparent reporting of who contributes to research, it remains difficult to determine whose perspectives are represented and whose may be missing. Future PPI reporting should therefore extend documenting how involvement occurred to systematically describing who was involved, enabling greater transparency and more meaningful evaluation of inclusive and representative PPI in stroke research.

Abbreviations

CINAHL

Cumulative Index to Nursing and Allied Health Literature

EBCD

Experience-Based Co-Design

GRIPP2

Guidance for Reporting Involvement of Patients and the Public 2

GRIPP2-SF

GRIPP2 Short Form

ICH

Intracerebral haemorrhage

IKT

Integrated Knowledge Translation

NOK

Next of kin

PICO

Population, Intervention, Comparator, Outcomes

PPI

Patient and Public Involvement

PRISMA

Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PROSPERO

International Prospective Register of Systematic Reviews

SES

Socioeconomic status

Declarations

Ethics approval and consent to participate

Not applicable.

Clinical trial registration

Not applicable.

Consent for publication

Not applicable.

Availability of data and materials

All data generated or analysed during this study are included in this article and its supplementary information files.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

M.C. conceptualized the study, developed the methodology, conducted the investigation and formal analysis, curated the data, drafted the original manuscript, and contributed to its review and editing. H.O. and S.B. contributed to the methodology, investigation, data curation, and formal analysis. M.L., D.W., A.W., and H.P. reviewed and edited the manuscript. A.D. supervised the study and contributed to the review and editing of the manuscript. All authors read and approved the final manuscript.

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Authors' information

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During manuscript preparation, the authors used ChatGPT (OpenAI) and Gemini (Google) to assist with language editing, clarity, and summarizing author-written material. These tools were not used to generate scientific concepts, analyse data, or formulate conclusions. The authors reviewed and verified all AI-assisted text and take full responsibility for the accuracy and integrity of the final manuscript.

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Figures

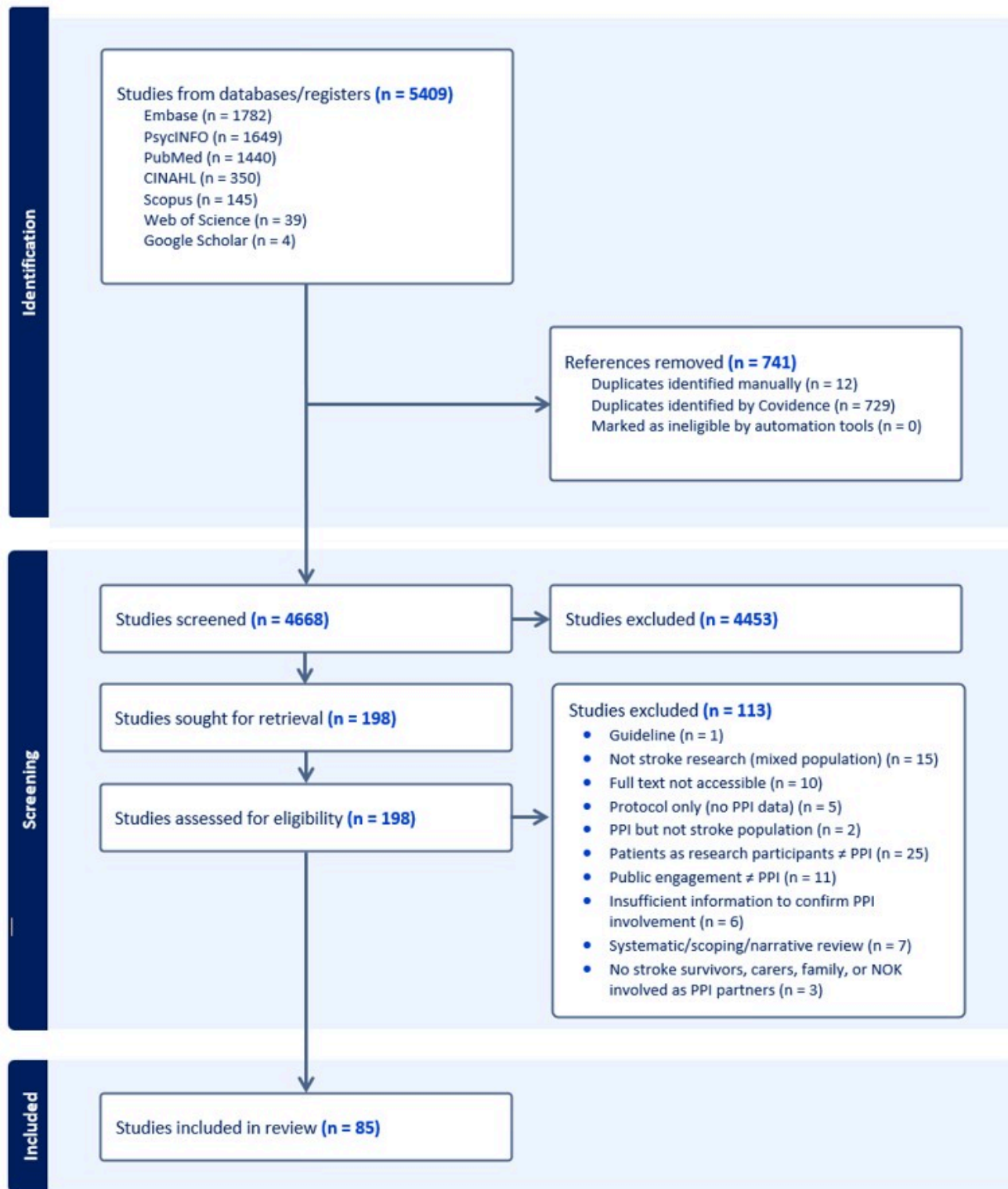


Figure 1

The PRISMA flow diagram for the review process

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