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Lynch, E.A., Bright, F.A.S., Chamberlain, S. et al. (2026) Advancing engagement of people with lived experience of stroke in recovery and rehabilitation research: Consensus-based core recommendations from the fourth Stroke Recovery and Rehabilitation Roundtable. International Journal of Stroke. ISSN: 1747-4930

https://doi.org/10.1177/17474930261466091

International Journal of Stroke
WSO

International Journal of Stroke
1–13

DOI: 10.1177/17474930261466091
journals.sagepub.com/home/wso
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Advancing engagement of people with lived experience of stroke in recovery and rehabilitation research: Consensus-based core recommendations from the fourth Stroke Recovery and Rehabilitation Roundtable

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Abstract

Rationale: There is a growing recognition of the importance of engaging with people with lived experience (PWLE) to support research relevance and impact. However, there is little specific guidance for stroke recovery and rehabilitation researchers about how best to engage with PWLE of stroke in research, who face additional barriers to engaging due to common post-stroke sequelae including communication and cognitive difficulties, sensory and perceptual impairments, emotional wellbeing, and fatigue. The aim of this roundtable was to develop recommendations to support researchers to engage with PWLE of stroke in primary and secondary research conducted in laboratory, clinical, health system, or community settings.

Methods: We convened an interdisciplinary, international taskforce comprising researchers and lived experience experts (n = 16) to create recommendations to support researchers to engage with PWLE of stroke meaningfully and respectfully. Guided by priorities and key gaps identified by taskforce members, and underpinned by gray and published literature, we formed discrete workgroups to develop consensus-based recommendations and guidance documents addressing common barriers to engagement in stroke research. The recommendations and guides were reviewed, and consensus was reached during a 2-day hybrid in-person/online meeting of the taskforce. These were further refined through consultation with international experts in research engagement.

Results: We created the EMBED (Engaging Meaningfully to Build research with people with lived experience to drive improvements in stroke research) framework, consisting of five consensus recommendations: Select the engagement approach; Identify people to engage with; Embed accessible and inclusive ways of working; Support and strengthen accessibility and inclusivity; and Report accessibility and inclusivity. Ten guidance documents provide practical support to researchers to engage with PWLE of stroke in all research settings.

Conclusions: The EMBED framework provides researchers with pragmatic and structured support to engage with PWLE in stroke research.

Keywords

Stroke, rehabilitation, recovery, consensus, patient public involvement, patient engagement, research engagement, lived experience

Received: 30 April 2026; accepted: 21 June 2026

Introduction

There is growing recognition that engaging with people with lived experience (PWLE) of stroke when conducting stroke research increases its quality, relevance, and impact and reduces research waste.[1–3] Engagement in research means doing research *with* PWLE of stroke in roles such as consultants, advisors, or partners, rather than research *on* or *for* PWLE, where PWLE are research participants only.[4] Engaging with PWLE of stroke facilitates research being shaped by the unique knowledge and insights about the practical, emotional, cognitive, and sociocultural realities of living with stroke.[5] Major national funders and stroke support organizations in many high-income countries now require researchers to describe how PWLE will be engaged throughout the research process.[4,6–10]

Engagement of PWLE in stroke research has tended to comprise one-off consultations at study commencement, rather than engagement across the whole study.[3] This may reflect limited confidence of both researchers and PWLE to adopt approaches that embed lived experience throughout the research process.[11] Common post-stroke impairments, such as aphasia, cognitive and physical difficulties, mood disorders, and fatigue, may also influence the depth and consistency of PWLE's engagement in research.[2,12] Furthermore, culturally and linguistically diverse communities, who are disproportionately affected by stroke incidence and disability,[13] remain underrepresented in engagement activities.[3] In a recent review of frameworks to support engagement of PWLE in research, only one framework was specific to stroke and was limited to identifying research priorities.[14] Few frameworks addressed common concerns such as how to find PWLE to engage with, whether engagement should be one-off or continuous, or how to address equity or diversity.[14]

The aim of this Stroke Recovery and Rehabilitation Roundtable was to build a framework to support researchers to engage with PWLE of stroke as active research contributors. The framework was designed to apply to primary and secondary research conducted in laboratory, clinical, health system, or community settings and in different sociocultural contexts. We acknowledge that terminology varies internationally (e.g. "patient and public involvement," "patient and public engagement," "consumer engagement")[15,16] and have opted to use "engagement in research" to align with the International Association for Public Participation (IAP2) framework[5] and "people with lived experience" as per published preferences[16] (see Figure 1 and Box 1 for terminology used in this article).

Methods

In December 2024, co-chairs (E.A.L. and L.K.) identified international researchers through Scopus searches and expert recommendations, inviting them to the taskforce. Members represented diversity in disciplinary or experiential knowledge, research focus, geography, socioeconomic contexts, and gender. Furthermore, we sought to include people with varying levels of experience in engaging with PWLE in research. Characteristics of taskforce members and our positionality statement are presented in

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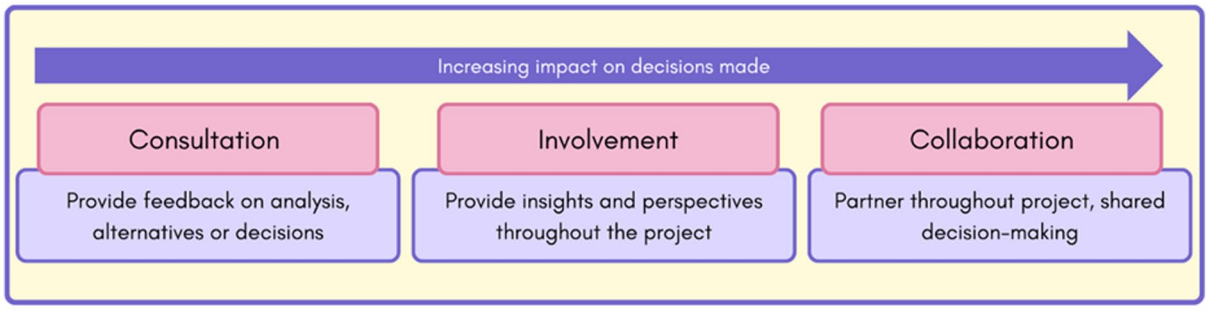
Figure 1. Engagement approaches (IAP2 terminology).[5]



Box 1. Terminology used in this article.

Accessibility: the ease with which PWLE can engage in research activities.
Advisory group: a group of PWLE who provide ongoing advice to the research team over the course of the project, often using the engagement approach of involvement.
Collaboration: engagement approach where PWLE partner and share decision-making throughout the life of the research project.
Consultation: engagement approach where researchers seek feedback from PWLE on approaches or decisions made regarding research, usually for discrete activities.
Cultural humility: the practice of genuinely listening with respect, recognizing the limits of one's own expertise, and valuing others' knowledge rather than assuming understanding over cultures beyond one's own.
Cultural safety: both an approach and an outcome which requires researchers and their organizations to examine themselves and the potential impact of their own culture on their interactions with PWLE, holding themselves accountable for providing a culturally safe research environment (as defined by PWLE) and as measured through progress toward achieving health equity.
Engagement: an umbrella term referring to a planned process where PWLE can influence decisions about the research. As per the IAP2 framework, engagement approaches include consultation, involvement, and collaboration.
Inclusivity: intentional creation of environments and processes where all people feel valued, respected, safe, and able to contribute regardless of background or experience.
Involvement: engagement approach where PWLE and researchers work together throughout the life of the research project, so perspectives of PWLE about the research can be understood and considered.
Person with lived experience (PWLE) of stroke: person who has had a stroke.
Note: this term often includes informal carers (e.g. partner, family members). We focus on engaging with survivors in this article due to their additional accessibility and inclusivity challenges.
Psychological safety: the creation of an environment where people feel comfortable sharing their views, questions, and experiences without fear or judgment or negative consequences.
Researcher: individual with formal research and/or health professional training who coordinates or contributes to research as part of their professional role.
Research team: team that oversees and makes decisions about the research project; may include PWLE of stroke.
Trauma-informed engagement: an approach that acknowledges the impact of trauma on people following an event, prioritizing safety and choice and actively minimizing harm.

Supplemental File 1. Three PWLE of stroke agreed to join the taskforce (S.C., A.A. at project commencement, D.T.C. in October 2025) and worked collaboratively, sharing decision-making and contributing to all roundtable activities. See Supplemental File 2 for additional details regarding engagement of PWLE in roundtable activities (including the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist).

Co-chairs met individually with each PWLE member to discuss accessibility needs and preferred ways of working. A Terms of Engagement document was drafted, refined with taskforce input, and finalized (Supplemental File 3), with taskforce members providing written agreement. The taskforce met monthly, while workgroups convened independently between meetings. Each workgroup presented to the taskforce at bi-monthly intervals (different groups presented each month). This facilitated awareness of ongoing activi-

ties, enabled alignment within and across groups, and provided opportunities for critical discussion and feedback.

Initial scoping and priority setting

To refine the priorities and key outputs of the roundtable, taskforce co-chairs (E.A.L., L.K.) and mentor (C.E.) developed a short survey containing open-ended questions, administered via Qualtrics in English (January 2025). The survey gathered taskforce members' perspectives on engaging PWLE of stroke in research, including unanswered questions, desired outputs, experiences of engagement approaches, features of good engagement, common challenges, key readings, and preferred ways of working.

Survey responses were collated and discussed via MS Teams and email. The taskforce agreed that the primary output would be a framework, supported by user-friendly guidance, to enable researchers to engage meaningfully, respectfully, and inclusively with PWLE of stroke. Understanding the broader context, including existing supports and barriers, training and capability-building resources, and relevant research funding policy, was recognized as essential to ensuring the framework could be implemented in practice and inform policy.

Evidence gathering and workgroups

Following the taskforce survey, workgroups were established to address identified priorities including mapping the existing evidence and gaps in engagement of PWLE in stroke research, defining core values and principles, examining funder roles, reviewing remuneration approaches, identifying training and capability–building resources, and exploring how stroke support organizations involve and support PWLE. Taskforce members were allocated to workgroups based on their expertise and interests; individuals could self-nominate or be invited by the co-chairs to join specific workgroups. The aim and methods of each workgroup are summarized in Supplemental File 4; some workgroups provided contextual insights on the broader landscape, while others contributed directly to the development of framework components and supporting materials.

A targeted review of gray and published literature on engaging PWLE in stroke research was conducted to provide background context and identify gaps. Evidence was not formally synthesized; instead, curated lists of potentially relevant studies were shared with respective working groups. Workgroups supplemented these with additional searches to identify further evidence when required. Relevant literature was incorporated iteratively into workgroup discussions to inform discussions and decision-making and identification of relevant resources.

When workgroups were established, one-off consultations with PWLE from taskforce members' respective countries and settings were conducted to seek wider views beyond the taskforce. Consultations were conducted in local languages, with participants invited to comment on whether the planned activities were suitably ambitious, identify any gaps, and share views on barriers to engagement, preferred ways of working, and how engagement should be reported (see Supplemental File 5). Feedback confirmed the scope of the roundtable, with no major changes identified. Insights were incorporated into subsequent discussions.

In-person roundtable meeting

A 2-day hybrid in-person/online meeting of the taskforce was held in Aberdeen, UK, in November 2025. Financial support was offered to PWLE and taskforce members from low- and middle-income countries (LMICs) to assist with travel costs. Prior to the meeting, each workgroup prepared a report summarizing their work and key recommendations, which informed the development of an initial draft framework by E.A.L. and L.K. The 2-day meeting provided an opportunity to discuss and critically review the framework through a series of facilitated sessions. These discussions helped refine the main components and address remaining areas needing clarification, such as accessibility, inclusivity, reporting and evaluation, approaches to identifying PWLE, and how the framework should be positioned and used. Consensus was achieved through iterations and discussions. In line with the Terms of Engagement document, differences of opinion between taskforce members were expected and welcomed, and discussions were constructive and supportive. When decisions needed to be made but clarity had not yet been achieved, the co-chairs invited specific input from members with the most pertinent expertise or experience, for example, PWLE, researchers living or with experience working in LMICs, or researchers who did not speak English as a first language. In these cases, the workgroup tended to defer to the suggestions of the taskforce member with the pertinent experience. Taskforce members with lived experience of stroke actively participated in all discussions, and their feedback was not treated any differently from other taskforce members. Following the meeting, key discussion points and agreed refinements were systematically incorporated, alongside further expert review (see section "Expert review and refinement"), to iteratively strengthen and finalize the framework.

Expert review and refinement

In February to March 2026, we sought external feedback on the revised framework through a targeted consultation exercise with 14 purposively selected international researchers. These researchers reflected diverse expertise and experiences including working with Indigenous communities, in laboratory settings, in low-income countries, in

Box 2. Principles underpinning this work.

Engaging with people with lived experience increases the real-world relevance of research.
People with lived experience of stroke and researchers each possess inherent worth and bring distinct forms of knowledge to the research team.
All research team members contribute more effectively when they feel safe and supported.

Figure 2. The EMBED framework recommendations and guidance documents.

different geographical areas (including Africa and South America), the use of multiple languages, and a range of engagement approaches. They were asked to comment on the framework's clarity, ease of use, relevance to their areas of work, and any gaps. The feedback largely confirmed the existing content of the framework, highlighting that it was relevant and accessible. Suggestions mainly focused on making key areas more explicit, strengthening clarity, and adding practical detail to support implementation. These insights directly informed iterative revisions to the framework and the content of the guidance documents (Supplemental File 6). The final framework and accompanying guidance documents were finalized in March 2026 following incorporation of expert feedback and a final review from the taskforce members.

Involvement of PWLE in taskforce activities

Taskforce members A.A. and S.C. both had extensive experience as lived experience contributors when they joined the roundtable. They participated actively in all taskforce meetings and contributed to workgroups alongside colleagues without lived experience of stroke. The expertise of A.A. and S.C. was consistently recognized by the group, and they were at times asked to adjudicate, for example, to clarify preferred wording or ways to manage engagement activities. D.C. joined the taskforce in October and attended a 2-day meeting in person alongside S.C., and A.A. joined online. D.C. joined in subsequent taskforce meetings and activities. All PWLE contributed to discussions, shared in decisions made, and contributed to worksheets and manuscript preparation.

Results

All aspects of this work are underpinned by the following principles (Box 2), which were identified and agreed on by the taskforce.

The EMBED framework (Engaging Meaningfully to Build research with PWLE to Drive improvements in stroke

research) comprises five consensus–based recommendations and aligned guidance documents to support the implementation of these in practice (see Figure 2). The framework is designed to support researchers to work with PWLE of stroke in ways that are accessible, inclusive, and psychologically and culturally safe. Conceptually, EMBED is underpinned by principles of trauma–informed engagement, reflexive practice, and cultural humility, recognizing that safe and meaningful engagement cannot be achieved through procedural approaches alone. Instead, it emphasizes the relational nature of engagement, valuing the knowledge and expertise of all involved, intentionally embedding PWLE perspectives in decision–making, and addressing power imbalances to support equitable research practice.

The framework recommendations are not necessarily linear, and researchers may move between different recommendations depending on the context or stage of their research. Each recommendation is presented in the following sections, and relevant guidance documents are referred to throughout to support researchers' work through common complexities when engaging with PWLE.

Recommendation: Select the engagement approach to suit the project, the research team, and the PWLE

Preferred engagement approaches may vary among researchers, PWLE, and research programs. The EMBED framework focuses on three levels of engagement as outlined in the IAP2 framework:[5] *consultation*, where feedback is sought from PWLE on specific aspects of the research, often at the start and finish of a project; *involvement*, where PWLE provide input over the course of the project, often in advisory groups; and *collaboration*, where PWLE are part of the research team, share decision-making throughout the project, and co-create research outputs.

Regardless of the approach used, engagement allows PWLE to contribute expertise to shape and conduct the research. This is different from research *participation*, where individuals consent to take part in research (e.g. enroll in a clinical trial, participate in interviews) and they provide data to answer the research question. Unlike research participation, research engagement activities do not require institutional ethics approvals; consider these activities as seeking advice from experts, akin to statistical expertise.

For illustrations of each engagement approach conducted in different settings, see Table 1 and Guidance Document A.[17]

How to choose which engagement approach to use? There is no right or wrong way to engage with PWLE. Researchers will frequently engage with PWLE in more than one way for the same project. For example, researchers may *collaborate* with PWLE as co–investigators who directly influence project decisions, *involve* PWLE through advisory groups to guide and shape the research, and *consult* individuals or groups on specific issues. Each engagement approach offers distinct benefits: *consultation* can provide insights on discrete items and facilitate greater diversity of views; *involvement* supports ongoing input across the research lifecycle, strengthening aspects of the study design, delivery, and interpretation; and *collaboration* enables deeper partnership, fostering shared ownership, enhanced relevance, and embedding shared decision–making from the start to the completion of the research.

Collaboration typically requires more established and nurtured relationships between researchers and PWLE, as well as greater skill in engagement practice, than approaches based solely on consultation or involvement. This is because collaborative approaches require teams to address accessibility and inclusivity across all research activities and to embed power–sharing strategies and systems that support shared decision–making.

Researchers commonly have research ideas and then invite PWLE to join the project, either in consultation, involvement, or collaboration roles. Alternatively, PWLE can reach out to researchers with ideas for projects which means researchers can respond to the ideas and start the discussion of whether and how they may want to work together; PWLE will usually assume collaboration or involvement roles in these scenarios. Another way is that researchers and PWLE come together with the intent of co-generating research ideas to work on together, before proceeding to carry out the research, illustrating collaboration from the start. Regardless of who initiates the discussion, it is always possible to move toward the collaboration level of engagement.

Different engagement approaches involve different considerations as outlined in Guidance Document A,[17] and variation is expected depending on the project, context, and approach used. When selecting the approach, potential factors to consider include:

- *Study type and setting*: laboratory–based research often uses consultation approaches (although the literature is growing on how to collaborate with PWLE in laboratory-based research); primary or secondary research in clinical, health system, or community settings can support consultation, involvement, or collaboration.
- *Team experience*: less experienced teams may find consultation more feasible, while more experienced teams can support involvement or collaboration.
- *Skills and capacity*: consultation requires focused facilitation; involvement requires relationship–building and ongoing input; collaboration requires skills in shared decision–making, power–sharing, and reflection, alongside trust, accessibility, and resourcing.

Table 1. Levels of involvement across different research settings.

Research type/setting	Consultation	Involvement	Collaboration
Laboratory-based research (e.g. analysis of human blood or cerebrospinal fluid)	PWLE could provide feedback on: • Whether the research question is clear and meaningful to PWLE • Practicality and acceptability of sample collection procedures • Clarity of explanations about laboratory processes and data use • How findings are communicated and linked to future relevance for stroke survivors	PWLE could be involved in advisory activities by: • Sharing lived experience insights to help ensure the project feels relevant and the purpose is clearly explained • Pointing out any concerns or barriers related to proposed methods or sample-handling procedures • Checking on project progress and identifying findings most relevant to stroke community	PWLE could collaborate as co-investigators by: • Co-developing research questions and giving input on procedures so the project reflects stroke community's needs and preferences • Taking part in key decisions with the laboratory research team • Contributing to funding application and co-authoring dissemination outputs
Clinic, health system, or community-based research (e.g. testing a treatment with stroke survivors and developing and implementing a rehabilitation intervention or interview study)	PWLE could provide feedback on: • Whether the research question is clear and addresses what matters to PWLE • How easy the outcome measures and data collection are for participants to complete or participate in • How easy and acceptable an intervention is for participants to take part in • How clear and easy to understand the information and consent materials are • Whether the plan for sharing results works well for clinicians, community groups, and stroke survivors	PWLE could be involved in advisory activities by: • Informing the research question, study design, and trial protocol to ensure they reflect what matters to stroke survivors and carers • Shaping the intervention and delivery approach so it is practical, accessible, and acceptable for participants • Reviewing participant materials, consent, recruitment processes, and data collection to improve clarity and ease of use • Checking trial progress and contributing to outcome selection and data interpretation, highlighting what is most meaningful to the stroke community	PWLE could collaborate as co-investigators by: • Co-developing the research question, study design, and trial protocol as co-investigators • Jointly shaping key decisions on the intervention, recruitment, outcome measures, and data collection • Contributing to data collection or analysis and helping interpret results using lived-experience insights • Co-authoring and co-presenting study findings, guiding what is shared and how it is communicated
Secondary research (e.g. systematic review, guideline development, and analysis of existing datasets)	PWLE could provide feedback on: • Relevance of the review question for PWLE • Whether the outcomes or review questions reflect what matters most to PWLE • Clarity of the plain-English summary	PWLE could be involved in advisory activities by: • Working with the team throughout the review to shape and refine the review question and outcomes, ensuring they reflect what matters most to PWLE • Bringing lived experience insights to inform screening, interpretation of studies and emerging findings, helping to understand what is meaningful • Informing the plain-English summary and guide how findings are shared, ensuring the review stays clear, relevant and accessible to the stroke community	PWLE could collaborate as co-investigators by: • Co-developing the review question and deciding which outcomes, comparisons, and data sources to include • Contributing to review processes, for example, screening studies, checking data, helping analyze and interpret findings, and using lived-experience insights • Co-creating and co-presenting the findings and outputs, including key messages, plain-English summaries, and dissemination plans

- *Preferences* of the team and individuals regarding engagement approach.
- *Intended users of the research outputs*: if research findings are intended to be used by PWLE (e.g. research about lifestyle changes to support secondary stroke prevention), then collaborative approaches are particularly relevant.

We recommend teams engage with PWLE as early as possible (e.g. when identifying research priorities) and be open and curious to explore how lived experience engagement can add value and insights to the research project, regardless of the approach they intend to use. When planning the approach, account for adequate time and budget to ensure success.

Recommendation: Identify PWLE to engage with

Consider who the research is designed to reach and impact, and whether "representativeness" of PWLE is relevant for the research project. This means considering whether PWLE are being asked to represent their personal experiences or those of the community and whether certain post-stroke sequelae, personal factors (e.g. age, ethnicity, gender, sexuality), or experience of a particular care pathway are particularly salient for the project. See Guidance Document B[17] for tips on identifying, approaching, and building relationships with PWLE.

Different engagement roles (consultation, involvement, collaboration) require different skills, attributes, and, in some cases, different knowledge. We recommend researchers prepare written descriptions to share with PWLE about the role/s, anticipated contributions, desirable expertise, and experiences, to ensure the best fit of the individual/s to the role/s and the project. This information can be shared via Expressions of Interest when looking to advertise engagement roles. See Guidance Documents C[17] and D[17] for examples of role descriptions and Expression of Interest templates.

PWLE on the taskforce emphasized the importance of emotional readiness of PWLE to engage with research. Early after stroke, processes of adjustment and emotional responses may influence whether individuals feel ready or able to take on a research engagement role. Rather than making assumptions based on time since stroke, researchers should support ongoing, two–way discussions to check whether the timing and nature of proposed engagement activities are appropriate for each person's individual stage of recovery. As research engagement can have emotional impacts for PWLE, attentiveness to well–being, emotional readiness, and adjustment is important throughout the research process, regardless of time post–stroke.

Existing networks of PWLE are often the first place to identify people to engage with, including personal networks of researchers or teams, or through channels such as stroke support organizations, health providers, stroke community or advocacy groups, or research registries. If research is focused on the needs of a specific community, another approach is to ask individuals from that community (e.g. people who speak a certain language or who have strong community networks) to liaise between the research team and the PWLE with whom they wish to engage.

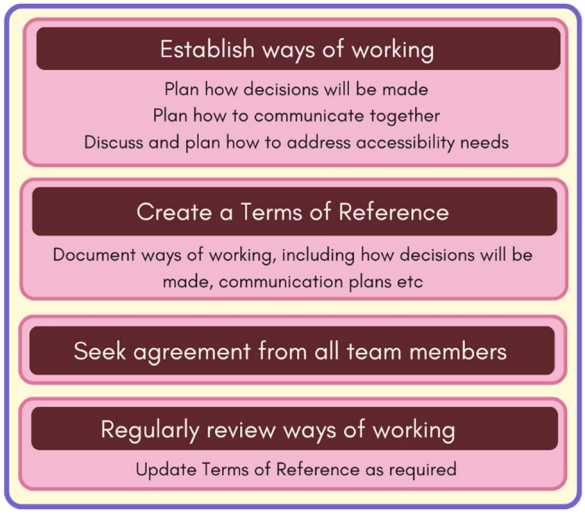
When seeking to work with a new community group, particularly one that has been marginalized or underserved, it is important to invest time to establish a respectful and mutually beneficial relationship. Check for availability of guidance documents or policies about conducting research with this community, such as those available in many colonized countries about conducting research with Indigenous communities. Investigate whether there are individuals or organizations that can facilitate introductions between researchers and community members—these might be unrelated to stroke but may be relevant to cultural identity, such as faith or ethnic/cultural groups. Prior to contacting the community, learn about how the community is impacted by stroke and by current and historical service provision as well as preferred terminology, values, social norms, and practices, including power structures and relational authority. When meeting with community representatives, explore the community's aspirations for research, how they would like the research to benefit the community, as well as concerns the community might have regarding engaging in research. Recognize that lived experience or expertise may take the form of cultural knowledge rather than personal experience of stroke or rehabilitation. See Guidance Document E[17] for more detail regarding principles of working cross-culturally for engaging PWLE.

Networks can help publicize engagement roles—this might look different between networks, such as an expression of interest on a stroke support organization social media feed or direct nomination from a community group. When establishing new engagement working relationships, it is common for researchers and PWLE to meet informally to determine their comfort and confidence that they can work productively and constructively together for the duration required in the role.

Recommendation: Embed accessible and inclusive ways of working

Understanding and valuing inclusive ways of working are integral to genuine engagement. We recommend that research teams explicitly plan and communicate how engaging with PWLE will inform and shape each project (see Figure 3). This can be facilitated by creating a Terms of Reference document, detailing the roles and

Figure 3. Establishing ways of working.



responsibilities of team members, how decisions will be made (including how disagreements will be resolved and who has final authority), and general ways of working. Guidance Document F[17] has templates and instructions on creating Terms of Reference for different engagement approaches.

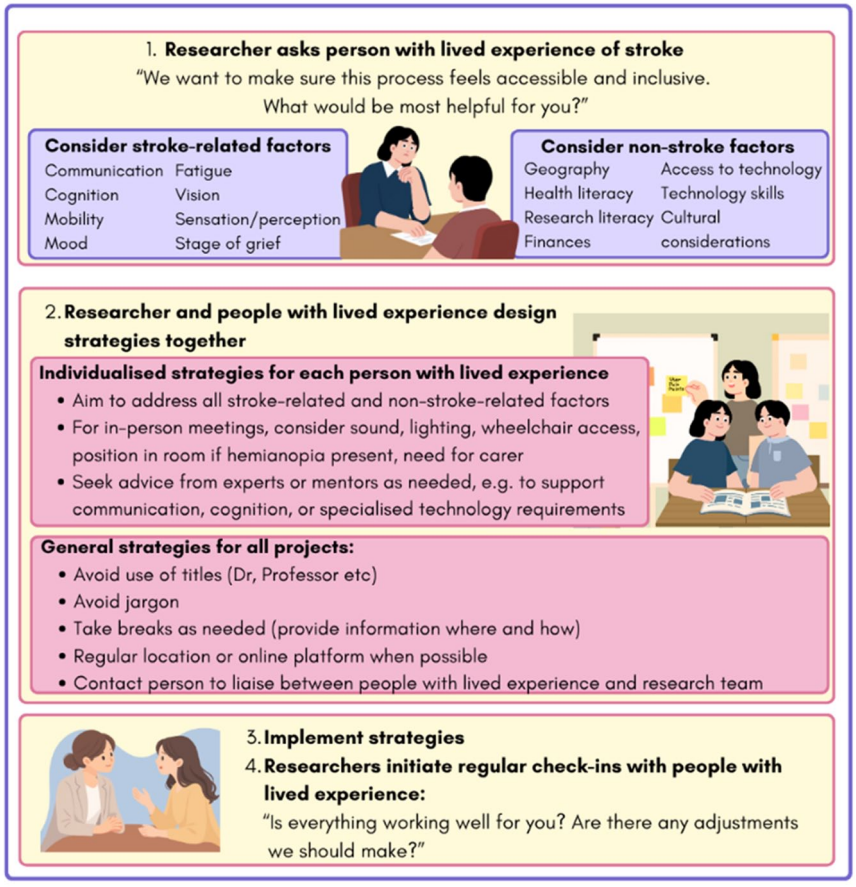
Preparing researchers. In preparation for engaging with PWLE, we recommend researchers reflect on their knowledge, skills, confidence, and past experiences in engaging with PWLE. It is important to acknowledge that engaging with PWLE requires different skills than engaging with researchers or health professionals. Members of the research team need to coordinate strategies to optimize accessibility and inclusivity while simultaneously ensuring project milestones are met. Self-reflection can highlight areas for future capability-building, for example, attending courses, observing other researchers' engagement activities, or seeking mentoring from researchers or PWLE with expertise in the selected engagement approach. We recommend that researchers new to engaging with PWLE in research seek mentoring and/or invite experts to the team specifically to contribute skills in engagement. Even researchers who are confident in their ability to lead engagement activities are encouraged to continuously reflect and refine their skills in creating inclusive environments, facilitating group discussions, building consensus within teams, resolving conflict constructively, and communicating accessibly, which underpin the more collaborative engagement approaches.

Preparing PWLE. We also recommend researchers discuss with PWLE working on the project any concerns or ambitions they have regarding their engagement capability. This can highlight areas and opportunities for potential capability-building, such as education and training, observation, practice, feedback, and mentoring. The focus of capability-building could be research-specific activities, for example, training to conduct interviews or facilitate advisory groups, or general, such as training to use software or technology. Peer mentoring can be particularly helpful for people new to engagement activities for learning and for moral support; PWLE on our team recommend always having more than one person bringing a lived experience perspective on projects to allow peer debriefing, greater diversity of views, and burden reduction. Capability-building initiatives should be tailored to individual needs and cultural considerations.

Addressing accessibility. It is the researcher's responsibility to proactively address accessibility needs of PWLE to facilitate their engagement (see Figure 4). Accessibility considerations include health and digital literacy, familiarity with research processes, language barriers, access to resources (e.g. Internet, personal devices), and health and community services, which are common across many research contexts. Other accessibility considerations relate to the effects of stroke, including changes in cognition, communication, mood, mobility, sensation/perception, and fatigue. We recommend early discussions with PWLE engaged in the project about their accessibility needs to develop and implement personalized strategies to optimize their ability to contribute. Teams may need to seek expertise from specialists to address some accessibility challenges, such as input from speech-language therapists to develop accessibility strategies for people with aphasia. We recommend teams be open-minded and consider working in ways different than anticipated to meet the accessibility needs of PWLE. Guidance Document G[17] provides guidance on assessing and addressing accessibility.

Addressing inclusivity. Along with accessibility needs, we recommend researchers proactively address inclusivity (Figure 4) through creating environments and processes where all people feel valued, respected, safe, and able to contribute. General rules like not using academic titles in interactions and avoiding unnecessary jargon can remove hierarchies of assumed expertise. Using a trauma-informed approach, we encourage researchers and PWLE to discuss proposed research activities, emotional readiness, and whether/how PWLE prefer to contribute to these activities. Providing materials in advance, pacing discussions appropriately, and remaining responsive to people's changing needs can further support engagement. When working with marginalized or underserved community groups, seek guidance on culturally appropriate ways of working (Guidance Document E).[17] An important feature of inclusivity is open and responsive communication that provides adequate detail to meet information needs but does not overwhelm PWLE. Having mechanisms for communicating openly

Figure 4. Planning for accessibility and inclusivity.



and transparently may differ between projects and between people—for example, project communication strategies would need to be purpose-designed with individuals without access to the Internet, with difficulty reading, and so on (Guidance Document F).[17] We recommend that researchers provide contact details of a nominated team member whose role is to support the PWLE engaged in the project. Support could be formal, with regular preparation and de-brief meetings before and after team meetings, or informal coffee or phone catch-ups. Having a designated contact person provides a channel for any issues or concerns of PWLE to be proactively identified and subsequently addressed by the research team. As mentioned above, we recommend teams be open-minded to working flexibly and prepared to support inclusivity in ways that work for PWLE. These ways of working and communication strategies can be detailed in the Terms of Reference, discussed and agreed on by all team members at the commencement of the research project, and then reviewed regularly.

Remuneration. In the context of this article, *remuneration* is the act of recognizing time, expertise, and contributions of PWLE to the research (see Guidance Document H[17] for more detailed considerations regarding remuneration). Remuneration should be offered to all PWLE who engage in research projects, but this may look different between individuals, projects, and contexts. Remuneration is different from *reimbursement*, which covers out-of-pocket expenses like parking or travel costs or caregiver costs if PWLE need to be accompanied to travel or attend meetings; it is also not a gift or token. When planning appropriate remuneration, we recommend that researchers familiarize themselves with organizational and governmental policies and systems, such as those relating to tax, social security, disability pensions, and employment. Open and transparent conversations can then be held with PWLE to learn about culturally acceptable forms of remuneration. Remuneration may be monetary, non-monetary, or a combination. Financial options might include gift cards, cash payments, casual employment, or charitable donations made on behalf of contributors. Non-monetary remuneration could include acts of service requested by the community, opportunities for professional development or training, conference attendance, or provision of assistive equipment or services.

Governance and organizational context. Outside the research team and project, the organizational context can influence engagement of PWLE. We recommend that researchers investigate the availability of established governance structures, remuneration policies, and accessible funding to support PWLE engaged in research.

Early engagement of PWLE to formulate research questions or prepare grant applications typically occurs at a stage when there is no funding for the project. Given that engagement of PWLE requires time and remuneration, we recommend that institutions offer early-stage support, such as microgrants, to support researchers to engage with PWLE when developing ideas for new research grant applications and identifying or prioritizing new research questions.

Our experience in many institutions in different parts of the world is that it has been necessary to advocate for suitable institutional policies, such as liaising with human resources to explain the purpose and value of formally supporting PWLE roles and establishing acceptable payment systems. We recommend that organizations work proactively to develop remuneration systems acceptable to PWLE, with straightforward payment methods and awareness of tax implications.

Recommendation: Support and strengthen accessibility and inclusivity of engagement throughout the project

Positive working relationships between researchers and PWLE are important, particularly when PWLE are involved in, or collaborate on, research. We recommend that teams self-reflect on ways of working: Do PWLE engaging on projects bring perspectives that are different from researchers' biases and assumptions or make contributions that stimulate the research moving in new directions? When PWLE challenge the current research narrative, are these perspectives considered with the same gravitas as those of other team members? Answers to these questions can guide whether work is required to enhance team culture and refine ways of working, aiming for PWLE to be confident and supported to contribute their expertise and for researchers to incorporate these perspectives to shape the research.

We recommend teams regularly reflect on the accessibility and inclusivity of engagement of PWLE throughout the research by reviewing patterns of engagement (see Guidance Document I[17] for considerations when reflecting on engagement). When PWLE are involved in group discussions within research teams or advisory groups, observe who is quieter and whether all individuals have opportunities to contribute, paying attention to people from marginalized or underserved groups and people with accessibility, communication, cognitive, or fatigue difficulties. We recommend at least one member of the research team directly check-in with PWLE to seek their feedback on what's working well and where any adjustments are needed, develop strategies together, and then implement these. These cycles of review and improvement can occur for the life of the project.

Recommendation: Report accessibility and inclusivity of engagement

Reporting on the engagement of PWLE enhances transparency and advances understanding about how to engage PWLE in research. In addition to using reporting guidelines such as GRIPP2,[18] to report involvement and engagement activities and engagement measures such as the Patient Engagement in Research Scale (PEIRS),[19] we recommend that researchers also specifically describe how relationships between researchers and PWLE were built, how trust and collaboration were fostered, and how diversity, inclusivity, and accessibility were addressed (see Guidance Document J[17] for reflective prompts to guide reporting). Reporting richer accounts of *how* engagement approaches are developed and experienced, particularly in the context of working with underserved groups or those with specific support needs or post-stroke sequelae, helps to advance collective learning, strengthen engagement practices, and promote equitable and inclusive research.

Discussion

The EMBED framework and associated guidance documents provide tangible support to researchers working in laboratory, clinical, health system, and community settings to meaningfully and sustainably engage with PWLE of stroke. The framework assumes an existing level of interest in engaging with PWLE and focuses on supporting its effective implementation; however, levels of awareness and prioritization of engaging with PWLE vary internationally, and ongoing efforts are needed to strengthen understanding of its value alongside implementation guidance.

The timing of research funding presents a barrier to meaningful engagement with PWLE. Most funding schemes provide little or no support for engagement during the formative, pre-award stages of a project. This constraint highlights the need for engagement models that extend beyond individual projects and for mechanisms (e.g. formalized organizational support) that enable engagement during project planning and grant development. These include sustained relationships with PWLE, opportunities for program-level engagement, and access to developmental funding that facilitates pre-award collaboration.

Ongoing barriers to engagement that we have not addressed and need future work include the development of sustainable governance systems. Beyond establishing remuneration systems, the research community faces ambiguity regarding how to coordinate insurance and other wellbeing coverage for PWLE engaging in research when they are not employees. Research activities where people share or reflect on their personal experiences of surviving a

stroke, receiving healthcare, or striving to regain function may trigger emotional responses, and the research team has an ethical responsibility to provide PWLE access to support.[20] One initiative being trialed in 2026 by the Stroke Foundation (Australia's stroke support organization) is for research teams to commission the Stroke Foundation to coordinate the engagement activities, offering services including convening PWLE to engage with; discussing each person's accessibility needs and inclusivity preferences; coordinating remuneration, travel, and accommodation; liaising between PWLE and research teams; and providing insurance coverage should PWLE be injured during engagement activities (S. Russell, personal communication 21/3/2026). We anticipate this initiative will address a major barrier to research engagement in the field of stroke. We encourage other research-active stroke support organizations and research institutions with dedicated PWLE engagement units to consider similar models.

Recognition of core competencies in research engagement is another area for future work. Our search only identified one source of capability-building material specific to engagement in stroke research,[21,22] but these addressed only foundational knowledge of researchers and PWLE and lacked assessment of users' skills or more complex knowledge constructs. Future work could explore the creation and validation of a structured competency framework outlining core skills, attitudes, and knowledge for PWLE, researchers, and research students which could then inform development of stroke-specific capability-building initiatives, self-assessment, and accreditation.

Finally, more work is required to define and guide reporting of holistic engagement, so researchers and PWLE can demonstrate that engagement has been meaningful and not tokenistic. This can then support reporting of engagement impact and evaluation, important for PWLE, researchers, funders, and publishers.

Conclusion

We have developed the EMBED framework, consisting of five consensus recommendations and ten guiding documents. Application of the framework will support researchers to improve stroke recovery and rehabilitation research through engaging with PWLE of stroke in research in ways that are meaningful, respectful, accessible, and inclusive while maintaining research rigor.

Acknowledgments

The authors acknowledge and thank the following individuals for their expert input and feedback as we drafted our recommendations and guiding documents: Noorazah Aziz and Deidre Da Silva for early contributions; Sarah Belson, Christina Bursill, Janet Kelly, Sally Robinson, Praveen Kumar, Marina Charalambous, Grace Turner, Dimple Dawer, Yina Quique, Mia Moth Wolffbrandt, Markus Wagner, Matthew Jeffers, Ali Aries, and Matthew Edwardson for feedback on draft documents; and Monika McCann for administrative support preparing the final documents. The authors acknowledge Julie Bernhardt, Taim Saeed, and Juan Pablo Saa for their assistance in planning and coordination of the core meetings for the fourth Stroke Recovery and Rehabilitation Roundtable (SRRR IV). The authors are grateful to Kate Hayward for facilitating the SRRR IV in-person meeting discussions and to Sean Dukelow, who convened the meeting, and to our funders of the in-person meeting (section "Funding"). SRRR IV is an initiative of the International Stroke Recovery and Rehabilitation Alliance (ISRRA).

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The authors are grateful for the financial support for the in-person meeting from the UK Stroke Forum and the Stroke Association (£8000), the CanStroke Recovery Trials group, and an unrestricted grant from Moleac. F.A.S.B. was supported by a Health Research Council of New Zealand grant (20/603). I.D.G. is a recipient of a CIHR Foundation Grant (FDN# 143237).

Ethical considerations and informed consent statements

Not applicable.

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Data availability statement

No primary data were collected for this review.

Statement of endorsement

The World Stroke Organization (WSO) endorses the goals of the fourth international Stroke Recovery and Rehabilitation Roundtable research activity which are consistent with the mission of the WSO.

Supplemental material

Supplemental material for this article is available online.

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