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**Life After
Stroke**
Forum

Abstract book

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#lifeafterstroke

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SCIENTIFIC

1 - Development of an educational video to enhance the perceived communication capabilities of conversation partners.

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Category: Communication, including swallowing difficulties

Background and aims

Aphasia is a communication disorder caused by damage or injury to the brain, most commonly from a stroke. People with aphasia (PWA) report difficulty engaging in conversations with others and are therefore at risk of social isolation. The aim of the study was to establish the impact of an education Aphasia Video on the knowledge and perceived capability of conversation partners for PWA.

Method

A video was developed by PWA, which aimed to explain how aphasia can affect communication and conversations and how PWA can communicate more effectively if supported. The 14-item aphasia-friendly questionnaire, which measures knowledge and perceived capability, was designed and disseminated to participants before and after watching the video.

Results

Fifty-three (n= 53) completed both pre- and post-questionnaires. Excellent internal consistency was found (Cronbach's alpha pre =0.904; post =0.953) and therefore the questionnaire was deemed to have acceptable internal reliability. Scale scores were calculated for pre- and post-questionnaires (n=92, mean 29.4, SD. 8.87) and post (n=71, mean 19.1, SD. 6.71). A statistically significant improved knowledge and perceived capability score was seen after watching the educational video ($Z=-5.327$, $n=53$, $p<.001$).

Conclusion

The questionnaire had good validity with PWA and internal reliability. Findings demonstrate that the educational video improved the knowledge and perceived capability of conversation partners for PWA.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

An educational aphasia video and questionnaires were created to assess the impact on the knowledge and perceived ability of conversation partners for people with aphasia. Results indicated improvements in both areas. This video has been utilised for educational purposes within public and higher education programmes, both nationally and internationally.

2 - Life through a lense - experiences of photovoice in a participatory study with adults with aphasia.

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Category: Communication, including swallowing difficulties

Background and aims

The photovoice method allows people to share their experiences in focus group interviews using personal photographs, thereby enabling participants' voices to be heard. The aim of this study was to explore experiences of utilizing photovoice to facilitate the involvement of people with aphasia after acquired brain injury (ABI).

Method

This study is part of the project, Participation in Society After an ABI, exploring how people with ABI experience aspects of participation and involving community researchers with lived experience of ABI throughout the process. Data were collected during photovoice focus group interviews, moderated by academic researchers and community researchers in collaboration, consisting of field notes and transcripts and analysed with thematic analysis.

Results

Two overall themes emerged: The need for continuous modifications and, The value of joint exploration of participant narratives. The first theme refers to unforeseen modifications between and during the focus group interviews in which community researchers filled a valuable role as conversation starters and cultural brokers. The second theme refers to participants' experience of utilizing photovoice to explore individual and collective narratives in which group size and group composition were important aspects in creating a safe and dynamic space.

Conclusion

The involvement of community researchers with lived experience of stroke induced aphasia played an important role in starting up and maintaining conversations by sharing their own experiences. The combination of making modifications before the photovoice focus group interviews and researchers' flexibility in addressing unforeseen modifications during the process facilitated the involvement of participants with different degrees of aphasia.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Limited capacity to communicate impact quality of life for people with aphasia, family members and care givers. Hence it is important to identify methods that support their participation. Photovoice can be used in many different contexts

and is appropriate for people with aphasia since it is based on visual communication.

3 - Development of the Aphasia customised ePRO (ACe-PRO) for stroke: navigating accessibility, complexity, and clinical practice

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Category: Communication, including swallowing difficulties

Background and aims

People with aphasia often face communication barriers, limiting their ability to express needs and participate in follow-up consultations. Electronic patient-reported outcome (ePRO) tools can support patient engagement, but their accessibility for people with cognitive and communicative difficulties is uncertain. The Aphasia Customised ePRO (ACe-PRO) was developed to address these gaps. This presentation presents key insights from the development, validation, and feasibility testing of ACe-PRO, highlighting both opportunities and challenges.

Method

ACe-PRO was developed as a complex intervention using iterative design, stakeholder involvement, and integration into clinical systems. Content was explored with stroke survivors with aphasia and healthcare professionals. Feasibility was examined through a multi method study at two Danish hospitals, where the questionnaire was routinely sent to all patients discharged after stroke. Quantitative distribution and completion data were combined with qualitative interviews and field observations.

Results

During 12 months, 994 questionnaires were distributed and 363 completed (36.5%). Completion was highest among younger and less impaired patients; those with greater cognitive or communication difficulties rarely responded. Although designed for people with aphasia, it was sent to all stroke patients, and benefits varied across groups. Relatives often supported completion, some patients found the tool demanding, and implementation differed due to workflow differences.

Conclusion

ACe-PRO demonstrates both the potential and complexity of implementing digital tools for people with aphasia. While it can support communication and highlight hidden difficulties, accessibility issues, emotional burden, and structural barriers must be addressed for equitable use. Digital health solutions are not universally beneficial, and careful adaptation is required.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Aphasia-customised ePRO tools may improve communication and participation after stroke, but their benefits are uncertain and further research is needed. ACe-PRO reveals challenges related to accessibility, clinical integration, and emotional demands. Realising the potential of digital tools in vulnerable groups requires nuanced design, implementation, and evaluation strategies.

4 - Dysphagia Evaluation After Stroke (DESIRE) – Part 1: Incidence of Dysphagia and Related Factors

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Category: Communication, including swallowing difficulties

Background and aims

There is a significant uncertainty of the incidence of swallowing difficulties (dysphagia) following a stroke. Dysphagia is often underestimated, despite its strong association with increased mortality, morbidity, and hospitalizations risks from pneumonia and malnutrition. This study, part of the Dysphagia Evaluation after Stroke (DESIRE) project, aims to explore dysphagia incidence and related factors in acute stroke patients receiving modern stroke care.

Method

Consecutive acute stroke patients at four stroke units in Sweden: Norrland University Hospital, Danderyd Hospital, Södersjukhuset, and Kungälv Hospital had their swallowing ability assessed within 96 hours of admission. A speech-language pathologist evaluated dysphagia using the validated Gugging Swallowing Screen (GUSS). Clinical data on stroke and dysphagia risk factors, pneumonia rates, and discharge forms were collected. Regression model analysis was conducted to evaluate factors associated with dysphagia post-stroke.

Results

A total of 1546 patients were included, with 679 women and a mean age of 72.1 ± 14.2 . The incidence of dysphagia was 37.1%. Significant predictors of dysphagia included female sex ($p=0.005$), dysarthria at admission ($p<0.001$), and higher stroke severity (e.g., severe stroke: $p<0.001$, OR=34.7; CI=13.7–87.7). Dysphagia was significantly linked to pneumonia ($p<0.001$) and resulted in an average hospital stay extended by 117 hours. It also predicted higher odds of discharge to care facilities and death (OR=95.2, CI=22.6–401.2; $p<0.001$).

Conclusion

Dysphagia is prevalent in 37% of stroke survivors in the acute phase, particularly among females, patients with dysarthria, and those with severe strokes. Its presence correlates with increased likelihood of pneumonia and discharge to alternative care settings or death during hospitalization.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This study will enhance post-stroke care by increasing awareness of dysphagia among healthcare providers, leading to earlier identification and intervention. By addressing swallowing difficulties effectively, we aim to

reduce complications such as pneumonia and malnutrition, ultimately improving the quality of life and recovery outcomes in stroke survivors.

5 - Dysphagia Evaluation After Stroke (DESIRE) – Part 2: Survival Rate

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Category: Communication, including swallowing difficulties

Background and aims

Dysphagia (difficulty swallowing) after stroke is often overlooked, despite its strong link to mortality, morbidity, and dependency due to heightened risks of aspiration pneumonia and malnutrition. Early identification is essential to improve outcomes. This study, part of the Dysphagia Evaluation after Stroke (DESIRE) project, examined 90-day survival in stroke patients at risk for dysphagia.

Method

We conducted a prospective study across four Swedish stroke centers (Norrlands University Hospital, Danderyd Hospital, Södersjukhuset, and Kungälv Hospital), including consecutive patients with first-ever stroke or TIA screened within 96 hours of admission. Dysphagia risk was assessed by a trained speech language pathologist using the Gugging Swallowing Screen (GUSS). Participants were followed for 90 days to assess functional status, measured by the modified Rankin Scale (mRS), and mortality. Clinical data on stroke and dysphagia risk factors were collected. The primary outcome was 90-day mortality. Cox regression models were used to estimate hazard ratios (HR) with 95% confidence intervals (CI).

Results

Results will be presented at the 4th European Life After Stroke Forum (ELASF).

Conclusion

The study will provide insights into the impact of dysphagia risk on short-term survival after stroke, highlighting the importance of early identification and systematic screening.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This study will enhance life after stroke by identifying the impact of dysphagia, leading to targeted interventions. By improving early detection and management of swallowing difficulties, we aim to reduce complications such as pneumonia and malnutrition, ultimately fostering better recovery outcomes and quality of life for stroke survivors.

6 - Dysphagia Evaluation After Stroke (DESIRE) – Part 3: A Randomized Controlled Trial of Oral Neuromuscular Training

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Category: Communication, including swallowing difficulties

Background and aims

This multicenter randomized control trial aims to investigate the effect of oral neuromuscular training with a novel oral device on dysphagia in patients with stroke. Randomized clinical trials (RCTs) are lacking on rehabilitative intervention to improve swallowing on a biomechanical level after stroke.

Method

P: 336 consecutive participants without history of previous dysphagia and with persistent dysphagia 3 months after ischemic stroke or intracerebral hemorrhage onset will be randomized 1:1 for

I: 3 months intervention with current routine care + oral neuromuscular training three times daily with an oral device, equipped with sensors for compliance feedback.

C: The controls will be given current routine care with compensatory strategies such as bolus modification, adapted swallowing postures and maneuvers.

O: The primary outcome is change in the degree of dysphagia at end of intervention, assessed with nasoendoscopy by blinded evaluators, and analyzed with ordinal regression models. Secondary outcome is change in nutritional status, pneumonia, mortality, and quality of life after 3 months intervention and at 6 months follow-up.

Results

The study design, methodology, and progression will be presented at the 4th European Life After Stroke Forum (ELASF). To date, a total of 94 out of the planned 336 participants have been successfully enrolled in the study.

Conclusion

This trial advances dysphagia treatment in stroke patients through innovative oral neuromuscular training, aiming to enhance swallowing and improve quality of life, with hopes of transforming recovery strategies for many affected individuals.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This study aims to significantly improve life after stroke for survivors by providing targeted rehabilitation through oral neuromuscular training. By addressing dysphagia at a biomechanical level, we anticipate enhanced swallowing function, reduced complications such as pneumonia, improved nutritional status, and ultimately better quality of life for participants

7- Improving collaboration in brain injury rehabilitation when family and healthcare professionals' recovery expectations differ

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Category: Emotional, cognitive and psychological impact of stroke

Background and aims

Many survivors of severe acquired brain injuries will have long-term disability, although prognostication is often complex and uncertain. During rehabilitation, family expectations of recovery often differ to healthcare professionals'. This can cause conflict that delays service processes, affects patient care, and can be distressing for all involved. This study aimed to determine how family expectations are currently managed and to identify modifiable areas of improvement.

Method

1. A scoping review was conducted using a 'best fit' framework synthesis approach. 2. Qualitative interviews (n=18) were conducted with staff at a single study site and were subject to thematic analysis.

Results

Twenty-one papers were included in the review. The key recommendation was 'rehabilitation as a shared process' between family, patient and staff. Three staff behaviours ('appropriate information provision', 'communication', 'family as a priority') and two system behaviours ('increase resource', 'culture change') supported this recommendation. The interview themes were 'the promise of rehabilitation', 'staff confidence with complexity', and 'developing family centred services'.

Conclusion

Differing expectations of recovery reflect a range of unmet family needs, which relate to power dynamics, professional-family communication, and their involvement in rehabilitation processes. The term rehabilitation does not appear to capture the scope of these services, which often includes disability management. Healthcare professionals need more support to communicate uncertainty and complexity with confidence and consistency, and to recognise hope as an important coping strategy. Identifying family and healthcare professional expectations early and reviewing these as they progress through different phases of care may prevent misunderstanding and conflict.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Poorly managed expectations following stroke can be detrimental to the health and wellbeing of all involved. This work has identified ways to improve the way staff manage family expectations, which includes greater collaboration to enable mutual understanding and respect. This will benefit the patient as well as families and staff.

8 - A qualitative study of lived experience 5-8 years after young-onset stroke

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Category: Emotional, cognitive and psychological impact of stroke

Background and aims

Stroke incidence in younger adults is increasing worldwide. This study aimed to explore the lived experiences and long-term recovery of individuals who experienced stroke at a young age.

Method

This embedded qualitative analysis formed part of a larger, ongoing observational follow-up study of individuals with young-onset stroke. Using an open-ended prompt at the end of a structured questionnaire, participants were invited to share further insights on their life after stroke, which formed this qualitative analysis. Two authors performed coding and theme development guided by reflexive thematic analysis. Theoretical framing used the biopsychosocial model and coping and adaptation theory. Telephone, electronic, or postal follow-up assessments were conducted between 13th September 2024 and 13th May 2025 with individuals who had been admitted to University College London Hospitals Hyperacute Stroke Unit (UCLH HASU) 5–8 years earlier with ischaemic stroke or intracerebral haemorrhage and were aged <55 at the time of stroke.

Results

Of 127 eligible participants, 80 responded (age range: 20-54 years). Four themes emerged: (1) persistent “hidden” disabilities affecting daily life; (2) loss of sense of self and disruption of age-normative roles; (3) systemic gaps in stroke awareness and long-term support; and (4) emotional resilience developed in response to life disruption.

Conclusion

Young-onset stroke has profound and lasting effects, including “hidden” disabilities that are prevalent years later. Our findings emphasise the need for increased public awareness of young-onset stroke and call for a more holistic, long-term post-stroke care model that supports not only functional recovery but also restoration of identity and life roles.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research makes suggestions to enhance awareness, access to age-appropriate support, and personalised long-term care for younger stroke survivors. It proposes early psychosocial intervention and structured follow-up to address hidden symptoms, emotional needs, and vocational goals, supporting recovery, psychological well-being, and reintegration.

9 - Upskilling diverse workforces to deliver inclusive, online group therapy for adjustment after stroke: WAtErS2 study

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Category: Emotional, cognitive and psychological impact of stroke

Background and aims

Psychological adjustment is a priority for life after stroke, yet services struggle to provide accessible support. The Wellbeing After Stroke-2(WAtErS2) study, co-developed with stroke survivors, tested the feasibility of an eight-session online group-based Acceptance and Commitment Therapy (ACT) intervention. It focused on upskilling a broad workforce and widening inclusion.

Method

Diverse facilitators, including NHS peer support workers, utilising novel combinations (e.g. third sector/NHS “buddying”), received training and supervision from clinical psychologists. Stroke survivors were recruited ≥ 4 months post-stroke, self-reporting psychological distress.

Qualitative and quantitative data explored the feasibility of recruitment, retention, data quality, safety, and fidelity of delivery.

Surveys and interviews with staff and survivors explored acceptability and impact. Online surveys post-group and at 3 months measured Mood, Wellbeing and Psychological Flexibility.

Results

Stroke survivors recruited across four sites ($n=19$). Mean (SD) months post stroke: 9.6 (8.4); 32% from minority ethnic communities and 50% with aphasia. Fourteen attended at least 6/8 sessions; no intervention-related adverse events. Trained facilitators ($n=13$) achieved good fidelity to clinical protocols. Survivors valued peer connection and ACT strategies like mindful breathing. Staff reported personal and professional benefits; embedding ACT skills in routine care. Inclusion of survivors with aphasia and from minority ethnic groups was achieved, although language support and recruitment routes were challenges. NHS/third sector workforce “buddying” and upskilling non-psychologists, including peer support workers, was feasible.

Conclusion

WAtErS2 indicates inclusive, online wellbeing groups can be delivered with fidelity by an upskilled, diverse workforce. Findings inform an implementation toolkit and future research to advance equitable post-stroke psychological care

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

WATER2 upskilled non-psychologist stroke workforces, including peer support workers, and tested novel workforce configurations to deliver inclusive, evidence-based, group, online therapy aimed to improve wellbeing after stroke. It could expand access to much-needed psychological care for underserved stroke survivors - including people with aphasia and from minority ethnic communities.

10 - Validation of Post-Stroke Checklist Items Against Gold-Standard Instruments

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Category: Emotional, cognitive and psychological impact of stroke

Background and aims

The Post-Stroke Checklist (PSC) is an internationally recommended tool designed to identify common post-stroke health problems and guide appropriate interventions. Despite its widespread use, comprehensive validation against gold standard instruments remains limited. This study aimed to evaluate the validity of selected PSC items—cognition, mood, and fatigue—by comparing them with established gold standard instruments.

Method

A total of 165 patients discharged home after ischemic or hemorrhagic stroke from Skåne University Hospital, Malmö, Sweden, were included. At the 3-month follow-up, patients completed the PSC along with the Montreal Cognitive Assessment (MoCA), Hospital Anxiety and Depression Scale (HADS), and Mental Fatigue Scale (MFS). Sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV), and level of agreement were calculated for each PSC item in comparison with its corresponding gold standard.

Results

The PSC demonstrated moderate validity for cognition ($\kappa=0.31$; sensitivity 53.7%; specificity 76.5%) and low validity for fatigue ($\kappa=0.12$; sensitivity 79.3%; specificity 66.4%). Mood showed high sensitivity but low agreement with HADS ($\kappa=0.29$). Across all domains, NPVs were relatively high (65.4–97%), indicating that the PSC effectively ruled out problems when patients reported none, whereas PPVs were lower, reflecting frequent overreporting. Patients with positive PSC responses generally exhibited greater dependency and a higher burden of post-stroke problems.

Conclusion

The PSC is a feasible and easy-to-use tool for screening post-stroke health problems, particularly effective in excluding issues when responses are negative. However, due to limited specificity, it should be used alongside validated assessments for more accurate diagnosis and management.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Denna forskning bidrar till bättre uppföljning efter stroke genom att validera Post-Stroke Checklist. Verktuget kan tidigt identifiera flera vanliga strokerelaterade hälsoproblem, vilket möjliggör snabbare insatser, förbättrad livskvalitet och effektivare sekundärprevention för att minska risken för återinsjuknande.

11 - Post-stroke checklist as screening-tool to detect cognitive disorders and its impact in daily life activities

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Category: Emotional, cognitive and psychological impact of stroke

Background and aims

Cognitive impairment is a frequent but often under-recognized complication after stroke, contributing substantially to long-term disability worldwide. Despite its clinical relevance, the actual prevalence of stroke-related cognitive dysfunction remains unknown. We aimed to assess the self-perceived prevalence of cognitive impairment among stroke survivors.

Method

Consecutive ischemic stroke patients enrolled in the TRUSTroke(Trustworthy AI for improvement of stroke Outcomes), European-granted project. Patients discharged home/rehabilitation-center were followed-up through NORA(app/phone-call) by a case manager(Occupational Therapist/Physiotherapist). A substudy was conducted across three participating hospitals focusing on cognitive complications identified through Post-Stroke Checklist (PSC).

Results

Over 8-month, 233 out of 420 patients completed the PSC at <70days post-discharge. 37.34% mentioned cognitive complications, having 58.62% of which difficulties in their daily life activities(ADLs). Besides, in Hospital1, the subgroup of patients with cognitive complaints compared with the overall series, showed a higher degree of stroke severity (median NIHSS2) and functional disability at discharge (median mRS2), and transfer to rehabilitation centers was more frequent($p<0.0005$). No differences on sex/age were detected. Importantly, the presence of anxious–depressive symptoms was strongly associated with cognitive impairment interfering with ADLs in this group($p<0.001$).

Conclusion

One-third of stroke survivors reported self-perceived cognitive impairment which has a direct grasp in their ADLs. PSC emerged to be a feasible first-screening tool for detecting cognitive complications in routine follow-up. Early identification through PSC may guide healthcare professionals in selecting patients for further neurocognitive assessment and targeted cognitive rehabilitation, ultimately promoting autonomy and participation in ADLs.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Cognitive dysfunction is one of the most frequent complications after stroke. Post-stroke checklist survey could be used as an appropriate secondary prevention screening tool for health professionals to improve patients management protocols after stroke.

12 - Qualitative study investigating living with post-stroke cognitive impairment and re-engaging with work and life participation.

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Category: Emotional, cognitive and psychological impact of stroke

Background and aims

Stroke occurrence in younger people is rising globally. Post-stroke cognitive impairment (PSCI) affects up to 60% of younger stroke survivors and negatively impacts quality of life, returning to work (RTW) and family roles. This study aimed to explore how PSCI impacts resumption of work and life participation in YSS including barriers and enablers.

Method

This exploratory qualitative study received ethical approval by the RCSI Research Ethics Committee and followed the Standards for Reporting Qualitative Research. A representative sample of working-age stroke survivors were recruited from the Irish Heart Foundation's younger stroke support network and participated in semi-structured interviews or focus groups depending on participant preference. Data was analysed using Braun and Clarke's six-stage reflexive thematic analysis. Methods to enhance rigour and credibility included PPI engagement, member checking, reflexivity, and peer-review.

Results

Thirteen participants completed interviews/focus groups, with <20% returning to work (RTW). Participants reported concentration, processing speed, executive dysfunction and memory deficits. Key barriers to RTW included invisible and persisting nature of PSCI by HCPs and employers, poor engagement between employer and stroke healthcare providers (HCP) and insufficient long-term support. A lack of a RTW protocol/pathway was highlighted. Financial strain and impact on relationships were additional negative consequences. Volunteering to determine RTW readiness and as a source of valued occupation was apparent.

Conclusion

PSCI negatively affects work and life outcomes. Findings highlight need for improved awareness and impact of PSCI among HCPs and employers and better long-term RTW support systems that are individualised to match employees' requirements.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research generates new knowledge and understanding of living with PSCI as a younger stroke survivor. It highlights the substantial negative impact and persisting nature of PSCI that may influence how healthcare

providers and employers take account of these impairments to optimise vocational and life participation outcomes for this population.

13 – Companionship and Communication: Why Pets Matter for People with Aphasia

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Category: Lifestyle (inc. self and personal care, domestic life, employment, economic self-sufficiency, diet and nutrition)

Background and aims

Not much is known about how people with aphasia experience pet ownership with regards to communicating with and about their pet. People with aphasia also experience reduced psycho-social well-being. Pets can facilitate independence and social interaction by providing emotional support and companionship, however, pets can also cause emotional distress because of the responsibility of care and physical risk. This study aims to explore the experiences of pet ownership for people with aphasia on well-being, pet care and human-pet relationships.

Method

A qualitative descriptive design was employed to produce meaningful research including co-design of questions with a person with aphasia. Semi-structured interviews with five PWA collected in-depth data, which was thematically analysed and mapped onto the International Classification of Functioning, Disability and Health (ICF) Framework to promote holistic and transferable findings. Various frameworks were implemented to ensure methodological rigour and prevent tokenism.

Results

Through inductive analysis, 106 codes were identified and organised into thirty categories, nine sub-themes and three themes, which were then mapped onto the domains of the ICF Framework.

Three primary themes were identified: Pet Care, Connection with Pets, and Connection with People. Mapping onto the ICF Framework emphasised pet impact across domains, and various facilitators and barriers at play.

Conclusion

This study contributes new knowledge on the experiences of pet ownership on psycho-social well-being for people with aphasia from which future research can build upon. The ultimate aim is to facilitate future development of best practice guidelines for healthcare professionals on supporting pet owners with aphasia in the rehabilitation process.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Research on pet ownership for people with aphasia can highlight benefits such as improved emotional well-being, social participation, and daily activity, empowering stroke survivors to live more fulfilling lives. Insights may also

guide rehabilitation strategies, foster independence, reduce isolation, and support healthier routines that contribute to secondary stroke prevention.

14 - Barriers and facilitators to participation for stroke survivors living in urban or rural communities

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Category: Lifestyle (inc. self and personal care, domestic life, employment, economic self-sufficiency, diet and nutrition)

Background and aims

The negative impact on social participation for stroke survivors is widely acknowledged. Rurality is known to impact access to healthcare. The correlation between place lived (urban or rural) and social participation is not well known for stroke survivors.

Aim: to identify the extent of studies which explore the impact on social participation for stroke survivors based on place lived. To identify the associated barriers and facilitators.

Method

A scoping review methodology was utilised. A comprehensive search was conducted identifying studies across five databases from date of inception - 4th April 2025. Subject headings and keyword search terms were used. Studies were selected by two reviewers.

Results

Eleven studies met the inclusion criteria offering an international perspective. Both barriers and facilitators were identified, linked to living place. Barriers to participation for both urban and rural dwellers included access to transport and difficult terrain.

Differences between rural and urban studies were also reported. Differences in facilitators included support from the local community (rural settings); and availability of facilities in close proximity (urban settings).

Some findings appeared culturally specific to the country/community in which the research was carried out.

Conclusion

Both barriers and facilitators to social participation were identified for rural and urban dwellers. There were common themes and differences.

Some of the findings from this review were common across a range of geographical contexts and could be applied to a UK context.

There is a need to explore the European context of impact of place lived on participation for stroke survivors.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

My clinical experience is with stroke survivors living in a coastal/rural community. I felt that this setting may be negatively impacting on participation, above what is already known about participation limitations. This review identifies gaps in research and considerations for stroke survivors, clinicians and policy makers.

15 - Improving follow-up care after minor stroke: a mixed-methods feasibility study investigating early, personalised follow-up care.

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Category: Lifestyle (inc. self and personal care, domestic life, employment, economic self-sufficiency, diet and nutrition)

Background and aims

Stroke is a major global health challenge, with one in four people predicted to experience a stroke in their lifetime. Up to half of all strokes are classified as 'minor', despite increased recurrence risk and hidden impairments affecting return to everyday roles and responsibilities. Many survivors' report unmet needs and limited follow-up care. This study aimed to develop and test the feasibility of a personalised intervention to address these gaps and unmet needs.

Method

The intervention was informed by extensive patient and public involvement, guided by self-determination theory, and developed using the MRC/NIHR framework for complex interventions. Follow-up appointments were delivered at 2- and 6-weeks post-discharge and provided tailored information, guidance, signposting, and referrals to support adjustment after stroke. Feasibility was evaluated using a pragmatic, explanatory sequential mixed-methods design. Qualitative interviews were analysed using a reflexive thematic approach.

Results

Sixty-two participants, broadly representative of the local stroke population, were recruited. Feasibility targets were achieved. The intervention was found to be acceptable and accessible. Participants experienced difficulties in completing some outcome measures, highlighting the need to review these for a future trial. Analysis of nineteen interviews generated three themes: (1) 'shock and the unknown' in hospital; (2) feeling 'adrift and in the dark' when first home; and (3) the value of 'being seen and heard', and contextual influences when trying to adjust to life after stroke.

Conclusion

A future multicentre trial of personalised, holistic follow-up care alongside routine services is feasible and warranted to better support minor stroke survivors.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This study lays the foundation for a future trial to test whether personalised follow-up improves stroke knowledge, quality of life, confidence in self-management, medication adherence and health outcomes. By addressing hidden needs after minor stroke, it aims to empower survivors, strengthen secondary prevention, and support meaningful recovery in daily life.

16 - Work After TIA: Engaging Stakeholders in the adaptation of the Make My Day Prevention Program

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Category: Lifestyle (inc. self and personal care, domestic life, employment, economic self-sufficiency, diet and nutrition)

Background and aims

Make My Day (MMD) is a multimodal interprofessional intervention using engaging everyday activities to support persons who have risk factors for stroke. Although the overall incidence of Transient Ischemic Attack (TIA) and stroke has decreased in high income countries, there is a concerning upward trend among younger adults. A TIA can impact individuals of working age and lead to a need for support in achieving a work-life balance that differs from those who have retired. The aim is to explore how stakeholders discuss experiences of persons with TIA in working age to develop resources for adapting the MMD intervention.

Method

A qualitative design with co-creation workshops was utilized to engage stakeholders in developing evidence-based resources for adapting the MMD intervention targeting primary healthcare. Qualitative data were analyzed using narrative and visual methods to enhance usability, delivery, and implementation strategies.

Results

Preliminary results show the need for redesigning the MMD intervention to include a module on return to work that addresses the following themes: work ability, work-life balance, and strategies to tackle barriers during return to work processes.

Conclusion

Failing to establish timely and sensitive ways to capture potential complications after a TIA can impact everyday activities. Support to the specific needs and challenges after a TIA in working age can be different than for older persons. Lessons learned from redesigning a stroke prevention intervention will be discussed.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research contributes with knowledge about working-age individuals following a TIA by promoting lifestyle changes, including the process of returning to work. By incorporating work-related components into the MMD stroke prevention program, we expect to enhance prevention efforts and encourage ongoing participation in meaningful and health-promoting activities.

17 - Leisure participation after stroke: A documentary analysis of online resources

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Category: Lifestyle (inc. self and personal care, domestic life, employment, economic self-sufficiency, diet and nutrition)

Background and aims

Two thirds of stroke survivors experience a reduction in valued leisure and social activities. This reduced participation is of concern because engagement in leisure activities has been shown to increase life expectancy and positively influence emotional well-being and sense of self. Yet this important aspect of life after stroke is often overlooked by professionals. This study explored currently and freely available online information that has been produced to guide stroke survivor re-engagement with leisure.

Method

Utilising documentary analysis methodology, and guided by stroke survivors, a systematic search was designed to retrieve information (available in the UK) relating to return to leisure participation after stroke. Online searches explored: charities, social media, libraries, health and social care organisations, and established clinical guidelines. Data were extracted into a piloted Excel spreadsheet. Documentary analysis was supported by NVivo 14.

Results

After removing duplicates, a total of 161 sources were analysed. Data were mainly from stroke survivors (155/161; 96%). Initial analysis led to 113 individual codes and revealed that most frequently reported information related to: activity adaptation and alternative leisure activities; the impact of fatigue; the importance of determination and motivation, support, and social connection.

Conclusion

This innovative approach highlights unique insights into online resources to support leisure participation post-stroke, specifically the amount of information and type of content. This, predominantly stroke survivor, perspective provides i) an overview of the available information and advice, and ii) a guide to locating post-stroke leisure engagement information. The findings will inform future studies to develop leisure participation interventions.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research provides a guide to locating post-stroke leisure engagement information and advice. The online information was predominantly stroke survivors sharing personal experiences with other stroke survivors. These unique insights into the amount and type of information available will support

post-stroke leisure participation and will inform future leisure interventions innovation.

From Voices to Action: A Women-Centred Toolkit for Parenting After Stroke

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Category: Lifestyle (inc. self and personal care, domestic life, employment, economic self-sufficiency, diet and nutrition)

Background and aims

Younger women recovering from stroke face unique challenges in balancing health, parenting, and family responsibilities. Despite this, educational resources remain generic and rarely address women's priorities in self-care and parenting. This study aimed to co-design, finalize, and evaluate an educational toolkit tailored to younger women's needs after stroke.

Method

Using a co-design framework, women with lived experience of stroke collaborated with researchers and clinicians in iterative working groups. The process included focus groups, content development, and design sessions. The finalized toolkit underwent evaluation using established readability, suitability, and actionability tools, alongside qualitative feedback from patient partners and health professionals.

Results

The toolkit integrates evidence-based lifestyle medicine strategies with peer-informed content on parenting, self-care, and navigating health and social systems. It is structured into six modules: (1) navigating stroke recovery, (2) mental health, (3) relationships and women's reproductive health, (4) menopause and stroke symptoms, (5) caring for children, and (6) managing finances. Key design features included women-centered visuals, plain language, and scenario-based activities. Evaluation showed high readability and suitability scores, with strong endorsement from participants who valued its practical focus, representation of women's voices, and family-centered approach.

Conclusion

Co-design produced a scalable intervention that reflects women's realities after stroke. The six-module toolkit supports recovery and parenting roles and has potential for integration into clinical practice and community services. Next steps include adapting the resource into a web-based, accessible, and translatable format to reach a wider audience of women and families worldwide.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This toolkit directly addresses younger women's recovery needs by combining parenting support with strategies for brain health. Centering women's voices ensures survivors feel validated, confident, and equipped with practical tools to balance family and self-care, improving quality of life after stroke.

18 - Informal caregivers: burden and quality of life after stroke - Online survey from German Stroke Foundation

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Category: Long term support (including carers and community support)

Background and aims

Like stroke survivors, informal caregivers face significant and long-lasting challenges following a stroke. Problems often arise when the patient is discharged from hospital and returns home. Further conflicts emerge in relation to the compatibility of work and family life (Damaiyanti et al. 2023, Jellema et al. 2019). The aim is to understand and improve the situation of informal caregivers.

Method

In collaboration with relatives and stroke survivors, we developed an online survey based on the Resilience and Stress Questionnaire (ResQ-Care) and the EQ-5D-5L to assess health-related quality of life (HRQoL). We supplemented the survey with additional topics relating to the situation of stroke survivors, usage of support services, family life, and work. Survey period: July–August 2025.

Results

393 responses were available for evaluation. The average age of informal caregivers was 58.9 years (SD=12.7). The majority were female (77.4%) and lived as partners (66.7%) with the stroke survivor in the same household (75.6%). 34.9% were retired, 29.0% worked full-time and 23.7% worked part-time. On average, 34.9 hours (SD=37.4) per week were spent on caregiving. The average length of caregiving was 5.8 years (SD=6.2). The average age of stroke survivors was 62.4 years (SD=19.6), predominantly male (63.3%), and had experienced their stroke an average of 6.2 years earlier (SD=7.4). HRQoL evaluations for informal caregivers in comparison with the reference values for the German population will be available for the congress.

Conclusion

The survey confirms the significant burden placed on informal caregivers in Germany and the difficulties of balancing work, family life and caregiving.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

The German Stroke Foundation will use the results to raise awareness for the burden of stroke and reduce deficits in support service usage by providing information. Understanding the needs of informal caregivers when it comes to balancing work, family life and caregiving is essential for long-term care of stroke survivors.

19 - A Scoping Review of Instruments Measuring Social Support and Collective Efficacy in Post-Stroke Rehabilitation

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Category: Long term support (including carers and community support)

Background and aims

As stroke rehabilitation increasingly shifts to the home settings, the role of social networks in supporting self-management has become more prominent. However, the scope of available instruments for measuring social support and collective efficacy has not been examined in depth, limiting the development of effective, evidence-based interventions.

Aims: This study aims to identify instruments that assess social support and collective efficacy among stroke survivors and adults with long-term conditions, as well as to map their reported quality and validation aspects.

Method

A scoping review following PRISMA-ScR guidelines is being conducted. Searches in CINAHL, Embase, and PubMed/MEDLINE identified 4,631 articles; after removal of duplicates, 4,121 abstracts were screened, resulting in 128 articles considered primarily relevant for full-text review. Of these, 46 has been selected for data extraction, which will be conducted in Covidence. Instruments will also be mapped with reference to the COSMIN framework.

Results

Preliminary findings identified 21 instruments with varying psychometric quality and relevance for stroke and other long-term conditions. Only one instrument specifically measured collective efficacy. Social support was assessed either through dedicated tools or via limited items within broader instruments. Data extraction and COSMIN mapping are ongoing.

Conclusion

This review will provide a comprehensive overview of instruments assessing social support and collective efficacy, identifying the most reliable tools to inform interventions that integrate social network perspectives into post-stroke rehabilitation.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This study identifies reliable tools to measure social support in stroke survivors. By guiding clinicians and researchers in selecting appropriate instruments, it enables more tailored self-management interventions, ultimately improving recovery, independence, and quality of life for individuals managing life after stroke.

20 - Understanding caregiver burden in life after stroke: A holistic systematic review

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Category: Long term support (including carers and community support)

Background and aims

Caring for stroke survivors often places a significant emotional, physical, social, and financial strain on informal caregivers. This burden can reduce quality of life and affect recovery outcomes for stroke survivors. The present study systematically reviewed recent evidence to describe the main domains of caregiver burden and highlight factors contributing to distress. The aim was to provide a holistic understanding of caregiver challenges to inform better post-stroke rehabilitation and community support.

Method

Following PRISMA guidelines, a systematic search of PubMed and Scopus identified peer-reviewed studies published between 2018 and 2023. Eligible studies included adult informal caregivers of stroke survivors. Data extraction focused on study characteristics, burden assessment tools, and the main findings related to emotional, physical, social, and financial impact. Study quality was appraised using the Newcastle–Ottawa Scale, and findings were synthesised narratively.

Results

Thirty-four studies from 18 countries met inclusion criteria, encompassing 4,068 caregivers. Caregivers frequently reported fatigue, sleep problems, and musculoskeletal pain. Emotional distress, particularly anxiety and depression, was prevalent and associated with stroke severity and limited social support. Financial strain and loss of employment further intensified the burden. Cultural and contextual factors shaped caregiver experiences, revealing inequities in access to support and rehabilitation resources.

Conclusion

Caregiver burden after stroke is multidimensional and persistent. Targeted interventions that integrate psychological counselling, peer support, and respite services are essential to sustain caregivers' wellbeing and promote stroke survivors' recovery.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research highlights the urgent need to support informal caregivers through tailored psychological, social, and practical interventions. Improving caregiver wellbeing enhances care quality, reduces burnout, and ultimately promotes better rehabilitation and community reintegration outcomes for stroke survivors.

21 - The role of social networks in older people's self-management after stroke

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Category: Long term support (including carers and community support)

Background and aims

Social support plays a crucial role for most people after stroke, and the involvement of close family members in the self-management process has been widely acknowledged in the literature. However, self-management can be seen as a process influenced by numerous individual, social and environmental factors, involving various places and people beyond close family members. This study uses a people-place-mapping method to explore how the extended social networks and meaningful places contribute to older people's self-management after stroke.

Method

Semi-structured qualitative interviews combined with a people-place-mapping exercise are being conducted with 15 community-dwelling stroke survivors aged 65 years and older. During the interviews, the meaningful people and places are illustrated on a physical board consisting of three concentric circles, representing their importance for self-management. The data will be analysed with thematic analysis and presented with illustrative quotations and participant-generated maps.

Results

This study will broaden the understanding of self-management support to older people with stroke; it will explore the support from the entire social network and the various kinds of support it provides. In addition, it will outline the characteristics of places that play a role in self-management.

Conclusion

The knowledge can contribute to a broader approach to self-management support that recognises the stroke survivors in their social and environmental context.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research will benefit stroke survivors' lives by highlighting the role of wide-ranging support and the social and environmental factors that influence self-management. This can inform health services to develop robust support structures inclusive to all people with stroke, which is of importance when rehabilitation takes place in the home.

22 - Post Stroke Unmet Need in the Community: Results of a Novel Interdisciplinary Clinic

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Category: Long term support (including carers and community support)

Background and aims

In 2023 a novel interdisciplinary clinic was created in an Irish stroke centre, led by a stroke specialist physiotherapist, speech and language therapist and Advanced Nurse Practitioner. A structured review is provided to all stroke survivors at 6 months post discharge, using the Greater Manchester Stroke Assessment Tool. Where required, survivors with rehabilitative needs are enrolled in a time-limited course of outpatient rehabilitation. A 'rapid review' service is also available for high-risk patients, providing semi-urgent outpatient assessment.

Method

Demographic data, the Greater Manchester Stroke Assessment Tool, and onward referrals were collected on all patients seen in the interdisciplinary clinic between 14/03/2023 and 01/09/2025.

Results

The interdisciplinary clinic reviewed 519 patients between 14/03/2023 and 01/09/2025, 35 of which were for non-stroke admissions. Of the 476 patients reviewed post stroke, 417 of these reviews took place at approximately 6 months post stroke; 68 were urgent reviews for patients felt to be at high risk of readmission, and occurred between 6 weeks and 22 years post index stroke.

At 6 months post-discharge, 391 (93.8%) of patients reported at least one unmet need in the community. The median number of unmet needs was 5 (IQR 2-7). The commonest unmet needs were fatigue (52.8%), not exercising regularly (44.6%) and pain (38.4%). Physiotherapy input was needed in 23.8%; speech and language therapy in 13.0%, general practitioner in 19.2% and dietetics in 17.1%.

Conclusion

This clinic identifies higher levels of unmet need in this cohort than in previous studies, in particular significantly higher levels of pain (Rothwell et al, 2012).

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

The interdisciplinary clinic enables immediate referral to specialist outpatient rehabilitation where unmet rehabilitative needs are identified. The provision of a therapist-led six-month review clinic may ameliorate unmet need in the chronic phase of stroke.

Mapping Stroke Services for stroke patients and their families: Creation of a National Protocol

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Category: Long term support (including carers and community support)

Background and aims

The National Clinical Programme for Stroke in Ireland aims to provide access to ongoing support across the entire continuum of care from primary prevention to life after stroke across Ireland. However, currently stroke survivors and families are often unaware of stroke support services and how to access them. This study aims to identify and map (i) stroke specific community-based services available in the six counties of Munster, Ireland, (ii) barriers, facilitators and gaps in service provision from the perspectives of stroke survivors, families, and healthcare professionals.

Method

A multi-phase approach to data collection was taken to help minimise gaps in service identification – direct contact with organisations, engagement with stroke survivors, families, and Healthcare Professionals. Systematic internet searches, including grey literature, and an online survey completion by identified stroke organisations captured the breadth of available services. PPI consultations, interviews with healthcare professionals, and stakeholder workshops ensured patient-centred relevance, validated findings, and gained expert insights into service provision gaps.

Results

Twenty-four Healthcare Professionals participated in interview/focus groups. Nine stroke survivors and six spouses took part in workshops/focus groups. A total of 29 organisations/volunteers that provide stroke support services in Munster were identified; five provide services in more than one county and five services are online. Seven organisations provide support to caregivers. No services that provide support for children of stroke survivors were identified.

Conclusion

Locating stroke service information required extensive searching and correspondence. This would be challenging for stroke survivors/families. More support is needed for caregivers and children.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This stroke service mapping document provides a 'one-stop-shop' of support services for stroke survivors and their families. This multi-phase approach may be a useful template for other countries to map out service for stroke which would be an invaluable guide for stroke survivors and families.

24 - Needs and challenges experienced by young people with stroke in Belgium: single center needs assessment

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Category: Long term support (including carers and community support)

Background and aims

Despite the prevailing misconception that strokes predominantly affect older populations, over 16% of stroke victims in Belgium are aged between 15 and 50, adding at least seven young stroke patients daily.

This study aims to identify the unmet needs of Belgian patients with stroke aged 18-55 in order to develop a tailored care pathway that addresses these specific needs.

Method

Participants, who had experienced a stroke of any type more than four months prior, were recruited from the outpatient stroke clinic of Antwerp University Hospital. Semi-structured interviews were conducted either face-to-face or remotely via Zoom, focusing on the lived experiences, unmet needs, and aspirations of the participants. The interviews were transcribed verbatim and analyzed using inductive thematic analysis.

Results

We conducted interviews with 20 stroke survivors (female 55%) with a mean age of 44 years at stroke onset and mean time since stroke of 37.5 months. Stroke types included: ischemic (13), hemorrhagic (1), subarachnoid hemorrhage (6) and cerebral venous thrombosis (1). The median modified Rankin scale score was 1.5.

Preliminary thematic analysis identified key challenges: (1) Lack of age-specific information about stroke; (2) Impact of invisible disability like fatigue; (3) Limited (access to) psychological support; (4) Limited support for returning to work.

Conclusion

This needs assessment will contribute to the development of a tailored care pathway that aligns with the recovery goals and age-specific needs of young people with stroke in Belgium.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This needs assessment will contribute to the development of a tailored care pathway that aligns with the recovery goals and age-specific needs of young people with stroke in Belgium.

25 - Facial Palsy after Stroke: First Step in Defining What Matters

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Category: Other (if other, describe your submission category)

* First step towards developing a Core Outcome Set for post-stroke facial paralysis

Background and aims

Facial palsy affects 45-60% of acute stroke patients, significantly impacting physical function, communication, and quality of life. Many different outcome measures are used in research and clinical practice, making it difficult to synthesise evidence and establish treatment effectiveness. We need a Core Outcome Set (COS). This study's aim was to complete step one - an international consensus on professionals' views of what should be measured.

Method

Two rounds of online Delphi surveys and a meeting were completed by international clinicians and researchers. Outcomes were rated for importance on a 1–9 GRADE scale. Pre-specified thresholds informed inclusion ($\geq 70\%$ rated 7–9= “critical”; $\geq 70\%$ voted “yes” at the meeting).

Results

In Round 1, 35 outcomes were rated by 60 clinicians and 41 researchers from 16 countries; 28 outcomes met the inclusion threshold. In round 2, 29 clinicians and 26 researchers from 12 countries, evaluated 32 outcomes, 26 were retained. At the consensus meeting (6 clinicians, 9 researchers from 6 countries), 23 outcomes were agreed upon and grouped into three domains: facial movement and sensation; everyday function (communication, eating, drinking, swallowing); and living with facial palsy.

Conclusion

Step 1 of this internationally informed COS indicates what professionals agree should be measured for post-stroke facial palsy; supporting standardised reporting, reduced heterogeneity and outcome reporting bias, and improved evidence synthesis. Step 2 is to include the views of those living with post-stroke facial palsy, before selecting measurement instruments and defining assessment timing to optimise feasibility and global uptake.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This is a step towards a Core Outcome Set, to ensure research consistently measures outcomes vital to stroke survivors with facial palsy. Standardised reporting will reduce wasted effort, improve treatment comparisons, and accelerate the development of effective, patient-centred rehabilitation. Ultimately, this will enhance recovery and quality of life after stroke.

26 - Unscheduled Hospital Readmissions in the 18 Months Following Stroke Discharge: a Retrospective Cohort Study.

*Dr Elizabeth Murphy, Ms Rachel Walsh, Ms Gillian Harte, Ms Susan Lawson, Dr Derek Hayden, Dr Dan Ryan, Ms Helen Hobson
Tallaght University Hospital, Dublin, Ireland*

Category: Other (if other, describe your submission category)

Medical complications following stroke survival

Background and aims

Stroke survivors are at risk of unscheduled hospital readmission in the months and years following stroke for reasons such as falls, fractures, aspiration pneumonias, seizures, cardiovascular disease and adverse medication events (Kumar, Selim and Kaplan, 2010).

Method

All live stroke discharges from a single Irish stroke centre between 01/07/2017 and 31/12/2018, and between 01/03/2022 and 28/02/2023, were followed for a period of 18 months to identify any unscheduled hospital readmissions. Because the COVID-19 pandemic altered hospital admission patterns significantly, this period of time was excluded. Data on the index stroke admission, aetiology, resultant disability, medical history and medication, as well as cause and duration of readmission, was collected retrospectively.

Results

In total, 591 patients were discharged following a stroke during the period of data collection and 213 (36.0%) had at least one unscheduled readmission in the 18 months post discharge, totalling 366 readmission events. Factors associated with readmission included age (71.6 vs 67.7, $p=0.001$), post stroke disability (MRS ≤ 2 in 57.1% vs 67.3%, $p=0.015$), polypharmacy (48.8% vs 32.9%, $p=0.012$), chronic kidney disease (17.2% vs 8.0%, $p=0.0017$), diabetes mellitus (29.8% vs 17.6%, $p=0.0011$), mild cognitive impairment (5.6% vs 1.8%, $p=0.032$), a history of pneumonia (14.6% vs 2.9%, $p<0.001$), and inpatient rehabilitation on discharge (16.3% vs 9.4%, $p=0.02$). The commonest causes of readmission were pneumonia (20.4%), recurrent stroke (13.9%) and falls (12.0%).

Conclusion

Our study confirmed high rates of unscheduled readmission in the 18 months following live stroke discharge. Risk factors such as polypharmacy and history of pneumonia pre-stroke have not previously been explored.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

In the Dijon Stroke Registry population, rehospitalisation was negatively associated with being alive at one year (OR 0.66), and hospitalisation is associated with worse outcomes and poorer quality of life. Enabling earlier

identification of patients at high risk of readmission may allow intervention to ameliorate the risk of hospital readmission.

27 - ARYAS (Accessible Resources for Young Adults with Stroke) Erasmus+ Project: Co-Creating Accessible Resources Across Europe

Dr Marina Charalambous

Cyprus University of Technology, Limassol, Cyprus

Category: Patient and public involvement (including policy, guidelines, research development and advocacy)

Background and aims

Young people with stroke (YPwS) face distinct challenges due to their life stage, including employment, parenting, and social participation. Despite a predicted 43.8% increase in strokes among 25–44-year-olds in Europe by 2047, few resources meet their age-specific, accessible, and communication-inclusive needs. The ARYAS project (Accessible Resources for Young Adults with Stroke) aims to co-develop digital and print resources with YPwS and aphasia across five European countries (Cyprus, Denmark, Hungary, Spain, and Portugal) to support self-management, chronic rehabilitation, and social reintegration.

Method

The ARYAS project uses a structured Patient and Public Involvement approach, guided by the PAOLI framework, to engage young people with stroke and aphasia, caregivers, and healthcare professionals in co-design groups across Europe. These groups combine lived and clinical expertise to develop targeted, aphasia-accessible resources, including a website, an application, videos, podcasts, and printed materials, to support chronic rehabilitation and self-management. All outputs are evaluated for accessibility and relevance by end-users. Resources will be placed in clinical and social settings.

Results

Co-design groups launched in the five European countries fostering peer support and empowering participants to shape content. Early prototypes of the website and digital materials show high engagement and accessibility. Clinical partners report increased awareness among healthcare staff regarding YPwS needs.

Conclusion

ARYAS addresses a critical gap in post-stroke care by placing young survivors at the centre of resource development. By co-creating accessible, age-appropriate materials and embedding them into real-world settings, the project empowers survivors to reclaim control over their recovery and everyday life.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

ARYAS empowers young people with stroke to actively manage their condition and improves their communication with caregivers and health

professionals, supporting more person-centered care. By encouraging peer connection and life reintegration, ARYAS aims to raise awareness and enhance long-term quality of life for young survivors across Europe.

28 - Experiences and perceptions of using a digital health intervention

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Category: Patient and public involvement (including policy, guidelines, research development and advocacy)

Background and aims

Technology-based solutions for healthcare specialities and rehabilitation have become favourable worldwide. However, we need to find out whether and how it is going to help patients. One innovation in healthcare is to change outpatient care using technology so that patients can be seen, diagnosed and managed with fewer hospital visits. The aim of this study was to explore public and patient experiences and perceptions of engaging or choosing not to engage with using Virtual Healthcare Platforms (including Virtual Lucy) for medical treatment.

Method

A qualitative approach was adopted. Eleven (n=11) participants were recruited from the Stroke Hub Wales (SHW) and Health Business Solutions Virtual Lucy research databases. Semi-structured interviews were conducted, and the verbatim transcriptions were analysed using reflective thematic analysis according to Braun and Clarke (2006).

Results

Pseudonyms were assigned to each participant with any identifiable information removed. Thematic analysis was conducted to evaluate participant experiences, perspectives, views, impact of, and to identify themes when using digital health interventions. Two preliminary main themes were identified: (1) Virtual Healthcare Technology: an enabler versus a barrier and (2) Healthcare technology the way forward: the provider.

Conclusion

Most participants embraced and acknowledged the use of technology (virtual consultations) for their healthcare, which provided a sense of efficiency, saved time, reduced stigma and was private and Impactful on healthcare. . The research presented here also offers insight into recognising the limitations of digital healthcare and persons who may not have access to supportive technologies and may have issues with digital literacy.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This project adds to the growing body of evidence in support of digital healthcare interventions for chronic conditions, including stroke rehabilitation from patient experiences and perspectives. It provides an underpinning for improvement to online offerings for future healthcare and rehabilitation.

29 - Patient involvement in German stroke Research – A survey of health care professionals and scientists

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Category: Patient and public involvement (including policy, guidelines, research development and advocacy)

Background and aims

To achieve meaningful clinical results that are also relevant to physicians' management decisions, it is becoming increasingly important to involve people with lived experience (PWLE) in stroke research. Germany is not as advanced as other countries in this respect. This study surveyed scientists to assess their experiences of and attitudes towards patient and public involvement (PPI) in German stroke research.

Method

We developed a questionnaire based on literature about PPI, and on our experiences as a patient organization that collaborates with scientists on research projects. The online survey was sent to over 300 contacts, including neurologists and other scientists, between 8 July and 5 August 2025.

Results

A total of 73 respondents completed the questionnaire, most of them male (69%). The majority work in a hospital as a physician, primarily in neurology. Only 8% responded that patients are already sufficiently involved in German stroke research. 33% of respondents stated that patients with stroke are more difficult to involve than those with other neurological diseases. Nevertheless, the advantages of PPI are clear and are also recognized by the respondents. The most frequently cited advantages were a stronger focus on patient needs (73%) or a better understanding of the target population (60%).

Conclusion

The involvement of PWLE in research is of the utmost importance. However, there are still some hurdles to overcome, particularly in relation to physical and cognitive impairments of PWLE, and the lack of financial compensation for PPI. Researchers should recognize the benefits that involving PWLE will have for their research.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

As a patient organization, we strive to overcome the barriers to PPI and act as patient advocates in collaborations with scientists. Our goal is to advocate for people with lived experience and improve the German healthcare system by raising awareness of PPI in stroke research.

30 - The relationship between personality and post-stroke functional outcomes: a systematic review

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Category: Rehabilitation in life after stroke

Background and aims

Factors such as age and stroke severity are commonly used to predict post-stroke functional outcomes and tailor stroke rehabilitation therapy. However, the role of personality in stroke rehabilitation and its influence on functional outcomes is unclear. This review aims to assess whether an association exists between personality and post-stroke functional outcomes.

Method

We searched Medline, AMED, APA PsychINFO, CENTRAL, CINAHL, and Scopus for studies published between database inception and October 22, 2024. Studies were included if they recruited adults with stroke, used a validated method to assess personality and post-stroke functional outcomes, and were published in a peer-reviewed journal.

Results

Five studies were identified (n=424): four cohort and one cross-sectional. There were no major concerns regarding risk of bias. Methods of assessing personality and post-stroke functional outcome both varied, with Eysenck's Personality Questionnaire and Barthel Index being the most frequently used. Extroversion, openness, and lie-tendency were associated with improved post-stroke functional outcomes, whilst Type D personality was negatively associated with post-stroke functional outcomes.

Conclusion

There is some evidence for an association between personality and post-stroke functional outcomes, but this is limited by the small number of relevant studies and small sample sizes. Further studies are needed to investigate this potential relationship which may provide valuable insight into the role of personality in stroke rehabilitation and facilitate greater individualisation of stroke rehabilitation programmes.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research identifies a potential relationship between personality and post-stroke functional outcomes, but the body of research is small. By highlighting this, we hope that further studies are conducted which may provide further

insight into this relationship and facilitate risk stratification and tailored rehabilitation informed by personality.

31 - Embedding Self-Management Support in Stroke Rehabilitation: A Process Evaluation of the Bridges Programme in Sweden

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Category: Rehabilitation in life after stroke

Background and aims

Background: Person-centred care and self-management support are widely advocated in stroke rehabilitation, yet their integration into routine practice remains inconsistent. Bridges is a UK-developed SMS programme designed to support healthcare professionals in enabling patient self-management. This study aimed to evaluate the implementation of Bridges in two Swedish stroke care settings.

Method

A process evaluation was conducted as part of a larger project using a case study design. The evaluation was guided by the Medical Research Council (MRC) process evaluation framework and Normalization Process Theory (NPT). Data included staff and patient interviews, structured observations, training fieldnotes, and questionnaire data (S-NoMAD, SSEQ). Thematic and content analyses were mapped deductively to MRC components (context, implementation, mechanisms, outcomes) and NPT constructs.

Results

Twenty-two staff members and forty-six stroke patients participated. Staff reported increased awareness of SMS, more reflective and collaborative interactions with patients, and renewed professional purpose. However, integration into daily practice varied by site and was influenced by contextual factors such as leadership stability, team continuity, and resource availability. S-NoMAD responses showed moderate engagement but highlighted barriers in collective action and sustainability. Patient-reported self-efficacy (SSEQ) remained largely unchanged. Patients generally associated SMS with functional recovery but reported limited involvement in care decisions.

Conclusion

The Bridges programme prompted changes in staff attitudes and practice related to SMS, supported by mechanisms such as professional reflection,

tool adoption, and peer dialogue. However, organizational and cultural conditions were critical to whether these changes became embedded. Embedding SMS requires, besides training, strategic alignment with context and sustained team-wide engagement.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

By learning more on how self-management support is embedded in everyday care, the Bridges programme may improve healthcare professionals in working more collaboratively with patients, fostering confidence, independence, and engagement in rehabilitation. Over time, this may empower people to better manage life after stroke.

32 - Individual and Environmental Predictors of Community Ambulation Among Stroke Survivors in Nigeria: A Mixed-Methods Analysis.

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Category: Rehabilitation in life after stroke

Please describe your submission category, if you have selected other above

This submission focuses on identifying physical, psychological, and environmental factors influencing community ambulation after stroke, which is central to post-stroke rehabilitation and functional recovery in daily life.

Background and aims

Restoring community ambulation is a central goal of post-stroke rehabilitation, yet many survivors remain restricted to household mobility, particularly in low-resource settings. While impairments in physical and psychological factors are known contributors, the interplay between these and contextual factors is poorly characterized in sub-Saharan Africa. This study investigated the individual and environmental predictors of community ambulation among stroke survivors in Nigeria.

Method

A convergent mixed-methods design was employed. Quantitatively, 85 stroke survivors (60.76 ± 11.20 years) were assessed using validated measures: balance (Berg Balance Scale), gait endurance (6-Minute Walk Test), fear of falling (FES-I), depression (PHQ-9), confidence (ABC scale), cognition (MoCA), muscle strength (Oxford MRC Scale), and a self-developed environmental questionnaire. Independent t-tests and chi-square tests examined associations between factors and community ambulation, while multivariable logistic regression identified independent predictors ($p < 0.05$). Qualitatively, focus group discussions explored barriers and facilitators to community ambulation, with data thematically analyzed.

Results

Quantitative analysis revealed that balance, muscle strength, endurance, psychological confidence, fear of falling, depression, cognition, and environmental factors (uneven surfaces, crowded areas, stair climbing, walking aids) were significantly associated with ambulation (all $p < 0.05$). Multivariable logistic regression confirmed muscle strength (OR = 7.99, $p = 0.010$), and fear of falling (OR = 0.83, $p = 0.006$) as independent predictors. Qualitative findings highlighted physical, psychosocial, environmental, and systemic factors as key barriers and facilitators.

Conclusion

Community ambulation among Nigerian stroke survivors is determined by physical, psychological, and environmental factors. Rehabilitation should integrate muscle strengthening and fear-of-falling interventions with strategies addressing confidence and contextual barriers.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research equips clinicians and policymakers with evidence to design rehabilitation that combines muscle strengthening, balance training, and fear-of-falling interventions with environmental and psychosocial support. By addressing both individual impairments and contextual barriers, it enhances survivors' capacity for safe community ambulation, restoring independence, participation, and quality of life after stroke.

33 - Language Rehabilitation in Chronic Aphasia: The Role of TMS Paradigms

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Category: Rehabilitation in life after stroke

Background and aims

To enhance language recovery in chronic aphasia, non-invasive brain stimulation techniques are being explored as adjuncts to speech and language therapy. The aim is to investigate the effectiveness of two paradigms of neuronavigated repetitive Transcranial Magnetic Stimulation (rTMS): i) 1 Hz rTMS and ii) continuous Theta Burst Stimulation (cTBS) each as a standalone treatment for chronic aphasia post-stroke.

Method

A single subject experimental design trial was carried out with six people with aphasia. Three individuals were treated with 1 Hz rTMS and the remaining three were treated with cTBS. In all cases, TMS was applied over the right pars Triangularis (pTr). Language assessment, with standardized and functional measures, and cognitive evaluations were carried out at four time points: twice prior to treatment (baseline), one day immediately post-treatment and at follow-up two months after treatment was terminated. Quality of life (QoL) was also assessed at baseline and two months post-treatment. In addition, one of the participants with severe global aphasia, was followed up again one and two years post-treatment.

Results

Both rTMS paradigms (1 Hz rTMS & cTBS) generated trends towards improvement in several language domains (i.e. verbal comprehension, expressive language, naming and reading) in the short- (one day post-treatment) and/or long-term (two months post-treatment). Rated quality of life (QoL) did not change as a result of the treatment for three participants.

Conclusion

It was concluded that inhibitory TMS over the right pTr, as a standalone treatment, has the potential to drive neuroplastic changes that facilitate language recovery in aphasia post-stroke

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Research on non-invasive brain stimulation could enhance stroke recovery by improving motor, cognitive, and speech functions, offering hope for better quality of life. It may also aid secondary prevention by promoting neural plasticity, reducing risk factors, and personalizing rehabilitation strategies, ultimately supporting independence and long-term brain health after stroke.

34 - Patients' experiences of an active training programme to prevent or relieve shoulder pain after stroke

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Category: Rehabilitation in life after stroke

Background and aims

Post-stroke shoulder pain occurs frequently and has mostly been addressed by passive measures against the symptom pain.

Aim: To examine patients' experiences of active training using gravity as one tool, instead of passive assisting aids, to prevent or relieve shoulder pain after stroke, in hospital with coaching from assistant nurses and during self-training at home after discharge.

Method

A feasibility study with an exploratory design, using a qualitative approach. Five stroke patients were recruited and followed for six months. The patients practiced a training programme, inspired by the Vasa Concept, where gravity is used as a tool, in different positions, to trigger muscular activity around the shoulder. Five interviews per patient were carried out with a semi-structured interview guide to examine experiences of training over time. Qualitative content analysis was used to analyse data in two rounds, from the hospital stay and from self-training at home.

Results

Six themes per round emerged. There was a wide spread of experiences of the training. Positive biopsychosocial effects and trust towards the exercises and staff were experienced. The traditional roles of assistant nurses as well as pain and fatigue were barriers to carrying out the training. Frequent support was requested when training was done at home.

Conclusion

Active training to prevent or relieve shoulder pain post-stroke was found to improve biopsychosocial well-being, both in hospital and in home environments. Further research is required to investigate how training can be optimized regarding the assistant nurses' potential role as coaches and factors that facilitate improved empowerment for self-training.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Post-stroke shoulder pain occurs frequently and causes great suffering for those affected. The studied training approach targets the underlying causes to shoulder pain, not only the symptom pain. The patients experienced biopsychosocial gains. However, a larger study is warranted in order to be able to draw more reliable conclusions.

35 - Clinical nurse specialists addressing unmet needs in life after stroke: A qualitative study

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Category: Rehabilitation in life after stroke

Background and aims

Stroke survivors, caregivers, and health professionals continue to face challenges beyond acute treatment. Unmet needs include communication barriers, limited rehabilitation, and psychosocial strain. Caregivers often experience stress and lack of training, while nurses report moral distress linked to resource gaps. This study explored these unmet needs and examined how clinical nurse specialists (CNSs), as advanced practice nurses (APNs), can strengthen person-centred long-term support.

Method

An exploratory qualitative design was applied. Semi-structured interviews were conducted with stroke patients with multiple deficits (n=4), relatives (n=4), and neurology/stroke nurses (n=4). Interviews were analysed using Kuckartz's content analysis framework to identify common themes across groups.

Results

Three categories emerged: communication barriers, insufficient structural resources, and lack of person-centred care. Patients reported uncertainty and inadequate follow-up after discharge. Relatives described emotional strain, isolation, and lack of training. Nurses highlighted moral stress related to unmet needs and limited resources. Across all groups, CNSs were recognised as key in bridging gaps through direct clinical expertise, caregiver coaching, interdisciplinary leadership, and psychosocial support.

Conclusion

Unmet needs persist after stroke, affecting patients, caregivers, and professionals. CNSs are uniquely positioned to improve continuity of care, empower survivors, and reduce caregiver burden. Embedding CNS roles into stroke pathways could enhance rehabilitation and long-term outcomes.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research shows how CNS-led care strengthens long-term support, improves quality of life for survivors, and reduces caregiver stress, offering scalable models for European stroke services.

36 - Physical Activity as a Double-Edged Sword: Experiences Among Individuals with Post-Stroke Fatigue

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Category: Rehabilitation in life after stroke

Background and aims

Post-stroke fatigue evidently entails burdensome symptoms and research is scarce. In this project, we aimed to explore how individuals living with post-stroke fatigue experience physical activity and exercise.

Method

In this qualitative and explorative study, twenty individuals participated. To describe participants, personal and sociodemographic characteristics were collected. Individual interviews were conducted, and data were analysed according to reflexive thematic analysis.

Results

Participants' mean age were 58 years, 48 % females and 44% had suffered from ischemic stroke. From the preliminary analyses, **one** overarching theme was created: **Physical activity as a double-edged sword**, signifying the double-sided nature of being physically active, its potential health effects, including fatigue-relieving effects, versus the requirement of rigorous adaptations and sacrifices necessary.

Under this umbrella, three themes were constructed. First, **Physical activity is a high-stake game** contains experiences of post-stroke fatigue, the requirement of support from family, friends and society and the constant trade-off between the choice to be physically active and the social, physical and psychological compromises necessary. Secondly, **Loss of identity**, includes experiences of shame and discomfort associated with knowing the health benefits of physical activity and desiring to be physically active, while being unable to do so due to fatigue. Third, **Environmental factors and perceived effects** contain descriptions of under which conditions physical activity may positively affect fatigue, as well as hindering and facilitating factors.

Conclusion

Post-stroke fatigue shapes physical activity as a double-edged experience, where the potential health benefits and relief of fatigue symptoms are counterbalanced by the strain that the physical activity entails.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

These findings can inform stroke survivors as well as health professionals by enhancing the understanding of post-stroke fatigue, thereby enabling more nuanced and empathetic engagement with individuals affected by it. Additionally, the insights may contribute to the development of more tailored and effective interventions for post-stroke fatigue.

37 - Simplifying the Post-stroke Spasticity Monitoring Questionnaire for remote monitoring to reduce patient and caregiver burden

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Category: Rehabilitation in life after stroke

Background and aims

The EPITOME study (NCT06055725) follows stroke survivors with paresis (muscle weakness) to see how many develop problematic spasticity (muscle stiffness) that may benefit from medication within a year of their stroke. The study uses a tool called the Post-Stroke Spasticity Monitoring Questionnaire (PSMQ) to screen for spasticity development. Using data from people already in the study, we evaluated how well the PSMQ predicts spasticity and explored simplifying the tool to reduce patient burden.

Method

Stroke survivors (aged 18-85y) joined within 4 weeks of their first stroke and completed the full 13-item PSMQ at defined intervals. If the PSMQ indicates the possible presence of spasticity (PSMQ score ≥ 2), participants have an in-clinic confirmatory assessment; participants without clinically-confirmed spasticity return to monitoring. For this analysis, all participants attended a clinic visit regardless of PSMQ score. We analysed which PSMQ questions best predicted spasticity.

Results

Of 151 study participants included in this analysis, 99 (65.6%) had a PSMQ score of ≥ 2 , and 69 (45.7%) developed confirmed spasticity. The PSMQ showed 81% sensitivity (it could correctly identify 81% of participants with PSS) but only 48% specificity (i.e. high [52%] rate of false positives). Analysis showed that using just questions 1 and 2 (about stiffness and difficulty moving the limb) gave slightly improved results to the full questionnaire, with less burden.

Conclusion

Nearly half of stroke survivors with paresis developed spasticity within a year. The simplified tool using only two questions will be used in the study to improve monitoring while reducing burden for patients.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Because stroke affects many people, long-term follow-up is costly. The study uses the PSMQ to remotely detect early signs of spasticity. Simplifying the PSMQ improves accuracy and reduces questionnaire burden on stroke survivors and their caregivers. This may help overcome the budgetary and logistic barriers to post-stroke spasticity monitoring.

Effectiveness of abobotulinumtoxinA in stroke survivors with lower limb spasticity

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Category: Rehabilitation in life after stroke

Background and aims

Spasticity affects up to 40% of stroke survivors and can make walking difficult or cause pain. This study looked at how well repeated injections of abobotulinumtoxinA (aboBoNT-A) helped people with leg spasticity reach their personal treatment goals over time.

Method

The AboLiSh study (NCT04050527) followed adult stroke survivors who received at least one injection cycle of botulinum toxin for leg spasticity over a 16-month period. One way to assess treatment success is by evaluating whether specific goals (e.g. improved walking), set jointly by stroke survivors and their clinicians, are achieved. This involves defining the expected outcomes before treatment begins and then measuring progress using a method called Goal Attainment Scaling (GAS). A GAS T score of 50 means that the person has achieved their goals as expected.

Results

Of 328 stroke survivors included in the analysis, most received 600 units of aboBoNT-A [range 100-1400 units], in four leg muscles. Overall, 64% were also treated for arm spasticity. Goals were met as expected with repeated treatment. After 16 months, the mean GAS-leg score was 48.2 [95%CI 47.5, 49.0], with a median of 50. The mean improvement was 9.9 points [9.1, 10.7] (median of 10), indicating meaningful progress.

Conclusion

This long-term study shows that repeated aboBoNT-A injections help stroke survivors with leg spasticity achieve their functional treatment goals.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Results show that treating leg spasticity with abobotulinumtoxinA is effective when there are clear and realistic treatment goals set. The study provides clear evidence that functional improvement and better care can be supported by the management of spasticity with abobotulinumtoxinA.

38 - Quality of life improvements in people with leg spasticity following treatment with abobotulinumtoxinA

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Category: Rehabilitation in life after stroke

Background and aims

Leg spasticity is a common problem after stroke. It can make walking difficult, cause pain, and reduce quality of life. We looked at how repeated treatment with the botulinum toxin, abobotulinumtoxinA, impacted quality of life in people with leg spasticity who were still able to walk.

Method

The study followed 384 adults with leg spasticity over 16 months. Participants received up to six abobotulinumtoxinA injections. Their progress was tracked using two patient self-report tools: the Leg Activity Measure (LegA), which focuses on leg function and quality of life, and the EQ-5D-5L, a general health questionnaire.

Results

Results showed that quality of life improved steadily over the first four treatment cycles. People reported less difficulty with daily activities and better overall well-being. Improvements in quality of life tended to increase with repeated treatments and were linked to improvements in the patient and/or caregiver ability to care for the affected limb (passive function) and activities that the patient can do themselves (active function). The LegA quality of life and EQ-5D-5L scores were closely linked (correlations were statistically significant for all four cycles, all $p < 0.0001$), confirming that both tools are useful for measuring impact of treatment on quality of life.

Conclusion

This is one of the first large studies to show that repeated abobotulinumtoxinA treatment can improve quality of life in people with leg spasticity who are still able to walk. The findings also support the use of LegA as a reliable measure for tracking progress in people with leg spasticity.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

These findings show that repeated injections of abobotulinumtoxinA can help people with spasticity care for their affected leg, do everyday tasks more easily, and feel better overall. This shows the treatment improves everyday

life – not just by easing muscle tightness, but by making daily routines easier and enhancing overall well-being.

39 - Stakeholder perspectives on needs and priorities in home-based stroke rehabilitation: a concept mapping study

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Category: Rehabilitation in life after stroke

Background and aims

Home-based rehabilitation is an established and effective alternative to institution-based care. However, stroke survivors often face complex and varying needs that extend beyond medical treatment and require support in everyday life. Despite this, knowledge is limited on how services can be designed to respond flexibly to these needs. This study explored different perspectives on how home-based rehabilitation can be better aligned with the needs of people after stroke. In addition, we sought to generate actionable insights to support bottom-up implementation of more responsive and sustainable rehabilitation at home.

Method

Concept mapping was employed to capture diverse perspectives on adapting home-based rehabilitation. A total of 89 stakeholders participated, including stroke survivors, significant others, healthcare professionals, managers, and architects. Participants generated, sorted, and rated statements about what matters most in home-based rehabilitation. A hierarchical cluster analysis was used to organize the data.

Results

Five clusters were identified: 1) social support at home and beyond; 2) professional competence; 3) supportive home environment; 4) teamwork and resources; and 5) patient involvement. Patient involvement was rated highest for importance and feasibility, followed by professional competence. Stakeholders emphasized that rehabilitation should be meaningful and tailored to the patient's needs. No ideas from the cluster "supportive home environment" appeared in the go-zone; adapting rehabilitation to diverse home settings was seen as crucial but difficult.

Conclusion

The findings highlight the need for individualized, context-sensitive approaches and suggest that strengthening professional competence, particularly in navigating varied home environments and engaging support networks, will be key to translating person-centered principles into practice.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

The study goes beyond reaffirming established principles by showing how diverse stakeholders, including rarely consulted groups such as architects, articulate priorities, environmental challenges, and feasibility gaps. These insights inform the design of more sustainable, person-centered, home-based rehabilitation, improving patient involvement, professional competence, and ultimately everyday life and recovery after stroke.

40 - Rehabilitation in everyday activities promotes patients' physical activity in Swedish stroke units - Nursing staff experiences.

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Category: Rehabilitation in life after stroke

Background and aims

Stroke unit care with early mobilization by multidisciplinary teams is prioritized. However, international studies show that patients remain inactive in stroke units—spending 50–90% of their day in bed. This qualitative study aims to explore nursing staff experiences of patients' physical activity and inactivity in Swedish stroke units.

Method

Sixteen nurses and assistant nurses with variation in age and experience, working at eight Swedish stroke units were interviewed. Data collection was performed with in-depth interviews, and data were analyzed using reflexive thematic analysis with a person-centered care perspective.

Results

Three themes with impact on patients' physical activity and inactivity were identified: Team cooperation with common goals; Organization, competence and staffing; Person-centered and individualized care.

The nursing staff emphasized that rehabilitation in everyday activities should be prioritized to promote patients' physical activity and independence.

However, this is more time consuming than just assisting the patients.

Multidisciplinary stroke teams with shared goals and good communication are essential keys to support patient independence. When staff lack experience, knowledge or motivation patients tend to become more passive. Patients are more active on weekdays, while weekends often are boring and inactive.

Nurses aim to encourage patients' resources and empower them to make decisions and participate actively in their care, resulting in patients feeling respected and involved.

Conclusion

Nursing staff play a vital role in promoting physical activity in the stroke unit, but inconsistent staffing and limited time are challenges. Enhancing knowledge, experience, and good attitudes among stroke unit staff may improve rehabilitation outcomes and encourage patient independence.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

To promote stroke unit care through physical activity and everyday rehabilitation can increase function and independence for people suffering a stroke. This is beneficial for all people suffering a stroke and can promote better stroke unit care for persons having a stroke in the future.

41 - How does a therapeutic relationship enhance confidence and resilience for self-management and wellbeing after stroke?

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Category: Rehabilitation in life after stroke

Background and aims

Emerging literature suggests that self-management after stroke may be beneficial to manage and adapt to life after stroke. Self-management is often understood by stroke survivors, practitioners and policy makers from an autonomous perspective. However, in this study it was argued that self-management needs to be supported within a relational sense, where social and therapeutic interactions play a pivotal role and can have a long-term impact on peoples' wellbeing and quality of life after stroke.

Method

A realist-informed methodology was used to explore for whom an intervention, aimed at encouraging stroke survivors to engage in self-management, was likely to work, how and under what circumstances. Two initial programme theories were developed; one focusing on motivation, the other on the therapeutic relationship. Stakeholders, including practitioners and stroke survivors were involved in refining these theories.

Results

The theoretical explanations deepened an understanding of how self-management can be supported in a relational sense, where social infrastructure may help people to develop confidence and control over their rehabilitation and where trusted therapeutic relationships can have a lasting impact on peoples' wellbeing and their quality of life after stroke. Genuine investment and good communication are core aspects of trusted relationships that help to provide encouragement, reassurance and emotional support to build trust, confidence and a sense of mastery over their longer-term wellbeing and self-management.

Conclusion

The findings lend support for viewing supported self-management within a relational framework, where the quality of supportive therapeutic relationship is essential for motivation, achieving rehabilitation goals and supporting longer-term self-management, resilience building and independence.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research will help to get an understanding of how people can be supported through social and therapeutic interactions in their self-management to enhance confidence and resilience for long-term self-management and wellbeing after stroke.

42 - Use of a smartphone app (iFlexo) to support rehabilitation in post-stroke spasticity: a proof-of-concept study

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Category: Rehabilitation in life after stroke

Background and aims

Post-stroke spasticity (PSS) significantly affects functional independence and quality of life. Frequent, guided rehabilitation is recommended, in combination with treatment, for effective management. Digital solutions, such as smartphone apps, offer alternative approaches when access to in-clinic rehabilitation is limited; however, to date there are no apps specifically for PSS. The iFlexo app is a goal-oriented, personalised approach designed to support patients with PSS in their rehabilitation journey. This study aimed to explore the usability of, and patient engagement with, iFlexo.

Method

Adults with spasticity were asked to complete a tailored programme in iFlexo, targeting their intended goal. The programme was completed at home, in the participants' own time and was structured to last for 12 weeks. It included sessions demonstrating physical exercises or educational aspects of PSS. User metrics were captured and a survey was conducted to assess satisfaction and compute a 'Net Promotor Score' (NPS), a standard outcome measuring how likely users are to recommend the app.

Results

A total of 134 adults were included. Among them, 133 had PSS and 1 had cerebral palsy. Users completed 895 sessions in total, with an average daily usage time of 8.53 minutes. Survey responses (n=55) yielded an NPS of 43, indicating high user satisfaction and strong potential for recommendation.

Conclusion

These findings suggest that iFlexo is a highly engaging and well-received digital tool for patients with PSS. Further development will focus on expanding content and enhancing personalisation to further empower patients during their rehabilitation.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

How this research will improve life after stroke for stroke survivors: The iFlexo app provides access to consistent guided rehabilitation that is tailored to patient needs. This gives patients control, allowing them to receive recommended, guided rehabilitation at their own pace, with no need for frequent clinic visits.

43 - Functional Outcomes in Stroke Survivors Continuing Rehabilitation: Influence of Stroke Type and Gender

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Category: Rehabilitation in life after stroke

Background and aims

Stroke is a leading cause of long-term disability, with more than half of survivors experiencing persistent motor, cognitive, or psychosocial impairments. Comprehensive rehabilitation is essential to improve independence and quality of life, yet optimal strategies and their clinical impact remain under investigation.

Method

This prospective cohort included 161 consecutive post-stroke patients (45 male, 116 female) enrolled at St.Nicola's Medical and Rehabilitation Center, Stroke subtypes were ischemic (n = 78) and hemorrhagic (n = 83). All patients received a standardized multidisciplinary rehabilitation course (physical therapy, physiotherapy, occupational therapy, speech therapy). Functional Independence Measure (FIM) was recorded at admission and after completion of the first rehabilitation course. Group means are presented; within-group changes were tested with paired analyses and between-group comparisons with independent tests, adjusting for age and baseline severity where appropriate.

Results

Overall mean FIM improved from 65 at baseline to 90 after the first course (mean change +25 points; $p < 0.001$). By subtype: ischemic patients (n = 78) improved from mean FIM 67 → 92 (mean change +25), and hemorrhagic patients (n = 83) improved from 63 → 88 (mean change +25). Both subtype improvements were highly significant ($p < 0.001$ within each group). The magnitude of mean change was effectively identical between subtypes (no significant between-group difference, $p = 0.92$). The majority of patients shifted from moderate dependence to markedly greater independence in activities of daily living.

Conclusion

A single course of structured multidisciplinary rehabilitation produced large, clinically meaningful gains in FIM for stroke survivors. These findings support continued, intensive rehabilitation for diverse stroke populations.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This study will help patients better understand the importance of rehabilitation after a stroke.

44 - Using technologies to transform rehabilitation after stroke: what matters to users?

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Category: Rehabilitation in life after stroke

Background and aims

Technologies have huge potential to transform rehabilitation after stroke but often struggle to be adopted in practice. This work, which is part of a larger project, sought to explore the key features that influence the usability of rehabilitation technologies.

Method

Two approaches were taken:

1. Interviews with 48 people involved in rehabilitation technology development, implementation and use, including 6 people after stroke (5 males, 1 female), who had used technologies as part of their rehabilitation in the UK's NHS, were undertaken to explore real-world experiences of technology implementation.
2. Iterative and collaborative co-design sessions using a user centred design approach with people after stroke and UK-based physio and occupational therapists explored key design features of rehabilitation technologies.

Results

The interviews identified that digital literacy, the technology's usability, its' perceived benefits, the provision of training and support from both clinical services and family, friends and carers to use the technologies, influenced their uptake. Both therapists and people after stroke identified similar key design features including: simple, text free interfaces, the use of icons, an ability to work without internet connectivity, avoidance of repeated logging on and a way to record and show progress.

Conclusion

This work highlights vital considerations that are likely to influence if and how people can utilise rehabilitation technologies. Whilst some design features could be argued to be obvious, the provision of ongoing support and understanding users' beliefs about the potential benefits the technology could provide are vital to consider when implementing technologies into rehabilitation.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This work enables people after stroke, those who care for them as well as technology developers and clinicians who provide rehabilitation, to better understand the features that make a rehabilitation technology usable after stroke. This knowledge enables judicious selection of optimally designed technologies to improve recovery and life after stroke.

45 - Stakeholder Perspectives on Built Environmental Factors to Support Stroke Rehabilitation and Return to Everyday Life

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Category: Rehabilitation in life after stroke

Background and aims

People with stroke often encounter challenges leading to activity and participation limitations and the recovery often involves long-term rehabilitation undertaken in the home or local neighbourhood. Evidence on how the built environment can support rehabilitation outcomes is scarce which calls for a deeper understanding of which aspects of the built environment are important for people with stroke.

Objective: To explore, from the perspectives of various stakeholders, how home and local neighbourhood environments support or hinder rehabilitation for people who have had a stroke.

Method

With a qualitative method, data was collected through interviews with 16 stakeholders: people with stroke (n=3), significant others (n=3), healthcare professionals (n=4), care managers (n=3) and architects (n=3). Content analysis was used to identify patterns and create themes.

Results

Our findings identify environmental limitations that are relevant to address in stroke rehabilitation. The main categories (supported by WHO age friendly environmental framework) and factors: (1) Outdoor environments: accessibility, safety, supportive. (2) Transport and mobility: accessible and reach central services. (3) Housing: adaptations, layout and accessibility. (4) Social participation: spaces that are varied and flexible. (5) Social inclusion and non-discrimination: shared decision-making. (6) Civic engagement and employment: supporting environments. (7) Communication and information: digital accessibility. (8) Community and health services: patient-centered approach and access to varied rehabilitation.

Conclusion

By integrating insights from multiple stakeholder perspectives, relevant built environmental factors have been identified in stroke rehabilitation. These findings contribute to the innovative development of home and neighbourhood environments to influence and support stroke rehabilitation.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

These findings highlight how built environmental factors in the home and local neighbourhood can support the transition to home-based rehabilitation, which can improve recovery and return to everyday life for people with stroke. The research essentially seeks to enhance the potential for stroke survivors to live active, independent lives.

46 - Improved shoulder pain and motor function after Constraint-Induced Movement Therapy in middle-aged chronic stroke.

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Category: Rehabilitation in life after stroke

Background and aims

Hemiplegic shoulder pain (HSP) is a common post stroke complication which may negatively impact the stroke patient's quality of life. Constraint-Induced Movement Therapy (CIMT) is a highly intensive treatment modality that has demonstrated efficiency in improving motor function after stroke. The possible positive effect of CIMT on shoulder pain has not yet been addressed. AIM: To investigate the effects of CIMT on shoulder pain, range of motion (ROM) and motor function in the subacute and chronic stages post stroke.

Method

A prospective cohort study including 101 participants with and 120 participants without shoulder pain before CIMT (median age 54 years). Participants underwent CIMT for 6 hrs/day, 5 days/week for 2 consecutive weeks, including daily shoulder strength and joint motion training. Outcome for shoulder pain at passive movement was assessed. Furthermore, the ability to perform arm and hand movements and passive and active shoulder range of motion was measured. All assessments were performed before, after and 3 months after CIMT.

Results

Shoulder pain was reduced for all directions of shoulder movement; flexion and abduction ($p < 0.001$) and for external- and internal rotation ($p < 0.005$). Passive and active ROM increased in the subgroup with pain ($p < 0.001$). Active ROM increased (flexion $p < 0.005$, abduction $p < 0.001$) in the subgroup without pain. Motor function improved for both subgroups ($p < 0.001$). Improvements persisted at 3-month follow-up.

Conclusion

CIMT, including daily shoulder strength and joint mobility exercises, may be a feasible treatment to overcome shoulder pain while simultaneously improving shoulder range of motion and motor function.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Recent research has reported the prevalence of HSP to be 39 to 55% and indicates that only a smaller portion of patients receive pain treatment in the later phases. This study may contribute to developing a much needed, novel approach to reducing HSP.

47 - Effectiveness of Virtual Environment Interventions in Upper Limb Rehabilitation in Sub-Acute Stroke: A Systematic Review

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Category: Rehabilitation in life after stroke

Background and aims

Dosage of upper limb (UL) therapy in stroke rehabilitation does not meet clinical guideline recommendations. Purpose-designed virtual environment (VE) interventions may increase dosage through repetitive, intensive practice. This review investigated the effectiveness of VE interventions in improving UL functional outcomes and dose of rehabilitation provided.

Method

The protocol was registered in PROSPERO (CRD42024581166). Six electronic databases were searched for RCTs comparing VE with time-dose-matched conventional therapy in sub-acute stroke. Primary outcome was UL function and activity (ICF domains), immediately post-intervention and follow-up. Methodological quality was assessed using the Cochrane Risk of Bias 2 tool and Certainty of Evidence (CoE) using Grading of Recommendations Assessment, Development and Evaluation. Standardised Mean Differences (SMDs) were pooled using random-effects analysis. Data for dosage were synthesised narratively.

Results

14 RCTs (n=718) were included, 8 had follow-up data. Findings showed a medium effect in favour of VE for UL function post-intervention (0.64; 95%CI 0.12 to 1.17, p=0.02, I²=61%), but no significant effect on activity (SMD 0.35; 95%CI -0.26 to 0.96, p=0.23, I²=81%). No significant between-group differences were found at follow-up for UL function (SMD 0.65; 95%CI -0.02 to 1.32, p=0.05, I² =82%) or activity (SMD 0.49; 95%CI -0.11 to 1.08, P=0.09, I²=84%). CoE was very low across most outcomes. Session length ranged from 15-60 minutes, total dosage between 300-3667 minutes.

Conclusion

VE may be an effective tool for UL function in sub-acute stroke rehabilitation. However, caution should be applied to results due to very low CoE. Reporting on dosage is inconsistent and RCTs lack medium and long-term follow-up.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This review demonstrates that purpose-designed VE interventions may improve UL function in sub-acute stroke. It highlights the heterogeneity in dosage reporting and recommends the use of structured reporting frameworks to enhance transparency. This will support clinicians in selecting appropriate interventions and dosages to optimise functional outcomes for stroke survivors.

48 - Functional Rating of Interaction Engagement Needs and Difficulties Scale (FRIENDS) for people with stroke aphasia

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Category: Relationship needs

Background and aims

Friendship is vital for the well-being and social integration of people with aphasia (PWA) post-stroke. The impact of chronic aphasia on the friendships and social engagement of PWA is often overlooked by rehabilitation clinicians. To co-create the Functional Rating of Interaction Engagement Needs and Difficulties Scale (FRIENDS), a self-report aphasia-friendly tool, in collaboration with PWA, and test its psychometric properties.

Method

A Patient and Public Involvement (PPI) approach was adopted, involving three people with a lived experience and a caregiver as research partners across eight co-design meetings. The psychometric properties of FRIENDS were evaluated using reliability and validity measures. The psychometric study involved 166 participants: 62 people with aphasia, 50 people with stroke without aphasia, and 54 healthy controls.

Results

FRIENDS demonstrated excellent internal consistency (Cronbach's $\alpha > 0.960$) and high test-retest reliability (ICC ≥ 0.99). The results demonstrated a significant difference amongst the three groups ($p < 0.001$), which verified known-groups validity. Significant correlations between FRIENDS and measures of aphasia severity, functional communication, and quality of life supported the tool's convergent validity. Results derived from analyzing the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) report supported its content validity.

Conclusion

FRIENDS is a psychometrically sound, patient-reported outcome measure, developed to rate changes in the friendships of PWA. Co-created with PWA, FRIENDS offers a broad view of chronic aphasia's impact on friendships, aiding clinicians in co-developing functional intervention plans, enabling person-centered care, and improving the social life of PWA.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research empowers people with aphasia by giving them a voice in assessing their social needs after a stroke. The FRIENDS tool supports person-centred care, promoting social connectedness and emotional well-being, key factors in post-stroke recovery. Strengthened friendships may also

encourage engagement in healthier lifestyles, contributing to secondary stroke prevention.

49 - 'Undressing' sexual wellbeing after stroke: revealing findings from a feasibility randomised controlled trial

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Category: Relationship needs

Background and aims

Neurological damage and psychosocial changes after stroke can cause relationship problems and declining sexual wellbeing. Sexual wellbeing is an essential component of mental health and overall wellbeing, but is not routinely supported in neurorehabilitation. Digital technologies can deliver much-needed support, resolve time constraints for professionals, and allow autonomy and anonymity for participants. This study assesses the feasibility of a digital self-management programme to support sexual wellbeing: HOPE4ABI.

Method

Mixed methods, parallel, 1:1 allocation, feasibility randomised controlled trial (RCT), with two arms: i) peer supported HOPE4ABI (intervention group); ii) self-directed HOPE4ABI without peer support (control group). Participants were self-referred to the study website following social media advertising via stroke and brain injury charities. Study documents and digital intervention were administered online.

Results

Fifty-three participants consented, representing 88.3% of the target (n=53/60; n=26 control, n=27 intervention). Primary outcome completion rate at 6-months was 84.9% (n=45/53). Nine participants never logged in (17.0%; n=9/53). Of those who accessed the intervention, 61.4% (n=27/44) met the engagement criteria, and 75.7% were satisfied with the content, delivery and ease of use. Results will be discussed in relation to participant demographics, trial arm preference, and improvement in sexual wellbeing outcomes.

Conclusion

Modifications, informed by lived-experience, have been implemented to support engagement and acceptability for the full trial. Sexual wellbeing scores increased at 6-months relative to baseline, with larger changes in the intervention group, consistent with the peer-supported self-management literature. Changes relative to standard care are unknown and thus warrants a definitive RCT to explore clinical- and cost-effectiveness of the HOPE4ABI interventions.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Our research aims to normalise conversations around sex and relationships after stroke and brain injury. The digital HOPE4ABI programme could be a sustainable, efficient solution to supporting sexual wellbeing after stroke. A

definitive RCT will provide robust evidence of the clinical- and cost-effectiveness of HOPE4ABI for stroke survivors.

50 - Knowledge, Comfort, and Practices in Post-Stroke Sexual Dysfunction: A Survey of Rehabilitation Professionals

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Category: Relationship needs

Background and aims

Post-stroke sexual dysfunction (PSSD) is a prevalent but under-recognised complication that adversely affects quality of life. Despite clinical guidelines recommending sexual health discussions, rehabilitation professionals often lack training and confidence, resulting in inconsistent care. This study aimed to evaluate knowledge, comfort, and clinical practices related to PSSD among rehabilitation clinicians within a UK stroke pathway.

Method

A cross-sectional online survey was distributed to multidisciplinary stroke rehabilitation teams in inpatient and community settings. Respondents reported demographics, self-rated knowledge and comfort using 5-point Likert scales, frequency of PSSD discussions, prior training, and perceived barriers. Quantitative data were analysed descriptively; t-tests compared knowledge and comfort by training status; logistic regression examined predictors of initiating PSSD conversations. Qualitative responses underwent thematic analysis.

Results

Fifty-three complete surveys were analysed. Mean knowledge (1.9/5) and comfort (2.6/5) were low; only 8% had prior training. Training significantly improved knowledge (3.25 vs. 1.73, $p=0.004$) and showed a positive trend for comfort. Knowledge predicted proactive discussion of PSSD ($\beta=1.79$, $p=0.003$), while comfort did not. Most clinicians rarely initiated (90%) or received (80%) patient queries about PSSD. Barriers included lack of knowledge (77%), resources (53%), and comfort (38%). Qualitative themes highlighted role ambiguity, difficulty initiating conversations, and strong demand for training and patient resources.

Conclusion

Rehabilitation clinicians recognise PSSD's importance but report low knowledge and confidence, leading to infrequent discussions. Structured training, clinical guidelines, and patient-centred resources are urgently needed to normalise sexual health conversations and improve holistic stroke care.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research can help encourage clinicians to reflect on their own provision of support for patients with post-stroke sexual dysfunction and how this is addressed within their service. Enhanced training and resources will normalise discussions, reduce stigma and promote holistic recovery.

51 - Friendship and Loneliness post-stroke: perspectives of stroke survivors and family members

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Category: Relationship needs

Background and aims

Friendship losses and reduced social support are common following stroke, often leading to loneliness and isolation. These experiences are often heightened for stroke survivors with aphasia due to limited communication abilities, negatively impacting their relationships. The family of stroke survivors are also affected, where roles can change from spouse/parent, to a care-giving role, leaving less time and energy to develop and maintain social networks.

This study aimed to (i) explore the experiences of friendship, loneliness and social support as experienced by stroke survivors/family, (ii) identify factors that help maintain friendships and social support following stroke, and (iii) explore available supports for stroke survivors/family.

Method

This mixed-methods study involved participants completing self-evaluation assessments of friendship, loneliness and social support networks (CASP, UCLA, MOS, B-SSNI). Semi-structured interviews explored participant experiences of friendship, support and loneliness before and after stroke. Interviews were analysed using thematic analysis.

Results

Eight stroke survivors (5 male) and two family (both female) participated. Themes identified included: 'psychological impact of stroke' (sub-themes: loneliness, relationship with self, grief, attitude, and caregiver burden); 'supports following stroke' (sub-themes: support services, rehabilitation, carers' role, family, and marriage); 'socialising following stroke' (sub-themes: friendship, communication when socialising, and socialising with others), and 'life integration following stroke' (sub-themes: employment, advocacy & research, and accessibility & availability of stroke services).

Conclusion

Changes in friendship are common following a stroke for both stroke survivors and families resulting, for many, in loneliness and isolation. Social support and increased support services were important factors in reducing feelings of loneliness and increasing well-being.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

The findings from this study highlight the experiences of living with changes in friendships, support networks, and loneliness following a stroke.

These lived experiences of stroke survivors and family members will help inform and guide future support availability to stroke survivors and the significant people in their lives.

52 - “I feel I am needed”: An exploratory study of experiences of belonging after stroke

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Category: Relationship needs

Background and aims

Many stroke survivors report losses of meaningful roles and shrinking social networks. Experiences of belonging in society, i.e., perceiving oneself as an “insider” in the groups and environments where one participates, are described by stroke survivors as an essential aspect of life. However, little is known about how such experiences are created in different life situations, and there is insufficient understanding of how experiences of belonging following stroke can be supported.

The aim of this study was to increase knowledge about how experiences of belonging in society are created.

Method

In this grounded theory study, nine individuals aged 35-64 who had experienced a stroke/ABI (n=6/3), between 1 and 29 years ago were interviewed.

Results

Preliminary findings suggest that experiences of belonging were created through being in mutual relationships within social contexts, emphasizing that such experiences are inherently relational, involving individuals or groups. Emerging as oneself was essential and required not being treated as different, as well as being in safe and predictable environments. Furthermore, participating in meaningful interactions and/or activities was crucial; these interactions and activities involved contributing to others and/or sharing common interests in ways that were perceived as meaningful. Adapting to the new life situation involved both accepting that life had changed and developing and using strategies that enabled experiences of belonging in situations and contexts that mattered.

Conclusion

Experiences of belonging after stroke/ABI were created through safe, predictable, and meaningful interactions with individuals and groups, in environments that allowed individuals to emerge as their true selves.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

The findings from this study will facilitate discussions and counseling with stroke survivors and their families on topics related to belonging and similar experiences. Further, the findings will inform the development of interventions

aimed at supporting conditions for belonging by targeting factors in the individuals' physical environments and social networks.

53 - Exploring patients' experiences of secondary prevention after stroke: a survey study.

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Category: Secondary prevention

Background and aims

Stroke secondary prevention focuses on reducing the likelihood of future strokes by addressing underlying risk factors and lifestyle factors that contribute to stroke. Nurses play an important role in stroke secondary prevention and recently as key team members in early supported discharge (ESD) teams. The aim of the survey was to describe stroke patients' experiences of and their needs in relation to secondary prevention in a community setting.

Method

A paper survey delivered to stroke patients recently discharged from hospital, receiving ESD. The survey assessed patients' experiences of secondary prevention focusing on three areas (i) secondary prevention at first contact (ii) format of the secondary prevention information received and (iii) secondary prevention in ESD. The study received ethics approval.

Results

50% replied, n=25. (i) 28% (n=7) received information on secondary prevention for the first time at home (ii) 68% (n=17) responded favourably to having a secondary prevention education booklet used to inform them and 20% (n=5) reported a nurse phone helpline would be beneficial if they had future questions regarding their care. (iii) 96% (n=24) of stroke survivors stated that they would prefer their secondary prevention information delivered at home by a nurse specialist.

Conclusion

Providing secondary prevention information to stroke patients in the community empowers patients to feel more in control at home in a familiar environment, reducing stress and anxiety. The findings in this survey will be used to inform the development of a secondary prevention education resource for use by stroke nurse specialists in early supported discharge.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

The survey findings highlight stroke survivors' preference is to have their stroke secondary prevention information delivered by a nurse specialist in their home. This allows a tailored approach as per national and international

guidelines. This research will inform future research on secondary prevention care in stroke early supported discharge services.

54 - Adapting Aerobic Exercise for Severely Impaired Stroke Survivors: A Scoping Review

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Category: Secondary prevention

Please describe your submission category, if you have selected other above

This category has been selected to include prevention of post stroke complications, one of which being further stroke.

Background and aims

A subgroup of fitness training, called “aerobic exercise”, trains the heart and lungs to reduce the chance of further circulatory disease after stroke. However, current research focuses on Stroke Survivors able to walk by themselves (Moderately impaired) not those needing assistance to walk (Severely impaired). The primary aim is to identify considerations for delivering aerobic exercise to severely impaired adult Stroke Survivors. The secondary aims are to establish: 1. What is being done to keep participants safe 2. How are any benefits of aerobic exercise being measured and 3. Are stroke survivors being asked for their views on exercise?

Method

The main source of evidence is primary data studies. Databases were searched from 2016 to 2nd April 2025. Limits included English language. The Joanna Briggs Institute source selection, data extraction, and data presentation principles were followed.

Results

The search retrieved 16153 articles. 13 articles from 15 studies were included. Study methods included feasibility and randomised controlled trials. Stroke Survivors represented each stage of recovery. The intensity, successful completion and safety of exercise were explored most. Intensity ranged from light to vigorous. Of note, safety considerations frequently cited the same 2014 American Heart Association guideline. Heart and lung parameters were used to measure benefit. Stroke Survivor views were only reported in one study.

Conclusion

Evidence is limited but intensity, successful completion and safety are the most common considerations for aerobic exercise in severely impaired stroke

survivors. Further research is needed and should include Stroke Survivor views to guide adapting this form of secondary prevention.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

This research will build Stroke Survivors' knowledge and confidence to exercise in a way that reduces their chance of further circulatory disease. This research shows inclusivity by exploring the severely impaired survivors, often overlooked in the literature.

55 - Medication Adherence Post-Stroke or TIA: An Updated Qualitative Meta-Synthesis

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Category: Secondary prevention

Please describe your submission category, if you have selected other above

Medication adherence for secondary prevention in stroke and TIA survivors

Background and aims

Stroke and TIA survivors often experience complex physical, cognitive, and emotional challenges that affect medication adherence (MA). This meta-synthesis updates and extends prior qualitative evidence to explore current factors influencing MA and identify areas for intervention improvement.

Method

A comprehensive search across MEDLINE, CINAHL, Embase, PsycINFO, Scopus, and Web of Science identified 5466 qualitative and mixed-method studies published since January 2018 included for title and abstract screening. 210 were accepted and progressed for full text review and subsequently 13 studies met inclusion criteria. Data was synthesised thematically following Thomas and Harden's (2008) approach, and quality was assessed using the JBI Critical Appraisal Checklist.

Results

Data extraction synthesis and analysis highlighted seven key themes including knowledge and understanding, beliefs and attitudes, practical barriers, social support, healthcare system factors, psychological influences and medication characteristics.

Conclusion

Interventions should be designed to address both emotional and structural influences on adherence, combining patient education, psychological support, and effective communication to enhance individual medication-taking behaviour.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Understanding modifiable barriers to adherence enables the development of focused education and improvements to follow-up care. Implementing these tailored approaches can empower stroke and TIA survivors to manage their health more effectively, reduce the risk of future events, and enhance long-term wellbeing across a diverse range of healthcare settings.

56 - 'Partners in prevention': A consensus-based strategy to improve secondary stroke prevention care

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Category: Secondary prevention

Background and aims

Despite advancements in secondary stroke prevention (SSP), the risk and impact of stroke recurrence remain high. A recent multi-stakeholder expert panel developed consensus statements on challenges in SSP. Based on these statements, we present actionable measures for the stroke community to improve treatment, support, and management.

Method

We conducted a modified Delphi study with 13 international stroke experts, including stroke survivors and patient advocates. After two anonymous survey rounds and one discussion, consensus ($\geq 75\%$ agreement) was achieved on 11 statements relating to challenges in SSP treatment and management. Our analysis identified specific measures for implementation and advocacy to improve outcomes for stroke survivors.

Results

Our study identified specific challenges in SSP—in particular, the lack of coordinated follow-up, which prevents stroke survivors from accessing long-term treatment and support. These gaps highlight the need for stroke survivors, care partners and multidisciplinary teams to act as 'partners in SSP'.

The stroke community can work towards this goal by advocating for consensus-based measures, such as a) partnership and engagement between stroke survivors, health care practitioners, and multidisciplinary teams; b) ongoing education for stroke survivors and care partners, including awareness of risk factors and lifestyle modifications; and c) coordinated follow-up to maintain long-term adherence.

Conclusion

The consensus statements from this Delphi panel highlight critical gaps in SSP treatment, support, and management. A 'partners in SSP' model is essential to addressing these gaps, alongside increased investment. Actionable, consensus-based strategies should be implemented and used to inform advocacy efforts that can improve care for stroke survivors.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Empowering the stroke community to advocate for a more effective and integrated SSP approach will better support stroke survivors and their care partners, ensure that they know how to limit recurrence risk, and improve adherence to prevention plans—ultimately improving their quality of life and reducing stroke recurrence.

57 - Enhancing Stroke Recovery in Menopausal Women: A Collaborative Quality Improvement Approach

Dr Leonet Reid

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Category: Secondary prevention

Background and aims

Stroke is a leading cause of death and long-term disability worldwide, with women accounting for approximately 60% of all stroke events. Women who experience a stroke during the menopausal transition face significant challenges due to both the neurological disability and hormonal changes associated with menopause transition. Unfortunately, symptoms such as fatigue, cognitive fog, mood swings, and sleep disturbances are often obscured in the post-stroke period since these symptoms overlap in both conditions, further complicating post-stroke care and subsequent stroke preventions. This can leave many women feeling unsupported and uninformed about their holistic recovery journey. Currently, post-stroke care in Canada lacks a systematic framework for evaluating menopause-related health concerns or delivering tailored education and management strategies for affected women. This project aims to explore how menopause transition symptoms are perceived and managed among post-stroke women aged 35–65, identify knowledge gaps, and understand their treatment needs and preferences for integrated model of care.

Method

This mixed-methods QI pilot project centers women with lived experience (n=30) to co-create educational tools and system-level improvements, using quantitative and qualitative instruments to identify gaps in care and support capacity building. Emerging themes from surveys and focus groups will be co-interpreted through triangulated statistical analysis and collaborative discussions with patient partners (n=5) and the evaluation team.

Results

Outcomes include gaps in knowledge and satisfaction regarding menopause care during stroke recovery, quality of life and patient-reported climacteric symptom severity.

Conclusion

Women navigating menopause often have their symptoms neglected or undertreated; insights gained will help develop responsive educational and clinical strategies.

How will this research positively impact on people with lived experience of stroke, or on the secondary prevention of stroke?

Ultimately, these findings will help shape the creation of educational materials emphasizing patient voices in advancing women's brain health and preventive neurology. Their voices will create Canada's first educational toolkit that

targets the intersectionality of post-stroke recovery and the needs of menopausal women.

SERVICE

58 - Turning survival into renewal: a survivor's vision for a connected and meaningful life after stroke

Mr Steffen Harnack

Category: Emotional, cognitive and psychological impact of stroke

Summary of the service development

At 34, I experienced a stroke that changed my life overnight. While acute treatment was excellent, I was left alone afterwards—facing isolation, uncertainty, and a lack of holistic support. This reality is shared by many survivors, especially younger adults. Stroke of Life was created in Germany from this lived experience. Currently in the planning phase and launching in 2026, it will combine three elements: **coaching** for self-efficacy, **content** that makes survivor voices visible, and **community** that transforms isolation into belonging. Together, these create a new, survivor-led model of long-term stroke support.

How this is relevant to other countries and what could be the potential impact across countries

The gaps Stroke of Life addresses are universal: psychosocial care is fragmented, peer networks are rare, and identity rebuilding is overlooked. By being survivor-led, digital-first, and scalable, the model is adaptable to different healthcare systems and cultures. Its impact potential lies in complementing medical services with accessible, low-cost structures that improve wellbeing, foster peer-to-peer connection, and promote healthier lifestyles. This approach can strengthen recovery, reduce depression and social withdrawal, and support secondary prevention across countries—offering a blueprint for sustainable post-stroke care in Europe.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

For survivors, Stroke of Life shifts the focus from surviving to truly living. Coaching helps rebuild confidence and resilience; content provides tools, knowledge, and role models; community ensures no one walks the path alone. Each survivor's story becomes a resource for healing and a source of inspiration for others. By empowering people to reconnect with meaning, relationships, and healthier choices, the initiative enhances quality of life and contributes to long-term recovery and secondary prevention.

59 - SLENDOR Care Model – simplifying stroke recovery and closing the knowledge-behaviour gap through lifestyle medicine

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Category: Lifestyle (inc. self and personal care, domestic life, employment, economic self-sufficiency, diet nutrition)

Summary of the service development

What's the healthier choice: eating an apple or pastry? Going for a 30-minute walk or watching a 30-minute show? Calming stress with meditation or wine? Everyday lifestyle behaviours significantly impact health. Most people can identify the healthier choice, but closing the knowledge-behaviour gap remains a challenge. This is especially true for stroke survivors.

To address this, the SLENDOR Care Model was developed, an eight-week hybrid secondary prevention program grounded in lifestyle medicine. It combines group medical visits, peer support, SMART goal-setting, and practical education to simplify stroke recovery. By embedding evidence-based strategies in a supportive community framework, SLENDOR supports stroke survivors to build sustainable habits by bridging the knowledge-behaviour gap for healthy lifestyle choices.

How this is relevant to other countries and what could be the potential impact across countries

Despite geographic, cultural, and systemic differences, many countries face similar challenges: fragmented post-stroke care, limited access to multidisciplinary follow-up, and an over reliance on pharmacological management. SLENDOR addresses these shared barriers through a scalable, cost-effective, and adaptable hybrid design that can be integrated across diverse health systems. International adaptation could involve tailoring modules to local diets, cultural attitudes, and available community resources. By simplifying recovery through lifestyle medicine, SLENDOR has the potential to improve long-term outcomes and reduce the risk of stroke recurrence.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

For stroke survivors, recovery extends far beyond the hospital. Many face ongoing fatigue, cognitive changes, low mood, and uncertainty about how to rebuild healthy habits. SLENDOR empowers stroke survivors to take an active role in recovery by closing the knowledge-behaviour gap, take charge of their recovery, and reduce the risk of stroke recurrence.

60 - Abric programme: unmet needs of stroke survivors and families.

*Mrs Silvia Miró, Mrs Marta Bonet, Mrs Esther Duarte
Fundacio Ictus, Barcelona, Spain*

Category: Long term support (including carers and community support)

Summary of the service development

Background: Stroke's the leading cause of long-term disability, with survivors often facing persistent physical, cognitive, emotional, and social challenges. Despite medical attention in acute care and rehabilitation, many patients report unmet needs. The Abric Programme of the Fundació Ictus is an unique, innovative and free: through active listening, emotional support, expert advice and providing information, affected people and their families are accompanied throughout the long road of post-stroke life.

Objective: to identify and characterize the unmet needs during the post-acute phase of recovery, identifying whether sex, age, socioeconomic conditions and the severity of stroke-related disability influence these needs.

Methods: A mixed-methods approach combining quantitative surveys with qualitative interviews among 218 stroke survivors and 170 caregivers who have been attended by our program since January 2025.

Results: most frequent unmet needs reported are related to home adaptation services, peer-to-peer support, rehabilitation services, procedures to access aid for dependency, cognitive and speech therapy, job & driving reintegration. The correlations between individuals' sociodemographic characteristics and the severity of stroke-related dependency and their unmet needs will be analyzed.

How this is relevant to other countries and what could be the potential impact across countries

The needs not covered in stroke survivors and their families, although it's a particularity of the health social system of each country, surely most are repeated in the different territories.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Make it clear that Health systems provide insufficient care according to what have been the sequelae after stroke.

Validate the feeling of disengagement and difficulties experienced by survivors and caregivers to be able to reincorporated in life after stroke.

61 - Testing approaches to evidence based outcome measures for integrated life after stroke services

Garry Jopling¹, Janet Schmitt², Jo Buck^{2,1}, Heidi James¹

1Stroke Association, United Kingdom. 2Somerset NHS Foundation Trust, United Kingdom

Category: Long term support (including carers and community support)

Summary of the service development

In the UK, Somerset NHS (National Health Service) Foundation Trust and the Stroke Association worked collaboratively to implement and evaluate the impact of keyworker based life after stroke support (2023-2025). Stroke survivors were offered a personalised review and needs assessment followed by one-to-one support.

Comparison of outcomes before and after the introduction of the service showed improved quality of life, patients better able to manage their own health, carers better supported and community stroke service staff better able to focus clinical time on therapy.

How this is relevant to other countries and what could be the potential impact across countries

There is an urgent need to improve availability and consistency of life after stroke support. Life after stroke support services can be life-changing; helping people cope with the emotional, social and physical impacts of stroke, to thrive, to live independently and prevent secondary stroke.

However, the evidence base is incomplete. This feeds into disparity and variation in service provision.

Looking ahead could we reach consensus among stroke survivors, health care professionals, policy makers, researchers and stroke support charities on a core set of outcomes for measurement? The Somerset work is offered as an example to feed into that conversation. The prize? An answer to the questions of – What is the value of life after stroke services for individuals, health and social care systems? And how can services be setup as an integrated partner in the stroke pathway to maximise benefit?

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

A core set of valid measures will strengthen the case for funding life after stroke services.

62 - Feasibility of 'One Stop Group Therapy Assessment Clinics' in long term stroke management

Ms Jessica Mortimore^{1,2}, Ms Amy Davey¹, Ms Kim Knight¹, Ms Olivia Hall van Laere¹, Ms Abi Hall²

1Torbay and South Devon NHS Foundation Trust, Torquay, Devon, United Kingdom. 2University of Exeter, Exeter, Devon, United Kingdom

Category: Long term support (including carers and community support)

Summary of the service development

Our aim was to establish if a 'One Stop Group Therapy Assessment Clinic' with access to Physiotherapy, Occupational Therapy, the voluntary sector including the Stroke Association and Stroke Support Groups would be feasible to help reduce waiting times and improve outcomes for stroke survivors.

Two groups of 12 people who had been on our neurophysiotherapy outpatient waiting list attended, and their carers, to attend a 'One Stop Group Therapy Assessment Clinic'. They had the opportunity to share as a group the problems that they face self managing their condition; including managing fatigue, deteriorating balance and accessing community support.

People were assessed one-to-one with a Physiotherapist, had an education session with an Occupational Therapist and spoke with peers and members of local community support services.

We used a confidence score and an activation measure at the start and end of the session. Confidence scores went up 43% within the first group's session and 21% in the second group's session. Also scores of 'knowing how well to take care of yourself' went up from 2 to 3 in the first group and 2.4 to 3 in the second group.

This project will help to reduce waiting times, redesign services and improve future outcomes.

How this is relevant to other countries and what could be the potential impact across countries

This model of working is one that could be adopted by other teams and services to provide integrated long term support to stroke survivors and their family and carers addressing input from the multi disciplinary team

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

The verbal and written feedback from stroke survivors attending was all very positive.

63 - GAM's – the Portuguese experience with stroke support groups

Mr Marta Gôja

Portugal AVC, Portalegre, Portugal

Category: Long term support (including carers and community support)

Summary of the service development

Portugal AVC is a stroke support organization in Portugal. Founded in 2016 by stroke survivors, mainly for stroke survivors, its mission is to improve life after stroke and promote stroke prevention.

One of its main initiatives, are the stroke support groups, in Portuguese GAM's (grupos de ajuda mútua), freely translated as mutual aid groups. There are 20 of these groups, spread across Portugal.

GAM's are local groups of stroke survivors that meet regularly (mostly once a month), supported by an organizing team of both stroke survivors and health care professionals.

In an informal atmosphere, each meeting is dedicated to a different theme. Stroke survivors have the opportunity to share their difficulties and experiences, learn more about stroke and stroke related issues, but also to make new friends and enjoy nice moments.

We asked the stroke survivors of the GAM's, why they joined the meetings and what these mean to them. Most of them expressed the importance of the sharing and the learning in the meetings, as well as the feeling of well-being associated to them. Other important feedback was the gratitude for the existence of the meetings, the feelings of hope and being welcomed in the group, the importance of the presence of health care professionals in the meetings. Other significant ideas that popped out were strength, growth, family, peer support.

We believe that the received feedback is a positive incentive to create more GAMs in Portugal, and that sharing our experience can be of value for other countries.

64 - Stroke in Spain: Data, Challenges, and Response from Freno al Ictus.

*Mrs CLAUDIA TRUJILLO AVENDAÑO
FOUNDATION FRENO AL ICTUS*

Category: Other (if other, describe your submission category)

Epidemiology and resources after a stroke

Summary of the service development

In Spain, stroke is a disease with an enormous social impact: 120,000 cases are affected each year.

It is the leading cause of death in women and the second leading cause globally.

One in four people will have a stroke in their lifetime.

It is the leading cause of acquired disability in adults.

By 2035, stroke cases will have increased by 35% in our region.

At the Freno al Ictus Foundation, we promote the "Guiar en Daño Cerebral Adquirido" project, a free service offering personalized guidance, support, and counseling. This program aims to facilitate access to the most appropriate procedures, resources, and support based on each patient's specific situation, covering areas such as social, healthcare, work, and family, among others, and offering help at any stage of the disease process.

How this is relevant to other countries and what could be the potential impact across countries

This information is relevant to other countries because it allows them to understand the current status of the disease in Spain, as well as access a completely comprehensive and holistic resource. We have developed a coordination network that involves both public entities, such as hospitals, and private entities, facilitating multidisciplinary and coordinated care for patients.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

This resource offers direct support to people affected by stroke, facilitating access to all the resources needed to improve their quality of life and daily routines. Furthermore, this comprehensive support has been shown to lead to greater adherence to treatment, which helps reduce the risk of suffering a second stroke.

65 - Understanding health information needs of linguistically diverse communities in the UK

Miss Caitlin Longman, Mrs Jenny Simpson, Mrs Angela Smith, Mrs Deborah Cairns, Mr Chris Fyfe
Stroke Association, United Kingdom

Category: Other (if other, describe your submission category)

Health information

Summary of the service development

Translation is a complex process, shaped not only by cultural differences, dialect variation, and the challenge of accurately conveying medical terminology, but by issues of accessibility, trust, timeliness, and cost. The Translation Sprint aims to improve access to health information for stroke survivors and families who do not speak or read English fluently. Phase 1 set the project scope, identified stakeholders, and mapped organisational challenges, revealing inconsistent processes, variable quality, and no needs-led approach. We reviewed translation models with peer organisations and created a staff advisory group to provide guidance. Phase 2 focused on collaboration with communities through Listening Sessions and interviews with Urdu-speaking survivors and carers, highlighting preferences for spoken formats, trusted community spaces, and culturally competent translation. The next steps are co-translating a health resource with the Urdu community and testing a replicable process.

How this is relevant to other countries and what could be the potential impact across countries

Multicultural societies worldwide face similar challenges. Without accessible health information, minority groups risk exclusion, poorer outcomes, and widening inequalities. Stroke makes this gap urgent, as some groups face higher risks and barriers to recovery. By combining community partnership, evidence-based prioritisation, and iterative design, our approach offers an accurate, trusted and actionable co-translation model. This framework has international relevance for organisations serving linguistically diverse populations.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Information in one's first language empowers survivors and families to support recovery, decision-making, and self-management. For staff, culturally appropriate resources improve service delivery and inclusion of hard-to-reach groups. Co-translation ensures translations are accurate and meaningful, building trust and uptake. Embedding this practice reduces barriers, strengthens engagement, and delivers fairer outcomes.

66 - Web-Based Stroke Education to Enhance Health Care Staff Competence – A Swedish Example

Dr Åsa Rejnö^{1,2,3}, Dr Ingrid Lindgen^{4,5}

1Stroke unit, Skaraborg Hospital, Skövde, Sweden. 2Department of Health Sciences, University West, Trollhättan, Sweden. 3Skaraborg institute for Research and Development, Skövde, Sweden. 4Department of Health Sciences, Lund University, Lund, Sweden. 5Department of Neurology, Rehabilitation Medicine, Memory Disorders and Geriatrics, Skåne University Hospital, Lund, Sweden

Category: Other (if other, describe your submission category)

A national web based competence enhancing education for all health professionals within the continuum of stroke care

Summary of the service development

The continuum of stroke care spans pre-hospital management, hospital care, and post-discharge follow-up, ideally provided by multidisciplinary teams. A major challenge is the substantial need for knowledge about stroke and its consequences among healthcare professionals, particularly in the later stages of the care pathway. To address this, a national web-based education program has been developed for stroke care teams in Sweden.

The education is offered as a university course at Umeå University.

Developed by a national working group, the program is accessible, flexible, and designed to strengthen teamwork. Short, recorded lectures are accessed online and prepare participants for four mandatory meetings focused on practical skills. Active participation in the meetings is required. Course materials, produced by experts from across the care pathway, currently include more than 70 lectures (≈10 hours), multiple-choice tests, case studies, discussion topics, and practical exercises.

How this is relevant to other countries and what could be the potential impact across countries

Since its launch 2018, near 2,500 professionals from stroke teams have completed the program. Most participants come from acute hospital stroke units, but with a share from community care. The program thus provides a scalable, evidence-informed model for strengthening competence and teamwork in stroke care across the care continuum possible to adapt and implement in other countries.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Enhanced skills in stroke care among health care professionals across the continuum of care have the potential to make a major difference for people who have had a stroke, both during the acute phase and throughout the remainder of their lives. Improved knowledge helps ensure the best possible stroke care.

67 - VALIDATE stroke literacy video series: development, dissemination and advocacy for stroke survivors.

*Mrs Mercedes Ayesta¹, Mrs Ester Sanchez-Gavilán², Mrs Cristina Guirao², Mrs Maria Baladas², Mrs Carolina Paredes, Mrs Marta Rubiera³
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Category: Other (if other, describe your submission category)

Category Stroke literacy and advocacy tool for patients and caregivers, Secondary prevention

Summary of the service development

Limited **stroke literacy**—patients' and caregivers' understanding of stroke, its causes, treatments, and prevention—can hinder engagement in care and reduce adherence to secondary prevention. As part of the **VALIDATE project** (Validation of a Trustworthy AI-based Clinical Decision Support System for Acute Stroke), **NORA Health** developed a series of six short, evidence-informed educational videos to strengthen stroke literacy and act as an **advocacy tool** for patient empowerment.

The series covers: What is a stroke, Thrombectomy, Undetermined stroke cause, Stenting, Stroke recurrence, and Stroke risk factors.

How this is relevant to other countries and what could be the potential impact across countries

The series was integrated into the **NORA App** and professional web platform and disseminated through partner hospitals, the VALIDATE project website, and social media. Videos are available in Spanish and English. Since launch in 2025, the videos have achieved **notable online reach**, including **830 LinkedIn impressions and 350 total views (as of 06.10.2025)**. Early feedback from clinicians, stroke support groups, and patient advocates highlights their **clarity, accessibility, and usefulness** in improving stroke literacy and fostering **self-advocacy** among survivors and caregivers.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Development followed a **structured, patient-centred methodology**. A comprehensive literature review on multimedia stroke education guided content priorities. A **needs assessment** with stroke survivors, caregivers, and clinicians identified key knowledge gaps and preferred learning formats. A multidisciplinary team—including neurologists, health educators, and media specialists—co-created scripts guided by **health literacy and patient advocacy principles**. Each video combines professional narration, patient and caregiver perspectives, and engaging visual aids (animations, infographics) to turn complex medical concepts into **clear, actionable messages** for both clinical education and public awareness.

Safe and inclusive patient involvement: Embedding lived experience in health policy and advocacy.

*Ms Kate Yearsley
Stroke Association, London, United Kingdom*

Category: Patient and public involvement (including policy, guidelines, research development and advocacy)

Summary of the service development

In 2024, the Stroke Association seized the opportunity of England's 10-Year Health Plan consultation to ensure stroke survivors, carers, and professionals shaped national health policy. Central to this work was a model of patient involvement designed for accessibility, inclusion, and psychological safety. Government "workshop-in-a-box" materials were adapted to NHS readability standards, with simple resources supporting people with cognitive or visual impairments. Facilitators were fully briefed to manage breakout discussions, create safe spaces, and ensure all voices were heard. Participants received advance preparation materials and, afterwards, a feedback report that summarised insights, acknowledged contributions, and outlined next steps—closing the loop often missing in patient involvement.

How this is relevant to other countries and what could be the potential impact across countries

This approach offers transferable lessons for stroke organisations internationally. It demonstrates how patient involvement can empower diverse voices, particularly those facing barriers from fatigue, communication challenges, or lack of confidence. By prioritising accessibility, strong facilitation, and accountability, stroke organisations can strengthen legitimacy in policy discussions and model good practice in inclusive engagement.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Stroke survivors reported feeling valued and reassured that their contributions mattered in shaping future health services. Their insights informed the Stroke Association's policy response and helped influence the Government's commitment to a cardiovascular disease framework, including stroke. More importantly, the process reinforced survivors' sense of agency and dignity, demonstrating that lived experience can drive meaningful health system change.

68 - SHINE: A Survivor-Led Model for Collaborative and Equitable Life After Stroke Systems

*Mrs Stacie Broek^{1,2}, Ms Stacy Quinn¹, Dr Melinda B. Roaldsen^{1,3,4,2}
1SHINE, Zürich, Switzerland. 2European Life After Stroke Forum Scientific Committee, Brussels, Belgium. 3COO for Stroke Action Plan for Europe, Basel, Switzerland. 4Associate Professor and MD with lived experience, Clinical Research Department, University Hospital of North Norway & Vice Head, Department of Clinical Medicine, UiT the Arctic University of Norway, Tromsø, Norway*

Category: Patient and public involvement (including policy, guidelines, research development and advocacy)

Summary of the service development

Although stroke survivor voices are increasingly included in stroke initiatives, involvement is often limited, inconsistent, and largely consultative (Hall et al., 2022; Lynch et al., 2024). SHINE was created to change this by shifting from participation to leadership, building the survivor-led structure that was missing, a network that connects survivor advocates across regions, amplifies their collective voice, and partners with organisations to drive meaningful change in life after stroke. To put this vision into practice, in our first year, we established survivor-led governance, formed an international advisory board with leaders from science and policy, and initiated international outreach.

How this is relevant to other countries and what could be the potential impact across countries

Our early engagement shows an appetite for survivor advocates in service design. While stroke systems vary between countries, evidence shows that long-term support remains fragmented, under-resourced, and unevenly distributed across regions (Feigin et al., 2021). SHINE offers a collaborative, transferable model that can connect leaders across borders and align survivor voices with existing frameworks such as WHO's Rehabilitation 2030 and the WSO's Global Stroke Bill of Rights. The potential impact is a more equitable, consistent, and innovative approach to post-stroke services internationally.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

By embedding survivor leadership into system design, SHINE helps make services more responsive to, and grounded in, the diverse priorities and long-term needs of people living with stroke. This approach strengthens engagement with secondary prevention strategies, makes professional education more relevant, and ensures survivors are partners in building systems that support recovery and sustainable health. Survivors bring insights that span the full spectrum of stroke care.

69 - Beyond diagnosis - The benefits of a holistic assessment of need for community-dwelling stroke survivors.

*Miss Fiona Smith, Ms Helen Gaynor
The Irish Heart Foundation, Dublin, Ireland*

Category: Rehabilitation in life after stroke

Summary of the service development

Upon referral to the Irish Heart Foundation's Stroke Connect Service, staff work collaboratively with stroke survivors and their families to carry out a holistic assessment of need. This process helps build a clear understanding of any unmet needs on transitioning home after hospital discharge.

Staff deliver the assessment in a structured but informal way, creating a comfortable environment that encourages open discussion. It explores social, psychological, emotional, and community-related needs, aiming to identify gaps in support and areas that require attention.

The assessment acts as a "living document," guiding goal setting and planning for the next steps.

A key benefit is that it enhances the effectiveness of follow-up support calls by providing insight into what matters most to the person. It also helps staff understand the individual's daily routine, identify risks early, and offer timely signposting to relevant services.

How this is relevant to other countries and what could be the potential impact across countries

Research consistently highlights the long-term challenges faced by stroke survivors. Andrew et al. (2016) further link unmet needs to reduced quality of life for both patients and caregivers.

Delivering an assessment of need as standard practice in stroke support organisations would ensure that needs do not fall through the cracks once a person is discharged home, focusing on what matters most from the outset. This approach increases overall long-term quality of life.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Staff structure the assessment to identify unmet information and secondary prevention needs early in the recovery stage. They also ensure the implementation of a plan and document any emerging needs.

70 - The Rebuild Programme

*Miss Beatriz Gomez Maestre
Croí, Galway, Ireland*

Category: Rehabilitation in life after stroke

Summary of the service development

The Croí Rebuild Programme is a 10-week, group-based intervention designed to improve physical ability, support brain function, and equip stroke survivors with the tools and knowledge to rediscover enjoyment and confidence in life after stroke. Each participant undergoes a one-to-one assessment at the start and end of the programme, receiving a personalised report to guide recovery and facilitate communication with healthcare professionals.

The weekly sessions consist of three key components: 1-hour stroke-specific exercise class, tailored to individual needs; 30 minute break for coffee, tea & biscuits with time to socialise; and 1 hour session each week, alternating between stroke-related.

How this is relevant to other countries and what could be the potential impact across countries

In Ireland, as in many European countries, community-based stroke services remain underfunded and fragmented. The Rebuild Programme addresses this gap through a community-driven model with an internal referral pathway, allowing survivors to self-refer or be referred by professionals, ensuring continuity of care beyond hospital discharge. The Rebuild Programme demonstrates how a holistic, person-centred approach can deliver lasting impact and meaningful recovery for people with lived experience of stroke.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

By combining rehabilitation with education on lifestyle and risk reduction, the Rebuild Programme contributes directly to secondary prevention. Participants are supported to adopt healthier behaviours, better understand their own health numbers, and engage with an exercise routine that lowers the likelihood of another stroke. The programme also builds a strong foundation of peer support, reducing isolation and creating opportunities to share lived experiences. Through facilitated social interaction, participants often rediscover purpose, motivation, and new ways to enjoy life after stroke.

71 - Gamified rehabilitation for stroke recovery: exploring the potential of home-based digital therapy

Mr Davide Azzalin

Category: Rehabilitation in life after stroke

This submission focuses on the role of training and telerehabilitation in supporting stroke survivors during their recovery and reintegration into daily life. It highlights the use of remote rehabilitation technologies and structured training programs to improve functional outcomes, enhance accessibility, and maintain continuity of care. Emphasis is placed on the effectiveness of virtual platforms in delivering physical, cognitive, and psychosocial rehabilitation, as well as training for both patients and healthcare providers to optimize engagement and outcomes in a post-stroke context.

Summary of the service development

Stroke survivors often face limited access to long-term rehabilitation, particularly after hospital discharge. Rehability is a digital, gamified rehabilitation platform designed to support stroke recovery through engaging, personalized virtual exercises that can be performed independently at home or in outpatient settings. The system combines physical, cognitive, and motivational elements using interactive game-like environments, adaptable personalised therapy plans, and real-time feedback.

How this is relevant to other countries and what could be the potential impact across countries

The platform has been implemented in rehabilitation contexts across several European countries, including Italy, the UK, Spain, Greece, and Poland. Preliminary observations suggest consistent usability across different healthcare settings. Its low technical requirements, remote monitoring capabilities, and language-independent design enhance its potential scalability in both urban and rural environments. The technology may offer value to healthcare systems seeking to extend rehabilitation access and reduce long-term costs.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Digital rehabilitation platforms may enhance motivation and participation in therapy, supporting continuity of care and promoting autonomy. By enabling flexible and engaging rehabilitation at home, such tools could contribute to improved functional outcomes and quality of life for stroke survivors.

72 - A comprehensive digital intervention for post-stroke speech and language rehabilitation and caregiver involvement

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3CoNurse.net, Tallinn. 4EdTech Estonia, Tallinn. 5SpeakTX, Tallinn*

Category: Rehabilitation in life after stroke

Summary of the service development

SpeakTX.com is a comprehensive digital service offering for post-stroke settings in patients with aphasia, dysarthria, dysphagia and related speech, language and swallowing difficulties.

Stroke pathway support is offered from SLT/SLP office setting to full remote enablement of therapy sessions, both therapist-supported and self-paced.

The interactive rehabilitation exercise pool includes a wide range of options from simple text-based word/phrase/sentence/narrative stimuli to clinical SLT supported video-based exercise content supporting strengthening of swallowing functions. Additional modules include support for stuttering, dyslexia and other applicable conditions.

Institutions utilizing SpeakTX compose patient-specific rehabilitation plans and monitor adherence to those through a simple web-based/mobile interface and make adjustments where needed.

How this is relevant to other countries and what could be the potential impact across countries

SpeakTX has been validated in severe stroke patient pathways in Estonia and as well piloted and localized in Germany in Klinik Altmühlfranken, with ongoing collaborations to include diagnosis-specific modules for uptake at mid/large healthcare providers.

SpeakTX is as well available for early childhood development and pediatric rehabilitation in a total of 7 countries, with new geographies being continuously evaluated. The core criteria for expansion and further impact includes countries with a severe shortage in SLT/SLP specialist resource availability. Direct reimbursement options are explored both in Estonia and Germany.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

The positive impact of SpeakTX has been documented through feasibility studies in Germany and Estonia, highlighted visually.

The impact factor of the digital service offering is estimated at 30-50X cost efficiency level when compared to standard in-person rehabilitation, enabling therapy anywhere, anytime when most convenient for the patient and caregiver(s).

73 - Early Supported Discharge – A Feasible and Effective Rehabilitation Pathway for Patients Post Lateral Medullary Stroke

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Category: Rehabilitation in life after stroke

Summary of the service development

This retrospective review evaluates Stroke Early Supported Discharge (Stroke-ESD) as a feasible and effective rehabilitation pathway for patients post lateral medullary stroke. Clinical manifestations include ataxia, dizziness, Horner's sign, hemisensory loss, vertigo, dysphagia, and dysphonia. Four patients are included in our case series, age range 37-72. All required enteral feeding post-stroke, with three requiring a radiologically inserted gastrostomy (RIG). As inpatient rehabilitation services were unable to accept these patients due to the RIG, the Stroke-ESD team proposed a pathway for discharge home with collaboration from community dietitians.

How this is relevant to other countries and what could be the potential impact across countries

There is a paucity of evidence on Stroke-ESD for this cohort, most studies focused on inpatient acute or rehabilitation. This Stroke-ESD pathway is feasible and effective for patients post lateral medullary stroke, supporting functional recovery within the community and reducing length of stay in hospital. It offers an alternative pathway compared to the usual care of inpatient rehabilitation.

Further evaluation in larger cohorts is recommended to validate these findings and provide further insights into clinical outcomes.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Outcome measures for activities of daily living (ADLs), swallow function, gait speed & balance improved for all patients. The average FIM+FAM improvement across all patients was 35 points. Improvement in swallow function resulted in removal of feeding tubes in all patients. All patients reported a positive experience of rehabilitation in their home.

74 - D.A.Re. - Remote Assistance for Dysphagia

Dr Maurizio MASSUCCI

Category: Rehabilitation in life after stroke

Summary of the service development

Background and aims

Dysphagia severely impacts the quality of life of patients who have suffered from stroke, their family members, and caregivers, as they must adopt precautions during meals, modify food consistency, and use compensatory strategies. The objective of the project is to provide digital support to patients with chronic stroke and their caregivers to help them manage dysphagia daily.

Methods

The web provide a panel of 26 videos and example images that are on line accessible via a personal QR code. Based on clinical and functional assessments, healthcare professionals will be able to select the appropriate content for each individual case and create a personalized counseling plan. Patients and caregivers at home will be able to access the platform by selecting the specific content chosen by the clinical team.

Results

18 speech therapists operating in some Italian regions recruited a total of 111 patients (61.67% of the available web stations). The average number of logins recorded per user was 25. The SUS (System Usability Scale) analysis produced a score of 76.25 which can be considered a "ok/good" value. A CATI (Computer Assisted Telephone Interview) survey conducted on 30 cases to know the quality perceived by the patient, produce a score greater than 86%.

Conclusions

Despite the small number of user samples, the D.A.Re. project demonstrated the feasibility and usefulness of an asynchronous telecare model for home management of dysphagia.

How this is relevant to other countries and what could be the potential impact across countries

Method replicable through video translation/dubbing

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Personalized digital tools ease caregiver stress, improve dysphagia care, and optimize health resources.

75 - Enriching the home environment to improve rehabilitation after stroke: Introducing the PEER-HOMECare project development

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Category: Rehabilitation in life after stroke

Summary of the service development

The intervention “Pedagogy and Enriched Environment for Home Based Stroke Rehabilitation” builds on the concept of Environmental Enrichment (EE), originally from animal-based research. EE has shown 25–50% improvements in motor and cognitive performance in animals by stimulating exploratory behavior and motor learning. Translating this concept to human, home-based rehabilitation is novel, thus the aim is to apply the EE principles in stroke rehabilitation.

The development followed four overlapping phases:

- i) conceptual and contextual foundation,
- ii) intervention outline,
- iii) programme theory outline,
- iv) refinement of both intervention and theory.

We are currently in phase iv. From January 2026, the intervention will be carried out in Norway, Latvia and Sweden. A feasibility study will run in parallel, exploring acceptability, adherence, and experiences of participants, families, and health care personnel in all three countries.

How this is relevant to other countries and what could be the potential impact across countries

The intervention is highly relevant internationally, as it occurs in the stroke survivor’s home using existing objects and daily activities for motor learning. This minimizes the burden on health care systems. EE principles are culturally adaptable, making the PEER-HOMECare intervention potentially effective across diverse countries and health care settings.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

EE principles are expected to promote motor learning through motor and cognitive problem-solving and exploration, and is hypothesized to enhance

functional abilities. Sustainability is key: stroke survivors and families will be trained to continue EE practices independently after the study period, in order to support long-term recovery and empowerment.

Sex and intimacy after stroke: developing an education package for healthcare staff

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Category: Relationship needs

Summary of the service development

Less than 10% of patients receive any advice despite 90% of patients hoping for advice relating to sexual dysfunction in stroke (Na et al, 2020)

One of the biggest barriers to receiving the information is reluctance of healthcare professionals to open conversations as they feel they have insufficient expertise (Fox et al 2020).

The Greater Manchester Neurorehabilitation and Integrated Stroke Delivery Network (GMNISDN) delivered two training events; an online webinar and an in person masterclass, to build capacity, knowledge and confidence in discussing sex and intimacy. These events heavily involved people with lived experience of stroke in the planning stages and throughout their delivery.

The initial webinar gave healthcare professionals an overview of how to introduce the subject of intimacy, what broad information service users want, and how to manage questions. The masterclass built on this with opportunities to practice conversations in role play, to look at equipment, to understand the limits of professional competence and when to seek further help.

The next step is to evaluate how it has impacted practice six months on from the event, and the results of this will be available by the time of the conference.

How this is relevant to other countries and what could be the potential impact across countries

The training could be shared and replicated across countries as the information is internationally sourced and builds on the skills of the MDT rather than relying on geographically significant treatment pathways.

How this will positively impact on people with lived experience of stroke, or on the secondary prevention of stroke

Addressing knowledge gaps and fear among HCPs allows open conversations to enable people to get the information they need to navigate living with stroke.