European
**Life After Stroke**
Forum

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# Abstract Book

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# SCIENTIFIC ABSTRACTS

## 1 - Building a Grounded Theory of Resilience in Chronic Ischemic Stroke

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Globally, stroke affects 15 million people annually, causing lasting physical, emotional, cognitive, and psycho-social effects. Recovery should focus on cultivating resilience in stroke survivors. However, gaps exist between theoretical models and interventional strategies for supporting resilience in chronic stroke. This study investigated an adapted Mindfulness-Based Stress Reduction program to address these gaps and aimed to build a grounded theory of stroke survivors' experiences of resilience.

### Method

The guiding research question was: “What are stroke survivors' experiences of resilience after participating in the Mindfulness-Based Recovery from Stroke program?” A convergent mixed methods pilot study was conducted with eight purposively chosen chronic ischemic stroke participants. The study involved an 8-week adapted Mindfulness-Based program, developed and led by a stroke survivor. Data sources included focus groups, pre and post-test scores on the Stroke Specific Quality of Life and Brief Resilience Scale, and a case study of extreme resilience.

### Results

Initial themes included: (a) Barriers to Resilience, (b) Facilitators through Mindfulness-Based Recovery from Stroke, and (c) Experience-Related Wellness Outcomes. Extreme resilience themes were: (a) Antecedents to Post-Stroke Resilience, (b) The Obstacle is the Way, and (c) Embodied Mindfulness. The selective code working toward a grounded theory is *Sand Mandala,* representing resilience, growth, and thriving after stroke.

### Conclusion

The program enhanced stroke recovery, offering a supportive community, trustworthy facilitators, and adaptive content, fulfilling an unmet need distinct from traditional stroke rehabilitation. The example of extreme resilience adds new dimensions to supporting psychological recovery.

### How will this research improve life after stroke for stroke survivors?

This research lays the theoretical groundwork for resilience in chronic stroke, developing new knowledge to meet the unmet needs of the stroke survivor. The intervention is adaptable, easily reproducible, flexible in modality, and cost effective. Most importantly, this work improves the inner and interpersonal world of stroke survivors.

## 2 - Adapting the Oxford Cognitive Screen for reduced visual acuity

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Specifically developed for acute stroke survivors the Oxford Cognitive Screen (OCS) is inclusive for individuals with aphasia, motor impairments and neglect. Reduced visual acuity has been shown to impact completion rates and performance, including lack of access to required reading glasses. This study aimed to assess completion rates and equivalence of contrast enhanced OCS-tasks to the original version.

### Method

Stroke survivors aged ≥17 years were recruited and completed two versions (original and adapted) of two OCS-tasks (broken hearts cancellation and trails) the administration order was randomised, to determine equivalency and relative completion rates. Results of an orthoptic vision assessment were also collected.

### Results

A total of 500 participants were recruited, 43.2% female, mean age 70.6 years. Near visual acuity had a mean of 0.278 (SD0.277) LogMAR. The broken hearts cancellation and trails tasks were completed by 2.2% ($p=0.041$) and 0.4% ($p=0.791$) more participants respectively with the contrast enhanced version. Equivalence was assessed using participants with good near visual acuity who completed both versions. Means were indicated as being equivalent by all lower and upper bounds of the two one-sided test of equivalence falling within the range of 0.5SD for all scores. Analysis of impairment detection revealed fair to good agreement.

### Conclusion

The adapted version allowed a higher proportion with reduced visual acuity to complete the assessment. In the presence of good visual acuity, the tasks were deemed to be equivalent. The contrast enhanced version of the OCS will be available to license holders to increase accessibility for stroke survivors with reduced visual acuity.

### How will this research improve life after stroke for stroke survivors?

This study and adaptation of the OCS has therefore broadened its accessibility further to stroke survivors with reduced visual acuity or simply do not have access to their reading glasses in hospital. The adaptation has already been adopted into other versions of the OCS e.g. mini-OCS.

## 3 - Prevalence, predictors, and patterns of non-motor outcomes 6 months after stroke: a large cohort study

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Post stroke non-motor outcomes place a major burden on both patients and caregivers, but current understanding is limited. Our aims are to evaluate: the prevalence of adverse non-motor outcomes in single and multiple health domains; their baseline predictors; and the co-occurrence of adverse outcomes in different domains.

### Method

We obtained data from the Stroke Investigation Group in North and Central London (SIGNAL) registry based at the University College London (UCH) Comprehensive Stroke Service. We included adult patients diagnosed with acute stroke due to cerebral ischaemia or intracerebral haemorrhage (ICH) from January 2017 to January 2020. We evaluated non-motor outcomes across 13 health domains at 6-month follow-up.

### Results

Follow-up was 92% complete for 3080 patients (2534 acute ischaemic stroke, 547 ICH). At 6 months, the most prevalent adverse non-motor outcomes were fatigue (57%), reduced social participation (55%), sleep disturbance (54%), and constipation (44%). Rates of $\geqslant$1, $\geqslant$2, $\geqslant$3, $\geqslant$4, and $\geqslant$5 adverse non-motor outcomes were 75%, 51%, 49%, 40%, 26%, respectively. Moderate correlations using kappa statistics were found between fatigue and sleep disturbance (k=0.72), memory and thinking impairment and reduced ADL/IADL (k=0.68), communication problems and ADL/IADL (k=0.70). In multivariate analysis common factors associated with adverse outcomes were ICH, NIHSS score>5 at admission, and previous stroke or TIA.

### Conclusion

Adverse non-motor outcomes are very common 6 months after stroke: fatigue, sleep disruption, and reduced social participation each affect over 50% of survivors, and one-quarter suffer from five adverse outcomes. Our findings support the need for targeted interventions to mitigate these adverse outcomes.

### How will this research improve life after stroke for stroke survivors?

This research will improve life after stroke by identifying common non-motor outcomes, their correlations, and associated factors. The findings will guide targeted interventions, patient-centered care, and refined diagnostic pathways. By addressing unmet needs and improving service delivery, particularly for underserved populations, it will enhance recovery and quality of life

## 4 - Support needs when living as a family with aphasia

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Aphasia results in negative consequences like social isolation, loneliness, depression, loss of friendships, reduced autonomy, and changed family dynamics. Similarly, aphasia impacts family members, e.g., changes in relationships, roles and responsibilities, job, and social life. Consequently, care and rehabilitation should include the whole family living with aphasia throughout the care pathway.
The aim of this project was to review interventions for families with aphasia, investigate the needs of families living with aphasia and based on those results co-create in a catalogue of ideas and solutions meeting the identified needs.

### Method

This three-legged study is based on 1) scoping review of 69 studies interventions for families with aphasia; 2) qualitative interviews of 26 people with aphasia and family members; and 3) workshops with people living with aphasia and health professionals co-creating ideas and solutions for future development and implementation in care and rehabilitation.

### Results

Five major areas of needs have been identified: services reaching out to families; community and belonging; autonomy, relief, and psychological support; support for new tasks and roles; and communication training and support. None of the interventions in the scoping review match all the identified needs although most interventions match one or two. The co-creation workshops have resulted in a catalogue of ideas and solutions for further development and implementation across the care pathway from acute care to civil society.

### Conclusion

The multifaceted needs experienced by families living with aphasia cannot be meet in existing interventions. A range of ideas and solutions has been suggested.

### How will this research improve life after stroke for stroke survivors?

Interventions addressing some of the communicative and psychological needs are now being developed in collaboration with families with aphasia and health professionals and will be tested in relevant care and rehabilitation settings. In the future they have the potential to be implemented into regular services.

## 5 - “Below the Tip of the Iceberg”: Experiences of High Risk and Stroke Younger Adult Patients

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Stroke incidence is rising among younger adults (≤65years) worldwide. During this dynamic period of their lives, post-stroke recovery and subsequent stroke prevention is integral. Yet, there is a dearth of research on the post-stroke experiences, lifestyle habits, associated facilitators and barriers, as well as recommendations and preferences for improved brain care initiatives among this unique population. The aim of the study was to explore these gaps to better understand the experience of younger adults’ post-stroke as well as their needs and preferences around brain health and post-stroke interventions.

### Method

A qualitative exploratory design was employed as part of a larger mixed-methods study. Virtual, semi-structured focus groups were conducted. Simultaneous data collection and analysis were performed. Inductive thematic analysis was conducted.

### Results

The sample comprised of 12 stroke patients (mean age 45 years, 67% male, 83% stroke, 27.3% neurological condition). Six themes emerged: 1) alignment of current lifestyle habits with the pillars of lifestyle medicine; 2) life 2.0 as a new self-identity post-stroke and not wanting to “come out” about their stroke; 3) standard of stroke care, but to whose standard; 4) dualism of social influence; 5) pressures of conforming to societal gender expectations; and 6) innovating post-stroke and brain health interventions.

### Conclusion

Study findings have mobilized our understanding of younger adult stroke patients’ experiences as well as the influencing facilitators and barriers to the adoption and sustainment of healthy habits for risk factor modification, and approaches to reconceptualize and redesign brain care education and interventions to meet the needs, preferences, and priorities.

**How will this research improve life after stroke for stroke survivors?**
Guide brain health and post-stroke initiatives and interventions.

## 6 - Social Expectations of Women and Permission for self care": Stroke and Younger Adult Women

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Women are disproportionately affected by stroke worldwide. There is also an increasing stroke burden among younger and middle-aged women (≤65 years). The adoption of healthy lifestyle habits is integral for stroke risk factor modification; however, little is known about younger adult women's lifestyle-related knowledge, behaviours, associated and influencing facilitators and barriers as well as support needs post-stroke to support brain health, which this study aimed to address.

### Method

As part of a larger mixed-methods study, a qualitative exploratory design was conducted. Virtual, semi-structured focus groups were conducted. Data were collected simultaneously with inductive thematic analysis conducted.

### Results

The sample comprised of 11 women who were of high stroke risk or had a stroke. A total of seven themes emerged: i) lifestyle habits supporting holistic post-stroke recovery; ii) health challenges receding in the rear-view mirror; iii) not being the same mother as before; iv) having to leave my career behind and pressures to return; v) social expectations of women and permission to self-care; vi) psychological safety and comfort that comes with women-centered interventions; and vii) not heard, seen or considered as a woman in the health care system.

### Conclusion

Findings have implications on i) the development of educational interventions that focus on holistic and incremental lifestyle changes and that are peer-led and group-based; ii) the utilization of motivational interviewing and integrating health coaching and a group visit approach to the current model of stroke and neurological care; and iii) the provision of supports to children and families to facilitate their coping with parental strokes.

**How will this research improve life after stroke for stroke survivors?**
Inform future interventions and initiatives to support younger adults post-stroke as well as their families.

## 7 - Digital self-management support for sexual wellbeing after stroke and brain injury

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Neurological damage (1) and psychosocial changes after stroke can cause relationship problems and declining sexual wellbeing (2,3). Sexual wellbeing is an essential component of mental health, but is not routinely supported (4). Digital technologies can deliver much-needed support, resolve time constraints for professionals, and allow autonomy, privacy, and anonymity for participants. This study assesses the feasibility of a digital self-management programme to support sexual wellbeing: HOPE4ABI (5).

### Method

We aimed to recruit sixty participants with diagnosed or suspected stroke or any other type of brain injury, randomised to the intervention (peer-supported) or control (self-directed) arm. HOPE4ABI is a co-designed 8-week psychological intervention, with new content released weekly. Participants completed surveys at baseline, 8-weeks, and 6-months to measure wellbeing, and post-course interviews to explore acceptability.

### Results

The recruitment target was initially exceeded (n=73), but only 53 participants completed baseline and randomisation (intervention n=27; control n=26). Acceptability interviews (n=10) indicate the content and activities were helpful, but participants may need more time to complete modules. Participants reported HOPE4ABI had helped them initiate personal conversations around sexual wellbeing. Response rates at 6-months are promising (~70%, *ongoing*), and indicate improvements in mean scores of quality of life and sexual wellbeing, across both trial arms.

### Conclusion

The feasibility results indicate that a fully powered trial is warranted, and preliminary findings are similar to studies with other clinical groups (9,10). The digital HOPE4ABI programme is potentially a sustainable, cost-effective solution to supporting mental and sexual wellbeing after stroke, brain injury and other limiting long-term conditions.

### How will this research improve life after stroke for stroke survivors?

There is very little support available for survivors to manage changes to their intimate relationships in the aftermath of stroke and brain injury. The digital intervention we have developed and tested could be an accessible and cost-effective means of support for stroke survivors globally.

## 8 - Patient-reported non-motor outcomes after thrombectomy and intravenous thrombolysis: a large cohort observational study

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Revascularization treatment with intravenous thrombolysis (IVT), endovascular thrombectomy (EVT), or both improves ischaemic stroke motor function measured by the modified Rankin Scale (mRS). However, understanding of patient-reported non-motor outcomes remains limited. We aim to conduct a comprehensive assessment of non-motor prevalence across 13 health domains, stratified by mRS scores, and identify associated factors at 6 months post-treatment.

### Method

Data were obtained from the Stroke Investigation in North and Central London (SIGNAL) registry. We included patients with acute ischaemic stroke treated with IVT, EVT, or both (2017-2020) at University College London Hospital's hyperacute stroke unit. At 6 months, motor function was measured using the mRS, and non-motor outcomes using Patient-Reported Outcomes Measurement Information System-29 (PROMIS-29), Stroke Impact Scale-59 (SIS-59), and the Barthel Index. Descriptive analysis estimated prevalence, while logistic regression identified factors associated with non-motor outcomes.

### Results

A total of 642 patients were included in our analysis, (mean age of 73 years, and 43.5% were female). Of these, 382 received IVT, 153 underwent EVT, and 107 received both treatments. The mean mRS score was 1 (range: 0–3), indicating a good clinical outcome. Among patients with good clinical outcome on mRS, adverse non-motor outcome prevalences ranged from 17% to 51%, with fatigue (51%), sleep disturbance (49%), and bowel dysfunction (39%) most common. Older age, stroke severity, and ESD independently associated with adverse outcomes.

### Conclusion

Half of patients, despite good mRS scores, report fatigue and sleep disturbances, while one-third experience bowel dysfunction. Future studies must include non-motor outcomes to reflect the real-world impact of stroke.

### How will this research improve life after stroke for stroke survivors?

This research will improve life after stroke by addressing non-motor outcomes across multiple domains, even with good mRS scores. Our findings will provide evidence for revascularization trials and guide clinicians in integrating these outcomes into routine practice, ultimately meeting the unmet needs of stroke survivors in real-world settings.

## 9 - Implementing Take Charge After stroke in routine care in a stroke support service

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Take Charge After Stroke (TACAS) is an evidence-based intervention that supports people to ‘take charge’ of their recovery. While there is increasing evidence of its effectiveness in improving independence, it has not been widely embedded in usual care in stroke services in New Zealand. This study sought to  understand the experiences implementing TACAS in a community stroke organisation to provide insights for future service provision.

### Method

A Qualitative Description study. Data included surveys with people with stroke (clients) and community stroke advisors (providers); fidelity data; and interviews and focus groups with clients, providers, and managers. Data were analysed using conventional content analysis and normalisation process theory (NPT).

### Results

TACAS was perceived as helpful for some clients in supporting them to look differently at the stroke, their identity, and to identify what was meaningful. However, it was not universally needed, appropriate or accessible. While TACAS appeared initially simple to provide, it became clear that it was a sophisticated practice that differed from usual practice, grounded in psychological safety, fostered by therapeutic relationships and skilled communication. Different elements of TACAS appeared useful in different contexts. Providers needed support to integrate into usual practice in ways that maintained the core theoretical and empirical underpinnings of TACAS.

### Conclusion

TACAS may be one of a suite of tools that can enable supported self-management. While TACAS has significant value, we identify a number of areas that need to be addressed so that providers can ‘normalise’ TACAS within everyday practices.

### How will this research improve life after stroke for stroke survivors?

Improving implementation of Take Charge will better support people to build their sense of capability and agency after stroke. Making Take Charge more accessible, and enhancing implementation will enable Take Charge to have the impacted evident in randomised controlled trials - enhanced self-determination, independence, and quality of life.

## 10 - Supporting well-being after stroke: A quality framework for stroke services

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Following stroke, a sense of well-being can be critical to a person's quality of life. However, it is commonly impacted by the stroke. People with stroke and practitioners all suggest it is poorly addressed in stroke services. We have undertaken a programme of work to examine why this is, and how supports could be improved. This paper details the development of a quality framework to guide services and practitioners in enhancing care.

### Method

Underpinned by Interpretive Description, we interviewed 24 people with stroke, 13 family members, and 34 practitioners. Using conventional content analysis and journey mapping, we identified characteristics of high quality care.

### Results

Eight characteristics of high quality care were identified: Supporting people through uncertainty; valuing people's knowledge and supporting their choices; attuning to the emotions of people with stroke and their whānau (family); honouring the strengths and needs of family, whānau and key support networks; supporting holistic long-term well-being; providing culturally safe care; prioritising relationships and connecting as people; and fostering a sense of belonging. While these care practices are enacted by practitioners, we detail organisational and stroke-system supports that are necessary to enable practitioners to embed well-being work in every-day practices.

### Conclusion

Stroke care happens in complex contexts which impact how practitioners work and how people experience care. By making the practices that support well-being visible, and by identifying how these practices can be supported by healthcare organisations, this framework provides a tangible, evidence-based resource that can enhance practice, inform education and policy, and support people's long-term well-being after stroke.

### How will this research improve life after stroke for stroke survivors?

Practitioners have often struggled to know how to support well-being. This framework provides tangible strategies that are anticipated to improve people's experiences in stroke services and intentionally address long-term well-being and quality of life from early in their stroke journey. This can benefit stroke survivors and those who support them.

## 11 - Lessons from the Support After Stroke with group-based classeS (SASS) feasibility trial

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**Category: Emotional, cognitive and psychological impact of stroke**

### Background and aims

Movement-based mindfulness (MBI) may improve post-stroke well-being and mood. The aims of this feasibility study were to explore differences in outcomes and perceptions between treatment arms in the Support After Stroke with group-based classeS (SASS) trial, comparing a co-designed MBI intervention (tailored yoga and meditation) to attention control (lifestyle education with socialisation) over 12 weeks post-stroke.

### Method

Eligible participants (~3-18mths post-stroke) were randomised (1:1 stratified by age and severity) to either MBI or attention control groups. Outcomes: quality-of-life, mood, fatigue, blood pressure, stress, participant satisfaction (closed and open questions). Analysis: descriptive statistics and Cohen's d (within-group change) and generalised linear modelling (between-group differences) were conducted, inductive thematic analysis for qualitative data. Trial registration: ACTRN12620000105943

### Results

36/38 (mean age: 70 years, male: 74%) completed. Classes had 2-5 participants; >90% participation both groups. Satisfaction surveys completed by 89%. No significant between-group differences found. Within-group effects were larger for MBI (vs control) in fatigue (0.22 vs. 0.18), quality-of-life (0.57 vs. 0.40), blood pressure (systolic: 0.35 vs control 0.10) and stress (perceived stress scale: 0.12 vs control 0). The MBI had smaller effects for reducing anxiety (0.25 vs. control 0.48) or depression (0.11 vs. control 0.48). The MBI group reported benefits from movement and meditation fostering a positive outlook and well-being. The attention control valued the social interactions. Both groups valued open conversations and recommended having larger classes.

### Conclusion

Promising small-to-medium within-group effects observed. Excellent engagement in both groups highlights the benefits of group-based programs. The complexities of designing attention control groups for MBIs will be discussed.

### How will this research improve life after stroke for stroke survivors?

This research highlights that participation in group-based programs, such as movement-based mindfulness and lifestyle education with socialisation, may enhance well-being, reduce anxiety, and foster a more positive outlook for survivors. Larger, well-powered studies are needed to confirm these findings in support of better long-term recovery and community reintegration after stroke.

## 12 - Lifestyle knowledge and behaviours among stroke and high stroke risk younger adult patients

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

### Background and aims

The epidemiological shift in stroke incidence among younger adults has transformed the stroke landscape. Recognizing that modifiable risk factors are associated with stroke and stroke risk, focusing on physical health through risk factor modification is imperative. However, it is integral to understand younger adult stroke and high-risk patients' lifestyle-related knowledge, behaviours and associated facilitators and barriers to such adoption. The study aimed to address this current gap in knowledge and research.

### Method

A cross-sectional study was conducted. Data on sociodemographic and clinical characteristics coupled with lifestyle-related knowledge, behaviours, associated facilitators and barriers were collected through an online self-reported survey. Data were analyzed using descriptive and inferential statistics.

### Results

A total of 104 participants comprised the study sample. Most participants (≥ 63%) understood current lifestyle recommendations around blood pressure, sleep, and alcohol consumption, but few (14.4%-25%) around diet and exercise. Almost half (45.6%) ate processed food weekly with emotions and social/family situations influencing eating habits. More than half (55.9%) reported moderate levels of exercise with work and family responsibilities as main barriers. Most participants (51.9%) slept <7 hours per night, had a sense of social connectedness, and moderate-manageable levels of stress. Gender, age, and stroke status differences were observed.

**Conclusion**
Findings showed variability in lifestyle-related knowledge and the adoption of healthy behaviours. Findings have implications on i) having lifestyle-related interventions as “standard of stroke care” in stroke and neurology practice; and ii) integrating lifestyle medicine prescriptions as an alternative means to support healthy lifestyle behaviours to support brain health among this unique patient population.

**How will this research improve life after stroke for stroke survivors?**
Findings have the potential to inform lifestyle-related educational and behavioural interventions for younger adult patients for risk factor modification.

## 13 - Stroke survivors' views of working relationships and self-management in community stroke rehabilitation.

*Miss Lauren Lucas*

*University of Manchester, Manchester, United Kingdom. Northern Care Alliance NHS Foundation Trust, Salford, United Kingdom*

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

### Background and aims

After a stroke, building strong working relationships with healthcare professionals is important for recovery and self-management. However, there is limited understanding of how these relationships form in community settings and how they affect self-management. This study with stroke survivors aims to understand: (1) how relationships with professionals develop in the community and their role in helping or hindering self-management, and (2) wider barriers and facilitators for self-management when community rehabilitation ends.

### Method

Qualitative interviews were conducted with stroke survivors recruited from community stroke teams and peer support groups in England. Seven people with lived experience of stroke helped develop the interview topic guide and contributed to the analysis. The interviews were analysed to find common themes using thematic analysis.

### Results

From the twenty interviews, two main themes emerged: ‘person centredness is the heart of supported self-management’ and ‘relationship with myself and others’. Together these reflect a bigger idea: self-management is a long and personal journey. Seven sub-themes highlight how working relationships impact self-management and the broader barriers and facilitators for stroke recovery.

### Conclusion

Building trust with professionals and focusing on personal goals helps stroke survivors manage their recovery. However, negative relationship experiences may lead to withdrawal from the relationship and avoidance seeking future help. Relationships with family, friends, peers and wider organisations also support self-management. The emotional trauma of stroke and changes to self-identity are important but often overlooked. Accepting a new sense of self after a stroke can help stroke survivors feel ready to manage their own recovery.

### How will this research improve life after stroke for stroke survivors?

Understanding and accepting a post-stroke identity may have an important role in self-management. Future research focusing on identity after stroke may highlight opportunities for professionals to use psychologically informed practices in community rehabilitation. Such approaches may better support the emotional needs of stroke survivors, improving self-management and quality of life.

## 14 - Differences in information needs of parents after pediatric stroke – Results of an online survey

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*German Stroke Foundation, Gütersloh, Germany*

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

### Background and aims

The burden of pediatric stroke manifests itself in parents as anxiety, depression and post-traumatic stress (Lehmann et al. 2020). Families have a wide range of needs in life after stroke and a gap in support services due to of the rarity of the disease (Gordon et al. 2018).

### Method

Before developing the online survey, we conducted interviews with four families to identify the existing range of issues and information needs. We identified differences by asking which needs were present at the time of the pediatric stroke and which were present at the time of the survey. 322 families from the German Stroke Foundation database were invited to take part in the survey in 2024.

### Results

163 families completed the survey (response 51%). The time since the stroke ranged from a minimum of six months to a maximum of 23 years, with an average of 8.0 years (SD=6.7 years). The average age of children who had a stroke was 4.7 years (SD=4.6 years).
The most important information needs at the time of the stroke were about the disease progression (79%), the stroke itself (62%), early childhood development (56%), physiotherapy (56%) and social-pediatric centers (46%). The major issues at the time of the survey were the relationship with family and friends (54%), the disability card (52%), the disease progression (49%), occupational therapy (48%) and physiotherapy (46%).

### Conclusion

The results show the need for further development of specific information services to reduce the burden of pediatric stroke, depending on the stage the families are in.

### How will this research improve life after stroke for stroke survivors?

The new awareness-raising project “Better together” of the German Stroke Foundation aims to develop new media based on this online-survey in cooperation with families affected by stroke to meet their identified information needs in the future. In addition, a community platform will offer the opportunity to network and exchange ideas.

## 15 - Speech-Language Pathology Group with Family Members of People with Post-Stroke Aphasia - a Brazilian Experience

*Thais Ferreira Fernandes, Professor Regina Yu Shon Chun, Professor Amanda Brait Zerbeto*
*University of Campinas, Campinas, Brazil*

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

### Background and aims

Introduction: Stroke is the leading cause of aphasia, characterized by language alterations. People with aphasia may require assistance in their daily lives, and their caregivers often experience physical and emotional strain. A SLP (speech-language pathology) group with family members can provide a space for sharing experiences and care.
Aim: To analyze SLP group care for people with post-stroke aphasia.

### Method

A documentary, retrospective, and cross-sectional study with a qualitative approach, approved by the Research Ethics Committee under no. 6.643.220. Six monthly meetings with family members were analyzed. These were conducts by SLP students from a public university in Brazil, under faculty supervision. Data were collected from records. Content analysis was performed.

### Results

Six women, all wives, participated, most with incomplete high school education, aged between 29-70 years. The adults with aphasia were mostly men aged 60-89 years. The meetings included: warming up, development, closing, and assessment. The aims of the meetings were to discuss: language and autonomy of the person with aphasia, caregiver self-care, the importance of the support network and other topics. Family members reported providing full-time care for others and having little time for self-care. Participants engaged in the group, sharing experiences and asking questions. The meetings were positively evaluated, with comments such as:"by talking, we discover a lot, many ways to get treatment."

### Conclusion

The SLP group has promoted interaction and sharing of experiences and concerns among participants, promoted health care, and reiterated the need for public policy actions in Brazil aimed at this population.

### How will this research improve life after stroke for stroke survivors?

Many stroke survivors have difficulty communicating with others. SLP group interventions with caregivers and family members of people with post-stroke aphasia can enhance communication between the survivor and their family members, reducing caregiver burden and promoting the health of everyone involved.

## 16 - Structured follow-up after stroke in a municipal primary care setting - healtcare professonals perspective

*Mr Johan Lundin*, *Mrs Hanna Persson, Mrs Emma Kjörk*

*Gothenburg Univursity, Gothenburg, Sweden*

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

### Background and aims

In Sweden approximatly 20% of the patients in municipality primary care have stroke. Structured follow-up after stroke not been studied in a municipal primary care setting. Structured follow-up after stroke have yet to be implemented in municpal primary care and few patients get structured follow-up after stroke. The aim of this study is to gain an understanding of healthcare professionals experience of a new structured multidisciplinary follow-up process for patients with stroke, in a municipal primary care setting.

### Method

This is a qualitative focus group study analyzed with Kruegers´s focus group methodology. Healthcare professionals (n = 27) in a multidisciplinary team followed a new process of structured follow-up after stroke when visiting patients. The process included a multidisciplinary approach and the tools Strokehealth and Poststroke checklist. The experience of this process was shared in focus group discussions.

### Results

Five focus group discussions were conducted. Three main themes were created; a *new workflow to identify health problems, a structured teamwork increases knowledge and preparations for the patient meeting* and *a tailored patient meeting creates emotions*.

### Conclusion

The structured follow-up after stroke in a municipal primary care setting was found feasible by the healthcare professionals in their attempt to identify health problems in patients with stroke. It was deemed as important to individually tailor the structured follow-up after stroke according to patients' prerequisites and to include next of kin as support.

### How will this research improve life after stroke for stroke survivors?

An implemented structured follow-up after stroke in municipal primary care can identify health problems at an earlier stage then today. This will make it possible to give the right intervention at the right time. Limiting suffering and long terms effect after stroke.

## 17 - Development of initial programme level theories for Life After Stroke support pathways

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

### Background and aims

Ever-growing numbers are surviving stroke events and living with the consequences. LIFE AFTER STROKE recognises the struggle to adapt and build a new life after stroke and considers family and others who support the stroke survivor. No consensus on how to best promote agency and fulfilment in life after stroke or the resources required to achieve this currently exists.

### Method

Initial programme theories related to LIFE AFTER STROKE, consisting of context–mechanism–outcome configurations (CMOCs) and any resources required, were developed during the preliminary phase of a realist review. This phase (RAMESES methodology) convenes an expert panel, conducts a scoping review of the literature, and develops initial programme theories.

### Results

A scoping of 40 key articles generated candidate programme theories (CPTs: N=11). Consultation between researchers provided a first-level refinement, separating out differing constructs. These were further refined to six initial programme theories (IPTs) following expert panel consultation events including stroke theorists, health care professionals, support agencies and people with lived experience of stroke (N=13). The resultant IPTs with defined context, mechanisms and outcomes related to **Supported self-management after stroke; Goals and priorities and identifying needs after stroke; Peer support; Communication; Psychological supports; Living well after stroke.**

### Conclusion

These IPTs help conceptualise supports for Life after Stroke as a dynamic real world process. A systematic review will now validate or further refine these theories to help explain how generative causation within the life after stroke pathway works, which mechanisms are activated or work well in specific contexts.

### How will this research improve life after stroke for stroke survivors?

This research helps us to know what mechanisms (active ingredients) enable interventions designed to support a personally meaningful life after stroke to work. It also allows the contextual factors and resources that are required to help these intereventions achieve a personally meaningful life after stroke be called out clearly.

## 18 - The feasibility of a tailored, follow-up service 6-months after stroke: a registry-based randomised controlled trial

*Professor Dominique Cadilhac[1,2], Dr Adele Gibbs[2], Dr Andrew Ross[2,3], Dr Jannette Blennerhassett[4,5], Dr Tara Purvis[1], Ms Julie Morrison[2], Ms Melissa Brooks[6], Ms Jessica Pyman[7], Mr Rajesh Khanna[8], Professor Timothy Kleinig[8], Professor Rohan Grimley[7], Professor Vincent Thijs[2,4], Professor Monique Kilkenny[1,2], Professor Sandy Middleton[9,10], Dr Joosup Kim[1,2]*

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

### Background and aims

In Australia, 1 in 5 survivors report extreme problems at 3-6 months.  We aimed to assess the feasibility of tailored, co-designed follow-up service for people with stroke compared with usual care.

### Method

This was a feasibility RCT (ACTRN12622001015730). Registrants from four hospitals participating in the Australian Stroke Clinical Registry (AuSCR) were eligible: if they reported an extreme problem in at least one dimension of the EQ-5D-3L or scored ≤60 on the Visual Analogue Scale 90-180 days post-stroke; were community-dwelling; and willing to be contacted for research. Registry staff conducted telephone baseline assessments and the 90-day outcome assessment (blinded). Participants were randomised 1:1 to intervention or control group, stratified by age (<65 years, 65+ years) and sex. The intervention group received a tailored phone assessment by a trained health professional based at each hospital with ongoing support for 12 weeks, as required. Control group received no additional support. Participants also completed a satisfaction survey. Feasibility outcomes included participant retention, trial acceptability and service satisfaction.

### Results

Between April 2023 and May 2024, 238 registrants were screened; 68/226 (26%) were eligible; 62 randomised (31 intervention, 31 control; median age 68 years, 34% female). Fifty (81%) participants completed the 12-week outcome assessment (intervention n=27), 43 completed the satisfaction survey (intervention n= 23); three died. Generally, participants reported a positive experience, and would recommend participation to others. Final data cleaning and analysis is in progress.

### Conclusion

The study protocol and procedures were feasible with acceptable retention of participants. The findings will inform a future effectiveness trial.

### How will this research improve life after stroke for stroke survivors?

This research provides evidence for a novel follow-up service to support survivors of stroke who have indicated poor quality-of-life on outcome surveys to the national stroke registry. The findings inform initial feedback about this type of service and ongoing cooperation with hospitals or if the registry should explore other options.

## 19 - Primary care based pathways for post-stroke follow-up for long term care: a systematic review

*Miss Hannah Ravenhall[1], Dr Emily Symington[1], Dr Rachael Raw[2], Miss Linda Errington[1], Serena Sabatini[3], Faye Tabone[4], Dr Rhiannon De Ivey[1], Dr Khalifa Mohammad[1], Dr Eugene Yee Hing Tang[1]*

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

### Background and aims

Primary and community care is fundamental in the long-term support of stroke patients. Currently, many stroke patients are not receiving timely follow-up which can lead to hidden unmet needs that could be addressed in the community. The aim of this systematic review was to investigate current pathways and holistic interventions used in primary and community care to support post-stroke patients.

### Method

The review is registered on PROSPERO (CRD42024575490). Four databases were searched (MEDLINE, Embase, CINAHL and the Cochrane Library) from 2008 to July 2024. All study types were eligible and were included if the intervention was based around a review of a stroke patient's overall health and social care and delivered by the primary care team only.

### Results

The initial search identified 15,166 articles and 22 articles were included for data extraction. Results are pending but various themes have been identified which support post-stroke follow-up in primary care. By far the most published intervention are the development and implementation of post-stroke checklists. Additional areas of holistic intervention include the use of telehealth, education and self-management. Full results will be available at the time of presentation.

### Conclusion

There is evidence of various modalities of post-stroke follow-up with the aim of improving care after discharge from hospital. Despite the current range of methods, further work is required to test the efficacy of such tools; validating the effectiveness of implementation and the extent to which patients feel their needs are met after discharge.

### How will this research improve life after stroke for stroke survivors?

Long-term stroke care is the responsibility of those in primary and community care. This review has highlighted various strategies that look to assist primary care teams in the long-term management of stroke patients to address their often hidden and unmet needs and can therefore inform the development of future interventions.

## 20 - Social support as part of self-management after stroke: A systematic mixed studies review

*Mrs Linnea McCarthy*[1], *Dr Maya Kylén*[2,1], *Dr Catharina Gustavsson*[3], *Professor Tracy Finch*[4], *Professor Fiona Jones*[5], *Professor Marie Elf*[1]

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

### Background and aims

Self-management after stroke is often considered an individual process with focus on personal behaviours and skills. There is, however, an increasing recognition of self-management as a common process, involving social interactions. This study aims to review the literature on how social support is influencing self-management after stroke, including to understand who is providing non-professional social support and how it contributes to the self-management process of the stroke survivor.

### Method

A mixed methods systematic review is being conducted. Search terms were elaborated by the research team and an informational specialist was consulted to conduct the literature search in five databases relevant to the field. The search yielded 2096 titles that are being screened for eligibility. Data from the included studies will be extracted to provide an overview of support providers, type of support, way of delivery and their contribution to self-management ability. A convergent integrated approach will be adopted to transform quantitative data to qualitative data, followed by content analysis of all retrieved data. Risk of bias in included studies will be assessed by using the Mixed Methods Appraisal Tool. All methodological steps in the study will involve interrater reliability checks of the conducting researchers.

### Results

The results will be presented based on the content analysis and examples from the included studies will be used to confirm the findings.

### Conclusion

This study will provide a comprehensive overview of what is known about the role of social support in self-management after stroke and contribute to the perspective of self-management as a collective process.

### How will this research improve life after stroke for stroke survivors?

This focus is beneficial to practitioners and researchers concerned with developing efficient support structures after stroke and therefore, not least, to people managing life after stroke.

## 21 - Experiences of using the previsit tool “Stroke health” before a follow-up visit

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

### Background and aims

Structured follow-up visits should be offered after a stroke enabling shared decision-making. A digital pre-visit tool (“Stroke health”) was co-designed to ensure people with stroke can prepare well in advance. The tool is based on the questions in the Post-stroke checklist together with health information. The aim was to explore people with strokes’ experiences of using the pre-visit tool before the follow-up visit and how well their stroke related health issues was captured.

### Method

Individuals were recruited prior to a follow-up visit after stroke. After completing the pre-visit tool, individual interviews were conducted with 33 participants (23 men, median age 67). Reflexive thematic analysis was used to data analyses and subsequent co-design workshops were held to improve the tool.

### Results

Findings highlights important aspects to consider when receiving and completing the pre-visit tool. First, when initiating the follow-up process, the purpose needs to be clearly expressed to enhance motivation. Second, the response process can be enhanced by explanatory texts and free-text. Optimizing the simplicity and user-friendliness was emphasized. Third, the pre-visit tool was perceived as a support for identifying needs and with potential to enhance the dialogue. Overall, the pre-visit tool was perceived as easy to use. Revised information was suggested to better capture health problems e.g., types of pain. In the co-design workshops, a final version of the tool was completed.

### Conclusion

Findings suggests that the digital pre-visit tool Stroke health was perceived as useful by people with stroke before a follow-up visit. Minor amendments were suggested to improve the tool.

### How will this research improve life after stroke for stroke survivors?

Preparation before a follow-up visit with a digital tool will empower people with stroke and their relatives. Identification of unmet needs and being informed about available support is a first step towards having the needs met.

## 22 - Developing a SLT telehealth assessment toolkit using the COM-B and TDF models for behaviour change

*Ms Amanda Comer, Dr Nicholas Behn, Dr Sarah Northcott, Dr Abi Roper, Dr Niamh Devane, Ms Jaycie Bohan, Professor Katerina Hilari*

*City, University of London, London, United Kingdom*

**Category: Other - Improving access to healthcare (also consider rehabilitation in life after stroke)**

### Background and aims

A survey of UK speech and language therapists (SLTs) suggests increased telehealth use since the COVID-19 pandemic, however few outcome measures have been tested for telehealth administration and little is known about how best to facilitate this process. The COM-B and Theoretical Domains Framework (TDF) provide a structured approach to identifying barriers and facilitators to behaviour. This study aimed to: investigate barriers and facilitators to SLTs delivering telehealth assessment; and explore which intervention functions are salient in the design of a telehealth assessment toolkit.

### Method

Qualitative data exploring the views and experiences of people with aphasia and SLTs in the UK, including PPI, interviews, focus groups and ethnographic observations of telehealth assessment, were synthesised using a meta-ethnography approach. Iterative themes (n=26) were identified for barriers and facilitators of telehealth assessment. These themes were deductively mapped to the 14 domains of the TDF, and intervention functions and related behaviour change techniques were identified.

### Results

Physical opportunity and cognitive capability facilitated telehealth assessment, with reduced motivation described as a barrier. Themes were mapped to 12 TDF domains, with intervention functions related to education, training and enablement identified as main functions to target. Related BCTs will directly influence the design of the prototype toolkit.

### Conclusion

Using the TDF COM-B models of behaviour change is suggested as a systematic and feasible method for designing a stakeholder informed telehealth assessment toolkit.

### How will this research improve life after stroke for stroke survivors?

This toolkit, with easily accessible resources and training, will help speech and language therapists improve their skills and develop confidence to implement telehealth assessment in rehabilitation offered to stroke survivors with aphasia. Telehealth offers benefits to stroke survivors, including flexible rehabilitation delivery and reduction in travel time and costs.

### 23 - Health and productivity burden of stroke in Ireland

*Ms Tumeliwa Mphepo*

*Royal College of Surgeons in Ireland (RCSI), Dublin, Ireland*

**Category: Other - Health economic impact of stroke**

**Background and aims**

Stroke is a leading cause of death and disability globally, with survivors often experiencing health and employment burden. The 2018-2030 European-Stroke-Action-Plan prioritises research on the health economic impact of stroke and the return on investment in stroke care. Although many other studies have estimated the economic burden of stroke in terms of money, less is known about its impact on health and productive years of patients. This study aimed to estimate losses in Life Expectancy (LE), Quality-Adjusted-Life-Years (QALYs) and Productivity-Adjusted-Life-Years (PALYs) by comparing adults with and without stroke in Ireland.

**Method**

A static-life-table-model simulated the 2021-2022 Irish population with stroke aged 25-85 years. In another model, the same population was assumed without stroke. Both models followed individuals up to 85 years in 1-year cycles. Population-based sex- and age-specific stroke prevalence and labour-force participation data were obtained from the Healthy Ireland Survey. All-cause-mortality-rates were obtained from the Irish Central Statistics Office. Health-Related-Quality-of-Life data were derived from the Irish population EQ-5D-5L-norm. Other relevant data were extracted from published studies. Stroke-related losses in LE, QALYs and PALYs were estimated as differences between adults with relative to adults without stroke. Outcomes were discounted at 4%.

**Results**

130,538 Irish people were modelled to have a stroke translating to 3.6% overall prevalence (4.1% among males, 3.1% among females). People with stroke experienced losses of 352,197 years in LE, 603,303 QALYs, 324,235 PALYs.

**Conclusion**

Stroke has substantial health and productivity consequences in Ireland, highlighting the need for more effective stroke prevention, and management strategies to support survivors' health and productivity.

**How will this research improve life after stroke for stroke survivors?**

Being first of its kind, it provides novel insights on long-term health and productivity losses experienced by stroke survivors. The research informs decision makers (policy-makers, healthcare providers, stakeholders in stroke healthcare) on better allocation of resources for interventions that will improve life expectancy, quality-of-life and productivity of stroke survivors.

## 24 - Examining methodologies in stroke-related cost studies: a scoping review

*Ms Tumeliwa Mphepo*

*Royal College of Surgeons in Ireland (RCSI), Dublin, Ireland*

Category: Other - Health economic impact of stroke

### Background and aims

Costing studies on stroke help prioritise interventions in resource-limited settings. However, variations in methods and data sources make comparisons difficult. With cognitive challenges often associated with stroke, it is crucial to address whether cost information obtained directly from stroke patients can be considered accurate. The challenge of valuing intangible costs, such as pain, by those without the experience of the disease arises if patient-reported estimates are to be questioned. This scoping review examines, analyses, and compares methodologies used in stroke-related cost studies.

### Method

The study was conducted according to Arksey and O'Malley framework and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews guideline. The Population, Concept, and Context framework was used to retrieve studies from three databases (PubMed, Scopus, Web of Science) published from January 2015 - September 2024. Costs were converted to US dollars for the year 2023, using Purchasing Power Parity and other relevant inflation indices.

### Results

A total of 2,250 articles were retrieved. This is an on-going study, but it anticipates continued variation in costing methodologies, with many studies relying on centrally collected and accessible data, without clearly identifying primary data sources. It is also expected that few studies will use cost data collected directly from individuals with stroke.

### Conclusion

To ensure more accurate and comparable data for policymakers and healthcare providers, it is necessary to define the common methods used in cost assessment and clarify when specific methodologies and data sources should be used, given the wide variability in the costs reported across different studies.

### How will this research improve life after stroke for stroke survivors?

This research highlights key areas for improvement in future studies. It emphasizes the need for balanced public patient involvement, if few studies used data from stroke survivors. This will enable decision-makers to allocate resources based on accurate cost estimates, ensuring that interventions addressing full range of survivors' needs are prioritized.

## 25 - Identifying priorities for life after stroke – a survey of healthcare professionals: the CLASP project

*Professor Frances Horgan*[1]*, Professor Olive Lennon*[2]*, Dr Mary O'Neill*[1]*, Ms Ciara Naughton*[1]*, Dr Sarah Murphy*[1]*, Mr Abdullah Sharaf*[1]

[1]*RCSI, Dublin, Ireland.* [2]*University College Dublin, Dublin, Ireland*

**Category: Other - Life after stroke**

### Background and aims

Stroke is an important health issue in Ireland. Over 5,500 adults were admitted to acute hospitals following stroke in 2020, 71% of whom were discharged home with a documented disability. Currently, ~80% of stroke survivors are discharged home. The Stroke Action Plan for Europe highlights the need to develop a life after stroke pathway. The aim of this survey of Irish healthcare professionals working in stroke care was to identify the priorities to be addressed in life after stroke. The survey is part of a wider project, the Co designing Life After Stroke support Pathways (CLASP).

### Method

A cross-sectional survey of community and hospital-based healthcare professionals working in stroke care was undertaken in July 2024. The survey was hosted on Survey monkey. The study received ethics approval from the university.

### Results

169 health care professionals responded. The majority of healthcare professionals worked in hospitals (43.75%) followed by a rehabilitation centre (32.81%). Physiotherapists and occupational therapists were the largest groups, 29% and 27% respectively. The results highlighted the need for a more specific approach in post-stroke management, current pathways often resemble a "geographic lottery". The respondents identified unmet needs and priority areas for life after stroke including; community support and transition to home care, key workers, patient, family, and caregiver education, access to supported self-management, peer support, vocational support and transportation.

### Conclusion

The findings of this CLASP healthcare professional survey highlights ongoing unmet needs in life after stroke from the perspective of healthcare professionals working in stroke services in Ireland.

### How will this research improve life after stroke for stroke survivors?

The CLASP
project will address the rehabilitation needs and potential unmet needs as identified by stroke patients an
d healthcare professionals to inform the co-design of a pathway for life after stroke in the community.

## 26 - Stroke survivors' experiences with stroke services in the Philippines: survey of rural and urban communities

*Professor Angela Logan[1], Ms Alyssa Marie Dar Juan[2,3], Professor Jonathan Marsden[1], Dr Myrna estrada[3], Mr Lancelyle de Jesus[3], Ms Sarah Buckingham[1], Dr Aira Ong[1], Dr Sharon Linog[3,4], Dr Elda Grace Anota[3,5]*

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**Category: Other**

### Background and aims

Stroke is a leading cause of morbidity and mortality in the Philippines, yet national data on the burden of stroke is limited. The aim of this study was to survey stroke survivors about their care after stroke, their symptoms, and the impact of stroke on functioning and quality of life.

### Method

Using a two-stage cluster sampling design, five regions across both rural and urban communities within the Philippines were surveyed. Data were collected by field enumerators using online and paper-based questionnaires. The survey explored patients' ability to work, current symptoms, medication, rehabilitation, and other support. Data were analysed using descriptive statistics and relationships between selected variables were investigated.

### Results

Respondents (N = 498) included stroke survivors from urban (n = 200) and rural (n = 278) areas. A diagnosis occurred within six hours in 68.3%. Rural respondents had fewer brain scans and prescribed stroke medication, and less frequent rehabilitation than urban respondents. Of the 50.8% that received rehabilitation, most (90.7%) paid out-of-pocket. Mean self-reported physical health status was 60/100 (SD 18.5) with lower health status associated with lower mobility and self-care. 40% of respondents reported feeling very sad, worried or unhappy. Only 19.7% were employed post-stroke compared to 62.8% pre-stroke.

### Conclusion

Despite timely stroke diagnosis, significant discrepancies in acute care and rehabilitation exist between urban and rural areas. Stroke survivors experience considerably high physical, emotional, and financial burden.

### How will this research improve life after stroke for stroke survivors?

The study captures the real-life experiences of stroke survivors and highlights the need for improved services, particularly in rural areas, to enhance long-term recovery and societal reintegration. The findings will contribute to provide data for shaping policies that address gaps in strokecare and improve outcomes and quality of life.

## 27 - Mapping the journey and experience of people living with post-stroke spasticity

*Mrs Diana Wong Ramos[1], Ms Grethe Lunde[2], Dr Maja Bozinovska Smiceska[3], Dr Marina Charalambous[4,5], Ms Elen Kirt[6], Dr Georgi Georgiev[7], Mx Jelka Jansa[8], Dr Liliia Zviagina[9], Mr Simon Page[10], Ms Sarah Thomas[10], Dr Oleks Gorbenko[10]*

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**Category: Other - Patient experience journey map**

### Background and aims

We aimed to develop a patient experience journey map (PEJM) to capture the experiences of people navigating the post-stroke spasticity (PSS) care pathway in Europe.

### Method

The PSS-PEJM was developed using qualitative methods, involving: 1) collation of patient experiences; 2) PEJM creation, insights generation and iterative validation by a multi-stakeholder working group consisting of Stroke Alliance for Europe (SAFE) members; and 3) external validation by an independent panel (people with PSS, a caregiver, patient organization representatives and healthcare professionals; n=23).

### Results

The PEJM revealed a complex and fragmented PSS care pathway. Following a stroke, the route to PSS diagnosis is heterogeneous, with no specific medical team assigned to look for PSS symptoms. People report feelings of shock and grief, with concerns more about the stroke itself than about PSS. Upon PSS diagnosis, there are no formalized referral and assessment processes, leading to difficulties and delays in receiving rehabilitation and treatment. People experience relief and hope at diagnosis but worry about the impact of PSS on their independence and can feel overwhelmed with information. Long-term monitoring and support in the community can be limited. Loneliness and depression are common, but the personal experience of the health system and support networks influences the emotions experienced. People learn to cope with their symptoms and hope for effective treatment that can improve their quality of life.

### Conclusion

For people with PSS, the lack of an optimized care pathway causes delays or difficulties in receiving a diagnosis, treatment and long-term support, causing many to experience emotional variability.

### How will this research improve life after stroke for stroke survivors?

There is limited understanding of the experiences of people living with PSS, which is needed to inform provision of post-stroke care. This PEJM provides actionable insights, goals and possible implementation steps to improve the lives of stroke survivors and supports the Stroke Action Plan for Europe.

## 28 - Analysis of Patient Behaviors in Acute Stroke

*Dr Pawel Wrona[1,2], Dr Paulina Sarba[2], Szymon Kotas[1], Dawid Rolkiewicz[1], Julia Blajszczak[1], Kaja Zdrojewska[1], Gabriela Kapral[1], Urszula Zacharska[1], Katarzyna Putylo[3]*

*[1]Jagiellonian University Medical College, Krakow, Poland. [2]Department of Neurology, University Hospital, Krakow, Poland. [3]Angels Initiative, Krakow, Poland*

**Category: Other: Stroke Education**

### Background and aims

Stroke is a predominant cause of long-term disability and the second most prevalent cause of mortality globally. This study aims to analyze patient behaviors at stroke onset, focusing on symptoms, the time from symptom onset to hospital admission, and factors causing delays in contacting emergency services.

### Method

A retrospective analysis was conducted involving 505 anonymous surveys administered to patients hospitalized between 2021 and 2024 in the Department of Neurology of the University Hospital in Krakow, all diagnosed with stroke in accordance with AHA/ASA 2013 criteria. Data collection was performed using electronic tablets via teleinformatics systems or through direct interviews.

### Results

A total of 500 surveys were administered. The mean age of the participants was 62.7 years. The most frequently reported symptoms included upper limb weakness (58%), dysarthria (52%), and lower limb weakness (47%). The average symptom-to-door time was 508 minutes. A substantial majority, 422 patients (83,56%), recognized 999 and 112 as emergency contact numbers. Alarmingly, 288 patients (57,03%) did not perceive their symptoms as potentially indicative of a stroke. Reasons for the delay in contacting emergency medical services included a preference to consult a family member first (20%), belief that the symptoms are not serious (20%) and the expectation that the symptoms would resolve spontaneously (19%).

### Conclusion

The study found that 57% of patients did not associate their symptoms with stroke, leading to significant delays in receiving care. These results highlight the urgent need for targeted educational initiatives to raise awareness about stroke symptoms and the importance of timely pre-hospital intervention.

### How will this research improve life after stroke for stroke survivors?

This research will improve life after stroke by identifying key factors contributing to delayed care at stroke onset. By highlighting the need for public education on stroke symptoms and timely response, it can guide awareness campaigns, potentially reducing delays in treatment and improving long-term recovery outcomes for stroke survivors.

## 29 - Impact of a stroke care pathway on self-perceived health 3 months after stroke.

*Miss Elin Bergh[1], Professor Torunn Askim[1], Professor Ole Morten Rønning[2], Professor Stian Lydersen[1], Miss Geske Luzum[1], Dr Bente Thommessen[2]*

*[1]Norwegian University of Technology and Science, Trondheim, Norway. [2]Akershus University Hospital, Lørenskog, Norway*

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

### Background and aims

A national stroke care pathway (SCP) aiming to reduce time-delays in acute stroke care was introduced in Norway in 2018. The aim of the present study was to evaluate if good adherence to the pathway had an impact on self-perceived health (SPH) 3 months after stroke.

### Method

We used data from the Norwegian stroke register. Patients registered with acute stroke in 2019, one year after implementation of the SCP, were included. Patients were categorized into an attainment, or a non-attainment group based on their achievement of the SCP goals. Linear regression analyses were used to assess associations between goal attainment and SPH evaluated by EQ-5D-5L and EQ-VAS 3 months post-stroke. A mediation analysis was conducted to explore if an association between the SCP and SPH was mediated by receiving thrombolysis.

### Results

In total 4133 patients with a mean age of 72 years, 1787 (43%) women, and 3786 (92%) with ischemic stroke were included in this study. A total of 908 patients (22%) qualified for the attainment group. We found no effect of goal attainment upon mean EQ-5D-5L (0.006, 95% CI -0.009 to 0.021, p=0.42) or EQ-VAS (-1.403; 95% CI -3.039- 0.234, p=0.093) at 3 months follow-up. However, adjusting for stroke severity assessed by National Institute of Health Stroke Scale attaining the SCP was significantly associated with SPH. The mediation analysis revealed no mediating effect of thrombolysis between goal achievement and SPH.

### Conclusion

In opposite to stroke severity, good adherence to the SCP was not associated with self-perceived health at 3 months post-stroke.

### How will this research improve life after stroke for stroke survivors?

By emphasizing the need to reduce treatment delays, this study could enhance stroke care and potentially improve life after stroke. Patient-reported outcomes offer important insights for improving stroke care.

## 30 - Meaningful engagement of Stroke Survivors in developing a roadmap to enhance social participation across Ireland.

*Dr Helen Kelly[1], Dr Orla Duffy[2], Dr James Green[3], Dr Caroline Jagoe[4], Dr Áine Kearns[3], Dr Ruth McMenamin[5], Dr Molly Manning[3], Ms Dorothy Clarke[2], Ms Yvonne Fitzmaurice[5]*

*[1]University College Cork, Cork, Ireland. [2]Ulster University, Derry, United Kingdom. [3]University of Limerick, Limerick, Ireland. [4]Trinity College Dublin, Dublin, Ireland. [5]University of Galway, Galway, Ireland*

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

### Background and aims

Communication is a basic human right. Irrespective of age, status, or capacity to communicate, people have the right to receive information and express themselves. There is an increasing prevalence of communication disability secondary to health conditions, e.g. stroke. Communication disability is a risk factor for social exclusion and restricted community participation, affecting relationships, employability, and mental well-being. ENSPIRED aims to collaborate with core stakeholders to address communication access issues, identify barriers to communication access, inform best-practice guidelines, and advance meaningful social inclusion.

### Method

A critical review of international literature, policies, and documentation related to communication rights and access was undertaken (Phase 1). Phase 2 involved iterative consultations with (i) Stroke Survivors in the role of PPI Advisors and (ii) Representatives from the Irish Heart Foundation and Stroke Association. Each consultation group reviewed the findings from Phase 1 in relation to identified barriers to communication access, participation, and inclusion in Irish society.

### Results

The PPI Advisor Stroke Survivors (n=8), and representative organisations (in separate meetings) reviewed and refined the six themes that were observed from Phase 1. Findings from both Phases are currently being integrated to produce preliminary recommendations for improving communication access in Ireland. Recommendations will be further reviewed and refined by PPI Advisors before finalising.

### Conclusion

The unique perspectives of PPI Advisors enhances the validity and relevance of literature findings in relation to their lived experience. The refined themes will contribute to a best-practice conceptual framework to promote communication access rights on the island of Ireland for those living with communication disabilities.

### How will this research improve life after stroke for stroke survivors?

This research meaningfully engages Stroke Survivors, to ensure their voices are central to identifying best-practice priorities, with recommendations for delivering communication access rights, and a roadmap for key implementation projects for people with communication disabilities.
**ENSPIRED – Enhancing Social Participation Across Ireland for people with communication disabilities and differences.*

## 31 - Improvement of an mHealth solution for increasing physical activity in people following stroke or TIA

*Sophia Humphries*

*Karolinska Institute, Huddinge, Sweden*

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

### Background and aims

Digital support via mobile health (mHealth) can be a way to increase access to support for physical activity following stroke or transient ischemic attack (TIA). We previously developed an mHealth programme via an app for promotion of physical activity. Results from a large pilot trial in Sweden support its feasibility and accessibility but also identified areas for improvement. The aim of this collaborative study was to improve the mHealth programme for physical activity after stroke or TIA together with people post-stroke or TIA and physiotherapists.

### Method

We recruited 15 participants with a history of stroke or TIA. Participants were divided into three workshop groups, including a group with previous experience of mHealth-delivered support from the feasibility trial. Upon identifying key areas in need of modification from the mHealth programme we conducted a series of digital workshops and interviews followed by user testing. Workshop themes covered: (1) preferences in relation to mHealth (2) physiotherapist-supervised training, and (3) prescription training i.e., instructional home-videos.

### Results

Findings from workshops and interviews showed that in addition to long-term individual follow-ups participants wanted more variation in supervised classes and prescribed exercises. Following these findings a new format of prescription aerobic training videos was subsequently developed and tested for feedback. Further individualisation and personalisation of the intervention (such as adaption of exercises) was a recurring theme which led to the development and testing of instructional videos.

### Conclusion

Workshops and user testing were imperative in the iterative development of new elements to the mHealth programme that may otherwise have been overlooked.

### How will this research improve life after stroke for stroke survivors?

This research has helped to further shape an mHealth intervention with regards to the individual needs and preferences of stroke survivors themselves. In this way we hope the intervention is better tailored to enable success in its use among stroke survivors and decreased risk for recurrent stroke.

## 32 - Patient and public involvement in the co-design of aphasia accessible medication instructions

*Ms Shauna Bell*[1]*, Professor Laura J. Sahm*[1]*, Mr Liam Kelleher*[2]*, Dr Helen Kelly*[1]

[1]*University College Cork, Cork, Ireland.* [2]*Stroke Survivor, Cork, Ireland*

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

### Background and aims

Stroke survivors have a high chance of experiencing another stroke. Medications can be effective in reducing the risk of recurrent stroke, but approximately 50% of patients face difficulties in taking their medications as prescribed. People with post-stroke aphasia (PwA) often find taking medication more difficult than other stroke survivors because of their communication difficulties. Current research highlights the importance of actively involving stroke survivors in research, particularly underrepresented groups such as PwA.

The aim of this study is to develop medication information that is easy for PwA to understand in collaboration with a Public and Patient (PPI) advisory panel.

### Method

The PPI advisory panel consisted of three stroke survivors with aphasia, all men. Communication assessments were carried out with each person before the workshops to ensure that all materials were suitable for their individual communication needs.

The advisory panel met for 5 workshops, facilitated by a speech and language therapist, between January 2024 and August 2024.

### Results

At the end of the PPI workshops we produced accessible medication instructions. These instructions consist of images, audio clips, and simplified language which provide information about a range of medications. Stroke survivors on the advisory panel gave feedback on their experiences in taking part in this research.

### Conclusion

The PPI panel agreed that there is no “one size fits all” solution to providing accessible medication instructions to PwA. Instead, different modes of communication—such as images, audio clips, and simplified language—should be made available to PwA in order to account for their individual communication needs.

### How will this research improve life after stroke for stroke survivors?

Supplementing existing patient information leaflets with images, audio clips, and simplified language can help PwA understand medication instructions. The co-design of materials ensures that information is tailored to the specific needs and preferences of PwA, promoting better understanding and adherence, thereby empowering patients to engage meaningfully in managing their medications.

## 33 - The effectiveness of sitting-balance treatments on sitting-balance outcomes in early-sub-acute-stroke. A systematic review and meta-analysis.

*Mrs Rebecca Rayner[1], Dr Kelly Walker[2], Dr John Stephenson[3], Professor Geert Verheyden[4], Dr Nicola Hancock[2], Mr Joseph Hartley-Palmer[2]*

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**Category: Rehabilitation in life after stroke**

### Background and aims

Difficulties with sitting-balance are common after stroke. The ability to sit unsupported is imperative for many daily tasks and is correlated to more positive outcomes. There is limited research on "sitting-balance" therapeutic interventions, their application and impact. This systematic review and meta-analysis aims to investigate the effectiveness of physiotherapy sitting-balance treatments on sitting-balance outcomes in people up to 3-months post-stroke.

### Method

The PRISMA checklist was followed and the review was registered on PROSPERO (CRD42023444050). Seven electronic databases were searched to October 2023 for studies comparing treatments, focussing on sitting-balance in adults who had suffered a cerebral stroke in the last three months. Studies were included if treatment predominantly focussed on seated exercises and reported sitting-balance outcomes.

### Results

15 studies (540 participants) were included: four pilot randomised controlled trials (RCT), and seven RCTs. Publications dated from 2007 to 2020: seven from Europe and eight from outside Europe. Data was synthesised narratively and quantitatively. Sitting-balance interventions were classified into four main categories: weight shift and reaching; core stability exercises; environmental modifications; and task practice. A random effects meta-analysis conducted on seven studies (194 participants) revealed interventions to be beneficial for sitting-balance (mean difference on Trunk Impairment Scale outcome 3.05; 95% confidence interval 2.04 to 4.05). Four studies demonstrated low risk of bias; and three showed some concerns.

### Conclusion

A variety of sitting-balance treatments are offered to early-sub-acute stroke survivors that show significant improvements in sitting-balance outcomes. Sitting-balance treatments can be categorised into four sub-types; making clinical application more unified and future research consistent.

### How will this research improve life after stroke for stroke survivors?

This work provides supporting evidence as to what sitting-balance interventions improve sitting-balance in early-sub-acute stroke survivors and the four categories aid clinical application and transferability. The work will aid an imperative part of the stroke rehabilitation process, on an element that is fundamental to positive outcomes.

## 34 - Improving quality of gait rehabilitation: short-term impact of the Stride One platform.

*Dr Sarah Meyer[1], Mr Jan Limet[2], Mr Piet Stevens[2], Mr Marc Michielsen[1]*

*[1]Jessa Ziekenhuis, Herk-de-Stad, Belgium. [2]Ceriter BV, Lanaken, Belgium*

**Category: Rehabilitation in life after stroke**

### Background and aims

Ceriter Stride One (CSO) is a smart insole that provides real-time audio feedback (cues) to the patient when performing walking exercises. It was the aim of this study to investigate the short-term impact of CSO use on the quality of gait in patients post stroke.

### Method

Ten inpatient stroke patients were offered gait rehabilitation using CSO for one week (1h/day, 5d/week). Patients underwent clinical testing before and immediately after the training period using qualitative gait parameters. Additionally, both patients and their therapists completed questionnaires about their experience with this new technology. One patient dropped out due to a fall.

### Results

Both therapists and patients reported an improvement in the quality of the foot roll-off in 100% of cases. This was also objectively determined in the data measured by CSO, with an average 8% improvement on CSO general quality parameter, and an average 25% improvement on CSO specific quality parameter (e.g., sufficient heal strike pressure). Furthermore, 89% of patients indicate that using CSO helps them understand their physiotherapist better, and 67% of patients indicate they can practice more and better with CSO.

### Conclusion

Practicing one week with CSO generates a positive clinical impact on the gait pattern as measured and indicated by patients and therapists. A lasting improvement in the gait pattern without using CSO, three to four days after the intervention, could not be demonstrated in this short time period. Further research is needed to evaluate the effect of CSO after more long-term use.

### How will this research improve life after stroke for stroke survivors?

Ceriter Stride One allows patients to train more and better, both with the therapist and remotely. This research shows the initial positive impact. Improving gait will directly impact quality of life, independence in ADL activities and will allow stroke survivors to remain independent for a longer time.

## 35 - Applying a co-design approach to determine key components of a transition-to-home support intervention following stroke.

*Ms Geraldine O'Callaghan[1], Mr Martin Fahy[1], Ms Patricia Hall[2], Dr Deirdre McCartan[1], Professor Peter Langhorne[3], Professor Rose Galvin[4], Professor Frances Horgan[1]*

*[1]RCSI, Dublin, Ireland. [2]UCD, Dublin, Ireland. [3]University of Glasgow, Glasgow, United Kingdom. [4]University of Limerick, Limerick, Ireland*

**Category: Rehabilitation in life after stroke**

### Background and aims

Unmet needs and feelings of abandonment often arise during hospital-to-home transitions as for many the concept of organised stroke care ends. This study aims to identify key components for a patient-centred support intervention for people with stroke transitioning home, exploring feasibility in a real-world context.

### Method

A series of three workshops, framed by Design Thinking and involving people with stroke (PWS), caregivers, healthcare professionals, and support organisations (n=42), were conducted in one healthcare context. Participants were facilitated in immersing themselves in the challenges of the transition-to-home phase and brainstorming solutions to support PWS during this critical period. Data collection methods included post-it notes, observations, summarising findings, and reaching consensus on outputs. In the final stage, key intervention components were prioritised, considering feasibility and potential impact. Patient and public involvement (PPI) contributed to the study design, co-facilitated the workshops and validated outputs.

### Results

Ten key intervention components to support people with stroke and their families during hospital-to-home transitions were identified. These components were categorised into activities aimed at enhancing collaboration, streamlining transition processes, and facilitating post-discharge support. One key component was the inclusion of a stroke coordinator to improve coordination and continuity of care. While the stroke coordinator was considered a top priority, activities under 'enhancing collaboration'—such as increased cross-setting information sharing and in-reach from community-based healthcare staff—were deemed the most feasible to implement.

### Conclusion

A co-designed transition-to-home support framework focussed on enhancing care coordination and continuity during transition-to-home has the potential to enhance outcomes for people with stroke and their families.

### How will this research improve life after stroke for stroke survivors?

If implemented, the framework developed in this research could facilitate a smoother transition from hospital to home, enhance communication between healthcare teams, improve coordination and continuity of care, and potentially enhance recovery and quality of life for stroke survivors, while reducing the burden on their families and the healthcare system.

## 36 - Improving Quality of Life via AI-based Personalized Rehabilitation

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**Category: Rehabilitation in life after stroke**

### Background and aims

The lack of precision medicine - personalized support and rehabilitation interventions - for chronic stroke suffers is a huge challenge. With most of the chronic stroke burden associated with informal care and patients' dependence in performing daily tasks, we develop artificial intelligence (AI)-based predictive analytics to improve quality of life (QoL) by tailoring rehabilitation to the specific needs of individual patients.

### Method

A variety of AI predictive data analyses were applied to over forty demographic, socioeconomic, clinical and functional characteristics (such as stroke risk factors, Barthel Index and Functional Independence Measure items, calculated QoL score), of a mostly male, young Mediterranean cohort of 395 patients, to stratify patients into optimal rehabilitation hospital lengths of stay (LOS) and to identify variable predictors for improving QoL.

### Results

Based on patient stratification, which identified optimal LOS, nearly 80% of patients exceeded their optimal LOS at the rehabilitation hospital. Although the biggest QoL improvements were during rehabilitation, very long LOS didn't have greatest QoL score gains, suggesting that rehabilitation programmes were not personalized. Predictors of good long-term QoL were independence in toilet use and transfers, as well as independence in mobility with assistance in bathing and feeding. The highest predicted QoL was for patients fully independent in toilet use.

### Conclusion

Utilizing AI-based analytics to develop personalized rehabilitation programmes focused on key activities of daily life predicted to most aid individuals' recovery can support optimal rehabilitation hospital LOS for the greatest improvement in QoL in chronic stroke patients.

### How will this research improve life after stroke for stroke survivors?

AI-based precision medicine implemented in predictive data analytics apps and software can support clinicians in efficient resource management and planning personalized interventions for optimal rehabilitation programmes, improvement of patients' QoL and smooth reintegration back into their regular lives after stroke.

## 37 - Factors influencing stroke survivor physical activity in acute and subacute stroke units: a systematic review.

*Miss Rachel Dance*[1], *Dr Elizabeth Hall*[1], *Mrs Claire Whitehouse*[1], *Mr Rene Gray*[1], *Dr Kath Mares*[2]

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**Category: Rehabilitation in life after stroke**

### Background and aims

Despite well-documented benefits, hospital physical activity (PA) levels outside of formal therapy sessions remain detrimentally low for acute and sub-acute stroke survivors. This systematic review aims to explore what factors might influence the implementation of PA from stroke survivor, visitor, and staff perspectives.

### Method

AMED, APA, CINAHL, MEDLINE and EMBASE databases were systematically searched from April 2015 to March 2024, to reflect post-AVERT trial perspectives. Data-specific subject headings and search terms synonymous with stroke, physical activity and facilitators/barriers were used. Cochrane database, search engines and reference lists were checked for any additional studies. Qualitative or mixed-methods studies exploring factors impacting PA outside of fully-supervised therapy time for acute or subacute inpatient stroke survivors were included. Authors independently screened title and abstracts, followed by full-text studies, then extracted data and appraised study quality. Codes and themes were generated using reflexive thematic analysis.

### Results

Seven studies (six high and one medium quality) were included, representing 77 stroke survivors, 11 visitors, and 69 staff across four countries and three continents. Four key themes were identified: motivation, post-stroke changes, resources and environment, and customs and culture.

### Conclusion

Findings from this review suggest that to implement PA outside of formal therapy sessions stroke survivors, visitors, and staff require education around its importance. Staff need to feel able to provide advice to empower both stroke survivors and visitors to promote PA. To enable a culture of PA, more needs to be done to ensure the risk of sedentary behaviour is recognised, instead of a hyper-focus on falls prevention.

### How will this research improve life after stroke for stroke survivors?

A better understanding of how to improve inpatient stroke survivor physical activity (PA) will help provide more recovery opportunities during the acute and sub-acute phase, which is beneficial in terms of neuroplastic recovery, improved functional outcomes and reduced cardiovascular disease risk. This aligns with international best practice guidelines.

## 38 - Nottingham Fatigue after Stroke: Who knows best? Co-designing a management programme for post-stroke fatigue.

*Dr Shirley Thomas[1], Dr Joanne Ablewhite[1], Professor Roshan das Nair[1], Professor Fiona Jones[2], Professor Nikki Sprigg[1], Ms Emily Toplis[1], Professor Heather Wharrard[1], Professor Avril Drummond[1]*

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Category - Rehabilitation in life after stroke

**Background and aims**

Post-stroke fatigue (PSF) affects 50% of stroke survivors and is one of the most distressing symptoms after stroke. The evidence base on PSF management is weak and previous research has failed to involve those with lived experience. Our aim was to develop a novel intervention to support PSF management for testing in a future trial. This study was conducted in four phases.

**Method**

Phases 1 and 2. We held co-design groups to agree programme content and resources.
Phase 3. We developed a training package for facilitators and provided training.
Phase 4. We tested the feasibility of the programme. Participants completed questionnaires at baseline and on completion and were invited to participate in interviews.

**Results**

Phases 1 and 2. We recruited 23 participants (16 stroke survivors with PSF, 2 carers and 5 healthcare professionals). We designed online resources and a workbook.
Phase 3. Ten people provided input into the training package. Seven (4 with PSF and 3 with experience in providing support) were trained to act as 'buddies'.
Phase 4. We recruited 15 people; 13 completed the programme (2 withdrew). Of these, 13 completed baseline and 11 follow-up questionnaires. All buddies (7/7) and 12/13 participants were interviewed. Participants were 7 men (8 women) with a mean age of 59 (SD 9.59; range 39-81).Overall, mean fatigue severity reduced, activity increased, and mood measures improved.

**Conclusion**

We met the specified criteria for feasibility study success although issues identified will need to be considered in future trial design

**How will this research improve life after stroke for stroke survivors?**

The study shows the potential for this programme to be tested in a definitive trial, this would be hugely impactful in the UK and internationally, if successful.

## 39 - Return to Driving Post Stroke: Balancing Patient Safety and Patient Independence

*Dr Zoe Adey-Wakeling[1,2], Professor Stacey George[1], Mr Paul Hakendorf[1]*

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Category: Rehabilitation in life after stroke

**Background and aims**

Driving is pivotal for independence and community participation. Return to driving post stroke is associated with increased life satisfaction, improved functional outcomes and reduced depression. Education and equitable access to return to driving pathways enhance rates of return to driving. This study aims to outline assessment processes and the vital role of Occupational Therapy practical driving assessment in promoting individualized recommendations.

**Method**

The Southern Adelaide Local Health Network Driving Fitness Assessment Clinic is a multidisciplinary specialized driving assessment service. A prospective database of patients has been collected since 2014. The database records information including reason for referral, screening assessment results, onward referrals and final recommendations regarding driving. Further data analysis 2021-current under way.

**Results**

1654 cases presented between 2014-2020, with mean age 73 (61-81) and 67% male. 36.8% of all referrals were post stroke. 830 (50%) of all patients were referred to Occupational Therapy (OT) on-road driving assessment. Overall rate of return to driving post OT assessment was 79%, but with 66% having individualized conditions or driver rehabilitation recommendations. All cognitive screening assessments were associated with positive predictive value of practical outcome ($p<0.001$) but could not account for necessary individualization provided by assessment in real-world environment.

**Conclusion**

Screening assessment battery sensitivity alone cannot provide individualized recommendations to maximize safe return to driving post stroke. OT assessment is the best available assessment and should attract government funding to support patients in return to life.

**How will this research improve life after stroke for stroke survivors?**

Evidence of patient and society impact of successful, safe return to driving supports need for enhanced services and funding to optimize return to life. Advocacy to government bodies for funding for OT assessment will reduce cost burden to clients and improve access to appropriate assessments.

## 40 - Primary Results of the Initial Validation of the SMD Decision Tree – I-REFER

*Dr Klemens Fheodroff[1], Professor Joerg Wissel[2,3], Dr Benjamin Waeschle[4], Dr Manuela Schuetzer[5], Dr Georg Comes[4]*

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**Category: Rehabilitation in life after stroke**

### Background and aims

Nurses and therapists play an important role in the management of post-stroke patients (PSPs) but validated tools to recognize evolving complications such as spasticity are scarce. The Spastic Movement Disorder Decision Tree (SMD-DT) assesses muscle tone, control of voluntary movements and stretch-induced pain in the upper limb, guiding healthcare providers' referral decision to a specialist for further spasticity management including botulinum neurotoxin injections. The results of the SMD-DT validation (I-REFER) are presented.

### Method

I-REFER is a cross-sectional validation and inter-rater reliability study, which explores the degree of agreement between nurses and physicians who are experienced in spasticity management (the 'gold standard'), by assessing PSP and determining the need for specialist referral using the SMD-DT (dichotomous endpoint: referral yes/no). The secondary objective is to examine the validity of the SMD-DT used by physio- and occupational therapists, compared to the same 'gold standard'.

### Results

Of those in an early post-acute to chronic phase, 69 PSP were included and have been described previously. The level of agreement was good (0.71) at 85.5% rate of agreement for nurses and very good (0.80) at 89.9% for therapists compared to 'gold standard'. Sensitivity and specificity were 0.85/0.87 for nurses and 0.87/0.93 for therapists. Positive predictive values and negative predictive values were 0.89/0.81 for nurses and 0.94/0.85 for therapists. All Kappa values were highly significant ($p < 0.001$).

### Conclusion

Nurses and therapists demonstrated substantial agreement with 'gold standard' evaluations when using the SMD-DT with favourable comparative parameters. The SMD-DT is a promising tool for spasticity recognition.

### How will this research improve life after stroke for stroke survivors?

Use of I-REFER may contribute to an earlier start of botulinum neurotoxin injection treatment by raising awareness for disabling symptoms of SMD in non-SMD experts

## 41 - Feasibility and acceptability of mHealth-delivered physical activity for people post stroke or transient ischaemic attack

*Dr David Moulaee Conradsson[1], Ms Charlotte Thurston[1], Dr Sophia Humphries[1], Dr Lucian Bezuidenhout[1], Dr Lisa Holmlund[1], Professor Lena von Kock[1], Professor Coralie English[2], Dr Sverker Johansson[1]*

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**Category: Rehabilitation in life after stroke**

### Background and aims

Physical activity is essential for secondary stroke prevention, and mobile health (mHealth) interventions have shown promise in enhancing physical activity. This study evaluated the feasibility and acceptability of a mHealth intervention for promoting physical activity among individuals post-stroke or transient ischemic attack (TIA).

### Method

In this two-arm feasibility randomized controlled trial, adults with stroke/TIA were randomized to the experimental group, receiving mHealth-delivered supervised exercise and behavioral change techniques, or the control group, receiving mHealth-delivered individual counseling. Reach, retention, adherence, fidelity, safety, and acceptability were evaluated based on pre-specified criteria.

### Results

Of 114 participants, 105 (92%) completed the 6-month intervention and 102 (89%) completed the 12-month follow-up assessment. The intervention reached individuals from 20 out of 21 Swedish regions. Of the participants, 68% had experienced a stroke, 64% were female, and they were aged on average 71 years (SD 9). The majority were born in Sweden (95%), had a high level of education (61%) and an average baseline physical activity level of 6451 steps per day. Completion of outcome measures ranged from 92%-98%. A total of 1781 supervised exercise sessions were delivered, with an adherence rate of 76%, and adherence to individual counselling and follow-up sessions was 96%. Ninety-five adverse events were recorded, of which 16 were related to the intervention but non-serious.

### Conclusion

The mHealth intervention was overall feasible and acceptable, however there is a need to develop recruitment procedures to increase diversity of included participants regarding socioeconomic status and physical activity level, prior to a Phase 3 trial.

### How will this research improve life after stroke for stroke survivors?

This research aims to help individuals post-stroke or TIA achieve better health and reduce the risk of recurrent stroke by enhancing their resources for engaging in physical activity. It seeks to improve service equity by reaching individuals in diverse geographic regions through a network of clinics across Sweden.

## 42 - Navigating a person-centred, mobile phone supported intervention after stroke – experiences of Face 2.0

*Mrs Kajsa Söderhielm*[1], *Dr Malin Tistad*[2,1], *Dr Charlotte Ytterberg*[1], *Professor Susanne Guidetti*[1]

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**Category: Rehabilitation in life after stroke**

### Background and aims

Using information-and communication technology (ICT) is suggested as a way of increasing rehabilitation access. ICT could make rehabilitation in the home, focusing on activities prioritised by the stroke survivor, available for people living far from a rehabilitation clinic. The use of ICT also comes with challenges. Altered cognition, communication, vision or motor functions may affect the ability to use devices such as mobile phones. It is therefore important to find out how the use of ICT in rehabilitation is perceived by stroke survivors. The aim of this study was to explore and describe experiences of rehabilitation with a novel ICT-supported intervention, F@ce 2.0.

### Method

F@ce 2.0 is a home-based person-centred intervention for stroke rehabilitation that focuses on daily activities and participation in everyday life and uses SMS-technology to support goal achievement. Twelve participants were interviewed after the intervention and again four months later using a semi-structured interview guide. Data were analysed using reflexive thematic analysis.

### Results

Three themes were developed; Setting personally relevant goals requires a trusting relationship, To be supportive, SMSs need to be integrated into the rehabilitation process and Support from the team is essential for recapturing daily activities after stroke.

### Conclusion

Supporting goal achievement through ICT in the form of SMSs may increase motivation and awareness in stroke rehabilitation. The results also illustrate the importance of personal meetings in rehabilitation, both for setting relevant goals and for finding strategies to reach those goals. ICT may therefore be best suited as a complement in stroke rehabilitation to support goal achievement.

### How will this research improve life after stroke for stroke survivors?

The study showed that digital solutions can increase access to rehabilitation but that there is a risk of the opposite effect if technology is hard to handle. Participants said that goal reminders and self-ratings had the potential to increase motivation, but also felt that technology cannot replace personal meetings.

## 43 - Effectiveness of home- and community-based stroke rehabilitation in low- and middle-income countries: A systematic review

*Dr Lorraine Faeldon*[1]*, Dr Sarah Buckingham*[2]*, Dr Aira Ong*[2]*, Dr Angela Logan*[2,3]*, Professor Bridie Kent*[2,4]*, Professor Jonathan Marsden*[2]

[1]*De La Salle University - Evelyn D Ang Institute of Biomedical Engineering and Health Technologies, Manila, Philippines.* [2]*University of Plymouth, Plymouth, United Kingdom.* [3]*Royal Devon University Healthcare NHS Foundation Trust, Exeter, United Kingdom.* [4]*The University of Plymouth Centre for Innovations in Health and Social Care: A JBI Centre of Excellence, Plymouth, United Kingdom*

**Category: Rehabilitation in life after stroke**

### Background and aims

Stroke prevalence in low- and middle-income countries (LMICs) is rising, yet rehabilitation post-discharge is often inadequate.

The aim was to determine the clinical effectiveness of home- and community-based rehabilitation (HCBR) for stroke survivors in improving recovery in LMICs.

### Method

Six electronic databases and grey literature were searched for studies with participants that suffered a stroke and engaged in HCBR programs with outcomes measuring function, participation or Quality of Life (QoL). Following screening and data extraction, studies were critically appraised using Joanna Briggs Institute tools. Data from ≥2 studies were included in a meta-analysis with standard mean difference (SMD) as the effect size measure. Evidence was assessed using the Grading of Recommendations, Assessment, Development, and Evaluations (GRADE) Framework.

### Results

Thirty-nine articles on 37 studies (25 randomized controlled trials & 12 quasi-experimental studies) were included. Interventions included physiotherapy-occupational therapy (PT-OT n=19); education & self-management (E-SM n=9); digital health (DH n=5) and other (n=4). Average PT-OT sessions lasted 1.4(±0.8) hours, provided x3 (±2.0) /week over 11.3(±6.8) weeks while E-SM and DH had varied contact frequencies.

Meta-analyses showed changes favoring the experimental group for the Barthel Index (SMD=2.46 (0.15-4.77)), QoL physical (SMD= 1.52 (1.21-1.83)) and psychological (SMD= 1.20(0.54-1.86)) scores. Only four studies included a measure of participation. Quality assessments indicated low blinding rates (4-8%), with evidence rated as “moderate” for QoL, “low” for both physical and psychological QoL, and “very low” for the Barthel Index.

### Conclusion

Overall, HCBR shows promise for improving the Barthel Index and QoL, though the quality of evidence is variable.

### How will this research improve life after stroke for stroke survivors?

This review adds to the limited evidence base on HCBR in LMICs and helps to identify what types of interventions are likely to improve recovery in terms of both function and quality of life for stroke survivors.

## 44 - Navigating the Transition from Rehabilitation to Home: Stroke Survivors' Perspectives on Discharge and After-Stroke Life

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**Category: Rehabilitation in life after stroke**

### Background and aims

This study aimed to investigate the multifaceted experiences and perspectives of stroke survivors during their transition from rehabilitation to home, with a particular focus on the challenges and their concerns surrounding the discharge process and adaptation to life after stroke.

### Method

A qualitative, phenomenological approach was adopted to capture the lived experiences of stroke survivors. A total of 100 stroke patients from a specialized rehabilitation center participated in unstructured, in-depth individual interviews. These interviews allowed for the free expression of concerns and personal narratives. Reflexive thematic analysis was employed to extract recurring patterns and themes, providing a rich, contextual understanding of the transition process from the patients' perspectives.

### Results

The analysis identified one overarching theme: the challenge of regaining independence. Within this theme, eight subthemes emerged, addressing specific concerns such as managing Activities of Daily Living (ADLs), emotional adjustment to home life, lack of support systems, fear of re-hospitalization, and uncertainty about future recovery. A significant finding was the varied levels of preparedness for discharge, with many participants expressing anxiety about their ability to manage everyday tasks and the sufficiency of post-discharge support.

### Conclusion

This study underscores the importance of a person-centered approach in discharge planning, emphasizing the need for tailored interventions that address both the physical and emotional challenges of stroke survivors. By focusing on individualized discharge strategies and comprehensive support systems, healthcare providers can better equip stroke patients for a smoother transition to independent living. The findings advocate for policy reforms that prioritize personalized care pathways to improve post-stroke recovery outcomes.

### How will this research improve life after stroke for stroke survivors?

The research advocates for more personalized, patient-centered discharge strategies. By addressing the diverse needs of stroke survivors healthcare providers can develop individualized care plans that better prepare patients for the challenges of returning home. The study also reveals the importance of continuous support systems post-discharge.

## 45 - Embodiment in aphasia: Adherence and effect of 2 weeks online action-observation therapy?

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**Category: Rehabilitation in life after stroke**

### Background and aims

Embodiment based language therapeuties (Boyle & Coelho, 1995; Francisco and al., 2024) have shown promising results. Marangolo and colleagues (2010) showed that non-fluent chronic lexico-phonological impaired aphasic patients improved in lexical retrieval as a result of “action observation” therapy. However, no study based on embodiment approach has been conducted using an online modality.
Test the adherence and the specific effect in chronic non-fluent people with aphasia (PwA) of an intensive home-training “action observation” therapy with online design.

### Method

15 chronic non-fluent PwA (>6 months post-stroke) were included and educated in an intensive training of 2 weeks (five days per week during 1 hour). They trained at home uncued naming abilities of 180 videos representing 127 human (63 trained, 64 untrained) and 53 trained non-human actions verb.Endpoints were number of drop-out, PRE- and POST-training correct naming performance of all videos. Statistics analyses were conducted using t-test.

### Results

Out of 15 participants, 14 (93%) completed the training. PRE- and POST-naming performances of action verbs showed in the videos were respectively 38.57 and 46.07 ($p < 0.001$) for trained human, 40.93 and 42.36 ($p = 0.355$) for untrained human and 31.93 and 35 ($p = 0.244$) for non-human trained action verbs. There was however a heterogeneity in the learning effect

### Conclusion

Our data suggest *i)* Excellent adherence of the participants ; *ii)* Significant improvement in the accuracy in naming action verbs for trained human items but neither for untrained human nor for non-human trained items. It suggests specific effect of Embodiment-based “action observation” therapy in online setting.

### How will this research improve life after stroke for stroke survivors?

By focusing on improving language abilities through innovative, accessible methods, this research can contribute to a better quality of life and greater satisfaction in everyday interactions for stroke survivors.

## 46 - Identifying priorities for life after - a survey of people living with stroke: The CLASP project

Dr Sarah Murphy[1], Professor Olive Lennon[2], Dr Mary O'Neill[1], Professor Frances Horgan[1]

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**Category: Rehabilitation in life after stroke**

### Background and aims

Over 5,500 adults were admitted to acute hospitals following stroke in 2020, 71% of whom were discharged home with a documented disability. Currently, ~80% of stroke survivors are discharged home. The Stroke Action Plan for Europe highlights the need to develop a life after stroke pathway. The aim of this survey was to identify the priorities to be addressed in life after stroke from the perspective of people living with stroke. The survey is part of a wider project, the Co designing Life After Stroke support Pathways (CLASP).

### Method

A cross-sectional survey of people living with stroke was conducted between July-September 2024. The survey was hosted on REDCAP. A national stroke charity and support organisations acted as gatekeepers and shared details of the survey with members. The study received university ethics approval.

### Results

There were 103 responses. Average age was 59 years (range 23-89), 52% of respondents were male, 65% married, and 32% lived in a rural setting. 63% reported ongoing issues with walking, balance 64%, fatigue 69%, concentration 55% and driving 51%. Respondents identified gaps in life after stroke supports: mental health/counselling, access to psychology, limited information about supports available after discharge, limited access to social workers and no stroke coordinator. They needed more help signposting/navigating community supports, information on entitlements after stroke, access to supported self-management, peer-support, vocational support and transportation.

### Conclusion

There was a low response, however the findings highlight unmet needs in life after stroke from the perspective of people living with stroke in Ireland.

### How will this research improve life after stroke for stroke survivors?

The CLASP project surveys will inform the co-design of a pathway for life after stroke in the community.

## 47 - Upper extremity pain trajectories and functional arm recovery after stroke

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**Category: Rehabilitation in life after stroke**

### Background and aims

Pain is a common post-stroke complication, and it may be underdiagnosed. The aim was to analyze the trajectories and determinants of upper extremity pain in the first 12 months after stroke.

### Method

A longitudinal study including people with upper extremity impairment three days after stroke. Motor impairment and pain was assessed at eight assessments during the first year after stroke with the Fugl-Meyer Upper Extremity Assessment. Latent class analysis was used to identify distinct trajectories of pain, logistic regressions were conducted to examine the relationship with recovery.

### Results

In total 122 participants with a median (IQR) age of 70 (63-80) years and 44% females. Two distinct trajectory groups were identified: increasing pain (36%) and stable low pain (64%). The increasing pain group had higher estimated pain scores at baseline (day 3) compared to the stable low pain group ($\beta_0 = 2.35$, SE = 0.36 vs. $\beta_0 = 1.50$, SE = 0.14, $P < 0.001$). The prevalence of severe motor impairments, sensory impairments and spasticity was higher at each follow-up in the increasing pain group. Increasing upper extremity pain and poor functional arm recovery at 12 months was associated, significant also after adjusting for age, sex and stroke type (OR = 8.64, 95% CI: 2.89-25.84, $P < 0.001$).

### Conclusion

Two distinct trajectories of upper extremity pain were identified after stroke: one characterized by increasing pain and another by stable low pain. Participants in the increasing pain group were more likely to exhibit severe motor and sensory impairments, spasticity, and other stroke-related complications, independent of baseline severity.

### How will this research improve life after stroke for stroke survivors?

This study contribute with new knowledge regarding patterns of pain in the upper extremity within the first year after stroke. With new insight regarding trajectories of pain, dose specific upper extremity motor rehabilitation and targeted treatment could be focused to people of highes risk of developing pain.

## 48 - Post-Stroke Facial Palsy: A Comprehensive Approach to Assessment, Management, and Outcome Measurement

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**Category: Rehabilitation in life after stroke**

### Background and aims

Post-stroke facial palsy is a common and often debilitating consequence of stroke, affecting patients' quality of life and social interactions. Despite its prevalence, clinical practice and research lack standardised assessment tools, treatment approaches, and outcome measures. This PhD research aims to enhance understanding and improve clinical practice for post-stroke facial palsy through interconnected studies.

### Method

The project is multi-faceted:

1. A completed cross-sectional survey of 96 UK healthcare professionals on current assessment and treatment practice.
2. A systematic review of measurement instruments for post-stroke facial palsy.
3. Developing a core outcome set for post-stroke facial palsy research using the Delphi method.
4. Incorporation of facial palsy assessments in the Speech after Stroke recovery study (SAYS), tracking recovery trajectories over two years and conducting qualitative interviews.

### Results

The findings will help us recommend facial palsy measurement instruments for stroke survivors. Additionally, learning about the long-term recovery trajectories of facial palsy and the impact of facial palsy on stroke survivors will help tailor interventions.

### Conclusion

This research program aims to standardise assessment practice, identify key outcomes for clinical trials, and deepen understanding of post-stroke facial palsy recovery as well as the psychological impact. By bridging gaps between research and clinical practice, this work will contribute to improved care pathways, targeted interventions, and enhanced quality of life for stroke survivors with facial palsy.

### How will this research improve life after stroke for stroke survivors?

This research provides essential insights into post-stroke facial palsy assessment, its changes over time, and the psychological impact on stroke survivors. It will enable us to identify what is important to measure in future research and clinical practice, allowing us to plan research to identify the best treatment.

## 49 - Challenges and perspectives in goal-setting for stroke rehabilitation: insights from physiotherapists, stroke survivors, and caregivers

*Mr André Vieira[1,2], Dr Carla Mendes Pereira[3,1], Dr Ana Goes[1]*

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**Category: Rehabilitation in life after stroke**

### Background and aims

Goal-setting is essential for person-centered rehabilitation and for stroke survivors to take ownership of their recovery. This study explored how goal-setting practice is interpreted by physiotherapists, stroke survivors, and caregivers in the Portuguese context and what factors may influence it.

### Method

A qualitative study was conducted with 16 physiotherapists, 15 stroke survivors, and seven caregivers. Four focus groups were composed of physiotherapists recruited from a variety of settings with at least three years of experience in stroke rehabilitation. Stroke survivors with at least three months of physiotherapy experience were interviewed individually or alongside their primary caregiver. Inductive and interpretative analysis was then conducted.

### Results

A major theme: “Readiness to patient-centered goal-setting on what really matters in stroke rehabilitation” derived with four subthemes supporting views of lack of readiness: i) “Physiotherapists at the center of decisions for stroke survivors own good and protection”; ii) “Uncertainty as a threat to goal-setting”; iii) “The crossroads of communicating rehabilitation goals”; and iv) “The adversities of setting person-centered goals in a fragile person-centered rehabilitation healthcare system”.

### Conclusion

Findings suggest that it is important for stroke survivors and caregivers to follow professional guidance and need time to feel empowered to make decisions about physiotherapy goals. Physiotherapists reported weaknesses in communicating about goals and managing expectations with stroke survivors and caregivers. Physiotherapists also highlighted that the healthcare environment and policies for stroke rehabilitation and community reintegration are poorly person-centered, which affects the personalization of goal-setting. Increased awareness of goal-setting tools and improved communication skills are required to optimize physiotherapy practice.

### How will this research improve life after stroke for stroke survivors?

This research aims to gain a deeper understanding of attitudes and practices related to goal-setting and what factors can be changed to optimize person-centered rehabilitation with supported involvement of stroke survivors and caregivers in their recovery process, with the objective of improving their self-management skills in life after stroke.

## 50 - carers’ experiences and views about being trained to deliver upper-limb therapy at home: semi-structured interviews

*Mr Remi Popoola, Dr Susan M. Hunter, Dr Jacqueline M. Winter*

*Keele University, Newcastle under Lyme, United Kingdom*

**Category: Rehabilitation in life after stroke**

### Background and aims

Upper limb (UL) weakness and sensorimotor dysfunction are common and long-lasting post stroke, but ongoing community rehabilitation is limited. Training carers to deliver effective interventions could potentially ensure that UL therapy is continued longer-term at home. This study explored carers' experiences, views, perceptions and concerns about being trained by a therapist to deliver somatosensory stimulation, an aspect of routine UL therapy, to their stroke survivors.

### Method

Following ethics approval, semi-structured interviews were undertaken with adult informal (unpaid) carers of stroke survivors. Participants were recruited from local stroke clubs in the East Midlands. Following piloting of the topic guide and questions, interviews were conducted face-to-face or virtually via Microsoft Teams. Data were audio-recorded and transcribed verbatim prior to thematic analysis.

### Results

Of the 13 participants interviewed, 84.6% (n=11) were female; all had been informal carers of a stroke survivor with UL impairment for >12 months. Themes identified from the study included: carer willingness to be trained and to undertake aspects of therapy; training and support required to deliver the therapy; and perceived constraints and enablers to delivering therapy. Lack of time was the overarching constraint identified.

### Conclusion

Informal carers are willing to be trained by a therapist to deliver aspects of therapy at home but are concerned about the time required to deliver therapy at a required dose for it to be effective. Further research is required to explore how carers can be taught to deliver aspects of routine therapy at home effectively without increasing carer burden.

### How will this research improve life after stroke for stroke survivors?

Extended Rehabilitation

Training carers to provide therapy at home would allow stroke survivors to continue receiving rehabilitation beyond the limited timeframe of formal therapy programs.

Increased Therapy Intensity

With carers able to deliver therapy at home, stroke survivors could potentially receive more frequent stimulation compared to relying solely on therapists.

## 51 - A survey of Irish stroke clinical nurse specialists and advanced nurse practitioners.

*Miss Sarah-Jane Byrne*[1,2], *Professor David J Williams*[1,2], *Professor Declan Patton*[1], *Professor Frances Horgan*[1]

[1]*Royal College of Surgeons Ireland, Dublin, Ireland.* [2]*Beaumont Hospital, Dublin, Ireland*

**Category: Secondary prevention**

### Background and aims

The clinical nurse specialist (CNS) in early supported discharge helps to reduce post-discharge challenges for patients and supports treatment compliance for secondary prevention, however the ESD CNS role is not well described in the literature. The aim was to describe the current role of stroke CNSs and stroke advanced nurse practitioners (ANPs) in Ireland to identify what elements of their role are transferable to the stroke CNS in an ESD model of care.

### Method

A survey was delivered to the current stroke CNS and ANP's in Ireland. Exploring their current practice in three areas of stroke care, (i) secondary prevention at first patient contact in hospital, (ii) secondary prevention on discharge from hospital, and (iii) secondary prevention in early supported discharge. The study received ethics approval.

### Results

Ongoing community care regarding education on secondary prevention and medication compliance was reported as ‘desperately needed’ with 70% reporting that follow up from the ESD CNS on discharge would benefit all stroke patients. It was reported that there is a need for more emphasis on secondary stroke prevention post-discharge as sometimes the patient is not in the correct frame of mind to take on board information provided as an inpatient.

### Conclusion

A CNS in a community role as part of an already established ESD team would be beneficial to both inpatient colleagues and the out-patient population for continuity of care following discharge from hospital. The secondary prevention topics discussed as an inpatient are transferable and provide continuity of care to patients in a community setting.

### How will this research improve life after stroke for stroke survivors?

There is growing recognition that patients’ needs post-stroke go beyond their brief inpatient hospital care. Patients are in a better frame of mind to discuss secondary prevention behaviours such as; smoking cessation, alcohol cessation, stress, nutrition, physical activity, medication compliance, blood pressure, management and working life balance.

# SERVICE DEVELOPMENT ABSTRACTS

## 52 - Social interaction opportunities for patients with communication difficulties in an acute stroke unit

*Ms Grace Burfield, Ms Alice Warburton, Ms Luisa Zenobi-Bird*

*The National Hospital for Neurology and Neurosurgery, London, United Kingdom*

**Category: Communication, including swallowing difficulties**

### Summary of the service development

Hospitalization negatively impacts patients' emotional wellbeing, increasing levels of anxiety and feelings of hopelessness (Alzahrani, 2021). Stroke patients are disproportionately marginalised in acute hospital settings due to the prevalence of communication impairments, resulting in fewer social interactions (Godecke, 2014).

A volunteer communication partner pilot was conducted across the hyper-acute and acute stroke units at The National Hospital for Neurology and Neurosurgery in London with the aim of increasing interaction opportunities for people with post-stroke communication difficulties and improving their wellbeing.

Three volunteers were recruited by the Stroke Speech and Language Therapy (SLT) team in collaboration with the hospital's volunteer service. The volunteers completed a communication partner training course delivered by the SLT team.

Seventy-seven stroke patients with communication difficulties participated in the project completing a total of 124 volunteer-supported social interactions between January and July 2024. Data was collected using an in-house 11-point self-rating scale aimed at measuring patients' wellbeing.

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

Collaborating with volunteers to deliver social interactions to patients with post-stroke communication difficulties is feasible and cost-effective within a busy acute stroke service. Patients in the early stage of their stroke journey in other European countries have the potential to benefit from similar initiatives.

### How this will improve life after stroke for stroke survivors

Statistical analysis of the data from this project showed a significant improvement in patients' wellbeing immediately following social interactions with volunteers compared to a pre-encounter baseline. Both volunteers and patients described the interactions as very enjoyable. This demonstrates the value of supported social interactions for patients living with communication difficulties in life after stroke.

## 53 - Co-designing a website to raise awareness of Aphasia with and for Stroke Survivors with aphasia.

*Dr Helen Kelly*[1]*, Mr Daniel Clancy*[1]*, Mr Martin Quinn*[2]*, Mr Phil Scott*[2]*, Mr Liam Kelleher*[2]*, Mr Larry Masterson*[2]

[1]*University College Cork, Cork, Ireland.* [2]*Aphasia Home Café, UCC, Cork, Ireland*

**Category: Communication, including swallowing difficulties**

**Summary of the service development**

Aphasia is a communication disability experienced by more than 1/3 of people who have a stroke. It can affect a person's ability to understand what they hear and read, and to express themselves when speaking or writing. Despite so many people living with aphasia, research shows that the general public does not know what aphasia is. Stroke survivors and their families also report a need for more understanding about aphasia and how to access relevant supports. Dr Helen Kelly invited stroke survivors with aphasia and a Digital Humanities student, to co-design a website to raise awareness of aphasia. Discussions shaped the content of the website, with a focus on the information that stroke survivors with aphasia need to know and the website design to ensure it is accessible for stroke survivors. Content considered important to our co-design group included, an explanation of what aphasia is, the impact of aphasia on people's lives, UCC's Aphasia Home Café, living successfully with aphasia, and providing signposts to resources that would be useful for stroke survivors and their families.

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

Aphasia is a global issue, so the content of this freely accessible website is relevant to stroke survivors and their families irrespective of location.

**How this will improve life after stroke for stroke survivors**

This website provides accessible information about aphasia, links to resources that can support stroke survivors and their families in their stroke recovery. In addition, video clips of people living with aphasia, from Ireland, UK and USA, will inspire and offer hope that there is quality of life after stroke with aphasia.

## 54 - Finding strength through support – overcoming barriers to Emotional Support

Ms Fern McClusky

Stroke Association, London, United Kingdom

**Category: Emotional, cognitive and psychological impact of stroke**

### Summary of the service development

The Stroke Association are currently providing four emotional support services in the UK and NI. We evaluate to improve the emotional support of stroke survivors, their families and create equitable services across GB.
In order to provide an equitable service, we need to overcome barriers: Health Inequality, Rurality, Deprivation, Access to Information, Funding.
Current services have been exploring this, looking at options for equitable counselling services that meets need, offers personalised support and is accessible.

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

Stroke survivors experience higher psychological and emotional needs due to the impact of brain injury on mood, behaviour, and cognition. Stroke changes everything and adjusting to life after stroke is challenging. The psychological effects can last years.

### Current Need in Europe

25% Suffer ongoing anxiety. 31% Develop depression in the first five years.12.5% Had suicidal ideation
Stroke survivors' risk of suicide attempt and death by suicide is around twice that of the general population.

### Great Britain

44% of people with Stroke report experiencing anxiety or depression.16% reporting suicidal thoughts.
Depression after aphasia is estimated to be 70% and is higher than in stroke survivors who do not have aphasia. **Three-quarters of people with emotional difficulties felt their needs had not been fully met.**

### How this will improve life after stroke for stroke survivors

An emotional support service provides stroke specific person-centred counselling, for stroke survivors and their families. Helping those affected by stroke come to terms with what has happened to them to alleviate psychological impact. 75% reported measurable decrease in anxiety and depression after intervention.

## 55 - Counselling as part of a stepped care model for psychological care in Northern Ireland.

*Ms Roisin O'Connor, Mr Alasdair O'Hara, Ms Sarah Belson*

*Stroke Association, London, United Kingdom*

**Category: Emotional, cognitive and psychological impact of stroke**

### Summary of the service development

The Regional Stroke Clinical Psychology Special Interest Group for Northern Ireland recommended a stepped-care model for psychological care in Northern Ireland. This model is based on the idea that all stroke patients will have psychological needs at some point in their journey of recovery, but not necessarily need to see a psychologist.

In Northern Ireland the Stroke Association’s Stroke Tailored Emotional and Psychological Support (STEPS) service is the only specialist stroke counselling service addressing need at Step One of the Stepped Model of Psychological Care for Stroke.

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

Stroke has a devastating emotional and psychological impact on both stroke survivors and their families. As in Northern Ireland, across Europe, despite the level of need, the emotional and psychological impact of stroke is not consistently being recognised or addressed.

STEPS in Northern Ireland, is an example of how an SSO service can raise awareness of the need for improved psychological and emotional support for people affected by stroke. This is an area where SSOs can be both a shaper and a deliverer of policy. The stroke specialism within the service allows clients to get the right interventions at the right time and reduces the revolving door effect of re-referrals back into clinical support, reducing pressures on the system.

### How this will improve life after stroke for stroke survivors

STEPS aims to empower stroke survivors and carers to develop emotional resilience, readjust to life after stroke, increase their independence and reintegrate into community life. Counselling providers must have a deep understanding of the full range of impacts that can affect people after stroke.

## 56 - GAM’s – the Portuguese experience with stroke support groups

*Mrs Marta Gôja*[1]*, Mr António Conceição*[2]*, Ms Diana Wong*[3]*, Ms Ana Campolargo*[4]*, Mr Vítor Saraiva*[4]*, Mr Óscar Pinto*[5]*, Mr Frederico Augusto*[4]

[1]*Portugal AVC, Portalegre, Portugal.* [2]*Portugal AVC, Viseu, Portugal.* [3]*Portugal AVC, Sintra, Portugal.* [4]*Portugal AVC, Porto, Portugal.* [5]*Portugal AVC, Vizela, 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.

## 57 - Freno al ictus foundation: inclusion project "guiar en dca"

*Mrs CLAUDIA TRUJILLO*

*FUNDACIÓN FRENO AL ICTUS, Madrid, Spain*

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

### Summary of the service development

In Spain, when a patient affected by a stroke is discharged from hospital, they find themselves in a situation of lack of information about the existing resources that they can access to improve their quality of life, well-being and recovery. For this reason, at the Freno al Ictus Foundation we carry out an inclusion project called “Guiar en Daño Cerebral Adquirido” where we guarantee our patients clear information about the process to follow once they have been discharged from hospital, streamlining the process of obtaining the necessary resources for the social, family and work integration of people affected by a stroke in our society.

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

It is relevant for other countries as they can understand the real situation of stroke in Spain and the shortcomings that exist in the system regarding support after a stroke for affected people and their families. In addition, our service can serve as a reference in other countries where people affected by brain damage find themselves in a situation of lack of information regarding the next steps they have to take after suffering the disease. Other organizations can also find an intervention model focused on personalized care for brain damage from a more social perspective.

### How this will improve life after stroke for stroke survivors

This service improves life after stroke for stroke survivors by giving them the opportunity to learn about all the resources that exist to improve their quality of life, autonomy and well-being and by providing them with support in accessing these resources as quickly and effectively as possible.

## 58 - An Experience-Informed Design Approach to Developing and Scaling a Post-Stroke Peer Support Network

Mrs Kerry Abbott

March of Dimes Canada, Toronto, Canada

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

**Summary of the service development**
The transition from clinical care to community life after a stroke presents emotional, physical, and social challenges. Peer support programs, grounded in shared experiences, address many complex needs of stroke survivors, providing information, resources, and social connection across all stages of recovery. These programs range from formal, organization-led groups to grassroots efforts, often run by volunteers with lived experience of stroke.
Using an experience-informed design approach, March of Dimes Canada (MODC) developed a Peer Support Network offering a centralized directory of peer support groups across Canada, and providing group leaders with opportunities to collaborate, share resources, and enhance capacity, reach, and impact.

Our design process was guided by participatory methodologies, involving stroke survivors, caregivers, subject matter experts, and collaboration with other organizations, particularly with Stroke Association (UK), where they had successfully implemented a peer support network.
The presentation will outline key facilitators and challenges identified and methods employed across design stages, including needs assessment, experience-informed design, pilot programs, implementation, and scale up. We will also discuss the evaluation and on-going measurement of outcomes developed for the Network.

**How this is relevant to other countries and what could be the potential impact across countries**
The exact nature of peer support may differ between countries and between groups themselves, yet fundamentally, it offers relevant support and connection between people with a shared lived experience. Learnings and resources from our work may help increase the reach and impact of peer support in other countries.

**How this will improve life after stroke for stroke survivors**
Employing a collaborative experience-informed design approach to develop a post-stroke peer support network can help more stroke survivors feel better connected, equipped, engaged and healthy.

## 59 - Online Peer Support for people affected by stroke

*Ms Charlotte Potter, Ms Nicola Miller*

*Stroke Association, London, United Kingdom*

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

**Summary of the service development**

Stroke Association’s Online Activities programme started during Covid. Activities which had taken place face to face switched to being held over Zoom.

Four years later and the offer is thriving. People affected by stroke sign up to the programme and receive regular emails alerting them to the range of virtual sessions to join for free. These include learning about the effects of stroke, sharing experiences, taking part in exercise groups and attending social quizzes. Some are bookable to limit numbers for small-group discussion and peer support but most are open-access.

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

As many SSOs across Europe deliver online activities there is huge potential for shared learning.

Stroke Association's activities have developed significantly following feedback. Low attendance for people under the age of 45 has been addressed by changing the time and format. The title of “Let’s Talk” was changed to “Share and Listen” to be more inclusive for people with communication problems. The option of text message reminders were introduced to those that wanted them. The sign-up process has been streamlined and web page optimised.

Potential areas for development include: how might the team help those people who are less confident with technology access the support, and; to what extent do people with communication difficulties feel the sessions are accessible to them.

**How this will improve life after stroke for stroke survivors**

90% of people responding to a feedback survey reported they can cope better with the impact of stroke as a result of attending these sessions. And 100% reported they can share their experience of stroke with people who understand.

## 60 - An online community for people with aphasia

*Dr Jytte Isaksen[1], Mr Yago Bundgaard[2], Mr Kenneth Bremer[2], Ms Maria Nysom Kjærgaard[3], Ms Sara Louise Larsen[1], Ms Sofie Fjord Lauridsen[1], Dr Birgitte Forchhammer[4], Ms Anne Hertz[4], Dr Julie Dalgaard Guldager[5,6]*

*[1]Department of Culture and Language, University of Southern Denmark, Odense, Denmark. [2]Stroke survivor, Aarhus, Denmark. [3]Center for Communication and Welfare Technology, Region of Southern Denmark, Odense, Denmark. [4]Danish Stroke Association, Høje Taastrup, Denmark. [5]University College South, Esbjerg, Denmark. [6]Department of Public Health, Esbjerg, Denmark*

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

### Summary of the service development

During the Covid-19 pandemic a Danish online aphasia community was made fighting isolation and loneliness that people with aphasia often experience. For post-pandemic continuation, further development was needed to form a sustainable online community. Specifically we have aimed at 1) developing a model for a sustainable online aphasia community; 2) evaluation of the members' experience, quality of life, and aphasia impact.

The online aphasia community groups has been running for 1,5 years as a part of the Danish Stroke Association with different group sizes, content and frequency, for example, group meetings with the same group members, and open groups with topics like news, quiz, arts and culture, parenting or open chats. The activities are run by people with aphasia and volunteers. Welcoming new members and placing them in the right groups need work from a staff member. The staff member is now a paid student assistant who works under the supervision of a qualified speech-language therapist. Volunteers require minimal supervision of training when they are either SLTs or SLT students.

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

A sustainable model for delivering online aphasia groups includes volunteers, student coordinator and supervisor and funding to continue to exist is developed and successfully implemented. We hope this model will inspire other countries to build collaboration between patient organisations and student volunteers.

### How this will improve life after stroke for stroke survivors

The online aphasia community is meaningful and valuable for people with aphasia. We have through interviews documented great satisfaction with the online community where the members felt at home and enjoyed the activities and company.

## 61 - Boosting workforce competence within a stroke support organization through varied learning pathways

*Mrs Suzanne Smith-Bayley, Mrs Rebecca Bourbonnais*

*March of Dimes Canada, Toronto, Canada*

**Category: Other - Workforce education and competencies**

**Summary of the service development**

March of Dimes Canada (MODC) After Stroke, offers a variety of programs and services to support individuals and families impacted by stroke living in the community. We have a network of staff across Canada providing program delivery. A competency self-assessment tool was created to help us ensure that our staff have the skills, knowledge and attitude required for this important client facing work. It was equally important to create strategies to support these competencies through ongoing and frequent learning and development opportunities for our team members.

We will discuss how using the principles of adult learning and videoconferencing, we created opportunities for self-directed, experiential, and problem centered learning that is relevant and motivating for our staff. This presentation will highlight the methods and resources that we have used to support the critical competencies. We will share the varied pathways in which we engage our staff in learning, development and leadership opportunities including the use of staff mentorship, “lunch n learn” sessions, external and internal subject matter experts and case based learning presentations. We will share feedback gained through formal and informal methods, from both new and seasoned staff regarding these opportunities.

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

The resources and tools highlighted in this presentation could be adapted by other stroke support organizations to support the competencies required within their organization.

**How this will improve life after stroke for stroke survivors**

Ensuring frontline staff are equipped with ongoing and frequent learning and development opportunities will support success in meeting the needs of stroke survivors and their families at all stages of recovery.

## 62 - I Am Alive: Life lessons from a stroke and brain surgery survivor.

*Mrs Christine Holubec-Jackson*

*Personal Memoir, Wetaskiwin, Canada*

**Category: Other - Perspectives and life lessons from a stroke and brain surgery survivor**

### Summary of the service development

To offer perspectives from a young survivor of multiple strokes and brain surgery survivor to enhance patient centred care and patient engagement. Connecting with people who are served by the healthcare industry focused on stroke and what matters to them.

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

My desire to present and the potential impact across countries is to build stronger connections and patient journeys.

I have written two personal memoirs, two children's books, with a brainy superhero, and hosted a podcast series dedicated to stroke. I've had the privilege of sharing my journey at several Women's Shows, Brain Injury Conferences, several Teacher Conventions, and volunteer on the Patient, Resident and Family Advisory Council, as co-chair, with Covenant Health.

### How this will improve life after stroke for stroke survivors

My message includes insights into life with a brain all while discovering our own personal superpower, even in the face of overwhelming challenges. I am so grateful for my renewed chance of life and the gift of being able to articulate my journey.

During my presentation I share all the losses caused by stroke including disability, family challenges, loss of career and even my identity to discovering the gifts within all the trials and tribulations as well as many valuable life lessons. Through all I have learned, I've realized how connected we all are, that we are all students and teachers in life. We all have a story to tell.

I want to share it wherever I can, hopeful it may help at least one more person! You can find more information on my website: 7jarsofhotpickledpeppers.com

## 63 - Developing a personalised approach to life after stroke support

*Ms Katherine Staley, Ms Laura Worthington, Ms Catherine Moore*

*Stroke Association, London, United Kingdom*

**Category: Other - Personalised support (includes many of the other categories)**

### Summary of the service development

Having a stroke is different for everyone and providing truly personalised life after stroke support can be life changing. The Stroke Association has been delivering support to stroke survivors and their loved ones for decades and we know the first conversation that we have with someone can be pivotal. It can help people feel listened to and understood, to feel supported and confident that they have somewhere to turn to if they need it and be clear about their next steps in their recovery journey.

This service development focuses on this initial conversation and describes our approach to cocreation, reflective practice and agile working so that we are having meaningful conversations which help people focus on what really matters to them.

We focused on preparing for different scenarios, ensuring the conversation was accessible, the types of open questions we might lead with, the ending of the conversation including what might be the next best step for that person and more challenging conversations we may encounter.

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

We'd like to share our experiences with other countries, demonstrating the impact of an early personalised conversation with someone shortly after stroke and to share the methodology through which we approached the service development.

### How this will improve life after stroke for stroke survivors

Throughout the development we wanted to ensure we were taking a truly 'outside in' approach and working with the stroke survivor or loved one to evolve our practice in line with what worked for them.

## 64 - stroke quality improvement for rehabilitation, community stroke service pilot project- reducing health inequalities through co-production

*Mrs Hayley Grice, Mrs Alison Wootton*

*Midlands Partnership University NHS Foundation Trust, A Keele University Teaching Trust, Lichfield, United Kingdom*

**Category: Other - Reducing health inequalities**

### Summary of the service development

The UK Royal College of Physician and National Institute for Health and Care Excellence guidelines outline an Integrated Community Stroke Service as best evidence-based practice. NHS England stroke funding has been used to: map current referral pathways; engage patients, support givers and key stakeholders including voluntary sector partnerships; complete a gap analysis; access local Core20plus5 data and complete a staff training needs analysis. A quality improvement methodology approach has been used that "puts service users and carers right at the centre and staff in the driving seat of change" to co-produce a pilot community multidisciplinary service, with the focus on reducing health inequalities. This commenced September 2024 with ongoing development of staff training; Life After Stroke Group; community and patient events, co-produced with stroke survivors and support givers.

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

The Action Plan for Stroke in Europe outlined ambitions for national stroke plans to encompass the entire care pathway. South-East Staffordshire is the only part of our regional Integrated Care System that does not have a commissioned community stroke service, mirroring many European regions. Our local stroke survivors through engagement feedback health inequalities: fragmented or non-existent pathways; longer waits; treatment delivered by non-specialists and variable experience which, aligns with international findings.

### How this will improve life after stroke for stroke survivors

By taking a co-production QI approach with PDSA (Plan, Do, Study and Act) the stroke survivors will be actively involved in all project stages. Data will be collected to comply with the UK Sentinel Stroke National Audit Programme 6-month review and used to produce a business case for long-term service provision.

## 65 - Transforming community-based stroke support: Developing three novel programs from existing resources.

*Mrs Suzanne Smith-Bayley*

*March of Dimes Canada, Toronto, Canada*

**Category: Other - Program development and delivery**

**Summary of the service development**
Stroke support organizations often struggle with limited resources to create and develop new programs. Evidence-based mental health support, stroke self-management education and supplementary exercise programs exist but must be adapted to the community setting.
This presentation will share how March of Dimes Canada (MODC) After Stroke, was able to identify three existing resources; Canadian Mental Health Association (CMHA) Living Life to the Full program™, Graded Repetitive Arm Supplementary program (GRASP) and the Toronto Stroke Networks Guide to Stroke Recovery™ and partnered with the developing organizations to adapt them to the needs of our clients and families.
A comprehensive review of each of 3 resources was completed to decide how the content would be adapted including the development of novel operating procedures. Details of the adaptations to content and operational procedures will be shared.

**How this is relevant to other countries and what could be the potential impact across countries**
These 3 resources could be adapted for use in other countries. This strategy of partnering and adapting existing evidence-based resources could be used by other stroke support organizations to develop all manner of novel programs.

**How this will improve life after stroke for stroke survivors**
This method of program development shortens the time from conceptualization to implementation and ensures these support services can be offered to stroke survivors as soon as possible as they transition from hospital back into their community.

## 66 - Data to dollars: Stroke support funding strategies

*Miss Rebecca Bourbonnais*

*March of Dimes Canada, Halifax, Canada*

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

### Summary of the service development

In the competitive landscape of nonprofit funding, leveraging data has become a critical strategy for stroke support organizations seeking financial sustainability. This work examines how data-driven approaches can enhance funding efforts, providing a roadmap for organizations to follow. Key strategies include collecting and analyzing relevant data, demonstrating impact through evidence-based outcomes, and effectively communicating these results to stakeholders and potential funders. We also explore the role of data in identifying funding opportunities, optimizing resource allocation, and building stronger cases for support. By harnessing the power of data, stroke support organizations can transform their funding strategies, ensuring long-term financial health and the ability to continue their vital work.

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

With more resources, global health organizations can work towards standardizing stroke care protocols, ensuring that all stroke survivors receive high-quality care regardless of where they live.

Overall, increased funding for stroke programs can lead to significant improvements in stroke prevention, treatment, and rehabilitation worldwide, ultimately reducing the global burden of stroke and improving the quality of life for millions of stroke survivors

### How this will improve life after stroke for stroke survivors

Increased funding can lead to a more holistic and effective approach to stroke recovery, addressing both the physical and emotional needs of survivors.

## 67 - Enhancing the voice of lived experience in a national stroke conference program

*Dr Elizabeth Lynch[1], Ms Saran Chamberlain[2,1], Professor Erin Godecke[3], Ms Alexis McMahon[4], Ms Kelly Andersen[5]*

*[1]Flinders University, Adelaide, Australia. [2]Lived Experience Expert, Adelaide, Australia. [3]Perron Institute, Perth, Australia. [4]St Vincent's Hospital, Sydney, Australia. [5]Tweed Byron Health Service, Tweed Heads, Australia*

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

**Summary of the service development**

SmartStrokes is an Australian national conference that has run annually since 2009. The conference was promoted as being “run by clinicians, for clinicians” to improve stroke care.

In recent years, the Directors of SmartStrokes sought to embed the voice of stroke survivors and carers within the conference program.

In 2023, SmartStrokes held a combined conference with Stroke Society of Australasia. A full day program within the 3-day conference was co-designed, including skills workshops for survivors and carers who were new to research, presentations by pairs of survivors and academics who had worked together discussing their experiences, and co-designed research presentations.

Progress in 2024 included having a survivor of stroke join the organising committee and open the conference. The conference was attended by 164 delegates, 9 of whom were survivors or carers. One invited plenary speaker was a stroke survivor with aphasia. Seven stroke survivors presented oral research papers.

In 2025, we are developing our strategic direction to include stroke survivors and carers within our target audience. This includes adjusting the networking function (cocktail party with finger food) to be more accessible for survivors and seeking funding to support conference attendance by survivors and carers.

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

This model is transferrable to other countries, and could facilitate international benchmarking of PPI activities.

**How this will improve life after stroke for stroke survivors**

The model supports capacity-building of stroke survivors/carers who are interested in contributing to research and service improvements. Further, it highlights to the clinical community the importance and value of including survivors and carers in service improvement and research activities.

## 68 - stroke quality improvement for rehabilitation, community stroke pilot – co-production with stroke survivors and support givers

*Mrs Hayley Grice, Mrs Alison Wootton*

*Midlands Partnership University NHS Foundation Trust, A Keele University Teaching Trust, Lichfield, United Kingdom*

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

### Summary of the service development

The UK Royal College of Physician and National Institute for Health and Care Excellence guidelines outline an Integrated Community Stroke Service as best evidence-based practice. NHS England stroke funding has been used to: map current referral pathways; engage patients, support givers and key stakeholders including voluntary sector partnerships; complete a gap analysis; access local Core20plus5 data and complete a staff training needs analysis. A quality improvement methodology approach has been used that "puts service users and carers right at the centre and staff in the driving seat of change" to co-produce a pilot community multidisciplinary service, with the focus on reducing health inequalities. This commenced September 2024 with ongoing development of staff training; Life After Stroke Group; community and patient events, co-produced with stroke survivors and support givers.

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

The Action Plan for Stroke in Europe outlined ambitions for national stroke plans to encompass the entire care pathway. South-East Staffordshire is the only part of our regional Integrated Care System that does not have a commissioned community stroke service, mirroring many European regions. Our local stroke survivor’s through engagement feedback health inequalities: fragmented or non-existent pathways; longer waits; treatment delivered by non-specialists and variable experience which, aligns with international findings.

### How this will improve life after stroke for stroke survivors

By taking a co-production QI approach with PDSA (Plan, Do, Study and Act) the stroke survivors will be actively involved in all project stages. Data will be collected to comply with the UK Sentinel Stroke National Audit Programme 6-month review and used to produce a business case for long-term service provision.

## 69 - Brain tango: the healing power of dance in stroke recovery

*Miss Tarja Huuskonen*

*Action for Results, Chelmsford, USA. Lisa Foundation, New York, USA. SameYou, London, United Kingdom*

### Category: Rehabilitation in life after stroke

**Summary of the service development**

Dance is a universal form of movement and human behavior that naturally enhances brain function and shows significant positive effects on several neurological conditions. While more studies will be needed to measure the clinical effects of dance therapy, research to-date has paved the way to positioning dance therapy as an inspiring, patient-centered improvement in post-stroke recovery.

This session explores dance as an empowering, easily repeatable and largely accessible community-based path to healing. Demonstration of dance practice, and how to adapt instruction to the abilities, goals and comfort-level of individuals, will be provided by a survivor and a dance instructor, followed by an interactive discussion on physical, emotional, social, and cognitive benefits of regular dance practice. A distinguishing benefit of dance therapy -- beyond its' sensory-motor components of improving balance, strength, and coordination -- is its power of connection with others and sense of joy and belonging.

This session is inspired by my personal experience of building a dance-based recovery plan after surviving a subarachnoid hemorrhage. Data from research in clinical, academic and community settings continues to validate the benefits but the recipe to adopt dance into recovery plans is still missing. For novel forms of healing to emerge, we must look beyond the current limits of healthcare systems and harness the power of patients and communities coming together. This session provides a roadmap for just that.

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

Dance is a universal option for creating more affordable and repeatable forms of on-going, community-based recovery support.

**How this will improve life after stroke for stroke survivors**

Improved balance, gait, strength, self-empowerment, social belonging and joy.

## 70 - stroke quality improvement for rehabilitation, community stroke service pilot project– the art of the possible?

*Mrs Hayley Grice, Mrs Alison Wootton*

*Midland Partnership University NHS Foundation Trust, A Keele University Teaching Trust, Lichfield, United Kingdom*

**Category: Rehabilitation in life after stroke**

### Summary of the service development

The UK Royal College of Physician and National Institute for Health and Care Excellence guidelines outline an Integrated Community Stroke Service as best evidence-based practice. NHS England stroke funding has been used to: map current referral pathways; engage patients, support givers and key stakeholders including voluntary sector partnerships; complete a gap analysis; access local Core20plus5 data and complete a staff training needs analysis. A quality improvement methodology approach has been used that "puts service users and carers right at the centre and staff in the driving seat of change" to co-produce a pilot community multidisciplinary service, with the focus on reducing health inequalities. This commenced September 2024 with ongoing development of staff training; Life After Stroke Group; community and patient events, co-produced with stroke survivors and support givers.

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

The Action Plan for Stroke in Europe outlined ambitions for national stroke plans to encompass the entire care pathway. South-East Staffordshire is the only part of our regional Integrated Care System that does not have a commissioned community stroke service, mirroring many European regions. Our local stroke survivor's health inequalities were impacted by: fragmented or non-existent pathways; longer waits; treatment delivered by non-specialists and variable experience which, aligns with international findings.

### How this will improve life after stroke for stroke survivors

By taking a co-production QI approach with PDSA (Plan, Do, Study and Act) the stroke survivors will be actively involved in all project stages. Data will be collected to comply with the UK Sentinel Stroke National Audit Programme 6-month review and used to produce a business case for long-term service provision.

## 71 - Systematic visual assessment of stroke survivors in the stroke unit

*Mrs Sigrid Bakkevold, Mrs Kine Rasmussen Vevatne*

*Haugesund hospital, Haugesund, Norway*

**Category: Rehabilitation in life after stroke**

**Summary of the service development**

**Methods:** The KROSS method (Competence, Rehabilitation of Sight after Stroke) was employed to systematically assess vision in all stroke patients at the stroke unit. Using a standardized assessment form, vision evaluation and follow-up became an integrated part of stroke treatment. A workshop was held with lecturers from NorVIS, alongside internal teaching within the healthcare organization to improve knowledge of cerebral visual impairments and to implement the assessment and related interventions.
**Results:** Measurements taken from 20.09.23 to 24.09.24 show that 164 stroke patients were referred to the Therapy Department. 31 patients were deemed non-testable using KROSS (due to factors such as cognitive suitability, drowsiness or medical instability), but their vision was still addressed during follow-up. A total of 133 patients were tested, and vision problems were identified in 74 patients (55%). Where visual deficits were uncovered, patients received tailored interventions and further referrals to relevant partners and vision rehabilitation.

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

**Conclusion:** KROSS is now an integrated part of the stroke treatment for stroke suvivors at Haugesund hospital, and necessary interventions are initiated. Addressing vision has become a natural component of care.
The study's results are immediately relevant to contries with similar healthcare systems, providing a foundation for further research, standardized assessements, and cost-effective interventions to improve stroke care and visual rehabilitation.

**How this will improve life after stroke for stroke survivors**

Improved expertise and structured assessments for patients with visual impairments will positively impact the patients themselves, their relatives, and the healthcare system. Addressing impaired vision means that a larger number of stroke survivors will receive vision rehabilitation.