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Life After
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Contents

European
Life After Stroke
Forum

Abstract Type:

Scientific Poster

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1 The narrative skills of people with chronic stroke-induced aphasia in an aphasia communication group

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Category
Communication

Background and aims
People with chronic aphasia (PWA) present with difficulties in narrating personal stories and maintaining meaningful dialogues with their interlocutors. This affects their daily functional communication and impacts their quality of life. This study aimed to investigate the narrative skills of PWA, before and after a group intervention, and to measure improvements in functional communication and quality of life.

Method
A case-study approach was followed. This included three people with chronic stroke-induced aphasia who were members of an aphasia communication group, in a university setting. PWA were supported by communication partners. The intervention consisted of eleven, 2-hour, weekly sessions. The intervention focused on using words and sentences to express macrostructure elements and was based on the LUNA (Linguistic Underpinnings of the Narrative in Aphasia) framework. The PAOLI (People with Aphasia and Other Layperson Involvement) guideline was followed to guide and monitor patient involvement. The topics of the narratives emerged from the personal narratives of PWA. For the evaluation of improvements in narrative skills, functional communication and quality of life, measurements (personal narratives, MAIN, AIQ-21-GR, Scenario Test-GR) pre and post-group intervention, were completed.

Results
Co-designing the group intervention by following the LUNA framework revealed advances in the narrative skills of PWA. Improvements were also observed in functional communication and quality of life for all participants with aphasia.

Conclusion
It is recommended that researchers use the LUNA framework and the co-design approach, in group interventions with people with chronic aphasia, to improve functional communication outcomes.

How will this research improve life after stroke for stroke survivors?
The involvement of PWA during the co-design of the group intervention improved their narrative skills, impacting positively on functional communication and overall quality of life.

2 Digital support for sexual wellbeing after stroke

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Category
Emotional, cognitive and psychological impact of stroke

Background and aims
Up to 75% of people experience sexual problems after stroke and other types of acquired brain injury (ABI). However, sexuality is not routinely addressed in rehabilitation. Indeed, sex is a taboo subject within wider society, particularly for people with disabilities or ill-health. There is a strong relationship between psychological and sexual wellbeing, so supporting sex and intimacy may also benefit mental health.

Method
Following the Experienced-Based Co-Design framework, we partnered with stroke and ABI survivors, professionals, and charitable organisations, to co-design a digital self-management programme for sexual wellbeing (HOPE4ABI). The HOPE4ABI programme was tested in a mixed-methods feasibility randomised controlled trial (RCT). Participants were randomised on a 1:1 ratio to the intervention arm (peer supported HOPE4ABI) or the control arm (self-directed HOPE4ABI).

Results
The results of the feasibility RCT are pending. We will present data on our primary outcomes relating to feasibility: i) recruitment and refusal rates, ii) retention and engagement rates, and iii) acceptability. In addition we will present an overview of pre- and post-programme secondary outcome measures relating to participants mental and sexual wellbeing.

Conclusion
Early indications show that the HOPE4ABI programme has been well received by participants. The comprehensive feasibility results will indicate whether a fully powered RCT is warranted. Similar studies with other clinical groups (e.g. cancer, multiple sclerosis) have shown promising evidence of the efficacy of self-management support on psychological wellbeing.

How will this research improve life after stroke for stroke survivors?
Our research has a broad aim to normalise conversations around sexual wellbeing after stroke and brain injury. The digital HOPE4ABI programme could be a sustainable, cost-effective solution to supporting mental and sexual wellbeing after stroke. A large-scale RCT will provide robust evidence of the effectiveness of HOPE4ABI.

3 Exploring the unmet needs for psychosexual wellbeing support after stroke and brain injury

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Category

Emotional, cognitive and psychological impact of stroke

Background and aims

Long term biological, psychological and social challenges are common after stroke. A complex interplay between these challenges can cause problems with intimate relationships and sexual wellbeing. Issues surrounding sexuality have become stigmatised, particularly for older adults and those with disabilities, and patients are reluctant to discuss their sexual wellbeing with healthcare professionals. In turn, healthcare professionals often feel underqualified or embarrassed to ask patients about sex. This results in limited opportunities for sexual education, and formation and maintenance of intimate relationships, especially after stroke.

Method

A series of focus groups, interviews, and written correspondence were combined in a qualitative analysis of experiences, perceptions, needs, and stigma surrounding sexual wellbeing after stroke and brain injury. Survivors (n=12) and professionals (n=8) participated in group or one-to-one discussions. Data were collected online via Microsoft Teams, and via email correspondence. Transcripts were coded and analysed using inductive thematic analysis.

Results

Full analysis is pending. Preliminary findings show that themes were centred around the self (mind, body, self-compassion), others (relationships, reliance, vulnerability, support), coping strategies and acceptance. Themes will be mapped against self-management strategies for development as a digital intervention.

Conclusion

Sexual wellbeing is often portrayed in terms of illness and disease in public health spheres, with disproportionate focus on undesirable outcomes such as sexually transmitted infections and unplanned pregnancy. This study has explored what sexual wellbeing means to stroke and brain injury survivors, and what can be done to support changes to psychosocial wellbeing that can negatively impact relationships.

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

This study provides important insight into the meaning of concepts such as sexual wellbeing and self-management for stroke survivors. Our participants have shared their experiences and recommendations for support that can be offered at a community-level, to improve personal and intimate aspects of life after stroke.

4 Structured follow-up pathway to support people after TIA and minor stroke (SUPPORT TIA): feasibility study

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Category

Emotional, cognitive and psychological impact of stroke

Background and aims

People who experience transient ischaemic attack (TIA) and minor stroke have limited follow-up care despite rapid specialist review in hospital. Consequently, they often have unmet needs and feel abandoned following discharge. Care needs after TIA/minor stroke include information provision, stroke prevention, and holistic care (residual problems and return to work/usual activities).

Method

We conducted a multicentre, randomised (1:1) feasibility study with a mixed-methods process evaluation at three hospital sites (England). The intervention was a nurse or allied health professional-led follow-up appointment four weeks after TIA/minor stroke. The multifaceted intervention included: a needs checklist, action plan, resources to support management of needs, a general practitioner letter, and training to deliver the intervention. Assessment of feasibility and acceptability included quantitative process variables (e.g. recruitment rates), structured observations of study processes, and interviews with a sub-sample of participants and clinical staff.

Results

We recruited 90% (54/60) of the recruitment target. The intervention and study design were feasible and acceptable. Qualitative interviews found participants and intervention delivers largely had positive experiences of the intervention. In particular, the checklist was valued, but engagement with resources and the action plan varied. Participants presented with a wide variety of residual unmet needs. Examples of addressing needs included reassurance, information provision, tailored lifestyle advice, and referral to support services (e.g. smoking cessation). However, not all participants felt a need for the appointment.

Conclusion

Our structured follow-up intervention was feasible and acceptable, and could provide a solution to proactively identity and address unmet needs after TIA/minor stroke.

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

Care needs after TIA/minor stroke are complex and individual. Needs should be proactively identified and addressed through a routine care pathway.

5 Acceptability of online, group acceptance and commitment therapy to stroke survivors: a qualitative interview study

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Category
Emotional, cognitive and psychological impact of stroke

Background and aims
Mental health issues are common after stroke, but services cannot meet demand. The Wellbeing After Stroke study (WAterS) co-developed a nine-week, online group intervention, based on Acceptance and Commitment Therapy (ACT), to support psychological adjustment post-stroke. The aim was to explore the acceptability of the WAterS intervention from the perspective of stroke survivors.

Method
Semi-structured interviews with stroke survivors after completing WAterS intervention. Interview guide was informed by components that are theorised to make up acceptability, including enjoyment, understanding and burden of the intervention. Template analysis was used to interpret the data, both inductively and deductively.

Results
All twelve participants were interviewed. Six main themes were generated. Results indicate that the intervention was accessible and understandable. Most participants were able to engage with ACT and apply it to their personal life. The social aspect of the group intervention was beneficial. Adapting the intervention to stroke supported accessibility. Online delivery was successful, with live facilitation and the use of a physical handbook. Group cohesion and understanding was supported by facilitators. Attending WAterS supported some participants to seek further support from other avenues; others were left feeling unsupported when the intervention was complete.

Conclusion
Stroke survivors found it acceptable to attend an online, group ACT intervention. This is a promising avenue in increasing the reach of interventions to support wellbeing. Further research with more participants, over a longer time period, is required to inform future developments of the intervention, including increasing reach to underserved populations.

How will this research improve life after stroke for stroke survivors?
This study focuses on the number one research priority for Life After Stroke, supporting psychological adjustment, and amplifies the perspective of stroke survivors themselves. Stroke survivors found an online group intervention for wellbeing acceptable to attend, and made recommendations for future improvements to the intervention.

6 Investigating testamentary capacity in the acute phase of stroke rehabilitation

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Category

Emotional, cognitive and psychological impact of stroke

Background and aims

This study delves into testamentary capacity (TC), a vital component of succession law governing the creation and validity of wills, particularly in the context of acute stroke survivors.

Method

The research focused on 62 first-time stroke survivors admitted within 24 hours of symptom onset, employing demographic and clinical data alongside cognitive assessment tools like the Addenbrooke's Cognitive Examination III (ACE-III) and the Testamentary Capacity Assessment Tool (TCAT).

Results

The findings revealed that TCAT scores remained largely unaffected by gender and age. They were positively correlated with education, the Barthel Index, Mini-Mental State Examination (MMSE), and ACE-III scores, while negatively associated with National Institutes of Health Stroke Scale (NIHSS) and Modified Rankin Scale (mRS) scores. Specific cognitive domains within ACE-III, such as memory and attention, significantly influenced TCAT scores. A TCAT score of 36.5 was identified as a reasonable threshold for classifying testamentary capacity, with satisfactory sensitivity and specificity. Logistic regression analysis demonstrated a heightened risk of testamentary incapacity in patients with low TCAT scores, even when considering demographic factors.

Conclusion

This research introduces TCAT as a valuable tool for assessing testamentary capacity in stroke survivors, emphasizing the nuanced nature of TC, which encompasses cognitive functioning, asset complexity, beneficiary relationships, and decision-making contexts. As the aging population and complex medical conditions become more prevalent, understanding the interplay between cognitive functioning and testamentary capacity gains significance for both legal and medical professionals.

How will this research improve life after stroke for stroke survivors?
This study offers a comprehensive view of testamentary capacity in stroke survivors and highlights the importance of tailored assessment tools like TCAT in safeguarding personal autonomy and decision-making rights.

7 Involving stroke survivors and families in developing a platform trial for life after stroke

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Category

Emotional, cognitive and psychological impact of stroke

Background and aims

We are developing a platform trial, which is a large research study to test different ways of improving life after stroke in a single study. We will describe how stroke survivors, family members and researchers have worked together to design a large-scale research project.

Method

A diverse Patient and Public Involvement (PPI) group of six stroke survivors with varying needs and two carers, was established by approaching stroke survivors and carers through professional networks and community groups (e.g. Different Strokes). An induction was provided covering support needs. Discussions informed decisions about key aspects of the trial design included: what makes a difference after stroke, what interventions should focus on, recruitment strategies, appropriate outcome measures and ways of collecting data. Next, we will explore barriers to participation, design and test materials for stroke survivors and researchers, and training materials for recruitment.

Results

Our PPI group has helped us develop a platform trial acceptable to stroke survivors. PPI activities have highlighted the value of adapting approaches to be more inclusive in a population with diverse and complex needs. We are now developing PPI guidance specific to stroke. This collaborative work unpins our funding application for the platform trial.

Conclusion

Working in partnership with stroke survivors and families we have developed the first platform study in stroke rehabilitation to address longer-term outcomes after stroke. Together, we will develop resources to share our learning on both platform trials and PPI approaches to increase understanding of this new method.

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

A platform trial is an efficient way of testing promising interventions which address longer-term outcomes after stroke. Inclusive PPI in platform design ensures the experiences of stroke survivors, family members and carers are embedded in research decision making, therefore increasing the quality of the research.

8 Variables associated with post-stroke PTSD; A systematic review and narrative synthesis

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Category
Emotional, cognitive and psychological impact of stroke

Background and aims
Stroke is often a sudden, traumatic, and potentially catastrophic event for those who experience it, leading to many stroke survivors experiencing post-stroke post-traumatic stress disorder (sPTSD). The development of sPTSD may impede patients' rehabilitation and negatively affect their long-term physical and psychological outcomes.

This review aims to identify and provide a narrative synthesis of the factors associated with sPTSD onset.

Method
Six databases (Web of Science, Social Sciences citation index, Embase, Pubmed, PsychInfo, Cinahl and PTSDPubs) were searched for studies that included samples of people who were 18 years of age or over, had had a stroke that was clinically recorded and who had a clinical diagnosis of PTSD post-stroke.

Results
A total of 21 studies were included in the review, with prevalence rates of stroke varying between 6.5% - 31%, and the PDS and PCL being the most frequent method of assessing PTSD. The most common factors found to be associated with the onset of PTSD were depression, younger age, symptoms of anxiety and lifetime history of psychiatric comorbidity.

Conclusion
Following stroke, patients are at an increased risk for developing sPTSD. Preliminary analyses would suggest certain factors such as gender, age and marital status impact the development of sPTSD. However, an agreed upon, standardised practice in measuring and reporting sPTSD is necessary to ensure findings can be readily contextualised against previous research in a sensible and meaningful way.

How will this research improve life after stroke for stroke survivors?
This review highlights the factors associated with sPTSD development that would allow healthcare workers to identify and provide those at risk of sPTSD with early interventions to minimise the impact that sPTSD may have on the stroke survivor's quality of life.

9 Initial participatory co-design conversations about developing & implementing integrated aphasia psychological care in Ireland.

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Category

Emotional, cognitive and psychological impact of stroke

Background and aims

People with aphasia experience access barriers to psychological support. Although there is an appetite for change, there is no consensus about what should be done. The aim was to facilitate initial conversations with inter-disciplinary clinicians about developing & implementing a coordinated model of aphasia psychological care in Ireland.

Method

A co-design group of 2 Speech and Language Therapists, 1 Occupational Therapist, 1 Clinical Psychologist and 1 Neuropsychologist working across diverse health settings attended 4x1.5 workshops online. Adapted Participatory Learning & Action techniques were achieved by using a Miro.com whiteboard and a live PowerPoint, which was circulated as a living record of revisions and agreements. Discussion points were underpinned by (1) Normalisation Process Theory; (2) literature on stepped psychological care in aphasia; and (3) parallel workshops with 3 PPI contributors who inputted into the planning and commented on the insights being generated.

Results

The clinician co-designers collectively developed ideal principles for coordinated aphasia psychological care and discerned implementation levers and barriers specific to the Irish context. These included a need for transdisciplinary working, clinician support, and specific psychological interventions. The group produced a dissemination and stakeholder engagement plan and agreed next steps. These were grounded in the lived experience of aphasia through ongoing PPI conversations.

Conclusion

Including clinical stakeholders as active co-designers is important for developing and embedding clinically relevant and evidence-informed interventions. This is the first study exploring the implementation of coordinated aphasia psychological care in Ireland and is part of a wider participatory health research project with aphasia Public and Patient Involvement contributors.

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

The findings will improve understanding of how a model of post-stroke aphasia psychological support might be adapted and implemented in local stroke and health contexts in Ireland.

10 An Investigation of Fear of Recurrence, Emotional Resilience and Self-Management Behaviours on Quality of Life

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Category

Emotional, cognitive and psychological impact of stroke

Background and aims

Stroke is a major medical illness and the most common acquired neurological disease in the adult population worldwide. While biomedical treatments form the basis for stroke recovery, individual and psychological factors such as self-management behaviours [SM] and emotional resilience [ER] are critical. Within three months of experiencing a stroke, approximately 18% of stroke survivors experience another stroke. As such, fear of stroke recurrence (FoR) is a common normal response to such a life-changing event and another potential factor contributing to peoples' post-stroke mental and physical well-being.

This research aims to investigate the relationship between Fear of Recurrence (FoR), Emotional Resilience (EM) and Self Management (SM) behaviours on stroke survivors' quality of life across six months to gain a greater insight into how these factors work together over time to impact a person's post-stroke physical and mental well-being.

Method

Adult stroke survivors were recruited to participate. A longitudinal study with three measurement time points across six months, each at 3-month intervals, is currently underway.

At each time point, participants are asked about their FoR, ER, SM and quality of life (QoL) using a variety of measures: The stroke Impact Scale (SIS), Adapted Fear of Recurrence Scale, The Conor-Davidson Resilience Scale (CD-RISC) and the Southampton Stroke Self-Management Questionnaire (SSSMQ).

Results

Descriptive and quantitative results from Time 1 will be analysed and presented.

Conclusion

Specifically, this initial investigation will provide preliminary insights into the relationship between FoR, ER, SM and the Quality of Life of a stroke survivor.

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

This will be the first study to examine Fear of Recurrence (FoR), Emotional Resilience (ER), and Self-Management (SM) behaviours, and their impact on quality of life over 6 months. This longitudinal research aims to provide valuable insights into post-stroke well-being and inform potential interventions.

11 A diagnostic validation of the sleep condition indicator as a tool to detect post-stroke insomnia

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Category

Emotional, cognitive and psychological impact of stroke

Background and aims

Insomnia is common after stroke and associated with poorer outcomes and greater risk of recurrent stroke. This prospective diagnostic validation investigated the discriminant validity and optimal diagnostic cut-off of the sleep condition indicator (SCI) when detecting DSM-V insomnia post-stroke.

Method

A sample of 178 (60.11% female) community dwelling, adult (≥18) stroke survivors were recruited via social media to complete an online questionnaire. Insomnia was assessed using a clinical interview styled sleep history, the Insomnia Severity Index, and the SCI. Statistical analyses explored discriminant validity, convergent validity, and internal consistency of the SCI. General information was also compared between groups.

Results

When detecting DSM-V insomnia post-stroke, the SCI demonstrated ‘excellent’ diagnostic accuracy with an AUC of 0.85, 95% CI [0.79, 0.90]. The optimal cut off was ≤13, yielding a sensitivity of 86.67%, a specificity of 71.57%. In only depressed participants (n = 86), the AUC was 0.83, 95% CI [0.74, 0.92]. The optimal threshold was ≤8, corresponding with a specificity of 75% and a sensitivity of 80.43%. A robust, negative relationship existed between the SCI and the ISI ($r = -0.86$, $p<.001$). The SCI demonstrated ‘good’ internal consistency, with a Cronbach’s α of 0.85, 95% CI [0.81, 0.87].

Conclusion

The SCI is a valid and reliable tool to detect DSM-V insomnia disorder in stroke survivors. Future research should explore subgroup analysis in larger samples. When selecting a tool for clinical or research use, one should consider whether validations of that tool have been conducted in a clinically meaningful sample related to the target population.

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

The correct diagnosis is as important as the correct treatment. By improving how accurately and efficiently we can detect post-stroke insomnia, we can provide timely diagnoses and interventions for those living with clinically significant sleep disruption. This study demonstrates the SCI can be used in clinical and research settings.

12 Social media listening study: The journey and unmet needs of people living with post-stroke spasticity.

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Category

Emotional, cognitive and psychological impact of stroke

Background and aims

Post-Stroke Spasticity (PSS) affects up to 40% of people after Stroke. [Jacinto, et al. 2022]. Recognising PSS patients' needs is crucial for enhancing care. This social media listening uncovered insights into patient experiences, unmet needs, and impact on their quality of life (QoL).

Method

An expert advisory board guided development of boolean queries to capture patient-centric discussions on major social platforms in France, Germany, UK, US.

Results

A total of 417 patient-centric posts were analyzed. Most discussed were patient journey stages (n=395/417, 95%), impact of PSS on QoL (n=237/417, 57%), and interactions with healthcare professionals (HCPs) (n=129/417, 31%). Patient journey posts centered around treatment options (n=278/395, 70%) and management techniques (n=118/395, 30%). Widely discussed treatments were botulinum toxin (n=103/278, 37%) and oral medications (n=71/278, 26%). Exercise (n=64/118, 54%) was the most adopted management technique. Emotions analysed pre-diagnosis were fear and worry, moving to hope and determination during treatment. Patients were most vocal about the physical (n=213/237, 90%) and emotional (n=95/237, 40%) impact of PSS. They expressed dissatisfaction (n=62/129, 48%) with their interactions with HCPs and sought online peer opinions when suggested treatment options were not considered effective. In 44% (183/417) of the conversations, an unmet need was identified, focusing on the need for satisfactory treatment options (n=78/183, 43%), well-informed HCPs (n=38/183, 21%), and better patient education on PSS (n=27/183, 15%).

Conclusion

The findings from this study highlight the need for improved education for both patients, caregivers and HCPs regarding PSS, better communication between patients and HCPs, and management of treatment expectations.

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

The research offers clear insights which shed light on the experiences and unmet needs along the PSS journey. This will support healthcare systems, clinics, physicians and advocacy groups to know where to direct their initiatives when seeking to address care challenges for those with PSS.

13 What are the unmet needs of young stroke? The perspectives of three key stakeholders

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Category
Emotional, cognitive and psychological impact of stroke

Background and aims
Young stroke survivors are often at a stage in their lives where they engage in an active social lifestyle, potentially raising a young family, caring for older dependents, paying off mortgages and working in physically/mentally demanding jobs (Singhal et al., 2013). Consequently, a wide array of needs can arise in this cohort that are often unmet (Low et al., 2003).

Method
This international study utilises a mixed-methodological approach incorporating online surveys and interviews on key young stroke stakeholders, including young stroke survivors aged 18-65 (N=317), carers of young stroke survivors (N=58) and stroke clinicians with experience treating young stroke (N=117). Qualitative survey responses and interview transcripts were thematically analysed (Braun & Clarke, 2021) to highlight the impact of young stroke and the unmet needs that arise. Quantitative survey responses were used to describe participant samples and linear multiple regressions were used to explore factors that may predict the impact of young stroke on young stroke survivors (SIS) and their carers (AC-QoL & ZBI).

Results
Stakeholder accounts established that stroke had impacted aspects of physical, psychosocial, cognitive, occupational, financial and overall quality of life in survivors and carers. Subsequent needs were raised in these areas, with many participants needing better signposting/information provision and follow-up post-discharge. Other supports do exist, but many participants found that they were not readily accessible or transferable to a younger patient population.

Conclusion
Overall, this study provides a strong and wide-encompassing overview on the unmet needs that are found in young stroke survivors and the impacts they have.

How will this research improve life after stroke for stroke survivors?
This study provides an account on a variety of post-stroke impacts and unmet needs experienced by young stroke survivors. Many of these factors are more impactful among this cohort and so this research will add to the evidence base of young stroke research which may subsequently inform future research/practices.

14 Impact of post stroke cognitive impairment on return to work following mild stroke and TIA

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Category
Emotional, cognitive and psychological impact of stroke

Background and aims
Stroke occurrence in younger people is rising and medical advancements have resulted in higher rates of minor strokes. Despite minor/no physical deficits, return to work (RTW) rates among younger stroke survivors (YSS) is low. Post-stroke cognitive impairment (PSCI) changes how the brain understands, processes, stores and uses information, and is a key determinant of RTW. Up to 60% of <65yr old stroke survivors continue to have PSCI at 1 year. This review aims to synthesize the evidence on PSCI and how it relates to RTW outcomes following minor stroke and TIA.

Method
We searched MEDLINE, EMBASE, CINAHL, and APA PsycINFO databases for original studies published from 2003 to September 2023 in English. A combination of Subject Headings and free text keywords and synonyms for minor stroke/TIA, cognition, and return to work were used. Two reviewers screened all titles and abstracts and selected studies for inclusion that met predetermined criteria. Two independent reviewers extracted data and appraised quality using JBI critical appraisal tools.

Results
Five observational non-intervention studies met criteria. Meta-analysis not calculated due to heterogeneity of sample, instruments, follow-up (3mo-7yrs). RTW rates ranged from 69.9% to 100%. One study examined performance at work with 40% reporting reduced work performance. Younger age, absence of anxiety and depression, stronger executive function, information processing and communication were significant factors associated with RTW.

Conclusion
RTW after mild stroke/TIA is associated with demographic, cognitive and psychological factors. Research is at an exploratory stage with a significant knowledge gap in effective interventions for this stroke population.

How will this research improve life after stroke for stroke survivors?
PSCI is the 2nd highest area of uncertainty in stroke rehabilitation research (Hill et al 2022). This SR synthesized current evidence and highlights significant research and clinical gaps to be redressed in order to improve return to work outcomes for working survivors of mild stroke and TIA.

15 The Measurement of Treatment Burden after Stroke (TRUSTED)

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Category
Lifestyle

Background and aims
Treatment burden is the workload of healthcare for people with long-term conditions and the impact of this work on wellbeing. Stroke survivors often experience arduous rehabilitation and long-term care needs, yet we lack a validated scale designed to measure treatment burden in stroke survivors. We adapted a patient-reported measure of treatment burden in multimorbidity, PETS (Patient Experience with Treatment and Self-Management), to create a stroke-specific measure, PETS-stroke.

We aimed to examine construct validity, reliability and feasibility of PETS-stroke.

Method
We recruited community-dwelling stroke survivors within one year of stroke. We evaluated construct validity against 3 other patient reported measures (PRMs): The Stroke Southampton Self-Management Questionnaire; The Satisfaction with Stroke Care Measure; and The Shortened Stroke Impact Scale. We evaluated test-retest reliability by readministering PETS-stroke to all participants 2 weeks after completion of the first questionnaire. Cronbach's alpha was used to examine internal consistency. Feasibility was examined by thematic analysis of participant interviews.

Results
Three-hundred-ninety-six participants were recruited. Population demographics were: median age 69 (IQR=13); 43% female; 5th quintile for area deprivation=23%, 4th quintile=23%, 3rd quintile=17%, 2nd quintile=19%, 1st quintile=18%; median number of comorbidities=2 (IQR=2); higher education=47%, school qualifications=36%, no qualifications=17%. We will provide data on construct validity at a future date. No major concerns arose about feasibility, but further work is needed in those with aphasia or cognitive impairments.

Conclusion
Completion will produce a validated measure of treatment burden in stroke that can be used to identify those with high burden and provide an outcome measurement for use in clinical trials.

How will this research improve life after stroke for stroke survivors?
Our measure will enable us to determine the level of treatment burden stroke survivors experience following stroke.

16 Positive and negative experiences and unmet needs of individuals making lifestyle behaviour changes after stroke

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Category

Lifestyle

Background and aims

A combination of lifestyle measures in addition to pharmacotherapy is recommended to enhance stroke secondary prevention and improve patient outcomes. Achieving behaviour-change that promotes better health after stroke is challenging, necessitating ongoing motivation and assistance, influenced by complex social settings and cultural factors. The purpose of this study was to gather stroke survivors' experiences and perceptions of where and how lifestyle related risk factors were addressed along their stroke journey.

Method

Purposive sampling of community-based stroke support groups facilitated participant recruitment. Data were collected nationally (8 group discussions), both urban and rural. Each focus group discussion was guided by semi-structured questions developed in collaboration with our stroke patient and public involvement (PPI) panel. A framework analysis of results generated, using the Theoretical Domains Framework (TDF) addressing constructs and theories of behaviour-change, was conducted to better understand individuals' experiences of making lifestyle changes after stroke.

Results

Data were coded, categorised and results mapped to eight TDF domains – Knowledge, Beliefs about Capabilities, Beliefs about Consequences, Reinforcement, Memory, Attention and Decision Processes, Social Influences, Emotions, and Behavioural Regulation. The most reported construct for behaviour-change was knowledge, the need for information or lack thereof. Participants reported lifestyle changes in the context of what they did themselves, what was directed by healthcare professionals or supported by family/community services.

Conclusion

TDF determinants of health behaviours and behaviour-change proved a valuable tool to link survivors' experiences and identified mediators for change with theoretical perspectives, to guide appropriate interventions designed to support individuals in risk reducing behaviours following stroke.

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

I am bringing together the evidence from this study and from current practice to a series of co-design workshops to develop a healthy lifestyle intervention to support people to stay well and reduce their risks after stroke.

17 The PAOLI (People with Aphasia and Other Layperson Involvement) framework for patient involvement in research

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Category

Long term support (including carers and community support)

Background and aims

Patient and Public Involvement in stroke research requires the inclusion of people with aphasia as partners. Yet the quality of reporting on their contributions is poorly documented in the absence of a framework. This study aimed to extract the content for the development of the PAOLI framework.

Method

The EQUATOR network's method was followed. This involved: (1) evidence from a scoping review, (2) a two-round Delphi survey for content selection and (3) an experts' consensus meeting. The research team involved two PPI partners with chronic stroke-induced aphasia. The research process involved co-design and was informed by the Dialogue model.

Results

Twenty-three panellists, from 13 countries, voted in round one with 87% (20/23) responding in round two. The final PAOLI framework includes the following 17 items (with 66 descriptive statements): establish collaborations, recruit patients, gain informed consent, organize induction meetings, train patient partners, create communication links, engage communication partners, conceptualize topics, establish research priorities, reach consensus, work with co-design methods, develop proposals, assist with dissemination of results, promote the implementation of the outcomes, support patient partners and promote self-evaluation, monitor progress and assess the impact of the patient involvement. The panellists considered these items as the most relevant for the involvement of people with aphasia as research partners.

Conclusion

The PAOLI is the first international consensus framework for guiding patient involvement in aphasia research. Researchers are encouraged to adopt the framework to improve the quality of their research by promoting the meaningful involvement of people with aphasia within the research team from the start.

How will this research improve life after stroke for stroke survivors?
The PAOLI framework represents a new frontier for the creation of participatory studies to identify stroke and aphasia rehabilitation needs in clinical/ social settings. PAOLI aims to place patients at the centre of healthcare-decisions, and empower researchers and stroke survivors to engage with mutual respect and experience positive research relationships.

18 Participant experiences from LAST-long: Life After Stroke - A Norwegian long-term follow-up project

Dr Katherine Algar-Skaife[1], Dr Mari Gunnes[2], Dr Anne Hokstad[1], Dr Bente Thommessen[3], Dr Håkon Ihle-Hansen[4], Professor Ingvild Saltvedt[5,1], Dr Karianne Berg[6], Dr Ronny Bergquist[1], Dr Øystein Døhl[7,1], Professor Torunn Askim[1]

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Category
Long term support (including carers and community support)

Background and aims
In Norway, around 10,000 people are admitted to hospitals with acute stroke every year. A national pathway of stroke care has been established to ensure patients receive evidence-based treatment and rehabilitation without time-delay for three months after discharge from hospital. The evidence for further follow-up is lacking, despite a significant proportion of stroke survivors still being dependent in activities of daily living. The LAST-long randomised controlled trial is investigating whether monthly meetings with a community-based stroke coordinator who offers a multimodal approach to long-term follow-up can prevent functional decline after stroke. As part of the ongoing process evaluation, we describe the experiences of participants receiving the LAST-long intervention to understand the impact as well as challenging and enabling factors to participation.

Method
Twenty-one semi-structured interviews were conducted with participants randomised to the intervention group. These were guided by the RE-AIM framework to evaluate the *reach*, *effectiveness*, *adoption*, and *implementation* of the intervention. Coordinator notes also provided additional data. Data were analysed using an inductive and deductive codebook thematic analysis approach.

Results
Preliminary results indicate that participants perceived the stroke coordinator as a conversation partner which facilitated the setting, achievement, and maintenance of long-term goals. This made them feel safe and helped them return to improved function in everyday life.

Conclusion
Participant perspectives provide important insight into the perceived impact of the intervention, such as maintenance of long-term goals. Results will support future implementation of long-term follow-up by a community-based stroke coordinator to improve the quality and effectiveness of provision for stroke survivors.

How will this research improve life after stroke for stroke survivors?
LAST-long participants benefit from closer follow-up over a longer period that not only focusses on physical activity and exercise, but also mental health, cognition, social function, and secondary prevention (medications and lifestyle factors). This project aims to ensure this becomes an offer for everyone affected by stroke in Norway.

19 What is being shared in a Facebook group for stroke survivors?

Dr Malin Tistad[1,2], Dr Lill Hultman[1], Dr Ulla-Karin Schön[3], Mrs Jeanette Nelson[1], Mr Mikael Åkerlund[1], Mr Fredrik Sandman[1], Dr Elisabet Åkesson[1], Professor Lena von Koch[1]

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Category

Long term support (including carers and community support)

Background and aims

Facebook groups are arenas where stroke survivors' and relatives' share their experiences and knowledge of life after stroke. With the view of Facebook groups as peer-support groups in which stroke survivors set the agenda for the exchange of experiences and knowledge, the purpose of this study was to increase the knowledge about what is being shared in posts and comments in a Facebook-group for stroke survivors.

Method

People with own experience of stroke were co-researchers in all phases of the research project. We collected data on posts and comments in a Facebook group for stroke survivors during a 3-month period. Together we analysed the post using the principles of qualitative content analysis.

Results

We created eight partly overlapping and preliminary categories: contacts with the health care system, consequences of stroke and practical issues, enjoyments and progress, setbacks and frustration, family life and leisure activities, exercise in everyday life, work-related issues and contacts with authorities, and words of wisdom. These categories captured the group members' sharing of experiences and reflections from everyday life, questions and/or wishes to take part of other members' experiences. In the comments generated by the posts, members confirmed experiences described in the posts and provided additional perspectives based on their own experience. In addition, new discussions on related topics arose in the comment threads.

Conclusion

A variety of topics are covered on Facebook groups for stroke survivors. Sharing experiences, learning from others' experiences, and getting recognition of what you are going through seems valuable.

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

Health professionals, relatives and friends can preferably inform stroke survivors about Facebook groups as a source of knowledge and support. Moreover, as social media increasingly is becoming an integral part of people's daily life, training in the use of social media should be part of stroke rehabilitation when relevant.

20 From newcomer to expert: the meaning of participating in a Facebook group for stroke survivors

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Karolinska Institutet, Stockholm, Sweden

Category

Long term support (including carers and community support)

Background and aims

Facebook groups have been described as important arenas for sharing experience-based knowledge of living with the consequences of a diagnosis, or a symptom. The aim of this study was to increase the knowledge about the meaning of being a member in a peer-support group at Facebook as described in the lived experience of members in a Facebook group for stroke survivors and in a group for people with fatigue.

Method

This study is part of a research project in which co-researchers with own experience of stroke identified Facebook as an important arena for sharing experience-based knowledge of living with stroke. Members of two Facebook groups; for stroke (n=14) and fatigue (n=8), were interviewed and data was analysed using the empirical phenomenological psychological method.

Results

The findings reflect the lived experience of being a member in Facebook groups for members with a diagnosis or a specific symptom and is presented as a preliminary meaning structure consisting of three main characteristics: *learning through others' experiences*, *confirmation of a new self*, and *finding a new role in supporting others*. The categories together reflect a process whereby members move from being newcomers with more pronounced needs to learn from others' experiences and have their own experiences validated, to taking on the role of expert and supporting others.

Conclusion

Sharing experience-based knowledge in a Facebook group can give support in finding self and identity after a stroke or when living with fatigue.

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

A Facebook group with members with experiences of the consequences of stroke can be a meaningful peer-support group after stroke. Social media is an integral part of people's daily life and has potential to provide peer-support. Hence, training in the use of social media should be part of stroke rehabilitation.

21 Why stroke patients suffer from Cognitive Fatigue

Mrs Anja Minheere

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Category

Long term support (including carers and community support)

Background and aims

Cognitive fatigue is a frequent sequel after a stroke. About fifty per cent of the patients in the chronic phase suffer from cognitive fatigue, and for nearly half of them, fatigue is the most disabling consequence of the stroke. Furthermore, severity changes not very much in the rest of a patient's life. Much research has been done on this experience, but the results are inconsistent. Therefore, fatigue after stroke is a poorly understood phenomenon.

Method

A non-systematic review.

Results

In stroke patients, the functional connectivity of the whole brain is less efficient, and compensation is necessary to overcome that for optimal performance. This extra activation for compensation leads, in turn, to a less(er) efficient brain network, which requires extra cognitive control and, therefore, extra mental effort. This is experienced as cognitive fatigue.

We suggest that cognitive fatigue is a self-reinforcing process or a downward spiral. After a few loops, the compensation mechanism can no longer be absorbed, the brain deteriorates, and the person experiences an overwhelming feeling of cognitive fatigue and is incapable of performing the cognitive task (demotivation).

Conclusion

We suggest the following definition for Cognitive Fatigue:
Cognitive fatigue is a concept conceptualized as (subjective) feeling gradually built up due to sustained mental effort for compensation or compensation in the cognitive control. To achieve optimal task performance addict, a national mental effort is required. This, in turn, results in variable and lower task performance, so additional mental effort is required. (Downwards spiral).

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

We hope our findings inspire researchers and pathways for new research on cognitive fatigue with the ultimate goal of better treatment opportunities.

22 HCP Perspectives of a Health Communication Passport for Stroke: An International UK and Ireland Survey

Ms Norma O' Leary, Dr Helen Kelly

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Category
Long term support (including carers and community support)

Background and aims
The Irish National Stroke Strategy (2022-2027) has recommended the introduction of a patient held resource such as a 'Stroke Passport' to allow patients to keep clear and current records of health treatment and support throughout their rehabilitation. To ensure successful uptake of this resource, the perspectives of all stakeholders, including HCPs, need to be considered, in particular regarding the purpose, design, format, and content.

Method
An online survey explored the opinions of healthcare professionals based in Ireland and the UK who work in stroke care. Numerical data was analysed using descriptive and inferential statistics. Opinions and comments made by participants were analysed using Thematic Content Analysis based on the Theoretical Domains Framework.

Results
A total of 111 (64% Ireland; 36% United Kingdom (UK) healthcare professionals completed the survey. The survey respondents identified the most common methods stroke information was provided to patients across settings as verbal discussions, booklets, leaflets, and telephone calls. UK respondents indicated a significantly greater perceived satisfaction by patients and family/caregiver with current information provision compared to their Irish counterparts. Most participants stated that a Stroke Passport should ideally be provided in both a digital and paper formats.

Conclusion
This survey provides important insights into current information provision practices of healthcare professionals working in the area of stroke. There was agreement about the importance of the provision of a standardised information resource, such as a Stroke Passport, to enhance stroke patient care.

How will this research improve life after stroke for stroke survivors?
Insight into current information provision practices, perceived barriers to implementation, and suggestions regarding the content and format of a patient held health record will contribute to the development of a patient held Stroke Passport. This ultimately has the potential to equip stroke patients in the active management of their healthcare.

23 Stroke coordinator experiences from LAST-long: Life After Stroke - A Norwegian long-term follow-up project

Dr Katherine Algar-Skaife[1], Dr Mari Gunnes[2], Dr Anne Hokstad[1], Dr Bente Thommessen[3], Dr Håkon Ihle-Hansen[4], Professor Ingvild Saltvedt[5,1], Dr Karianne Berg[6], Dr Ronny Bergquist[1], Dr Øystein Døhl[7], Professor Torunn Askim[1]

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Category

Long term support (including carers and community support)

Background and aims

In Norway, around 10,000 people are admitted to hospitals with acute stroke every year. A national pathway of stroke care ensures that patients receive evidence-based treatment and rehabilitation without time-delay for three months after discharge from hospital. Further follow-up is not currently provided despite a significant proportion of stroke survivors still being dependent in activities of daily living. The LAST-long randomised controlled trial is investigating whether monthly meetings with a community-based stroke coordinator who offers a multimodal approach to long-term follow-up can prevent functional decline after stroke. As part of the ongoing process evaluation, we describe the experiences of stroke coordinators delivering the LAST-long intervention, including challenging and enabling factors to implementation.

Method

A focus group was conducted with stroke coordinators in 2021 and 2023. Seven stroke coordinators participated overall, with four participating in both. The focus groups were guided by the RE-AIM framework to evaluate the *reach, effectiveness*, *adoption*, and *implementation* of the intervention. Data were analysed using an inductive and deductive codebook thematic analysis approach.

Results

Preliminary results indicate that stroke coordinators felt they were fulfilling an unmet need within the community and helping stroke survivors return to participation in daily life. They experienced good support from their managers, however, they sometimes found operating within the context of a research study a challenge.

Conclusion

Stroke coordinator perspectives support the need for long-term community-based follow-up. Understanding challenging and enabling factors will improve future research practices and implementation of the intervention to improve the quality and effectiveness of provision for stroke survivors.

How will this research improve life after stroke for stroke survivors?
Long-term follow-up by a stroke coordinator can help maintain good function and quality of life in people with stroke in the long term. Understanding what helps and hinders implementation will create more sustainable services with appropriate allocation of resources to improve the quality and effectiveness of health services.

24 Improving the patient and public involvement meeting for stroke survivors with aphasia

Dr David Wyatt, Dr Sophie Rowland-Coomber

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Category
Long term support (including carers and community support)

Background and aims
Patient and public involvement (PPI) is vital for impactful research that meets the needs of stroke survivors. While there are various ways to complete PPI, PPI often takes place in a formal meeting setting, either face-to-face or via video conference, limited in part by budgetary constraints. This, however, facilitates the participation of some stroke survivors but can inhibit those with greater stroke-related impairments. We worked with stroke survivors with aphasia to coproduce simple guidelines on how we can make the routine PPI meeting more accessible for, and better support the contribution of, those with aphasia.

Method
We convened three coproduction workshops with stroke survivors with aphasia.

Results
Participants suggested and supported the development of guidelines for researchers including guidance on researcher presentations – they should be a maximum of 5 minutes, pre-recorded using simple language and images, and questions specified in advance, so PPI participants have time to think. Participants wanted ways to contribute their thoughts after the meeting too, when they were able to express them clearly. Participants also wanted to promote our PPI work with those with aphasia using their own voices, so we produced a short video using audio from brief interviews with participants.

Conclusion
PPI needs to be accessible to all stroke survivors, irrespective of stroke-related impairment. Further work is needed (and planned) to pilot these guidelines for researchers and explore how we can make PPI more equitable and accessible to all stroke survivors within the typical PPI meeting and in other digital and face-to-face formats.

How will this research improve life after stroke for stroke survivors?
Meaningful patient and public involvement (PPI) underpins good, impactful research with the potential to improve the lives of stroke survivors. Our work supports the inclusion of the perspectives of those with aphasia in routine PPI work where funds for more advanced speech and language support are not available.

25 A discourse analysis of identities and subject positions in a Facebook community for stroke survivors

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Category

Long term support (including carers and community support)

Background and aims

Connecting with people who have gone through similar experiences can be a helpful way to get support. Online stroke communities provide environments in which people with similar health concerns can interact and exchange experiences. In this study, we explore how members of an online community for people with own experience of stroke create different understandings of stroke and utilize different types of narratives to construct different identities and roles, namely, subject positions.

Method

To identify central subject positions, the protocols were read and reread. To operationalize the analysis, we relied on discourse analysis in which key concepts constructed different subject positions, that were connected, and defined by chains of equivalence. For 3 months interactions between members were collected in structured protocols that describe the content of communication through posts and comments.

Results

Five central subject positions with corresponding equivalence chains were identified: survivor, mentor, pathfinder, struggler, and misfit. The five positions were gathered under two major positions: (1) struggles with recovery and work rehabilitation and (2) struggles with self-care and constructing an identity. Those positions represented different types of challenges and roles that people with own experience of stroke and their close relatives can claim after the onset of stroke. There are variations within each position; the participants can hold several positions simultaneously or change between different positions.

Conclusion

By sharing experience-based knowledge stroke survivors can help each other to adapt to a new life situation. Exchanging experiences increases the collective knowledge in the group which allows everyone to be a knowledge producer.

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

Facebook communities offer a safe space for people to try out new identities, and as such it can generate important experience-based knowledge. By strengthening and encouraging members to share their perspectives with healthcare professionals, the knowledge developed in online communities could contribute to informing professional development of stroke care interventions.

26 Supporting after stroke: significant others' understanding of and perceived role in self-management

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Category

Long term support (including carers and community support)

Background and aims

Self-management support is important in persons adaptation to a new life after stroke. Significant others often provide a meaningful part of that support. The impact on family members caring for a person after stroke has been extensively studied, however there is a lack of research into significant others' understanding and experiences of self-management after stroke. Therefore, this study aimed to explore how significant others understand self-management and how they perceive their role in supporting self-management in post-stroke rehabilitation at home.

Method

Qualitative, semi-structured interviews were conducted with 28 significant others of persons in rehabilitation after stroke. Data were analysed using inductive content analysis.

Results

The preliminary results showed that significant others commonly relate self-management to activities of daily living (ADL) and rehabilitation training. Participants saw their role as important not only to assist the stroke survivor practically, but also to provide emotional support and companionship.

Conclusion

There is an emerging discrepancy between descriptions in the literature and significant others' perceptions of and actions to support self-management. If significant others obtained a clearer understanding of the concept of self-management, their support could be more efficient in strengthening self-efficacy and self-management abilities in stroke survivors.

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

By highlighting the characteristics of significant others' self-management support and their understanding of the concept, interventions to enhance self-management support for stroke survivors can be improved in the future.

27 Improving stroke outcomes and care through technology: stakeholders' perspectives on the use of patient portals

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Category
Long term support (including carers and community support)

Background and aims
Substantial data is held on stroke survivors in clinical records and research databases, such as the South London Stroke Register. We are developing a patient portal to allow stroke survivors real-time and dynamic access to their health and research data. We conducted a study to explore the informational needs, functionality requirements, and the barriers and enablers of portal use with stroke survivors and their carers, clinicians, allied health professionals, researchers and healthcare managers.

Method
Semi-structured interviews were completed with a maximum variation sample of: stroke survivors (20) and carers (15); GPs and other clinicians, including allied health professionals (25); healthcare managers, commissioners, and policymakers (15). Data were analysed using inductive thematic analysis.

Results
Accessible design features (e.g. text-to-speech, images and plain language) were identified as crucial for a usable portal, but stroke survivors and carers were more concerned with how a portal can provide additional support and value – from giving a place to record blood pressure readings through to helping them navigate care post-stroke by providing access and or direction to available resources. For broader stakeholders, the portal offered a way to support stroke survivors in managing the risk of stroke recurrence and allow stroke survivors to contribute new data for future data-driven research.

Conclusion
The study provides vital information on the potential utility and effectiveness of patient portal technology to improve stroke care and reduce stroke recurrence. Work is needed, however, to explore how similar benefits can be achieved with those unable to access a portal website.

How will this research improve life after stroke for stroke survivors?
Stroke survivors consistently request better information on stroke, their stroke care and available support. Portals offer huge potential to address some of these issues, while also supporting self-management. This project works to make sure our portal will be as valuable as possible to stroke survivors and their needs.

28 Struggling to recover: long-term Impact of Stroke, the voices of Stroke Survivors, Carers and Clinicians

Dr NIAMH KENNEDY

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Category
Long term support (including carers and community support)

Background and aims
By understanding the lasting impact stroke can leave and the extent of the damage stroke survivors live with,this can help inform how to best care for and support stroke survivors, both during hospital and after discharge. This increased understanding could help design treatment protocols and provide stroke survivors with a better quality of life both physically and mentally.

The purpose of this project is to examine the long-term effects of stroke by gathering information from stroke survivors, carers and clinicians and to understand the standard of current care, where the gaps are and how future care could be better.

Method
Three targeted questionnaires were developed for stroke survivors (aphasia friendly), carers and professions working across the whole stroke pathway. The questionnaires were distributed via professional networks, the Stroke support groups, social media and newspaper advertisement.

Results
305 stroke survivors (aged 19-95), 101 clinicians working in stroke care across acute and community, 75 respondents to the carers survey. There was common themes across all 3 surveys regarding long term impact and support following stroke. These included increased psychological support and acknowledgement of ‘hidden’ effects of stroke as well as improved length, impact of younger stroke, intensity and delivery of rehabilitation to stroke patients. The individual groups also highlighted the need for increased public awareness of long lasting effects of stroke, improved transition and more support for carers.

Conclusion
Across all 3 groups limitations of post-acute care were highlighted resulting in 6 recommendations to address the unmet needs of stroke survivors.

How will this research improve life after stroke for stroke survivors?
To allow their voices to help influence design of long term support services. To highlight the areas of concerns of the stakeholders in long term stroke recovery

29 Barriers, Facilitators and Design of a Health Communication Passport for Stroke: Perspectives of Healthcare Professionals

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Category

Long term support (including carers and community support)

Background and aims

The Irish National Stroke Strategy (2022-2027) has recommended the introduction of a Stroke Passport. The purpose of this resource would be to allow patients to keep a record of their healthcare throughout their stroke journey from acute hospital discharge to living in the community. However, the perspectives of stakeholders, including healthcare professionals, on the purpose, design, format, and content of a Stroke Passport is not yet known.

Method

Focus groups interviews were conducted with Healthcare Professionals who worked in an acute stroke ward and/or Early Stroke Discharge (ESD) Team in Ireland. Data were analysed using Braun & Clark's (2022) Thematic Analysis framework.

Results

Twenty-two healthcare professionals took part in one of four focus groups (acute stroke ward n=19, ESD n=3). Participants included: Allied Health Professionals (n=10), nursing staff (n=6), medical doctors (n=3), Pharmacy (n=1), Psychology (n=1), Medical Social Work (n=1). Preliminary findings suggest that a Stroke Passport, as a central source of information, has the potential to empower patients and family/caregivers. There was a general agreement that a Stroke Passport should be digital rather than paper based as issues relating to data protection, longevity, and user buy-in are more challenging with a paper version. A key potential obstacle to implementation is lack of digital infrastructure.

Conclusion

The provision of a Stroke Passport was considered an important asset to patient care. However, more focus on addressing current gaps in our stroke healthcare system, particularly digital infrastructure, during the transition from hospital to home is required prior to its implementation.

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

A patient held health resource such as a Stroke Passport will enable better self-management of patient healthcare. For implementation to be successful, all stakeholders need to be included in discussions around its development. This study offers the perspectives of healthcare professionals who will be populating and using this resource.

30 After stroke you are not alone. Results of Programa Abric

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Category

Long term support (including carers and community support)

Background and aims

In 2021, the Programa Abric by Fundació Ictus was launched to offer free advice, information and training to people affected by stroke and caregivers.
The objective was to evaluate the characteristics of the cases treated by the multidisciplinary team, detect the most requested areas of care and know the overall acceptance of the program by users.

Method

Observational, descriptive, retrospective study. The cases treated by multidisciplinary team made up of a nurse (N), physiatrist (P), neuropsychologist (NP) and social worker (SW) between January 2021 and June 2023 were analyzed. In the reception interview, the needs of each case were detected and referred to multidisciplinary group or individual interviews depending on the field of experience.

Results

1001 cases were attended, 577 patients (57.5% men, mean age 63.9 years) and 424 caregivers (71.2% women, average age 49.5 years). 59.4% ischemic strokes, 18% hemorrhagic. The time elapsed from the stroke to the consultation with the Programa Abric was: <7 days in 4.4% of cases; 7-90d in 34.7%; 90-180d in 15.8% and >180d in 45.1%.

With regard to interventions, 548 reception interviews, 167 group meetings and 101 individual meetings were carried out. Interventions by professional profile: N 21.7%, P 26.1% of cases, NP 29.4% and SW 22.8%. Users' acceptance of the program was excellent in 78% of cases.

Conclusion

The users served are mainly male patients and female caregivers. The majority of cases were treated in the chronic phase. The most in-demand area of care is neuropsychology. The program has an excellent rating from users.

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

After suffering a stroke, both the patient and their family or caregivers can feel alone and overwhelmed. The Abric program offers information, training and support at any time during the evolution of the disease, thereby helping to improve their quality of life.

31 Prevalence, patterns, and predictors of patient-reported non-motor outcomes at 30 days after acute stroke

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Category
Other

Please describe your submission category, if you have selected other above
Patient reported health outcomes

Background and aims
Adverse non-motor outcomes are common after acute stroke and substantially affect quality of life, yet few studies have comprehensively assessed non-motor outcomes across multiple health domains. We aim to identify the prevalence, patterns and the factors associated with non-motor outcomes 30 days after stroke.

Method
This prospective observational hospital cohort study identified patients with acute ischaemic stroke or intracerebral haemorrhage (ICH) admitted to the Hyperacute Stroke Unit (HASU) University College Hospital (UCH), London, between August 1st 2018 and August 31st 2019. We assessed non-motor outcomes (anxiety, depression, fatigue, sleep, participation in social roles and activities, pain, bowel, and bladder function) at 30-day follow-up.

Results
We included 605/719 (84.1%) eligible patients (mean age 72.0 years; 48.3% female; 521 with ischaemic stroke, 84 with ICH). Anxiety (57.0%), fatigue (52.7%), bladder dysfunction (50.2%), reduced social participation (49.2%), and pain (47.9%) were the commonest adverse non-motor outcomes. The rates of adverse non-motor outcomes in ≥1, ≥2 and ≥3 domains were 89%, 66.3% and 45.8%, respectively; in adjusted analyses, stroke due to ICH and admission stroke severity were the strongest and most consistent predictors. There were significant correlations between; bowel dysfunction and bladder dysfunction (κ= 0.908); reduced social participation and bladder dysfunction (κ= 0.844); and anxiety and fatigue (κ= 0.613). We did not identify correlation for other pairs of non-motor domains.

Conclusion

One month after a stroke, nearly 90% of patients face multiple non-motor problems in pairs such as anxiety and fatigue, especially after severe strokes and ICH. Comprehensive recovery programs needs a multi-domain approach.

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

Our findings regarding the prevalence, patterns and predictors of adverse patient reported non-motor outcomes should help stroke services to plan pathways to first ascertain and then address these patient-reported adverse outcomes to improve post-stroke quality of life and provide patient-centred stroke care pathways.

32 Developing the National Stroke Audit to Enhance the Quality of Acute Stroke Care in Ireland

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Category

Other

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

Audit & service provision

Background and aims

Population ageing, treatment advances, evolving models of care, and between-hospital variation in patient outcomes highlight the need for continual audit of stroke care services to evaluate whether patients are being delivered evidence-based practice in a high quality, equitable manner. This project aims to review international practice and guidelines to develop core minimum datasets for acute and non-acute stroke care for integration into the newly-developed Irish National Audit of Stroke (INAS).

Method

In the acute phase, a scoping review of international practice identified 21 stroke registries/audits with national coverage and continuous data collection. Acute stroke care data items were extracted from data dictionaries, translated, and charted. Data charting was performed to compare Irish and international items to identify commonalities and/or gaps in coverage.

Results

A synthesised inventory of acute care data items [existing Irish items (n=103), the most frequently-collected international items (n=97), and additionally suggested items (n= 22)] were reviewed by key stakeholders in a three-stage Delphi process regarding their potential inclusion in INAS. Following consensus, a core minimum dataset comprising 86 acute care and 35 thrombectomy items was finalised. Examples of items recommended for INAS include history of risk factors and complications.

Conclusion

The minimum datasets, as guided by best practice international standards, local priorities, and iterative cycles of stakeholder engagement, will act as the "gold standard" for monitoring stroke care in Ireland. The national clinical audit may facilitate prospective data collection of high quality, rich data that can be used by those who deliver, manage, and monitor stroke healthcare.

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

The ultimate aims of the resulting minimum audit datasets for monitoring stroke healthcare are to enhance patient outcomes and recovery, review unmet needs, assess accessibility and equitability of service use, better understand the lived experience of stroke survivors, and support local and national quality improvement.

33 Transitioning to home and beyond following stroke: a prospective cohort study of outcomes and needs.

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Category
Rehabilitation

Background and aims
The needs of people with stroke at hospital discharge are poorly understood. This study aimed to profile and document the needs of individuals with stroke upon hospital discharge to home and within the first six months.

Method
A prospective cohort study enrolling stroke patients from three hospitals, transitioning directly home, after rehabilitation, or with early supported discharge teams. Using validated questionnaires and surveys, their outcomes (global health, cognition, function, quality of life) and needs were described at 7–10 days, 3–, and 6–months after discharge.

Results
72 patients were recruited at hospital discharge; mean age 70 (SD 13); 61% female; median NIHSS score 4 (IQR 0-20). 62 (86%), 54 (75%), and 45 (63%) individuals were available respectively at each data-collection time-point.

At hospital discharge, perceived disability was high (51% with mRS>3), and while decreased at three months, it began to increase (35% with mRS>3 at six months). Mean physical health and social functioning were “fair” at hospital discharge and ongoing; while HR-QOL, although improved over time, remained impaired at 6-months (0.69+/-0.28). At 6-months cognitive impairment was present in 40%. Unmet needs included participation in care planning and decisions, as well as for support, information, and rehabilitation. The median number of unmet needs at discharge was four (range:1-9), and three (range:1-7) at 6-months.

Conclusion
Reintegrating into the community after a stroke is difficult for people with stroke and their families due to significant unmet needs. It is essential to understand the needs of survivors in order to develop and implement effective interventions.

How will this research improve life after stroke for stroke survivors?
Understanding the transitional care needs of people with stroke is crucial for developing targeted interventions that meet these needs and address service gaps, thereby optimising post-stroke outcomes, reducing adverse events, and enhancing satisfaction and well-being for the person with stroke and their family.

34 Nottingham Fatigue after Stroke: Codesign to develop an intervention to support management of post-stroke fatigue.

Dr Joanne Ablewhite[1], Professor Fioan Jones[2], Ms Lydia Jones[1], Professor Roshan das Nair[1], Mr Michael Taylor[1], Dr Shirley Thomas[1], Ms Emily Toplis[1], Professor Heather Wharrard[1], Professor Avril Drummond[1]

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Category
Rehabilitation

Background and aims
Fatigue is a common and debilitating symptom which is believed to affect over 50% of individuals of stroke survivors. It presents a significant challenge to recovery. However existing evidence on how to best manage fatigue after stroke is limited, and many guidelines fail to involve stroke survivors with lived experience in making recommendations to manage it.

Our aim is to develop a ‘pick and mix’ (a term suggested by our patient and public involvement group), intervention that can be tailored to the unique needs of stroke survivors in managing their fatigue. Using codesign groups, we will include the input of people with lived experience of managing post-stroke fatigue, as well as their informal caregivers and clinicians.

Method
The study comprises four phases:

Phase 1. Codesign groups to develop an online resource and workbook to aid understanding of the impact of post-stroke fatigue.

Phase 2. Codesign groups to develop an online resource to showcase strategies that can be used to support fatigue management.

Phase 3. People with lived experience of managing fatigue after stroke will be recruited and trained as ‘buddy’ facilitators. The training will also be developed using a codesign approach.

Phase 4. A feasibility trial to test the programme.

Results
We will present our findings to show how this intervention can be tailored to the unique needs of stroke survivors with fatigue.

Conclusion

The lived experiences of stroke survivors and their informal caregivers are being used to directly inform and develop this post-stroke intervention.

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

By addressing the lack of research that includes lived experience, we will equip stroke survivors, family members and healthcare professionals with an intervention to support the management of fatigue after stroke.

35 Healthcare professionals views of working relationships and self-management in community stroke rehabilitation.

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Category
Rehabilitation

Background and aims
A patient-provider partnership, or working relationship, constitutes one-of-five core self-management skills but is not well understood in community stroke settings and has not been explored in relation to stroke self-management. The aim of this study with healthcare professionals is to understand: (i) how self-management is perceived in community stroke rehabilitation, (ii) how relationships are developed, maintained, and repaired, and (iii) which aspects of the relationship are perceived to help or hinder self-management.

Method
Qualitative, semi-structured interviews were conducted with healthcare professionals from four NHS community stroke services. A group of seven people with lived experience of stroke helped develop the interview schedule and contributed to analysis. Inductive thematic analysis, using Braun and Clarke's 6-stages and NVivo, developed the themes.

Results
Analysis of nineteen interviews produced three themes and ten subthemes. 'Confusion about what self-management is' leads to impairment-focused support, with less recognition of emotional management. Relationships are complex and developed on the premiss that 'we're not going to be here forever'. Buy-in and managing expectations contribute to developing and maintaining relationships. In the context of rehabilitation, relationships are considered important for rehab success. 'Unpicking the magic but muddying the waters' highlights where confusion remains about transitioning to relationships conducive to self-management success, as well as rehab success.

Conclusion
Staff training and education about what self-management is for stroke survivors, beyond focusing on impairments, may address the complex psychosocial consequences of stroke and introduce co-production opportunities within services. Adopting evidence-based interventions may enhance community relationships to be conducive for both rehab and self-management success.

How will this research improve life after stroke for stroke survivors?
This research has developed recommendations for practice that aim to improve self-management support for people accessing community stroke services. It highlights opportunities for co-production with stroke survivors, their families, and service providers around addressing what self-management can look like after stroke, including the management of long-term emotional and psychosocial consequences.

36 Wellbeing After Stroke (WATERS) feasibility study: Acceptance and Commitment Therapy addressing psychological adjustment post-stroke

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Category

Rehabilitation

Background and aims

Stroke services struggle to prevent mental health crises, in part due to insufficient evidence-based interventions and workforce capacity. We aimed to co-develop and test the feasibility of a group intervention based on Acceptance and Commitment Therapy (ACT), facilitated by trained staff, supervised by clinical psychologist.

Method

A 2-stage study: co-development and feasibility testing.

Co-development included Patient Carer and Public Involvement (PCPI).

Qualitative and quantitative data explored: Feasibility of recruitment and retention; data quality; safety. Clinical and demographic information collected at baseline. Stroke survivor participants were recruited >=4months post-stroke, self-reporting psychological distress.

Patient Reported Outcome Measures (PROMs) via online surveys at multiple timepoints included Mood (HADS), Wellbeing (ONS4), and Psychological Flexibility (AAQ-ABI).

Fidelity explored via video-recorded intervention sessions.

Results

We successfully co-developed the WAterS intervention: nine weekly structured online sessions, supported by client handbook; and workforce training programme. We trained eight facilitators and recruited 17 stroke survivors with mild-to-moderate cognitive difficulties at baseline. 12/17(71%) joined three intervention groups with 98% attendance and no related adverse events. Data suggests acceptable fidelity to protocol. PROMS data were well-completed. HADS is a possible future primary outcome (self-reported depression improved on average by 1.3 points: 8.5 baseline to 7.1 at 3 month follow up; 95% CI 0.4 to 3.2). Interviews suggest high acceptability and perceived effectiveness. Feedback has informed improvements to intervention design and delivery.

Conclusion

The WAterS intervention appears acceptable and feasible and warrants further investigation to support wellbeing after stroke. Funding has been secured to develop the intervention, considering implementation and health equality.

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

This research addresses the Life After Stroke number one research priority: supporting psychological adjustment. WAterS, an applied psychotherapy intervention, appears safe and feasible for non-psychologists to deliver online to groups of stroke survivors. Additional research is now underway to consider how best to implement widely while considering health inequality.

37 Conversations about life after stroke: What is (and is not) discussed in stroke services

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Category

Rehabilitation

Background and aims

Stroke survivors often feel unprepared for returning home and navigating life after stroke. Yet it is possible for clinicians to support people in this, through their interactions. Our research examined how life after stroke is discussed in patient-clinician interactions in in-patient stroke services in New Zealand.

Method

Using ethnographic approaches, we observed interactions between five people with stroke and 36 clinicians in three stroke services, completing 300 hours of observations and 76 interviews. Data were analysed using reflexive thematic analysis.

Results

Conversations about life after stroke were limited: limited in topic, focusing on people's health condition, impairments, clinician interventions, and discharge; and limited in time, focusing on time within stroke services and first days after discharge. Many aspects of life that people with stroke consider important were not discussed. Clinicians recognised conversations about life after stroke were important but felt they did not have time, and nor was it the right time for the conversations.

Conclusion

The lack of future-focused conversations may contribute to people feeling unprepared for discharge and exacerbate long-term impacts of stroke. It is essential that we attend to how communication assists people to move forward in their recovery with support and hope, and support clinicians to prioritise these conversations. Given its role in supporting people to move forward in life, communication must be seen as a core clinical skill and a clinical intervention in its own right.

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

If we can improve conversations about life after stroke, and expand the topics and timelines discussed, people may feel better supported and prepared for living life after discharge.

38 Technical feasibility of an upper limb rehabilitation system (NeuroVirt) for home-based post-stroke rehabilitation.

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Category
Rehabilitation

Background and aims
80% of stroke survivors have upper limb (UL) disability. NeuroVirt is a portable immersive virtual reality platform that is designed to encourage high-repetition and high-quality UL movement training.

The aim of the study is to investigate the technical feasibility, and the useability and acceptability of NeuroVirt.

Method
Participants used the device at home for up to two 1-hour sessions each day, 6 days a week, for 6 weeks. Participants also received a 15-minute weekly call.

Participants were adults with a stroke at least 3-months previously, with at least a little motion of the UL, and able to navigate NeuroVirt.

Technical feasibility was measured by the percentage of WiFi disconnections, data push failures, and mean scene frames per second (FPS). Usability and acceptability were explored through interview feedback. We also recorded the number of movement repetitions per session as an indication of compliance.

Results
In this cohort (n=11), the mean age was 61, 36.5% were female, and 45.5% had right side strokes.

Results indicated good Wi-Fi stability with 1.51% disconnections, 0.09% push attempt failed and no data loss. An overall mean of 67.5 (2.27) FPS during a session.

Participants found NeuroVirt acceptable and indicated improvements in function.

On average patients performed 338.2 (172.7) movement repetitions per session.

Conclusion
NeuroVirt had consistent Wi-Fi stability, with no data loss. The frame rate was above the industry standards required to prevent motion sickness. Preliminary useability and acceptability results showed that a Home-based NeuroVirt program for stroke survivors with UL impairments was both, feasible and well accepted.

How will this research improve life after stroke for stroke survivors?
NeuroVirt was designed to increase UL exercise doses for stroke survivors. To enhance UL function, patients need high-intensity exercise, and it is crucial to find ways to achieve this. We assessed NeuroVirt's technical feasibility and its preliminary usability and acceptability for stroke survivors in their own homes.

39 Development of a national stroke audit in Ireland: Dataset for non-acute stroke care and rehabilitation

Dr Isabelle Jeffares[1], Dr Catherine N Moran[1], Dr Niamh A Merriman[1], Ms Joan McCormack[2], Professor Joseph Harbison[2], Dr Eithne Sexton[1], Professor David Williams[3,4], Professor Peter J Kelly[5,6], Professor Frances Horgan[7], Professor Ronan Collins[8], Ms Mairín Ní Bhreacáin[9], Dr Elaine Byrne[10], Professor John Thornton[11], Ms Collette Tully[2], Professor Anne Hickey[1]

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Category

Rehabilitation

Background and aims

The collection of stroke rehabilitation data through audit provides a valuable insight into the quality of post-acute stroke care and rehabilitation services. To date, stroke rehabilitation (non-acute) data has not been collected comprehensively in the Irish National Audit of Stroke (INAS). The aim of this project is to establish a core minimum dataset for non-acute stroke care to be included as part of the newly-developed INAS.

Method

This study developed a core minimum dataset for audit of stroke rehabilitation, which builds on the existing Health and Social Care Professionals (HSCP) dataset and a scoping review of international stroke audits. Qualitative interviews with Healthcare professionals (HCPs), researchers, stroke survivors and caregivers helped to determine aspects of rehabilitative care which should be measured in the audit. HCPs and stroke researchers also participated in a two-round Delphi consultation process, during which participants voted on the inclusion, exclusion or revision of audit items. This work will be informed by a systematic review of patient-reported outcome measures (PROMs).

Results

The final revised stroke rehabilitation dataset contains an additional 23 individual audit items distributed across three core disciplines. Participants frequently recommended revision of existing audit items and response categories. They also suggested the potential inclusion of other disciplines (e.g., psychology) and extension of the audit beyond the acute hospital setting. However, this would require increased resourcing of stroke rehabilitation professionals nationally.

Conclusion

This study has delivered a comprehensive, internationally benchmarked dataset for audit of stroke rehabilitation, and provides a gold-standard for evaluating and improving stroke rehabilitative care in Ireland.

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

It is vital we monitor whether patients are receiving the best stroke rehabilitative care from their healthcare services. This can be accomplished through national audit, by gathering high-quality, reliable, and precise comparative data for service delivery improvement. This study has established a core minimum dataset for audit of stroke rehabilitation.

40 Tele-OT: A new intervention tool to facilitate occupational performance for stroke patients

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Category
Rehabilitation

Background and aims
After a stroke, coming back home is difficult for most stroke patients. Occupational Therapy (OT) promotes coping with this situation but in-home intervention is scarce. OT can detect possible needs that have been altered in areas of occupational performance (OP), through the PROMs/ PREMs results. We aimed to evaluate a tele-OT intervention through a holistic app to provide OT after discharge from a comprehensive stroke center.

Method
Consecutive stroke patients discharged home were included in a digital follow-up program NORA-app validated for communication, education, adherence, risk factors control and PROMs/PREMs recollection. Patients with OT needs are offered a telematic visit to solve stroke-related doubts, everyday activities, home modifications promoting patient’s autonomy and self-care. A tele-OT satisfaction questionnaire was recollected.

Results
Over two years, 993 patients were included in NORA follow-up and reported PROMs at 7-30 days. 147 patients presented OT needs and were included in our tele-OT intervention. Sixty-one were men, with a mean age of 68.5y and a median mRS of 2 at hospital discharge. Tele-OT patients reported worse PROMs than the global series: in HADS, 40.8% anxiety and 34.2% depression and in PROMIS-10 89.3% altered mental health and 82.1% altered physical health, as compared with 13.1%, 17.7%, 64.7%, and 54.8% respectively ($p<0.001$). 108 patients answered the tele-OT PREM. The median usefulness of intervention (0-10) was 8.2 and 65% reported being “very satisfied”.

Conclusion
Tele-OT intervention is feasible and considered useful for most stroke patients with OT requirements. Poor PROMs may help with the selection of patients for tele-OT intervention.

How will this research improve life after stroke for stroke survivors?
Stroke has a direct impact on a person’s occupational performance, therefore an OT as a professional expert of the occupation, should be in charge of carrying out this follow-up to provide the appropriate tools to facilitate occupation in areas of self-care, productivity and leisure.

41 Knowledge improve awarness:Visual health literacy among stroke survivors.

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Category

Rehabilitation

Background and aims

Health care personnel often do not know enough about visual impairments (VIs) as a consequence of stroke. This result in inadequate transfer of knowledge regarding visual problems which may results in poor visual health literacy.

This study aim to gain knowledge about stroke survivors demand of appropriate health literacy level to reduce visual problems.

Method

The researchers used a method called photovoice, which involves taking and sharing photos to express one's experiences and perspectives. The study involved 16 participants who had VIs after a stroke. They were 6 men and 10 women, all older than 55 years, and they agreed to take part in the study. The participants used their own phones to take pictures for 14 days and then selected five photos each to present in four focus group interviews. The researchers asked the participants questions based on the SHOWED protocol.

The researchers recorded and transcribed the interviews and then analyzed the texts using thematic analysis, a method that involves identifying, describing, and interpreting patterns or themes in the data.

Results

Informants experienced lack of available visual information, too difficult to navigate in visual health care options. Digital platforms were often to complex to find useful. Reason for this was also the visual problems and experience of fatigue.

Conclusion

Stroke survivors need easy accessible vision care. Health care personel must enhance own knowledge to improve visual health literacy among stroke survivors.

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

Increased and detailed knowledge about VIs is essential to reduce the burden of visual symptoms and problems stroke survivors experience.

42 Barriers and facilitators addressing sexuality: Analysis of qualitative research using the Theoretical Domains Framework

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Category

Rehabilitation

Background and aims

Health professionals rarely address sexuality when working with people living with chronic disease and disability. Many studies have explored why health professionals fail to address sexuality, but few studies have examined barriers to sexual rehabilitation provision using a theoretically-driven approach. The paper aims to synthesise barriers and facilitators reported in original studies by healthcare professionals to addressing sexuality with adults living with chronic disease and disability.

Method

A systematic review of qualitative research was conducted. SCOPUS, PubMed, PsycINFO, CINAHL, AMED and MedLine databases were searched for studies published in English up to October 2023 Methodological quality was rated using the Critical Appraisal Checklist for Qualitative Research. Deductive analysis was used to code findings using the Theoretical Domains Framework, and mapped to the Behaviour Change Wheel.

Results

The search yielded 58 eligible papers from 55 unique studies, involving 1544 health professionals from 15 countries. Attitudes and beliefs of professionals was the major barrier. Professionals and patients believe that there are more important goals and priorities than sexuality and that sexuality is a private taboo topic. Conversely, facilitators included professionals having knowledge about, and awareness of the need to discuss sexuality, wanting extra skills and training and accepting sexuality discussions as part of their role.

Conclusion

Most self-reported barriers represent unhelpful attitudes and beliefs. Sexuality is a basic human right, which needs to become a higher priority in healthcare. Behaviour change interventions can influence attitudes, beliefs, knowledge, and skills, and encourage professionals to initiate discussions.

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

Sexuality is an important aspect of stroke survivor's recovery but is routinely ignored by professionals. Practice change is imperative and should be informed by evidence based strategies.

43 Profiling the characteristics of people after stroke in Ireland discharged home with and without ESD

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Category

Rehabilitation

Background and aims

Early Supported Discharge (ESD) after stroke has demonstrated cost savings, reducing hospital length of stay and long-term dependency. The Irish National Stroke Strategy 2022-2027 aims for ESD to be available to 92% of the stroke inpatient population. This study aims to profile the clinical characteristics and rehabilitation needs of those referred to ESD on discharge versus those discharged without it in Ireland.

Method

This study represents secondary analysis of an anonymised nationally representative prospective cohort study; the Irish National Audit of Stroke. Data were retrieved for 2018-2020. A subset of 20 variables were used to profile the clinical characteristics and rehabilitation needs of those referred to ESD on discharge versus those discharged home without it. Data were analysed descriptively.

Results

In 2018, 139 (3.8%) people were discharged home with ESD which increased to 207 (4.9%) in 2019 and to 325 (6.6%) in 2020. Those aged 65-79 years represented the largest proportion of those discharged home with and without ESD. For those discharged with ESD, the mean LOS reduced each year from 17 days (SD=20) in 2018 to 13 days (SD=13) in 2020. Those with a modified Rankin Scale score of 1, 2 at discharge represented the highest proportion of those returning home with ESD (59.3%) and without ESD (40.8%). Of those returning home with ESD, 10.8% were seen by a psychologist.

Conclusion
There is a need for significant scale-up of ESD to meet National Stroke Strategy targets. Consensus on ESD eligibility criteria nationally needs to be established. Access to psychology services needs expansion.

How will this research improve life after stroke for stroke survivors?
There has been an increase in access to ESD in Ireland between 2018 - 2020. People after stroke who have accessed ESD have also spent less time in hospital. The implementation of the Irish National Stroke Strategy aims to further increase access to ESD for 92% of the stroke inpatient population.

44 Conceptualisation of risk within stroke rehabilitation literature: an inductive content analysis and critical narrative synthesis

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Category

Rehabilitation

Background and aims

Many people feel unprepared for life following discharge from stroke services. Rehabilitation occurs within a harm-reduction framework, but evidence suggests risk-taking is crucial for recovery. How risk is conceptualised within the literature is unknown, along with how factors including identity and resumption of valued activities are considered within risk-management practices.

Method

A literature search (including Embase, Pubmed, CINHAL and PsychInfo) was undertaken, including qualitative, quantitative and mixed-methods studies in post-stroke adults >18 years. Inductive content analysis described current risk conceptualisation. Critical narrative synthesis examined qualitative papers challenging dominant risk conceptualisations relating to post-stroke activities and identity.

Results

Content analysis included 245 papers. Most (n=233) were described by the theme ‘safety first’, divided into sub-themes: i) Physical safety; ii) Societal and organisational protection; and iii) Cognitive, affective and communication risks. Remaining papers were described by sub-theme 2: ‘taking risks is necessary and subjective’. Critical narrative synthesis included fifteen papers, demonstrating the imposition of ‘rules’ for safety on people post-stroke, despite risk-taking being important.

Conclusion

The predominant narrative prioritises safety and harm-reduction during stroke rehabilitation, overlooking unintended consequences for post-stroke identity and resumption of valued activities. The voice of people post-stroke is largely absent in decision-making around risk prioritisation and management. Further qualitative research is needed to understand their experiences and inform service co-design.

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

Risk-taking is an important part of stroke recovery. However, there is no agreed conceptualisation of risk within stroke rehabilitation. Evidence suggests that perceptions of risk are individual and subjective; current practices prioritise safety and harm-reduction. Crucially, the voice of people post-stroke is largely absent. Development of shared understandings is essential.

45 Evaluation of telerehabilitation to support needs-led community stroke rehabilitation in the East of England.

Ms Elizabeth Chandler[1], Professor Valerie Pomeroy[1], Ms Charlotte Dorer[2], Dr Nicola Hancock[1]

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Category

Rehabilitation

Background and aims

National Health Service (NHS England) policy drivers have led to the development of an evidence-based Integrated Community Stroke Service model (ICSS). The ICSS recognises that the COVID-19 pandemic accelerated the adoption of digital solutions to deliver telerehabilitation, but that evaluation of digital delivery, including engagement with people with stroke, is needed.

This service evaluation aims to deepen understanding about telerehabilitation use in community stroke rehabilitation teams in East of England. Specifically, to determine where, when, and how remote working and telerehabilitation work best to:

a) support the delivery of needs-based stroke rehabilitation

b) enhance the delivery of interventions with optimal efficacy and efficiency

Method

A mixed-methods service evaluation comprising:

1. Discussion groups with members of a stroke patient and public volunteer group (PPV), and multi-disciplinary (MDT) staff, exploring views and experiences of people delivering/receiving telerehabilitation.
2. A questionnaire, administered to a wider group of clinicians, carers and people who have experienced stroke.
3. Follow-up interviews exploring findings from parts one and two.

Results

N=20 people participated in the discussion groups, generating three themes to underpin a framework for the questionnaire and interviews. Themes supporting telerehabilitation and remote delivery were- shaping individualised approaches to rehabilitation, support/training for staff, and understanding risks and benefits of remote delivery.

N=92 questionnaire responses have been received to date (October 2023) and their analysis is underway.

Conclusion
The evaluation is ongoing, results will be available for reporting March 2024. Findings will demonstrate how telerehabilitation might best be used to support people in their needs-led rehabilitation after stroke.

How will this research improve life after stroke for stroke survivors?
Telerehabilitation needs further evaluation. We need to understand the views of people with stroke and their caregivers. This service evaluation explores those views in depth, alongside people delivering services. It will determine the best way for telerehabilitation to support people's needs-led rehabilitation.

46 The TRICEPS trial protocol: TRranscutaneous Ilmb reCovEry Post-Stroke

Professor Arshad Majid[1], Professor Avril Drummond[2], Ms Cara Mooney[1], Dr Jessia Redgrave[1], Dr Ali Ali[1], Dr Munya Dimairo[1], Dr Sheharyar Baig[1], Professor Cindy Cooper[1], Professor Jesse Dawson[3], Ms Esther Herbert[1], Professor Li Su[1], Ms Kirsty Mckendrick[1], Ms Katie Biggs[1], Ms Kate Duffy[1], Ms Shamila Ditta[1]

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Category
Rehabilitation

Background and aims
Over 15 million people have a stroke worldwide every year. One third are left with arm weakness causing difficulties with daily activities. However recent research has shown that stimulating the vagus nerve whilst moving the weak arm may help to improve arm recovery, even six months after stroke.

TRICEPS aims to determine whether Transcutaneous Vagus Nerve Stimulation (TVNS) alongside other therapy of the affected arm post-stroke improves motor function in participants with arm weakness.

Method
We will recruit 243 patients into this UK multi-centre, 3-arm, double-blinded, parallel-group, individually randomised, controlled, adaptive design trial. Participants will be aged 18 years+ who have arm weakness 6 months to 10 years post-stroke and are not undergoing active rehabilitation therapy.

Participants will be randomised to sham TVNS (very low stimulation) or active TVNS and will wear the TVNS device whilst completing self-delivered, rehabilitation therapy. Some participants will also wear the TVNS device during daily activities. We will follow-up participants at 3 and 6 months after starting treatment. The mean difference in ULFM total score at 3 months will be the primary outcome treatment effect measure. A mechanistic sub-study will also assess if TVNS produces changes in the brain via fMRI and, in some cases, PET scans.

Results
Results will be available in approximately 3 years' time. We will publish results in peer-reviewed academic journals, present at relevant conferences, and disseminate via patient groups.

Conclusion
TRICEPS has potential to provide definitive data on effectiveness of TVNS for arm recovery post-stroke, improve patient outcomes, and inform clinical guidelines.

How will this research improve life after stroke for stroke survivors?
TRICEPS has the potential to improve arm recovery and consequently improve quality of life after stroke.

47 Evaluation of Goal setting and Action Planning (G-AP) training to support person-centred stroke rehabilitation

Dr Lesley Scobbie[1,2], Dr Sally Boa[3], Ms Emily Chesnet[2], Ms Lynn Grayson[2], Ms Iona Izat[2], Ms Katherine Elliott[1], Professor Mark Barber[2], Dr Rebecca Fisher[4]

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Category

Rehabilitation

Background and aims

Stroke survivors' goals reflect their hopes and priorities for life after stroke. Person-centred goal setting supports life after stroke, but its implementation in practice is challenging. A G-AP training resource (incorporating online training and webinars) has been developed to support implementation of person-centred goal-setting practice. We aimed to evaluate the G-AP training resource and its impact on early G-AP implementation in three Scottish community rehabilitation teams.

Method

G-AP online training and webinars were delivered to rehabilitation staff (n=48) across participating teams. A mixed-methods evaluation was conducted one month post-training using a training questionnaire and focus group discussion. Questionnaire data were analysed descriptively; focus group data were analysed using a framework approach.

Results

85% of staff (41/48) completed the online questionnaire; 17% (8/48) participated in the focus group. 97% of staff rated both the online training as excellent (n=25/40) or good (n=14/40) and the webinars as excellent (n=26/41) or good (n=14/41). Following training, staff agreed they were knowledgeable about G-AP (37/41; 90%) and had the confidence (35/40; 88%) and skills (35/40; 88%) to use it in practice. Contextual factors (e.g. leadership support, Covid-19) impacted on their learning experience and implementation efforts. Following training, individual staff delivered G-AP to stroke survivors, including those with communication difficulties. Transitioning to G-AP implementation at a team level was more challenging, requiring new working practices.

Conclusion

G-AP training was rated highly, preparing individual staff to deliver G-AP and begin the transition to team implementation. A follow-up study evaluating longer term G-AP implementation and stroke survivor experiences is underway.

How will this research improve life after stroke for stroke survivors?
A skilled and knowledgeable rehabilitation workforce is required to support stroke survivors to improve their life after stroke. G-AP training has been developed to enhance person-centred goal-setting practice. In this initial evaluation, we report positive findings. A follow-up study evaluating longer-term G-AP implementation and incorporating stroke survivors' perspectives is underway.

48 Stroke survivors’ knowledge, experience, and perspectives of aerobic exercise in the United Kingdom (UK)

Ms Nicola Gaskins[1], Dr Emma Bray[1], Dr Alexander Harrison[2], Professor Louise Connell[3,4]

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Category

Secondary prevention

Background and aims

Aerobic exercise, such as walking or cycling, improves cardiorespiratory fitness and is recommended in the 2023 National Clinical Guideline for Stroke. This study aimed to explore stroke survivors’ views of aerobic exercise in the UK.

Method

An electronic survey was developed based on existing literature and involvement from people with lived experience of stroke. This explored adult stroke survivors views and knowledge of aerobic exercise, and what influenced their participation.

Results

Fifty-one stroke survivors from England, Wales and Scotland completed the survey. Just over half were female and half were aged 55-64 years. Most were of white ethnicity, independently mobile, at least one-year post-stroke and lived alone.

The majority knew what aerobic exercise was, believed it was important and recommended following stroke. Most respondents had participated in aerobic exercise before stroke (80%) and post-stroke (69%). Most did not do or were not offered aerobic exercise post-stroke (70%) and reported that their healthcare team had not spoken with them about aerobic exercise (74%).

Barriers to taking part in aerobic exercise included lack of knowledge about how to exercise, fear of injury and lack of motivation. Having the option of group exercise, supervision from an exercise professional, and information about exercising safely were enablers.

Conclusion

This study provided the perspectives of a small number of stroke survivors on aerobic exercise in the UK, including factors influencing their participation. However, as most survey respondents were engaged with aerobic exercise both before and since their stroke, this survey needs repeating with a larger number of stroke survivors.

How will this research improve life after stroke for stroke survivors?
Efforts should be made to equip healthcare professionals with the knowledge and skills to prescribe, and provide information about, aerobic exercise following stroke. The factors identified as influencing stroke survivors' participation should be considered when developing aerobic exercise provision within stroke rehabilitation services.

49 Association of Atrial Fibrillation with ischaemic stroke severity in Ireland.

Mrs Aileen Callanan[1], Professor Patricia Kearney[1], Professor Colin Bradley[1], Dr Diarmuid Quinlan[2], Dr Linda O'Keeffe[1], Dr Kate O'Neill[1], Ms Joan McCormack[3], Dr Claire Buckley[1], Professor Joseph Harbison[4]

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Category

Secondary prevention

Background and aims

Atrial fibrillation (AF) related strokes have been reported to be more severe than non-AF related strokes with increased morbidity and mortality. There are currently no estimates for morbidity and mortality associated with AF related stroke in Ireland. This study investigates the morbidity and mortality associated with AF related and non-AF related ischaemic strokes in Ireland.

Method

This secondary analysis of data from the Irish National Audit of Stroke (INAS) (2017-2019) compared characteristics and outcomes of ischaemic stroke patients with AF related and non-AF related stroke. This study refers to those patients who had AF on admission with stroke as AF related strokes. The association between AF and non-AF related stroke and stroke severity, using the modified Rankin Score, and death was investigated using logistic regression models.

Results

Of 10,528 ischaemic strokes patients, 4489 (43%) were in females; the mean age of sufferers was 74 (SD 13) years. Patients with AF related stroke were older 78 (SD 9.9) than patients with non-AF related stroke 70 (SD14), p-value <0.001. The odds of a severe stroke were higher in the AF related stroke group in univariate, OR 2.1 (1.9-2.3, p=<0.001), and multivariate, OR 1.4 (1.3-1.6, p-value=<0.001) logistic regression models. Patients with AF related strokes had higher odds of mortality than those with non-AF related strokes in univariate 2.6 (2.2-3.0, p=<0.001) and multivariate 1.9 (1.6-2.3, p=<0.001) logistic models.

Conclusion

This study demonstrates that, in the Irish population, AF related strokes have poorer outcomes than non-AF related strokes associated with increased morbidity and mortality.

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

This research quantifies the burden associated with AF related stroke in Ireland. The study demonstrates the increased morbidity and mortality associated with AF related strokes in the Irish population. This can be used to inform stroke prevention strategies that focus on AF as a risk factor for ischaemic stroke.

European
Life After Stroke
Forum

Abstract Type:

Service Poster

SAFE
STROKE ALLIANCE FOR EUROPE

50 Aphasia and evidence-based methods to facilitate informed consent to stroke care and research: It’s possible!

Ms Elyse Shumway[1,2], Ms Natalie Gierman[1], Dr Aura Kagan[1]

[1]Aphasia Institute, Toronto, Canada. [2]University of Toronto, Toronto, Canada

Category

Communication

Summary of the service development

Individuals with post-stroke aphasia are frequently excluded from research participation and pivotal life decisions related to healthcare, finances, legal matters, and other contexts necessitating informed consent discussions. Supported Conversation for Adults with Aphasia (SCA™) is an evidence-based communication method that serves as a valuable tool to counteract this systemic exclusion. This method is ideally suited to enabling complex conversations often needed for consent discussions. Research indicates that it is possible to train health care providers, family members, and others in SCA™ and that participation of people with aphasia is significantly increased when communicating with a trained communication partner.

In relation to the decision-making process, SCA™ has a distinct advantage as it focuses on techniques to aid comprehension of relevant information and facilitate the expression of choices. In addition, “verification” is a signature feature of SCA™ where information that has been shared is reviewed for accuracy. Verification is a critical step for conversations where accuracy of information exchange is paramount. It is aligned with the ‘teach-back’ method often used to ensure understanding of essential health information. Additional communication supports can facilitate the verbal reasoning required to appreciate consequences and choose a decision option.

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

SCA pictographic materials can assist communication across all language barriers.

How this will improve life after stroke for stroke survivors

Inclusion of people with aphasia in vital stroke care and research decisions is an ethical and moral issue worthy of attention. SCA™, with its relevance to a variety of stroke-related settings, provides a promising solution. This presentation will provide practical examples and links to relevant free SCA™ resources.

51 Stroke Association UK Communication Support Pack

Ms Katherine Staley, Ms Caitlin Longman, Ms Catherine Moore

Stroke Association, London, United Kingdom

Category

Communication

Summary of the service development

In May 2023 we launched the Communication Support Pack, which includes aphasia-friendly health information, a communication card and the option to include a Communication Picture Book to support communication with images.

These resources were co-created with ‘Aphasia and Accessible Voices’, a stroke survivor group with lived experience of different access needs. The group was essential in making decisions about what topics to include, ensuring the text and layout was accessible and developing images to support the understanding of the text. Since it launched, there have been over 6000 hard copies and online orders and we have received incredible feedback from people affected by aphasia, and healthcare professionals.

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

A lot of learning can be shared from the development and co-creation of these new resources. Listening to the priorities and insight from people with lived experience helped ensure the resources were meaningful and effective. The new accessible images are available for third party use and could lead to the development of new accessible digital and hard copy materials for people affected by stroke. There is also the potential for these resources to be adapted into additional languages.

How this will improve life after stroke for stroke survivors

People now have access to accessible information about stroke and communication difficulties. This knowledge reduces anxiety and increases people’s ability to look forward to recovery. The Communication Picture Book provides tools to communicate basic needs and have independence and autonomy in decision making. Evaluation shows that the majority of stroke survivors have recognised a positive impact, and they would recommend the resources to others.

52 CHATS: A guide for adults to help them talk to and support children after stroke.

Ms Wendy Moynan[1], Dr Aine Connolly[1,2], Dr Dan Ryan[1], Professor Rónán Collins[1]

[1]Tallaght University Hospital, Dublin, Ireland. [2]St James Hospital, Dublin, Ireland

Category
Emotional, cognitive and psychological impact of stroke

Summary of the service development
Research shows that providing children and young people (CYP) with good quality information when a close relative suffers serious illness can help them to manage their feelings and protect their mental health.

We could not find a stroke specific resource to help adults talk to and support their CYP after stroke.

Therefore, with input from six Irish families, all of whom had children of varying ages at the time of their stroke, we developed the CHATS resource.

It aims to help adults

- Recognise the importance of communication with CYP about stroke;
- Start conversations;
- Understand CYP reactions and support them;

How this is relevant to other countries and what could be the potential impact across countries
The sudden impact of stroke on families is universal.

CHATS fills an information and support gap for families in the acute stages.

Its content and illustrations reflect family experiences and summarise key messages in an accessible way for people with aphasia, dyslexia and multi-lingual families.

CHATS could be translated into different languages and made available internationally, digitally, or in print.

CHATS could raise healthcare staff awareness about stroke impact on CYP and provide a tool to help them support families.

How this will improve life after stroke for stroke survivors
Stroke survivors and families know their CYP better than any healthcare professionals.

If CYP are not supported at the time of stroke some may have difficulty managing their feelings and behaviour, adding to family stress.

CHATS helps families understand common reactions for CYP, start conversations and give support.

This can prevent the development of long-term psychological difficulties for CYP, which benefits stroke survivors and promotes family health and well-being.

53 Ask and Act – an approach to evaluation

Mrs Katherine Staley, Ms Jo Fisher

Stroke Association, London, United Kingdom

Category
Long term support (including carers and community support)

Summary of the service development
The Stroke Association UK is committed to being “Stroke to the core” and to “Know how to make an impact”. The Ask and Act evaluation approach has been developed to further both of these principles. The approach is being co-created with beneficiaries, staff and volunteers, and is being rolled out across all of our work with beneficiaries. We’re aiming to focus on the difference we make, rather than the work that we do.

We have worked to co-create our measures with people affected by stroke in line with the following principles:

- Focusing on experiences and outcomes

- Using beneficiary voices

- Person centred

- Empowering learning and action

How this is relevant to other countries and what could be the potential impact across countries
Many SSOs are delivering services in the community for people affected by stroke and we all need to be intentional about understanding whether these services are meeting the expressed needs of beneficiaries. This approach has the potential to enable SSO staff and volunteers to learn from beneficiary feedback and identify future priorities together.

How this will improve life after stroke for stroke survivors
Ask and Act aims to be empowering for beneficiaries - enabling them to tell their story, and at a time and in a way that suits them.

54 A Childhood Stroke Support Service in the UK

Ms Katherine Staley, Ms Anne Doyle

Stroke Association, London, United Kingdom

Category
Long term support (including carers and community support)

Summary of the service development
In April 2022, Stroke Association launched a new UK wide offer tailored for families affected by Childhood Stroke, shaped through co-production with Parents and NHS professionals.

The initial phase established a Childhood Stroke Support Team, addressing queries and providing emotional support to families, at all stages of their journey, via phone or email. The service connects families to local support and resources, individualised to specific needs

The second phase involved co-creation of specialised written health information about childhood stroke. Parents identified priority areas and co-developed comprehensive information on impacts of stroke e.g., behaviour and emotional, mobility, fatigue, communication, memory and cognition with our specialist writer and NHS staff

The third phase introduced Parent-To-Parent Volunteer Calls, connecting parents with trained volunteers with lived experience. We carefully match Parents with a volunteer, for two phone conversations for meaningful peer support.

Since inception almost 70 families have utilised our new offer and evaluation indicated the experience was a positive one.

How this is relevant to other countries and what could be the potential impact across countries
This initiative demonstrates the feasibility of implementing a nationwide offer for childhood stroke, underscoring the value of personalised support. Insights gained demonstrate promise for informing similar services internationally.

How this will improve life after stroke for stroke survivors
This comprehensive approach addresses challenges faced by parents in accessing practical and emotional support, especially when leaving the acute sector. By connecting families with staff who understand and peers with lived experience, this service empowers parents in navigating the complexities linked to childhood stroke. Our learning is that our offer would ideally expand to parent groups, creating a flexible, varied offer, meeting varied needs.

55 The MODC After Stroke outcomes framework: prioritizing health and wellbeing

Dr Michelle Nelson[1,2], Mr Evan MacEachern[1], Ms Suzanne Smith Bayley[3], Ms Erika Clark[3], Ms Christina Sperling[3]

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Category

Long term support (including carers and community support)

Summary of the service development

The March of Dimes Canada (MODC) After Stroke Outcomes Framework, was developed to guide services that address the needs of individuals affected by stroke. The Outcomes Framework offers a holistic collection of outcomes, indicators, and potential measures with a focus on wellbeing priorities and their determinants. This Outcomes Framework allows MODC staff to embrace an outcomes-focused approach when designing, delivering, and evaluating programs. The Outcomes Framework revolves around six person-centred domains: 'Connected, Healthy, Equipped, Empowered, Safe, Engaged'. These domains were identified following consultations with people living with stroke, and a review of research on the factors that influence overall well-being. A survey was conducted to validate The Outcome Framework for use in the Canadian context. The MODC After Stroke Outcomes Framework is a critical tool for enhancing the quality of life and wellbeing of stroke survivors and their families and caregivers. It ensures that services and programs align with the needs and aspirations of individuals impacted by stroke while addressing health and well-being inequalities where they exist.

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

Both the development process and the resulting framework would have broad global applicability, however transferring outcome frameworks to other contexts may require modifications based on socio-political considerations.

How this will improve life after stroke for stroke survivors

Outcome frameworks are instrumental to quality improvement and measuring effectiveness of services. By focusing on clients' needs and evaluating progression, program developers are enabled to design purpose-built programs and services. By aligning service offerings with client priorities to facilitate continuous improvement, these frameworks play a critical role in enhancing client outcomes and overall well-being.

56 Harnessing the power of digital: community interventions to support life after stroke

Professor Andy Turner[1,2], Dr Aimee Walker-Clarke[1], Dr Hayley Wright[1]

[1]Coventry University, Coventry, United Kingdom. [2]Hope For The Community (H4C) Community Interest Company, Coventry, United Kingdom

Category
Long term support (including carers and community support)

Summary of the service development
Hope For The Community (H4C) is a Community Interest Company providing self-management support for people affected by long term conditions. H4C has a white-label digital platform, which can be used to host a range of educational, therapeutic, or community support tools for stroke rehabilitation.

Our flagship intervention, the Hope Programme (HOPE), has been co-developed with patients and professionals over the past 15 years. It started as an in-person peer-facilitated self-management course, and is now a digital intervention that has supported more than 10,000 people to manage a range of long-term conditions.

More recently, the H4C digital platform is being used by researchers and survivors to co-produce bespoke interventions to improve life after stroke; i) supporting survivors to self-manage mental and sexual wellbeing; ii) peer-support for partners of survivors; iii) digital resources for professionals in stroke care; iv) toolkit for educators/teachers of child stroke survivors.

H4C work with researchers, the NHS, charities and other third sector organisations to improve health and wellbeing through person-centred support.

How this is relevant to other countries and what could be the potential impact across countries
H4C is a not-for-profit social enterprise, and University spin-out company. We have a track-record of delivering digital self-management support programmes in the community - with no geographical boundaries. The digital platform can host research projects, RCTs, toolkits, or educational resources that can be accessed anywhere in the world.

How this will improve life after stroke for stroke survivors
Digital interventions can complement rehabilitation and long-term recovery from stroke and alleviate pressure on front-line healthcare services. H4C can provide a range of digital support solutions to improve life after stroke.

57 The Sussex Transition Support project, keeping people practicing, connecting and supported

Mrs Tara Lakin[1], Mrs Anna McClean[2], Mrs Karen Poole[3], Mrs Emma Jupp[4]

[1]Stroke association, Kent, United Kingdom. [2]University Hospitals Sussex, Haywards Heath, United Kingdom. [3]East Sussex Hospital Foundation Trust, Bexhill, United Kingdom. [4]Sussex ICB, Brighton, United Kingdom

Category

Rehabilitation

Summary of the service development

The project is a ‘waiting well’ transition service from the in-bed rehabilitation unit, (Sussex Rehabilitation Centre) for 100 patients with diagnosis of stroke. Patients currently experience an average of a 9 week wait for community neuro therapy.

‘Waiting well’ is a common problem across Europe, and it is common to see reduced effects from intensive therapy in an acute setting when people go home. This service provides a model of transitional care that brings collaboration with a charitable partner and social/community support sectors.

Through an-registered workforce approach, Transition Support Workers (TSW) provide intensive therapeutic interventions with implementation of personalised approaches, the TSW will complete a rehab prescription.

This is combined with a Stroke Association coordinator to ‘keywork’ and maximise community resources to promote a wellbeing model. 3rd sector opportunities like peer groups, exercise groups will help achieve meaningful activity.

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

- This service sees people confident and achieving rehabilitation goals in their own home.
- We are testing the understanding of a tool to share the rehabilitation needs across a pathway
- We are testing effective methods of sharing resources and policies between organizations for effective working.
- We are measuring cost savings, deconditioning levels, confidence and activation measures, therapy intensity, length of stay, length of care, EQ5D data.
- The service will test frequent, intense and repetition of therapeutic activity.

How this will improve life after stroke for stroke survivors

- Reduce patient and carer anxiety
- Improve the overall patient experience
- intensive intervention, aid transition of rehabilitation goals and strategies
- Alleviate the fear and anxiety
- Facilitate carers
- Promote self-management and self-advocacy
- Continuous rehabilitation

58 Barcelona Stroke Functional Impact Rehabilitation Register

Dr Esther Duarte[1], Dr Susana Rodriguez[2], Dr Conxita Closa[3], Dr Helena Bascuñana[4], Dr Anna Guillen-Solà[1], Dr Sara Laxe[3]

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Category
Rehabilitation

Summary of the service development
The study will aim to evaluate the functional and health status of post-stroke patient at Stroke Unit discharge and at 6-month follow up, to deliver quality care for stroke patients and to improve the short- and long-term clinical quality for disabled stroke patients.

The main objectives include: 1) to generate data about the functional and health status from post-stroke patients as well as a documented rehabilitation program at hospital discharge; 2) to evaluate functional and health status 6 months after stroke and, 3) to understand the compliance of rehabilitation program prescribed and, potentially, their impact on patient's functional and health status.

Furthermore, carrying out this study will allow us to homogenize the rehabilitation plan at hospital discharge from the stroke unit among participant hospitals and to validate the stroke rehabilitation registry and methodology for a possible scale-up at the level of the Catalonia region.

Around 350 patients are going to be included by 4 sites in Barcelona.

How this is relevant to other countries and what could be the potential impact across countries
In countries where national registries of the clinical quality of stroke care have been established, the publication and sharing of the collected data have led to an improvement in the quality of care and survival of patients. However, information on rehabilitation programs and outcomes are often lacking across Europe.

How this will improve life after stroke for stroke survivors
Providing a documented plan for community rehabilitation and self-management support at hospital discharge. Ensuring a review of the rehabilitation and other needs at 3-6 months after stroke and annually thereafter. Enhance the best recovery and quality of life after stroke.

59 Current trends in Stroke Survivors Rehabilitation Needs

Ms Kate Curtin, Dr Kinley Roberts, Dr Sabrina McAlister

National Rehabilitation Hospital, Dublin, Ireland

Category
Rehabilitation

Summary of the service development
Advances in medicine have seen an increase in people surviving strokes that may not have before. A national tertiary level 1 stroke unit in the National Rehabilitation Hospital receives referrals for the most complex stroke survivors throughout the country of Ireland for rehabilitation. This places the organisation in a good position to review trends in the complexity of stroke survivors. Rehabilitation Complexity Scale Extended (RCSE) scores were completed on all stroke patients admitted to the service over a five year period and analysed annually. The results show a steady increase in the complexity of stroke survivors requiring rehabilitation over the last five years.

How this is relevant to other countries and what could be the potential impact across countries
The findings of this service review are applicable internationally. As the review was conducted in a national centre were the most complex strokes throughout the country are admitted it means that the results can be applied to other countries were there may be multiple services available and they may not be able to analyse the national impact.

How this will improve life after stroke for stroke survivors
This review shows the positive impact of stroke campaigns and advances in medicine in saving people with stroke is resulting in a direct knock on effect of increase in complexity of stroke survivors requiring rehabilitation based on RCSE scores. Patients with more complex needs will require greater lengths of stay, high intensity and treatment by multiple therapists within each discipline to achieve their goals. Investment in rehabilitation services is required to keep pace with the excellent improvements in acute stroke care to add quality to the lives saved.

60 The Development of a Stroke Multidisciplinary Team Therapy Outcome Measure Scale – Is it Reliable?

Mrs Freyja Bell

Croydon Health Services NHS Trust, London, United Kingdom

Category

Rehabilitation

Summary of the service development

The Multidisciplinary Team (MDT) Stroke 'Therapy Outcome Measure Scale' (TOMs) was developed as a quick, psychometrically robust, clinical outcome measure to encourage MDT collaboration, patient centred care and effective communication. It was also developed to monitor trends within services, to highlight areas in need of change, and for the purpose of reducing recording time, improving interdisciplinary working and communication.

The MDT Stroke TOMs was developed by amalgamating and rewording 4-profession specific adapted scales followed by iterative trials and discussion to include communication, cognition and swallowing. 150 MDT members were trained in the MDT Stroke TOMs, followed by blind scoring practice to assess inter- and intra-rater reliability and improve technique and confidence in scoring.

There was a good to excellent concurrence between raters in relation to scoring and it can be used with confidence by the MDT. It provides the team with an opportunity to collaborate at an early-stage in the patient's rehabilitation journey.

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

The MDT Stroke TOMs could be used world-wide as a holistic stroke measure in rehabilitation. It is beneficial across the entire stroke pathway and can be rated by any members of the Stroke MDT. If used by many services across countries, there could be comparable stroke data available.

How this will improve life after stroke for stroke survivors

This will improve team communication and collaboration when treating patients, maximizing rehabilitation potential. This will contribute to improvement in life after stroke, as they will have measures of their progress thus far and will have benefitted from timely and cohesive MDT communication.

61 Brain Gym - An Evidence-based Cognitive Rehabilitation Programme on an Inpatient Stroke Unit.

Mr Jordan Collins, Ms Siobhán Kerr

National Rehabilitation Hospital, Dublin, Ireland

Category

Rehabilitation

Summary of the service development

The "Brain Gym"- a 4-week intensive cognitive rehabilitation group was developed and delivered on an inpatient stroke rehabilitation unit on review of contemporary research and practice evidence. The group targets core cognitive domains and consists of three 45-minute direct sessions and two 30-minute indirect sessions. The group provides education, skills training, and functional task practice. Group aims, objectives, criteria, and resources were developed to standardise intervention delivery locally. Outcomes were measured quantitatively using the cognitive items on the FIM/FAM and qualitatively using a participant questionnaire. Group participants demonstrated improvements across all cognitive items on assessment. Qualitative feedback highlighted the benefits of peer support and learning when engaged in an immersive environment targeting cognitive challenges after stroke.

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

It is known that individuals have limited opportunities to engage in intensive cognitive rehabilitation programmes across Europe. Holistic approaches to stroke recovery recommend that stroke survivors are provided with the opportunity to engage in an intensive cognitive rehabilitation programme during their hospital admission, and equipped with the knowledge and skills to self-manage identified cognitive changes. The delivery of the Brain Gym may offer a solution to stroke services when considering resource management, and evidence based rehabilitation.

How this will improve life after stroke for stroke survivors

The goal of cognitive rehabilitation focuses on minimising the impact of cognitive impairments in activities of daily living for stroke survivors and their families. The "Brain Gym" provided increased intensity of cognitive rehabilitation and enhanced opportunity for learning and reflection in a group environment focusing on equipping participants with skills to manage their cognitive changes long term.

62 Delivering a virtual secondary prevention programme for patients within an Early Supported Stroke Discharge Service.

Mrs Natalie Spibey, Mrs Joanne Radcliffe

Derbyshire community health services, Derbyshire, United Kingdom

Category

Secondary prevention

Summary of the service development

We are seeing increasing referral rates across a large geographical area with no increased nursing capacity. The Programme is led by ESSD Nurses. As stated in the 2023 National Clinical Guidelines for Stroke, ‘Ensuring the identification and modification of all risk factors, including lifestyle issues, should lead to more effective secondary prevention of stroke and other vascular events’. Previous patient satisfaction questionnaires have identified patients want more information in this area.

The digital transformation project provided 10 IPADs, used for those without devices. We have a Suitability checklist, Risk assessment and ‘how to access guide’. Each programme supports up to 6 patients using Microsoft teams, two staff members to facilitate and runs over 4 weeks in 1-hour sessions. We have a presentation with topics including types of strokes, risk factors, fatigue and emotional impact after stroke. Followed by discussion and Q&A

25 patients have participated and feedback from evaluation forms has been very positive. One patient who was experiencing a mental health crisis at the time of the programme has since fed back he found the group a ‘massive support’, making him feel ‘safe’, and ‘empowered’ to share.

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

We are able to share across countries more efficient ways of working and how we have embraced digital opportunities.

How this will improve life after stroke for stroke survivors

Overall, the programme has been a great success and continues to run on a regular basis, enhancing quality of care and efficiency of service delivery. Key themes are patients enjoying sharing experiences through peer support whilst accessing vital secondary prevention information.

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Abstract Type:

Scientific Oral Presentation

SAFE
STROKE ALLIANCE FOR EUROPE

63 Life one year after stroke – results from the Swedish Riksstroke quality-of-care review

Professor Mia von Euler

Riksstroke, Umeå, Sweden. School of Medicine, Örebro University, Örebro, Sweden

Category
Other

Please describe your submission category, if you have selected other above
Quality of care review

Background and aims
Life after stroke and how health care has been able to meet the needs are important. Thus, the Swedish stroke register, Riksstroke, has reviewed the outcome at one year after stroke.

Method
The 14,291 individuals >18 years of age with a stroke during 2020, registered in the Swedish quality register Riksstroke who were alive at one year after stroke received a questionnaire as part of the quality-of-care review performed by the quality register.

Results
During 2020, 19,388 persons were registered in Riksstroke and 4,397 (23%) died during the first year after stroke. In all, 10,386 persons responded to the 1 year post-stroke questionnaire (73%). Of the respondents, 76% were living independently. Need of help in activities of daily living (ADL) was higher in persons >75 years, 19% compared to younger patients where 9% were dependent in ADL. However, 41% reported having fatigue often/always, women more than men. A majority, 55%, did not report a need of rehabilitation, 16% had ongoing rehabilitation and 20% reported to have a need but no ongoing rehabilitation. Satisfaction with rehabilitation was 86%. As in earlier 1-year-reviews the last 5 years, 76% reported a good/very good health status one year after stroke.

Conclusion
On a national level, the Riksstroke quality-of-care review shows that many persons live a rather good life after stroke. However, 1/4 report poor/very poor health status. There is room for improvements in services offered. Also, there could be improvements in services offered particularly in some regions.

How will this research improve life after stroke for stroke survivors?
Quality-of-care reviews can play an important role in visualizing problems stroke survivors meet in daily life after the acute phase of stroke. By showing the unmet needs, work can be initiated to rectify this which will benefit stroke survivors.

64 Addressing sexuality post-stroke: Can a targeted implementation change practice?

Professor Margaret McGrath[1,2], Ms Sandra Lever[3], Professor Emma Power[4]

[1]University of Sydney, Sydney, Australia. [2]University College Cork, Cork, Ireland. [3]NSW Health, Sydney, Australia. [4]University of Technology Sydney, Sydney, Australia

Category

Rehabilitation

Background and aims

Despite recognition of the importance of sexuality post-stroke most stroke survivors do not receive information or education relating to sexuality. This paper presents an implementation protocol to support stroke services to address relationships, intimacy and sexuality as well as the preliminary results of this study.

Method

A pragmatic non controlled before and after implementation study involving metro and rural inpatient stroke rehabilitation units in two Local Health Districts using mixed methods evaluation. Data included medical record audits, online survey of stroke rehabilitation professionals and interviews/focus groups with key champions at each site 12 month before and immediately after the implementation period.

Results

Preliminary results indicated moderate levels of knowledge. comfort and positive attitudes towards addressing sexuality after stroke. Key barriers to implementing clinical guidelines were staff beliefs about capabilities, social and professional identities and education. Clinical audit indicated variable compliance with clinical guidelines. A tailored implementation approach has been developed for each site.

Conclusion

A tailored implementation approach offers the potential to change practice relating to sexual rehabilitation post stroke.

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

Sexuality is important to stroke survivors but rarely addressed. This paper presents an innovative approach to practice change.

European
Life After Stroke
Forum

Abstract Type:

Service Oral Presentation

SAFE
STROKE ALLIANCE FOR EUROPE

65 Socialising from home - Peer support and communication practice at the Aphasia Cafe

Dr Helen Kelly, Miss Shauna Bell, Miss Andrea Horgan

University College Cork, Cork, Ireland

Category
Long term support (including carers and community support)

Summary of the service development
More than 1/3 of people who have a stroke experience a communication impairment called aphasia. Aphasia can affect a person’s ability to understand what they hear and read and to express themselves in the spoken and/or written word. Therefore, people living with aphasia (PwA) can have limited opportunities for social engagement resulting in isolation, loneliness, and depression. In fact, the incidence of depression is markedly higher for PwA than for people who don’t have aphasia following a stroke. Peer support and opportunities to practice conversations can benefit PwA, though lacking in Ireland. This prompted the establishment of the Aphasia Café. Founded in 2017 by UCC Speech and Language Therapy (SLT) students with Dr Helen Kelly, a local café was adapted to provide a communicatively supported environment, e.g., SLT student volunteers, accessible menus, trained café staff, low-noise environment. Pandemic-related social restrictions closed the café. In response, the Aphasia Café moved online: the first online conversational space for PwA in Ireland.

How this is relevant to other countries and what could be the potential impact across countries
The café continues fortnightly with >80 members from urban and rural areas within Ireland as well as the UK, USA, and Europe. The online format of the Aphasia Café has been successful in bringing together PwA from different backgrounds, different national and international geographical locations. Dr Kelly has been approached by professionals in Ireland and Europe who are interested in establishing a similar service.

How this will improve life after stroke for stroke survivors
The café provides a safe space for communication practice and peer support where PwA can develop skills and confidence for use in wider social participation contexts.

66 Enhancing the competency of coordinators in a stroke support organization; creating a self-assessment framework.

Mrs Suzanne Smith-Bayley

March of Dimes Canada, Toronto, Canada

Category
Other

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

Summary of the service development
Community organizations often employ staff with varying educational backgrounds to provide stroke recovery support to individuals and families impacted by stroke. March of Dimes Canada has created the role of After Stroke Coordinators who provide community-based stroke support. Outside of healthcare settings, there are no widely accepted competency frameworks for this type of community-based system coordinator role.

We undertook the creation and validation a self-assessment competency framework with performance indicators for use with community stroke coordinator role. Published competency documents for corresponding roles were reviewed. A framework of relevant competency domains was developed. Indicators of competency for each domain were identified. The framework was then assessed for content validity, piloted tested, revised and then deployed amongst all coordinators. Data was collected on the following: competency goals identified, learning and development opportunities recommended, ongoing feedback in use of the tool, challenges in the deployment and use.

The resulting competency framework has 14 competencies, each with a set of corresponding indicators. Feedback resulted in several enhancements. A list off training options have been identified. Additional usages of the tool were demonstrated.

How this is relevant to other countries and what could be the potential impact across countries
Implementation of a competency framework demonstrates a commitment to provide consistent, high-quality service to clients and facilitates identification of staff learning and development opportunities.   This novel competency framework developed for community-based stroke coordinators could be useful for other stroke support organizations.

How this will improve life after stroke for stroke survivors
This research ensures that people living with the effects of stroke (stroke survivors and caregivers) receive consistent, evidence informed care and navigation from personnel with specialized competencies.