



Measuring the Performance of Rehabilitation and Life After Stroke in the East of England

A Summary Report from the CoastGEM project

Overview

This report summarises the key findings from the *Rehabilitation and Life After Stroke Workshop*, held in February 2024. The workshop was part of the Stroke-Targeted Health System Performance Assessment (STHSPA) workstream, conducted under the *CoastGEM (Coastal Gap Inequality for Stroke Care Management)* project, a collaborative initiative between the University of Essex and ESNEFT aimed at investigating disparities and inequalities in stroke care within coastal regions.

The aim of the workshop was to critically assess system-level challenges and successes influencing disparities and inequalities in stroke rehabilitation and long-term care services within East Suffolk and North Essex NHS Foundation Trust (ESNEFT), and to explore effective strategies and solutions to reduce them.

Participants, including rehabilitation specialists, senior therapists, field leaders, academic contributors to post-stroke care initiatives, and community advocates, engaged in an in-depth discussion on the challenges and opportunities within the post-stroke care system across ESNEFT.

The discussions underscored that systemic, individual, physical, and environmental factors contribute to disparities in stroke care, though there is an overarching goal of improving rehabilitation outcomes and ensuring equitable access to services for all stroke patients across the region.

Analysis Based on the Health System Framework

The findings were summarised using components of the health system framework, with a focus on identifying limitations and challenges contributing to disparities and inequalities in post-stroke care. By applying the health system framework, we gained a structured understanding of how these components interact and impact access to and the quality of post-stroke care. It will also help to identify actionable strategies to improve equity and reduce disparities in rehabilitation and life after stroke services.

A. Service Delivery

- **Specialised care:** The report identifies significant disparities in access to specialised stroke care, particularly between urban and rural residents, where there are limited stroke rehabilitation facilities and expertise. Stroke survivors in rural areas often face lengthy travel distances to access specialised care, exacerbating inequalities, which is compounded even more so for those with mobility issues or cognitive impairments.
- **The fragmented delivery of care** is another concern, with patients often having to navigate disconnected services that lack coordination between acute care, rehabilitation, and long-term post-stroke care. This lack of integration reduces the quality of rehabilitation and impacts on access to tailored care that addresses the specific needs of each patient.
- **Governance of service delivery:** There is a noted lack of conversation and shared decision-making between healthcare providers and stroke survivors, decisions around treatment plans, medications, and rehabilitation strategies are often clinician-driven, with insufficient input from patients, which undermines patient autonomy and satisfaction. This disconnect also limits the ability of healthcare providers to tailor care plans to the personal preferences and life circumstances of patients.

B. Resource Generation

- **Workforce:** The shortage of skilled staff, including physiotherapists, occupational therapists, and speech and language therapists, is one of the most pressing issues affecting stroke rehabilitation which results in long waiting lists and pressure to reduce the amount of time given to each person during their appointment. Additionally, complex training pathways delay the entry of new professionals into the field, while limited CPD opportunities and a culture for implementing new learn mean that existing staff are often not equipped with the latest techniques. High staff turnover exacerbates this problem, as many professionals return to their home countries or leave for more lucrative positions in urban areas.
- **Infrastructure and medical equipment:** Geographic disparities in stroke care are worsened by the absence of adequate infrastructure, including rehabilitation centres especially in coastal areas. There is a gap in suitable public transportation options, which further limits access to rehabilitation facilities for patients in remote areas .

C. Financing

- **Financial Support:** Financial barriers significantly limit access to stroke rehabilitation. The high costs of accessing ongoing therapy, and obtaining assistive devices, can deter patients from pursuing necessary treatment. These exacerbate inequalities in rehabilitation outcomes.

D. Governance

- **Policy and Vision:** The report identifies gaps in current policy frameworks, particularly in addressing disparities in post stroke care related to structural factors such as language, culture, gender, and geography. Many policies do not adequately consider the specific needs of minority patients/hard-to-reach groups or those in coastal areas.

- **Stakeholder Voice:** There is a lack of structured mechanisms for integrating the voices of patients and their families into the governance of stroke rehabilitation services. This results in misaligned expectations and dissatisfaction with the care provided.
- **Information and Intelligence:** The unavailability of disaggregated data prevents healthcare providers from identifying and addressing specific disparities in stroke care. This lack of data makes it difficult to allocate resources effectively and target interventions.
- **Legislation and Regulation:** Current regulatory frameworks and financial resource are insufficient to support the integration of advanced technologies into stroke care.

Conclusion

These findings underscore the need for targeted interventions to address challenges in stroke rehabilitation requires a holistic approach that considers healthcare infrastructure, access to care, inter-professional collaboration, technology integration, and policy support. It is important to ensure that all stroke patients have equitable access to effective rehabilitation services regardless of their language, location, gender, cognitive status, or financial situation. By working on the barriers and leveraging opportunities for improvement, healthcare systems can enhance the quality and effectiveness of stroke rehabilitation, ultimately leading to better outcomes for patients.