European
Life After Stroke
Forum

Enhancing Patient Involvement in Non-Motor Stroke Research

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Disclosures

European Life After Stroke Forum

Personal: No relevant conflict of interest to disclose X

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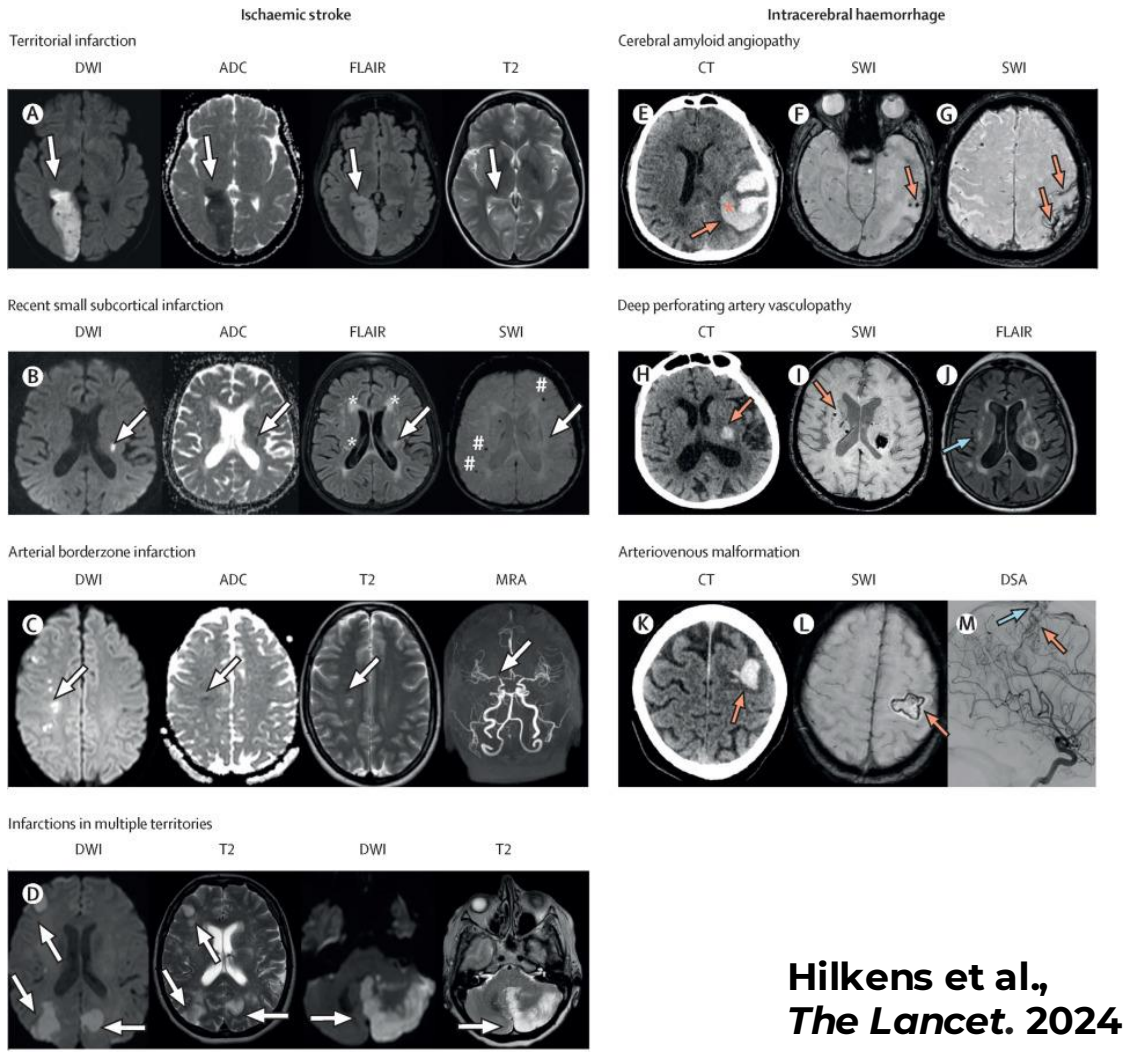
WHAT?

Stroke affects up to **one in five** people during their lifetime in some **high-income** countries, and up to almost **one in two** in **low-income** countries

The global absolute incidence of stroke **increased** by 70% and the prevalence by **85% between 1990 and 2019**

In the U.K the **societal cost** of stroke is £26 billion per year, including **£8.6 billion for NHS and social care**

The **largest** component of total cost was **UNPAID CARE** (61%) and ongoing life after stroke care



Hilkens et al., *The Lancet*. 2024

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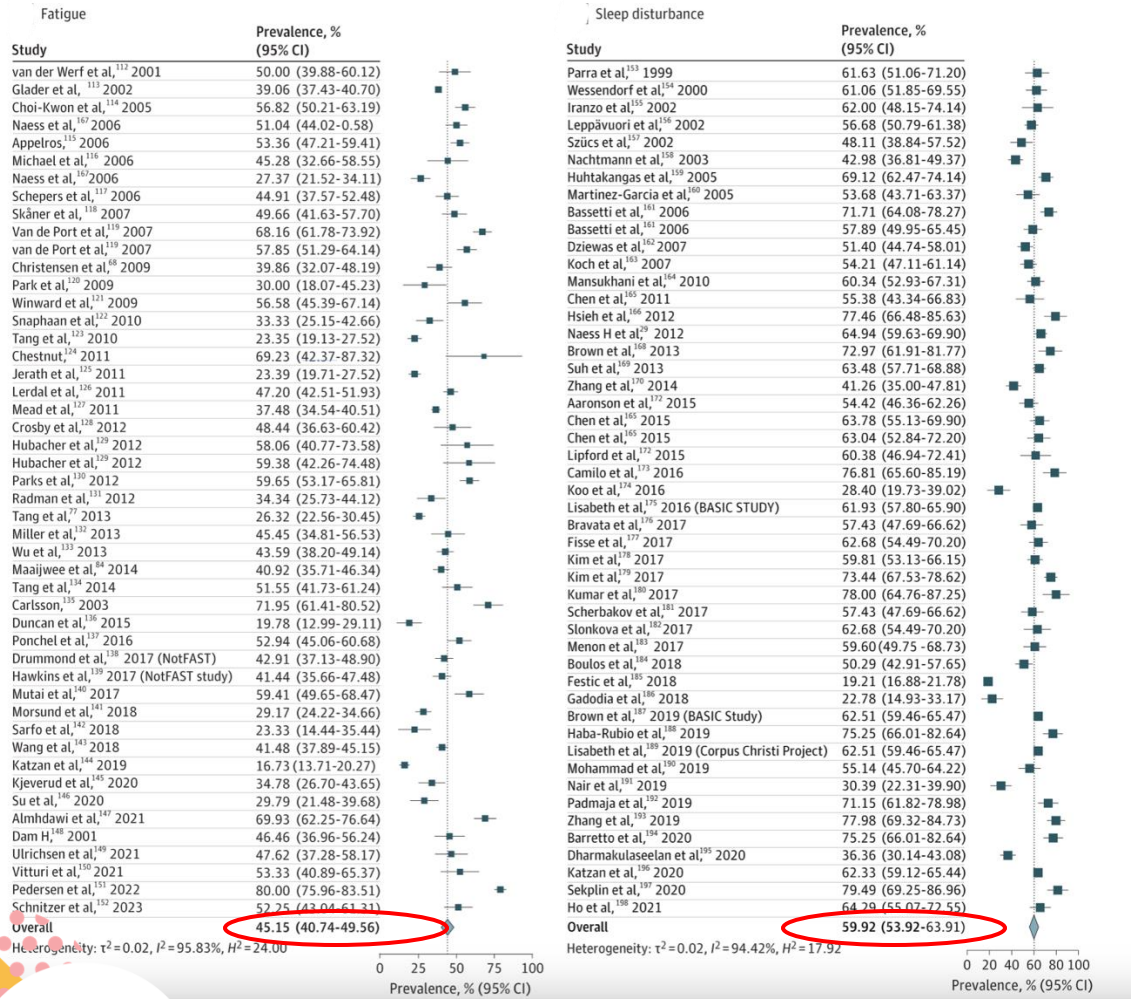
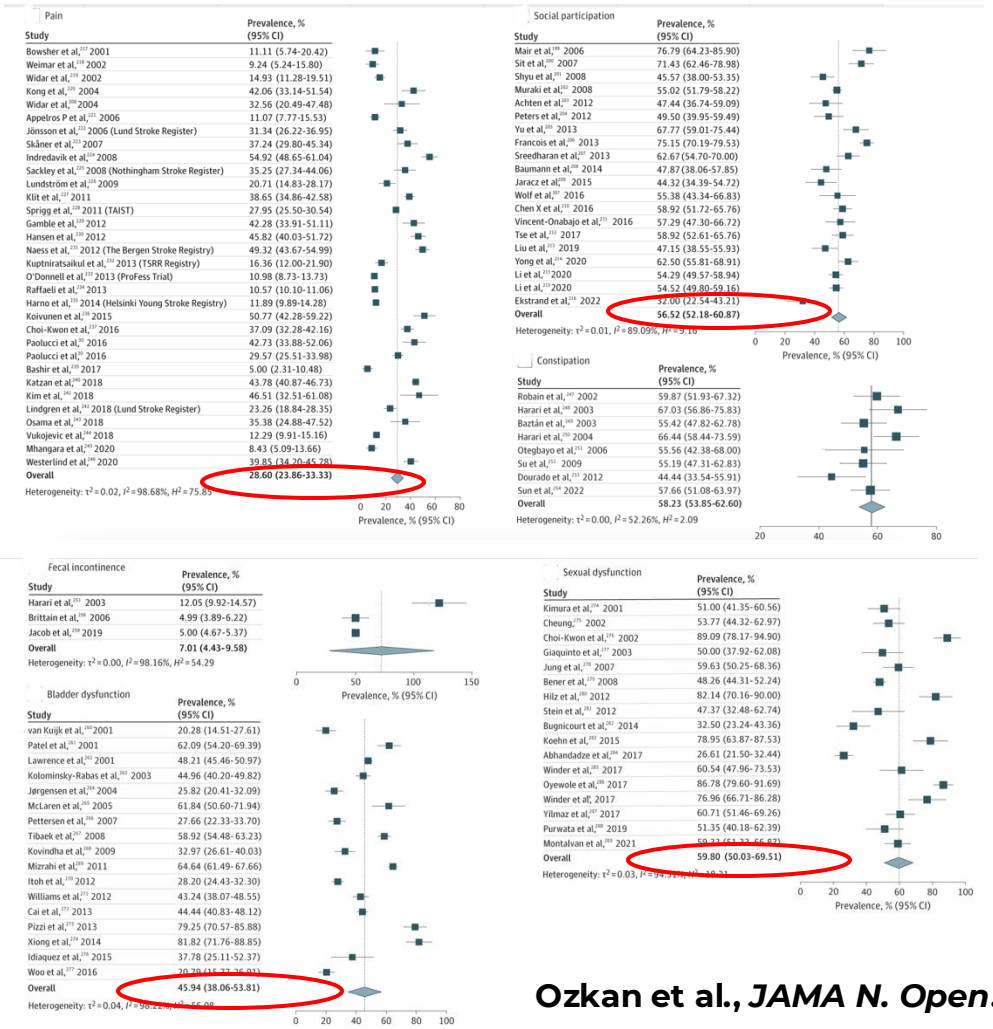
Why does this matter?

To Read





Ozkan et al., *JAMA N. Open*. 2025

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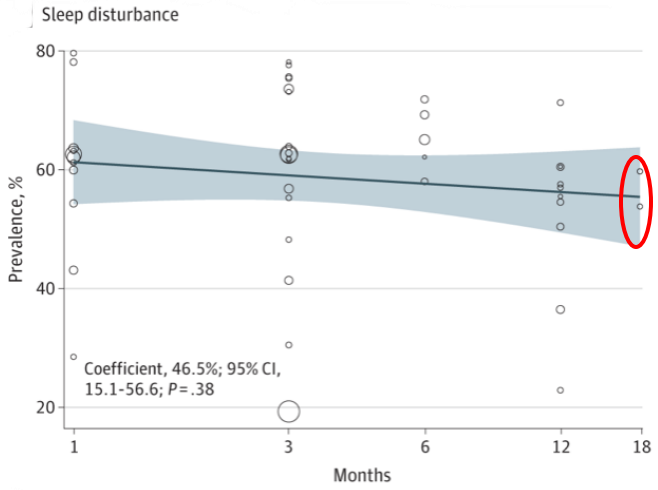
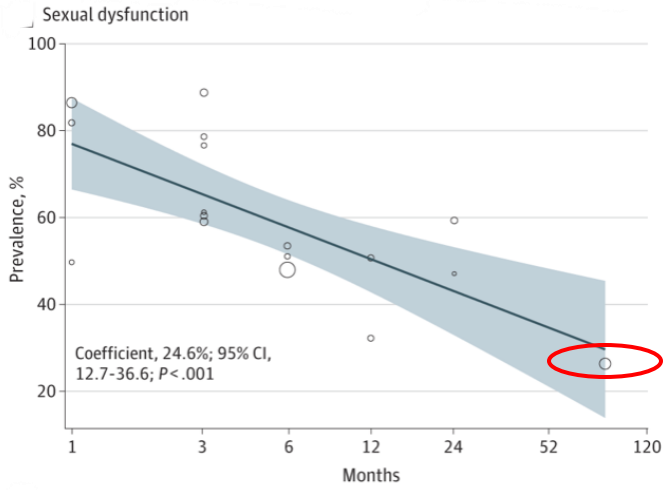
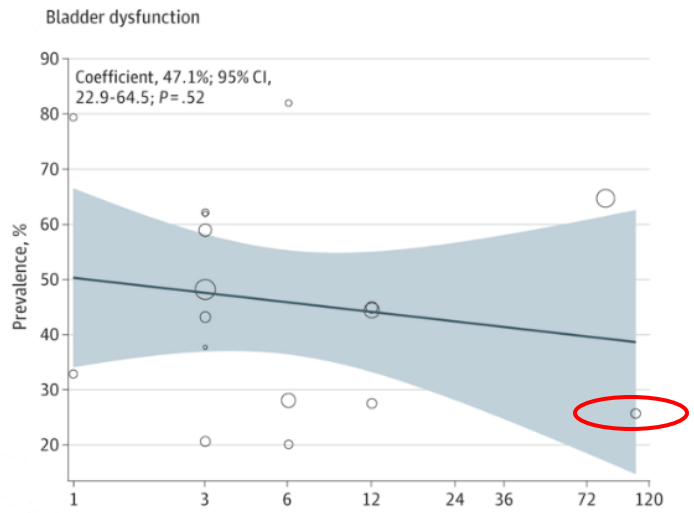
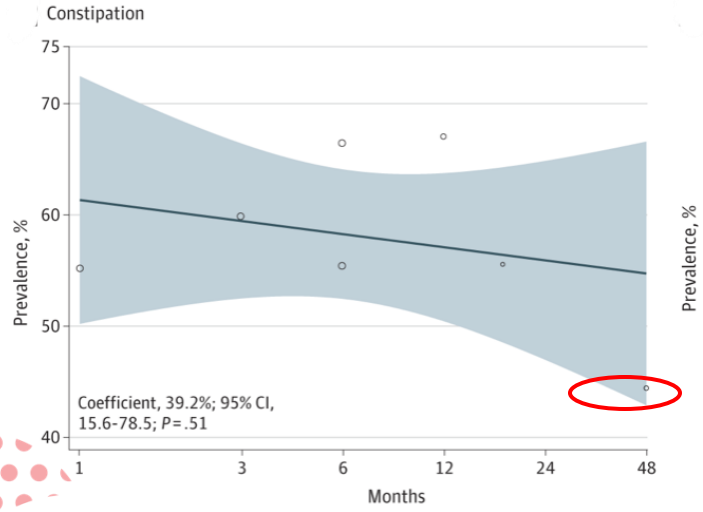
Time Trends and Number of Long-term Studies

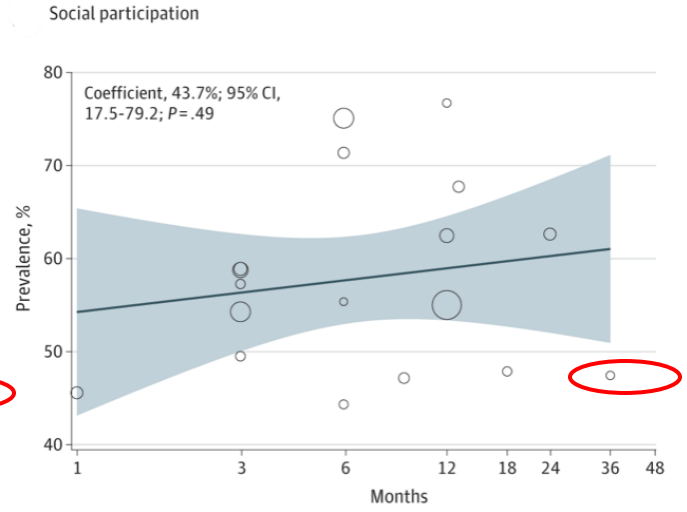
To Read

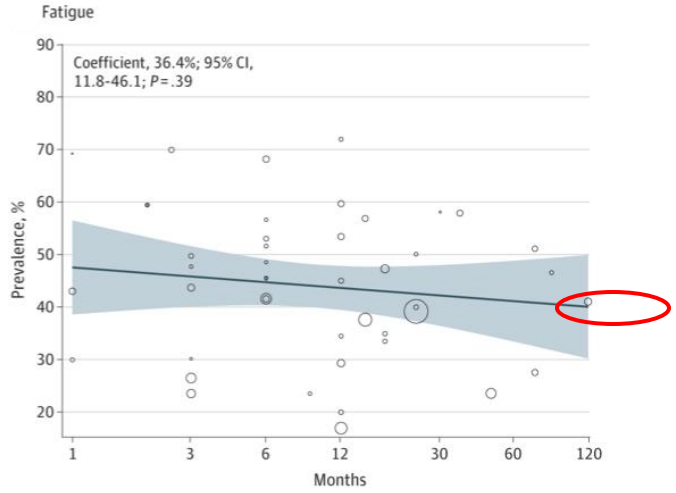












Ozkan et al., *JAMA N. Open.* 2025

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Barriers to Involvement

Lack of Awareness & Accessibility
📌 Patients may not know how to engage in research or face health, mobility, or digital literacy barriers

Stroke-Related Disabilities
📌 Cognitive impairment, aphasia, and fatigue can make it difficult for patients to engage in discussions and research activities

Ethnic & Religious Differences
📌 Cultural perspectives, religious beliefs, and historical mistrust in research may affect participation

Tokenistic Involvement
📌 Patients are sometimes included as a formality rather than as equal partners, limiting their influence.

Communication & Language Barriers
📌 Medical jargon and language differences can hinder confidence and participation.

Time & Financial Constraints
📌 Travel costs, caregiving duties, and unpaid involvement make participation challenging

1. Strategies for Engagement

Understand	Understand your study **design**: whether it's observational or interventional, cohort or case-control, single-center or multi-center
Embed	Embed **inclusion** from the start, define the **target group** early—consider stroke type, patient characteristics, severity, and primary outcome
Consider	Consider **demographics** such as age group, sex, post-code, ethnic diversity, and social determinants
Ensure	Ensure **accessibility** by providing study information in multiple formats, languages, including large print, audio, and video

1.1 Strategies for Engagement

Use **translated** materials, **hybrid** meetings, and slow-paced, **aphasia-friendly** discussions to accommodate diverse needs.

Incorporate **mixed-method follow-ups** and multiple touchpoints to enhance engagement and inclusivity.

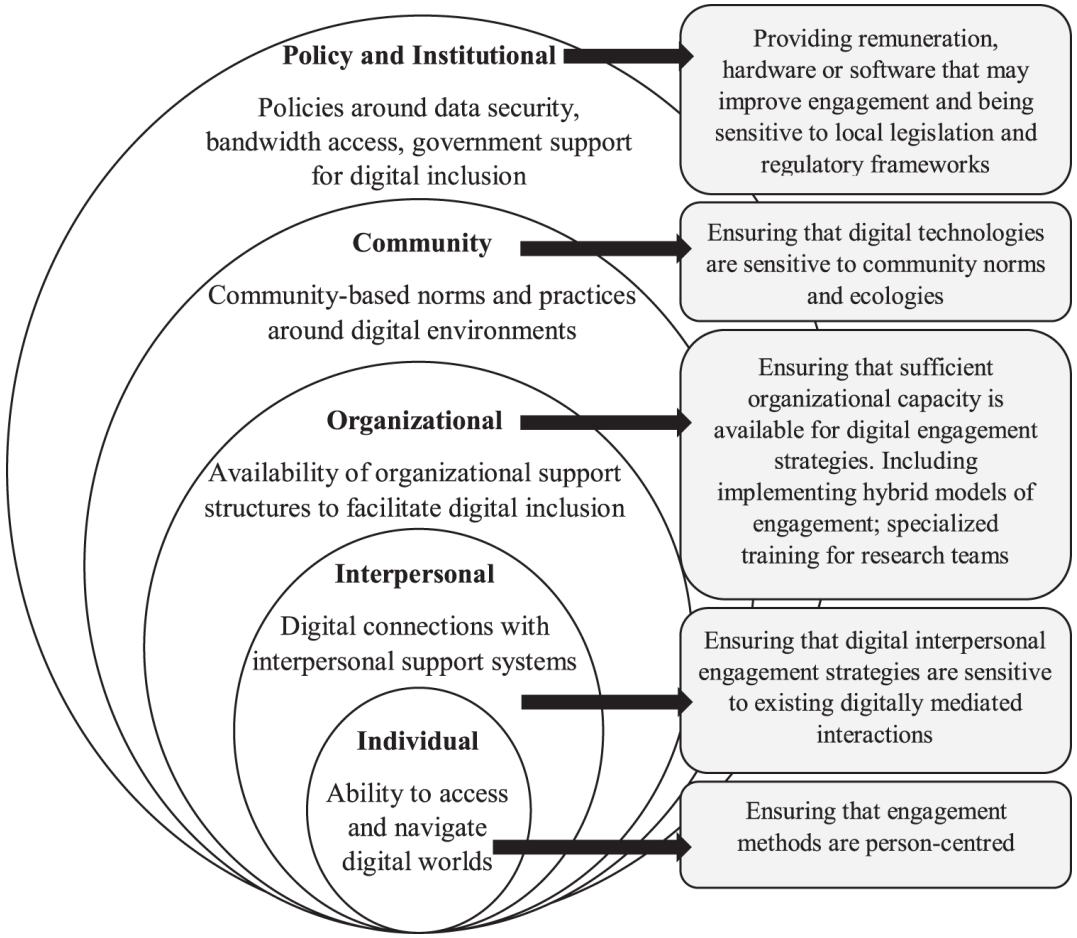
Build **trust and strong relationships** with lived experience group , charities, and patient advocates by involving them in study design, not just as participants but as research partners.

Recognize their roles beyond consultation and empower them as **active partners** in shaping research, ensuring their insights drive meaningful impact.

Role of Technology

Technology plays a significant role in amplifying **patient voices**. Telehealth, mobile **apps**, and social media **platforms** provide new avenues for patients to share their experiences and participate in research, making their **voices** more heard than ever.

Digital platforms enable **remote** participation, breaking down geographical and **mobility barriers**. **Speech-to-text tools** and AI-driven **language support** assist those with aphasia and cognitive challenges. Wearable devices and mobile apps empower patients to track symptoms, contribute real-world data, and stay **engaged**.

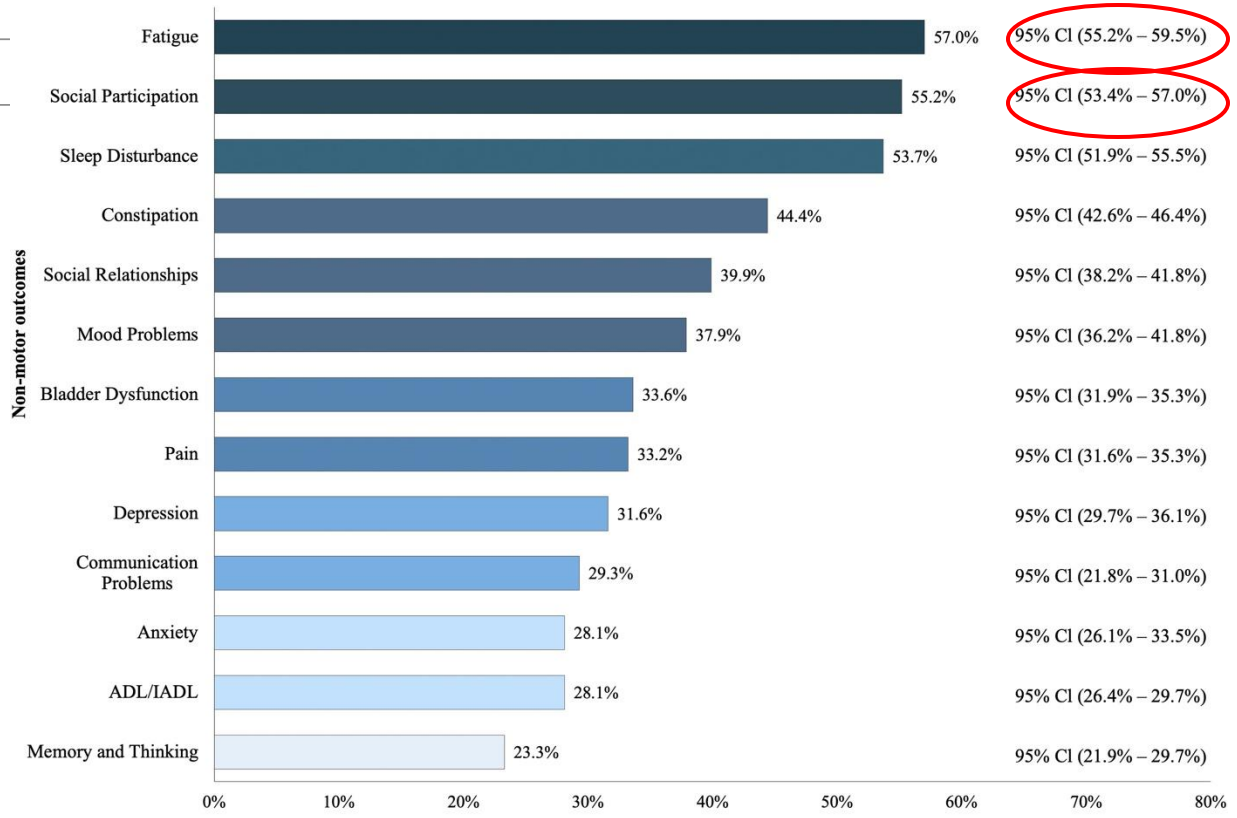


Tan et al., Nature Digital. 2022

Case Studies of Success

Table 1. Baseline patient characteristics.

	All patients (N = 3080)
Age, mean (SD) y	71.2 ± 14.6
Female sex, N (%)	1379 (44.8%)
Stroke type, N (%)	
Ischaemic stroke	2534 (82.2%)
ICH	547 (17.8%)
Ethnicity, N (%) (2994)	
White	1774 (59.3%)
Asian	505 (16.9%)
Black	519 (17.3%)
Other	196 (6.6%)



Ozkan et al., Lancet Regional Health. 2024

Team







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Patients

Effective communication with patients during their hospital stay is crucial for fostering inclusion in research

Engaging patients early ensures they understand research opportunities, feel valued, and can actively contribute

Clear, accessible discussions help bridge gaps in awareness, empowering diverse voices to shape stroke care and recovery

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Methods Used to Enhance Involvement

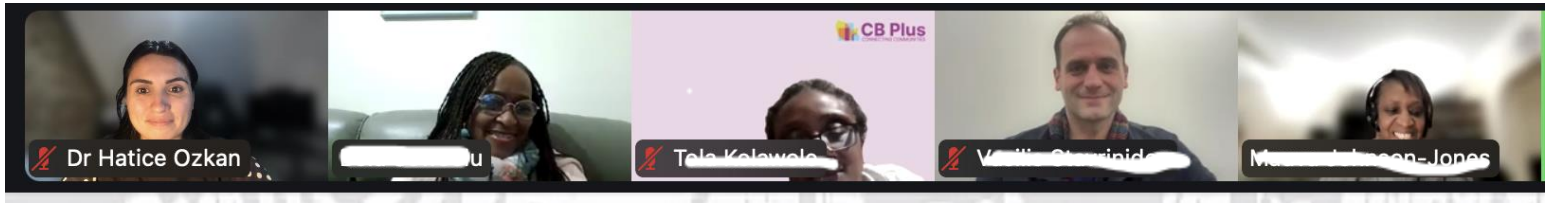
1. **Multiple** Follow-Up Approaches: Use telephone calls, outpatient clinics (both local and sector-based), and primary care collaborations to reach a diverse patient population.

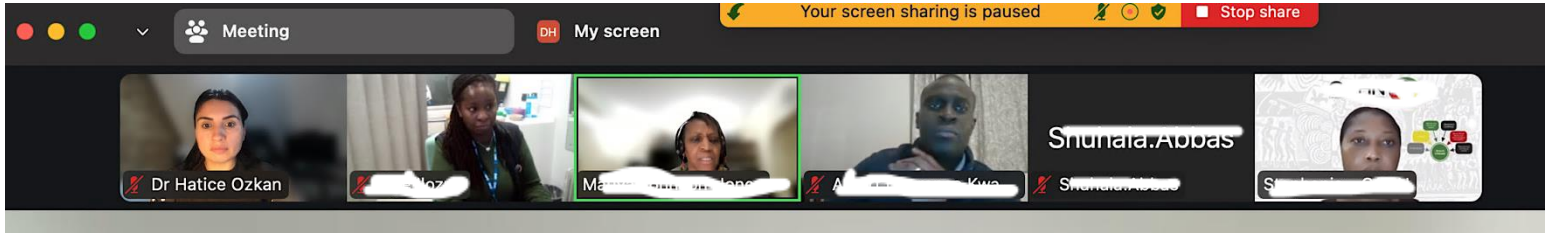
2. **Flexible** Participation Options: Offer postal surveys, hybrid (in-person/remote) follow-ups, and proxy responders for patients with communication or cognitive difficulties.

3. **Patient-Centered** Approach: Consider patient needs by incorporating regular breaks, clear communication, and accessible formats (large print, easy-read materials, interpreters).

4. Budgeting for **Inclusivity:** Allocate funds for travel reimbursement, flexible meeting formats, and additional support to ensure participation is not limited by financial constraints.

Partnership and Trust Building





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I Am More Than My Stroke

"I am a 41-year-old Black man. In April 2024, my life changed—I had a stroke.

Before that, I was strong. I was a **built man**, hitting the gym four times a week, showing up at my community center, and being a respected figure in my circle. My job was more than just work—it was my **identity, my income, my laughter.** I looked forward to those monthly meetups with my work friends, sharing jokes, sharing life.

Then stroke hit.

My voice was weakened, my left side no longer moved as it should. A week after I was discharged, a team came to check on me. The second week, a physio came. I had **two weeks of Speech and Language Therapy.** Seven months later, I saw my stroke consultant. They checked my eyes, my ability to walk, and my ability to talk.

But no one asked about the rest of me."

"**Before** my stroke, I was more than a man who lifted weights, walked through my neighbourhood, and met friends.

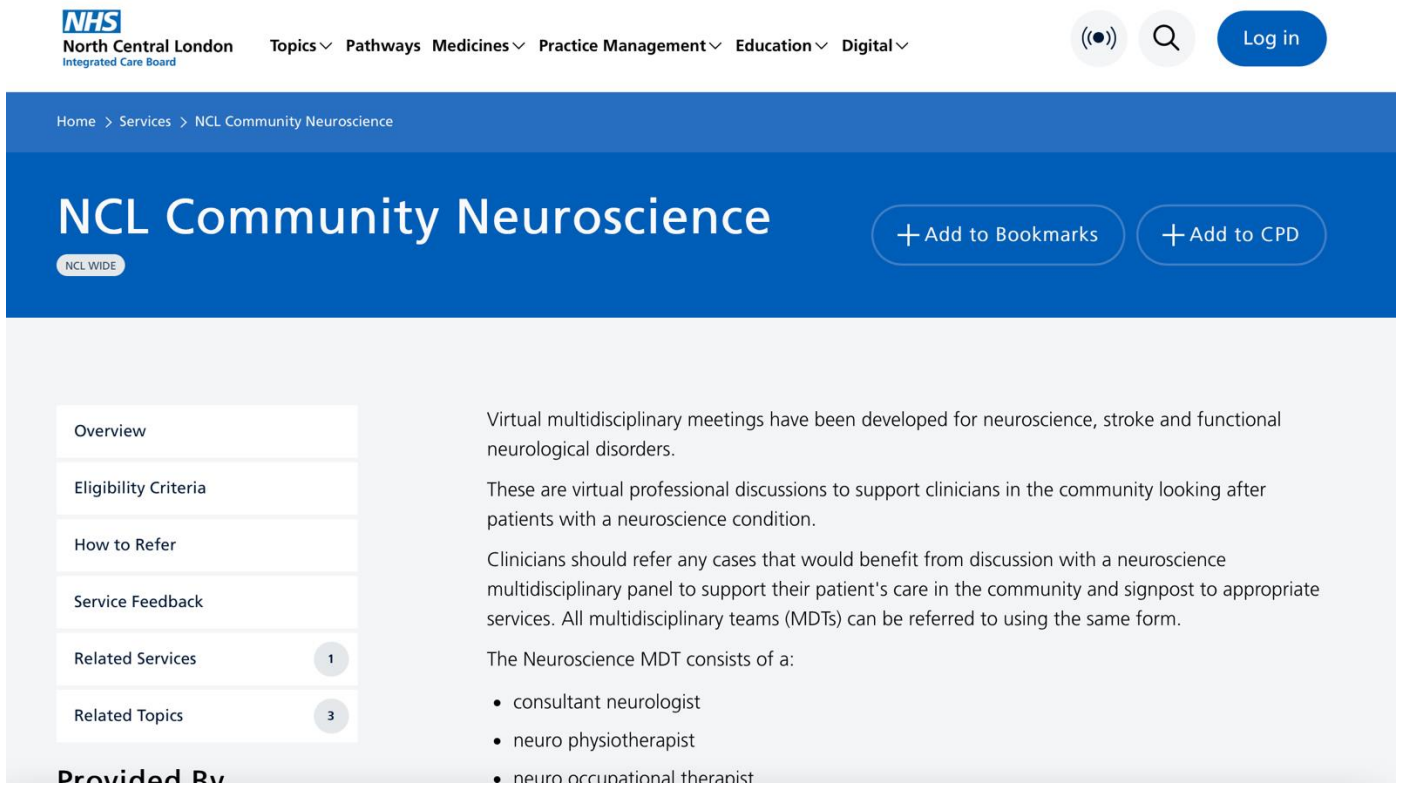
But after?
No one checked why I was **hiding** in my house.
No one asked why I wasn't **reintegrating** back into my community.
No one noticed I wasn't **sleeping**.
No one questioned why I felt so depressed, why I stayed indoors for days.

Before stroke, I thought talking about these struggles would **damage my pride**.

Now, I realize that **every stroke survivor** in the room experiences at least one of these symptoms—yet these conversations remain **hidden**, **buried** in research papers or overlooked in hospitals. But thanks to the Stroke MDT team at UCLH, I continue to receive the care I needed."

Future...

We need to move towards integrated Stroke Services



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THANK YOU!

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