European
Life After
Stroke
Forum

Enhancing Patient Involvement in Non-Motor Stroke Research

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Disclosures

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Personal: No relevant conflict of interest to disclose

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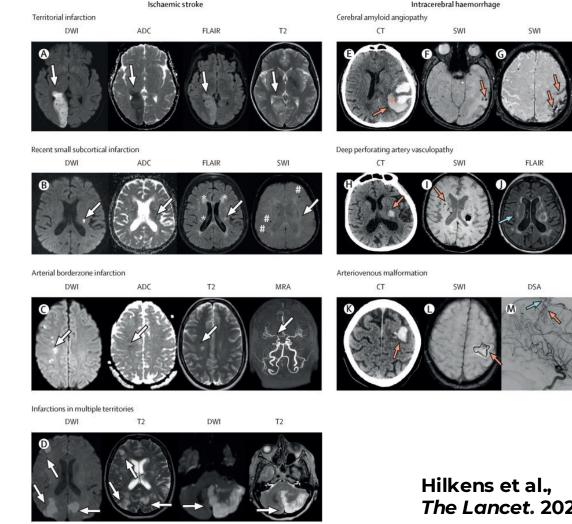
WHAT?

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



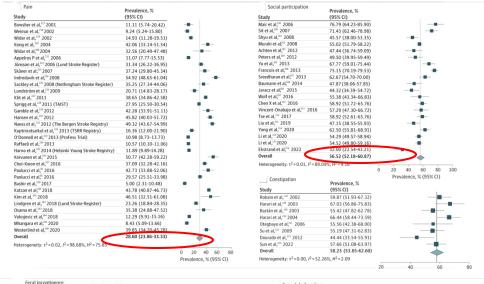




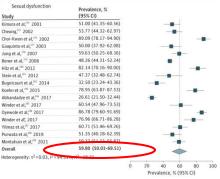
Why does this matter?



Fatigue Study	Prevalence, % (95% CI)		Sleep disturbance	Prevalence, % (95% CI)	
van der Werf et al. 112 2001	50.00 (39.88-60.12)		Parra et al, ¹⁵³ 1999	61.63 (51.06-71.20)	1
Glader et al, 113 2002	39.06 (37.43-40.70)		Wessendorf et al, 1999		
Choi-Kwon et al, 114 2005	56.82 (50.21-63.19)	-	Iranzo et al, 2002	61.06 (51.85-69.55)	
				62.00 (48.15-74.14)	
Naess et al, 167 2006	51.04 (44.02-0.58)		Leppävuori et al, ¹⁵⁶ 2002 Szücs et al, ¹⁵⁷ 2002	56.68 (50.79-61.38)	
Appelros,115 2006	53.36 (47.21-59.41)		Nachtmann et al. 158 2003	48.11 (38.84-57.52)	
Michael et al, 116 2006	45.28 (32.66-58.55)			42.98 (36.81-49.37)	-
Naess et al, 1672006	27.37 (21.52-34.11)	-	Huhtakangas et al, ¹⁵⁹ 2005	69.12 (62.47-74.14)	
Schepers et al, 117 2006	44.91 (37.57-52.48)	-	Martinez-Garcia et al, ¹⁶⁰ 2005 Bassetti et al, ¹⁶¹ 2006	53.68 (43.71-63.37)	
skåner et al, ¹¹⁸ 2007	49.66 (41.63-57.70)	-	Bassetti et al, 2006	71.71 (64.08-78.27)	4
/an de Port et al, ¹¹⁹ 2007	68.16 (61.78-73.92)	-	Dziewas et al, 162 2007	57.89 (49.95-65.45)	
van de Port et al, 119 2007	57.85 (51.29-64.14)		Koch et al, 163 2007	51.40 (44.74-58.01)	
Christensen et al, ⁶⁸ 2009	39.86 (32.07-48.19)			54.21 (47.11-61.14)	
Park et al, ¹²⁰ 2009	30.00 (18.07-45.23)		Mansukhani et al, ¹⁶⁴ 2010	60.34 (52.93-67.31)	-
Winward et al, ¹²¹ 2009	56.58 (45.39-67.14)		Chen et al,165 2011	55.38 (43.34-66.83)	-
onaphaan et al, 2010	33.33 (25.15-42.66)		Hsieh et al, 166 2012	77.46 (66.48-85.63)	
Tang et al, 123 2010	23.35 (19.13-27.52)	-	Naess H et al. 2012	64.94 (59.63-69.90)	•
Chestnut, 2011	69.23 (42.37-87.32)	-	Brown et al, 168 2013	72.97 (61.91-81.77)	-
lerath et al, 125 2011	23.39 (19.71-27.52)	-	Suh et al, 170 2013	63.48 (57.71-68.88)	
erdal et al, ¹²⁶ 2011	47.20 (42.51-51.93)		Zhang et al, ¹⁷⁰ 2014	41.26 (35.00-47.81)	-
Mead et al, 127 2011	37.48 (34.54-40.51)		Aaronson et al, ¹⁷² 2015	54.42 (46.36-62.26)	-
Crosby et al, 128 2012	48.44 (36.63-60.42)		Chen et al, 165 2015	63.78 (55.13-69.90)	-
Hubacher et al, 129 2012	58.06 (40.77-73.58)		Chen et al,165 2015	63.04 (52.84-72.20)	-
lubacher et al,129 2012	59.38 (42.26-74.48)		Lipford et al, 172 2015	60.38 (46.94-72.41)	-
Parks et al, 130 2012	59.65 (53.17-65.81)		Camilo et al, 173 2016	76.81 (65.60-85.19)	-
Radman et al, 131 2012	34.34 (25.73-44.12)		Koo et al, ¹⁷⁴ 2016	28.40 (19.73-39.02)	-
Tang et al, ⁷⁷ 2013	26.32 (22.56-30.45)	-	Lisabeth et al, 175 2016 (BASIC STUDY)	61.93 (57.80-65.90)	
Miller et al, 132 2013	45.45 (34.81-56.53)		Bravata et al, 176 2017	57.43 (47.69-66.62)	-
Vu et al. 133 2013	43.59 (38.20-49.14)		Fisse et al, 177 2017	62.68 (54.49-70.20)	-
Maaijwee et al. 84 2014	40.92 (35.71-46.34)		Kim et al, 178 2017	59.81 (53.13-66.15)	
Tang et al, 134 2014	51.55 (41.73-61.24)		Kim et al, ¹⁷⁹ 2017	73.44 (67.53-78.62)	-
Carlsson, 135 2003	71.95 (61.41-80.52)		Kumar et al, ¹⁸⁰ 2017	78.00 (64.76-87.25)	
Juncan et al. 136 2015			Scherbakov et al, 181 2017	57.43 (47.69-66.62)	-
Ponchel et al, 2016	19.78 (12.99-29.11)		Slonkova et al, 182 2017	62.68 (54.49-70.20)	-
Unicited et al., 2016	52.94 (45.06-60.68)		Menon et al, 183 2017	59.60 (49.75 - 68.73)	-
Orummond et al, 138 2017 (NotFAST) Hawkins et al, 139 2017 (NotFAST study)	42.91 (37.13-48.90)		Boulos et al, ¹⁸⁴ 2018	50.29 (42.91-57.65)	
	41.44 (35.66-47.48)	-	Festic et al, ¹⁸⁵ 2018	19.21 (16.88-21.78)	
Mutai et al, 140 2017	59.41 (49.65-68.47)		Gadodia et al,186 2018	22.78 (14.93-33.17)	-
Morsund et al, 141 2018	29.17 (24.22-34.66)		Brown et al, 187 2019 (BASIC Study)	62.51 (59.46-65.47)	
earfo et al, 142 2018	23.33 (14.44-35.44)		Haba-Rubio et al, ¹⁸⁸ 2019	75.25 (66.01-82.64)	
Vang et al, 143 2018	41.48 (37.89-45.15)	-	Lisabeth et al, 189 2019 (Corpus Christi Project)	62.51 (59.46-65.47)	
(atzan et al, ¹⁴⁴ 2019	16.73 (13.71-20.27)	•	Mohammad et al,190 2019	55.14 (45.70-64.22)	-
(jeverud et al, ¹⁴⁵ 2020	34.78 (26.70-43.65)	-	Nair et al, ¹⁹¹ 2019	30.39 (22.31-39.90)	-
ou et al, ¹⁴⁶ 2020	29.79 (21.48-39.68)		Padmaja et al, 192 2019	71.15 (61.82-78.98)	-
llmhdawi et al, ¹⁴⁷ 2021	69.93 (62.25-76.64)		Zhang et al, 193 2019	77.98 (69.32-84.73)	-
Dam H, ¹⁴⁸ 2001	46.46 (36.96-56.24)		Barretto et al, 194 2020	75.25 (66.01-82.64)	-
Jlrichsen et al, 49 2021	47.62 (37.28-58.17)	-	Dharmakulaseelan et al, 2020	36.36 (30.14-43.08)	-
litturi et al, ¹⁵⁰ 2021	53.33 (40.89-65.37)	-	Katzan et al, 196 2020	62.33 (59.12-65.44)	
edersen et al, ¹⁵¹ 2022	80.00 (75.96-83.51)		Sekplin et al, ¹⁹⁷ 2020	79.49 (69.25-86.96)	-8
Schnitzer et al, 152 2023	52.25 (43.04-61.31)		Ho et al, 198 2021	64 29 (55 07-72.55)	-
overall	45.15 (40.74-49.56)		Overall	59.92 (53.92-63.91)	
Here $\sigma_{\rm e}$ = 0.02, I^2 = 95.83%, H^2			Heterogeneity: $\tau^2 = 0.02$, $I^2 = 94.42\%$, $H^2 = 17.9$		Y
eterogenetty: t0.02, 133.83%, ff"	-24.00	25 50 75 100	neterogeneity: t0.02, r34.42%, H= 17.9	-	20 40 60 80



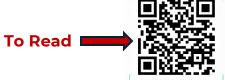
Study	(95% CI)				
Harari et al,251 2003	12.05 (9.92-14.57)				-
Brittain et al,258 2006	4.99 (3.89-6.22)		-		
Jacob et al,250 2019	5.00 (4.67-5.37)				
Overall	7.01 (4.43-9.58)				
Heterogeneity: $\tau^2 = 0.00$, $I^2 = 98.16$	6%, H ² = 54.29				
		0	50	100	15
Bladder dysfunction Study	Prevalence, % (95% CI)		Prevalenc	ce, % (95% CI)	
van Kuijk et al, 2001	20.28 (14.51-27.61)	-	-		
Patel et al, ³⁴¹ 2001	62.09 (54.20-69.39)			-	
Lawrence et al, No 2001	48.21 (45.46-50.97)				
Kolominsky-Rabas et al,261 2003	44.96 (40.20-49.82)		-80-		
Jørgensen et al,244 2004	25.82 (20.41-32.09)		-8-		
McLaren et al,265 2005	61.84 (50.60-71.94)		-		
Pettersen et al,265 2007	27.66 (22.33-33.70)		-		
Tibaek et al,217 2008	58.92 (54.48-63.23)				
Kovindha et al, 2009	32.97 (26.61-40.03)		-8-		
Mizrahi et al,200 2011	64.64 (61.49-67.66)				
Itoh et al,270 2012	28.20 (24.43-32.30)				
Williams et al,221 2012	43.24 (38.07-48.55)		-		
Cai et al, ²⁷² 2013	44.44 (40.83-48.12)				
Pizzi et al,273 2013	79.25 (70.57-85.88)			-	
Xiong et al,274 2014	81.82 (71.76-88.85)				
Idiaquez et al,276 2015	37.78 (25.11-52.37)		-		
Woo et al,277 2016	20 79 (15 77 26 91)	-	-		
Overall	45.94 (38.06-53.81)				
Heterogeneity: τ ² =0.04, I ² =98.22	10,10 -55.00	_			

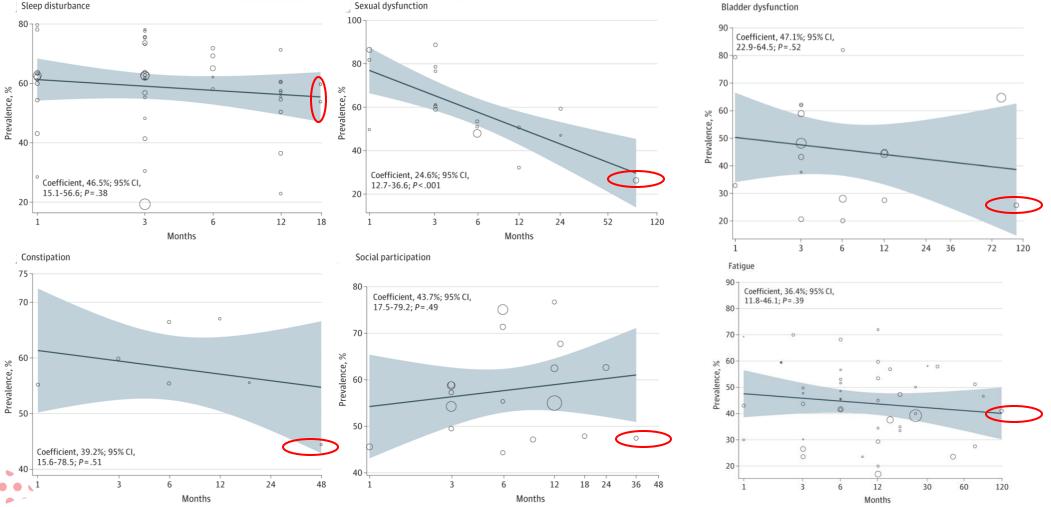


Ozkan et al., JAMA N. Open. 2025



Time Trends and Number of Long-term Studies





10-11 March 2025



Ozkan et al., JAMA N. Open. 2025

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.



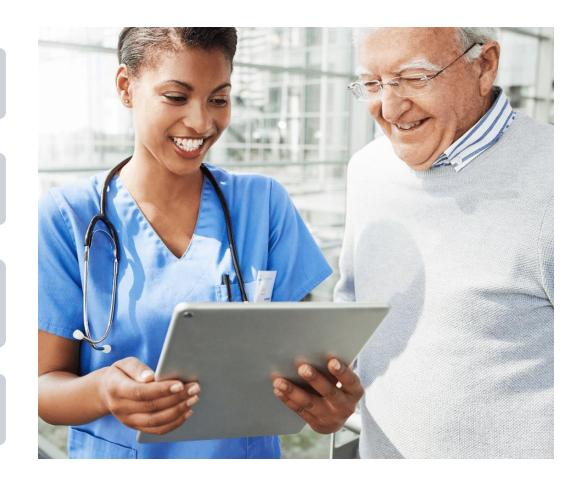
Incorporate **mixed-method follow-ups** and multiple touchpoints to enhance engagement and inclusivity.



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.



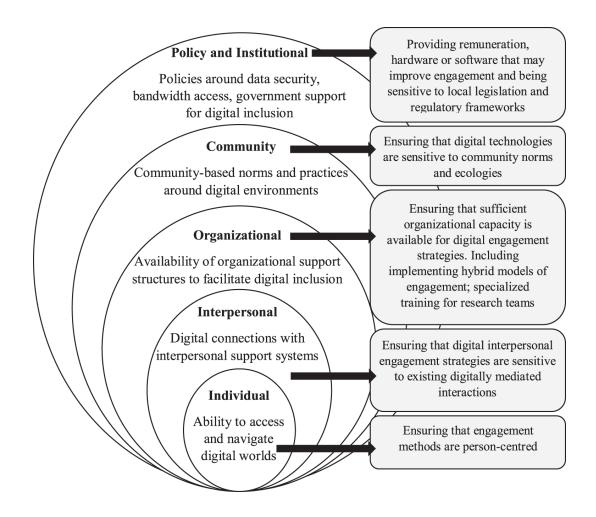




Role of Technology

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 Al-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**.





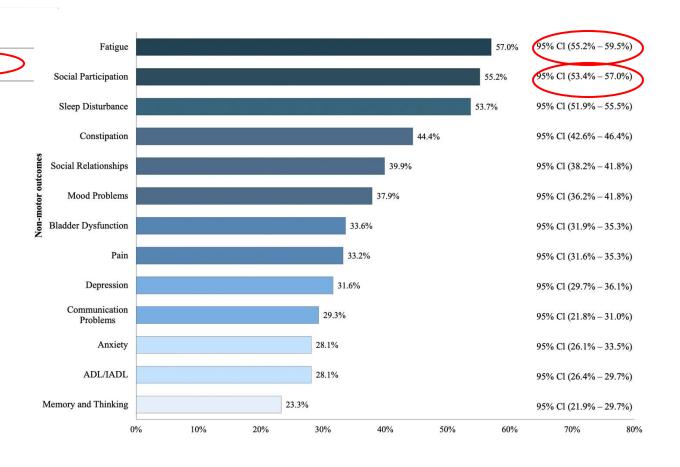




Case Studies of Success

Table 1. Baseline patient characteristics.

	All patients N = 30
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























Patients



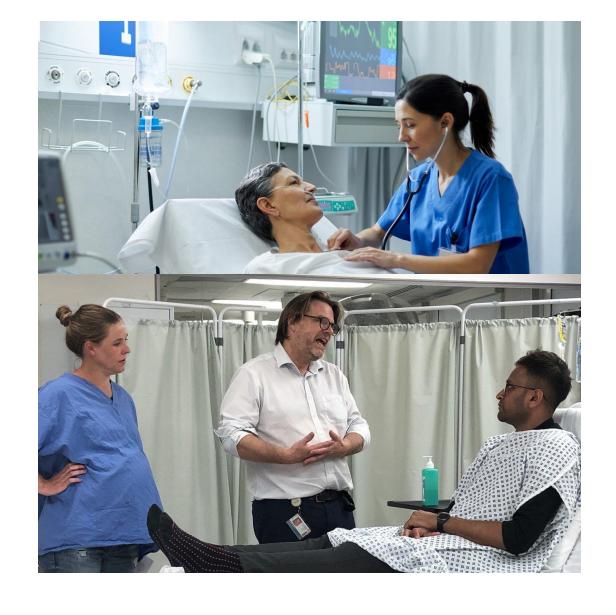
Effective communication with patients during their hospital stay is crucial for fostering inclusion in research



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







Methods Used to Enhance Involvement

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

hybrid (in-person/remote) follow-ups, and proxy responders for patients with communication or cognitive difficulties.

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

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







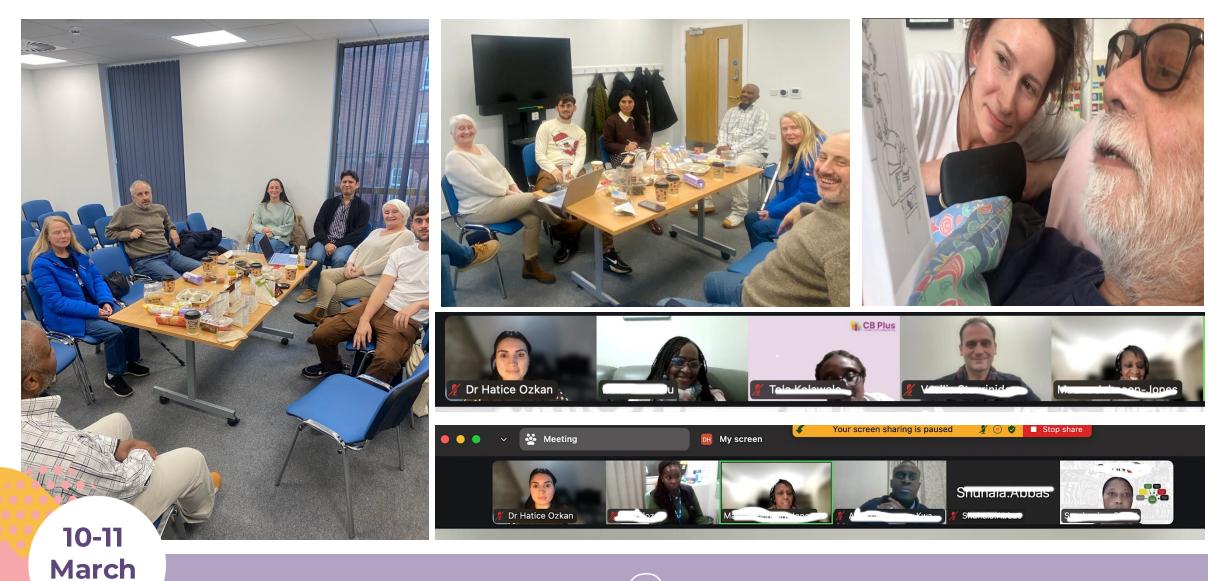






Partnership and Trust Building

2025





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.

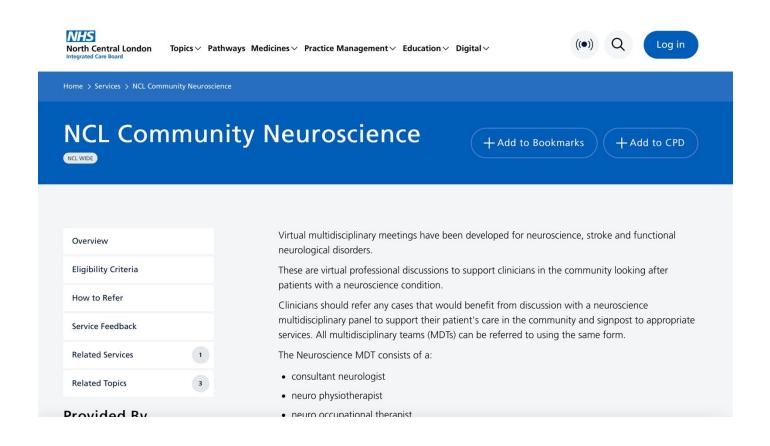
Before stroke, I thought talking about these struggles would **damage my pride**.

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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