

INCLUSION OF LIVED EXPERIENCE OF STROKE ACROSS THE STROKE HEALTH ECOSYSTEM: MEANINGFUL ENGAGEMENT WITH PEOPLE AFFECTED BY DIVERSE HEALTH CONDITIONS IN TREATMENT AND CARE INNOVATION

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Introduction

- Stroke represents a major health burden worldwide¹ and the incidence of stroke is projected to increase by ~81% from 2025 to 2050².
- Alarming, stroke increasingly affects younger people (<55 years)^{3,4} and stroke recurrence rates remain unacceptably high^{5,6}.
- Engaging people with lived experience of a disease is key to bridging existing gaps in care⁷, improving health outcomes⁸, and enhancing research design and conduct⁹; however, stroke survivors are frequently excluded from individual and systemic decision-making processes^{10–12}.
- In this poster, we highlight the urgent need for inclusion of survivors across the stroke health ecosystem.

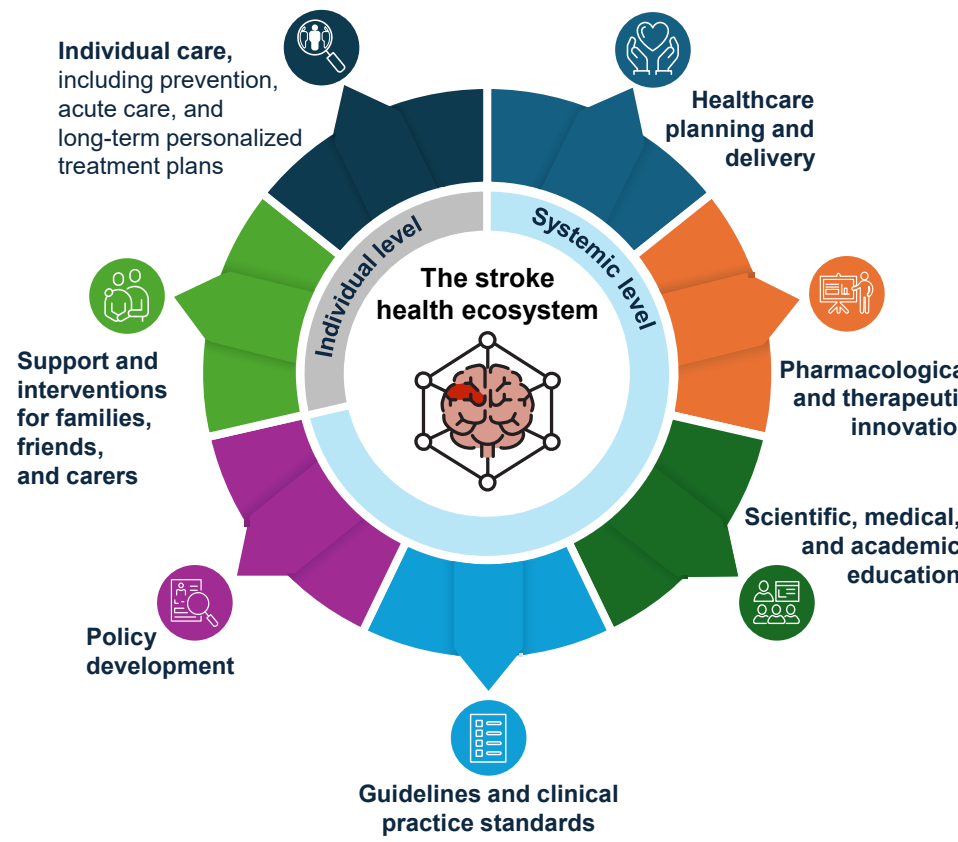
Methods

- Multi-stakeholder perspectives were gathered (N=4) through:
 - Structured interviews with a stroke survivor actively participating in initiatives to advance stroke care and treatment innovation; a medical device industry representative and a stroke scientist with clinical and lived experience of stroke.
 - Unstructured discussions from a medicine innovation industry representative.
- The interviews and discussions focused on the opportunities and practicalities of involving survivors across the stroke health ecosystem, differentiating between individual and systemic decision-making processes.

Results

- The stroke health ecosystem comprises individual care; support for family and friends; healthcare planning and delivery; pharmacological and therapeutic innovation; scientific, medical, and academic education; guidelines and clinical practice standards; and policy development (Figure 1).

Figure 1. The stroke health ecosystem



Conclusions

- Stroke represents a major health burden worldwide and stroke recurrence rates remain unacceptably high^{1,5,6}.
- Meaningful involvement of stroke survivors across the stroke health ecosystem may help to address the current gap in stroke treatment, ultimately improving patient outcomes.
- Individual long-term recovery depends on the inclusion of survivors in the design of their treatment plans to ensure their goals reflect personal hopes and passions.
- On a systemic level, building an effective and successful stroke care infrastructure requires collaborating with survivors, given they are the only stakeholders with experience navigating the entire stroke health ecosystem and are therefore uniquely positioned to share valuable insights.
- Survivor inclusion across the ecosystem must be meaningful, respectful, and proactive to truly help to improve stroke care.

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Conflicts of interest / Disclosures

SB declares no conflicts of interest. **EAM** is an employee of Bayer AG, and may own shares or share options in the company. **AB** is an employee of Philips Healthcare, and may own shares or share options in the company. **MBR** was a manager at TWIST (the main source of funding of the TWIST trial was from the National Program for Clinical Treatment Research in the Specialist Health Service in Norway. In addition, TWIST was funded by the British Heart Foundation, Swiss Heart Foundation, and Boehringer Ingelheim), received PhD funding from the Norwegian Health Association, has received grants from Cochrane, and received speaker fees from Daiichi Sankyo.

- Involving stroke survivors across the stroke health ecosystem has the potential to result in significant benefits (Table 1):
 - On an individual level, enabling shared decision-making and development of a treatment plan that reflects a stroke survivor’s hopes and passions, which may result in higher levels of motivation and commitment to recovery.
 - On a systemic level, stroke survivors are the only stakeholders with experience navigating the entire stroke healthcare system. As such, they are uniquely positioned to share valuable insights to shape effective stroke care and inform innovation, ultimately helping to reduce the global burden of stroke.

Table 1. Potential benefits of involving stroke survivors across the stroke health ecosystem, including in individual- and systemic-level decision-making processes

Potential benefits of involving stroke survivors		
 Individual level	Individual care, including shared decision-making and personalized treatment plans that reflect survivors’ goals and passions	- High levels of motivation and commitment to recovery - Increased confidence - Mutual respect between survivors and healthcare professionals - May help to improve mental health and independence - May help to reduce long-term disability
	Support and interventions for families, friends, and carers [†]	Services and interventions that better reflect the needs and realities of people affected by stroke
 Systemic level	Healthcare planning and delivery, including standards of care and clinical practice	- Exchange of valuable insights – stroke survivors are the only stakeholders with experience of the disease and of navigating the entire stroke healthcare system - Construction of an effective stroke infrastructure, helping to improve care and reduce the global burden of stroke - Informing decision-making on advancements in stroke care as lived experience experts
	Guidelines and clinical practice standards	
	Policy development	
	Pharmacological and therapeutic innovation	- Sharing of insights that enrich the research process, such as barriers to study enrolment and ongoing participation - Ensuring innovation and advancements in clinical practice are aligned to real-world needs of survivors
	Scientific, medical, and academic education	Design of educational programs that raise awareness of the needs of survivors, and the tangible benefits of personalizing treatment plans

[†]There is a need to directly gain insights from family members, friends and carers to ensure that these services reflect their needs.

- When involving survivors in initiatives that aim to advance stroke care, it is recommended to follow best-practice approaches (Figure 2).
 - Best-practice approaches include forward planning and early involvement of survivors within the lifecycle of an initiative, formalizing roles, ensuring diverse representation, providing support and training, partnership-led models, fair compensation, addressing stigmas and biases, measuring impact, and co-creation.
 - These approaches are key to meaningful collaborations; implementing them helps to ensure that survivors are able to share high-quality information and that the collaboration is a positive experience for survivors.

Figure 2. Best-practice approaches to ensure meaningful inclusion of survivors in initiatives that aim to advance stroke care

