A Framework for Stroke Survivor Leadership in Healthcare Governance

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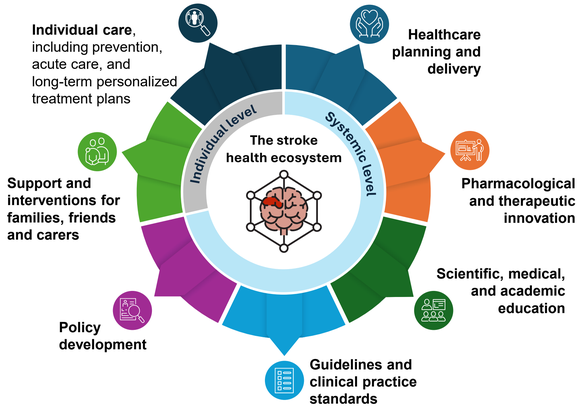
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Background

- Stroke is a major global health burden,[1] with stroke incidence projected to increase from around 12 million currently to over 21 million in 2050.[2]
- The 'stroke health ecosystem' identifies where lived experience should be embedded (**Figure 1**).[3]

Figure 1. The stroke health ecosystem



- Engaging individuals with lived experience is essential for advancing treatment and addressing gaps in their care; however, stroke survivors may be underrepresented in decision-making processes.[4–6]
- Gaps within the stroke community may be addressed by taking learnings from established frameworks in other therapeutic areas.

Objective

- This targeted literature review aims to identify practical, impactful examples of survivor leadership across disease communities, to generate insights for the stroke survivor community.

Methods

- A targeted literature review identified current governance elements and mapped roles, decision points, and accountability structures, then synthesized these into a comparative framework, complemented by engagement with stroke survivors, caregivers, and clinicians.
- Four key research questions were considered, based on the stroke health ecosystem:
  1. How can people with lived experience lead the transition from acute care to long-term life after stroke?
  2. How can sustainable leadership and representation be built across the healthcare ecosystem?
  3. How can lived experience meaningfully lead guideline development and implementation?
  4. How can people with lived experience become trusted partners in medicines development and innovation?
- **'Bright spot'** initiatives were identified .
  - HIV/AIDS, rare disease, and oncology were prioritized as these represent the historical, methodological, and regulatory vanguard of patient engagement and have spearheaded the modern multistakeholder collaborative healthcare policy.

Results

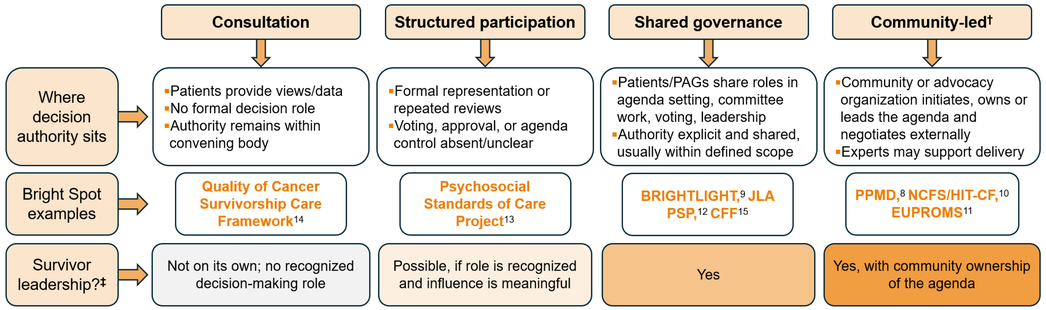
- Twenty-one Bright Spot initiatives were identified with potential relevance to the stroke survivor community; key examples are summarized in **Table 1**.

Table 1. Key examples of the identified Bright Spot initiatives

Bright spot initiative	Documented impact
Policy and regulatory	
HIV/AIDS activism group (ACT UP) moved from protest to negotiation with FDA and NIH[7]	▪Accelerated drug approval became permanent FDA practice ▪Patients given voting-rights on advisory-committee seats ▪Benefit–risk views written into law
Parent Project Muscular Dystrophy led community-wide process to develop proposed FDA guidance, governed by steering committee and expert working groups[8]	▪Help develop first PAG-initiated draft FDA guidance for a rare disease ▪PAG has a role in steering committee and working groups
Research priority and involvement	
BRIGHTLIGHT evolved from National Cancer Research Institute's teenage and young adult Clinical Services Group (built evidence for NICE guidance)[9]	▪Young people (13–24 years) shaped research priorities and design ▪Sex, body image, and relationships included in research agenda ▪Members joined other cancer research groups and became national charity trustees
Dutch Cystic Fibrosis Foundation research program (NCFS)/HIT-CF used online surveys to identify/rank patient/parent research priorities[10]	▪Patient/parent-defined priorities shaped research agenda, included psychosocial issues ▪Steer to patient/parent-driven personalized medicine drove research testing ▪Patient/parent roles in steering committee and review of research proposals
EUPROMS, the European prostate cancer patient organization Europa Uomo, initiated EUPROMS as a survey "from patients for patients"[11]	▪Patient-led survey gathered QoL evidence from 2943 men in 24 European countries to inform treatment discussions
JLA Priority Setting Partnership, utilised for paediatric cancer[12]	▪Framework replicated across communities to agree Top 10 research priority list ▪Creates patient/family-informed agenda to inform future research and funding decisions
Healthcare planning and standards of care	
Psychosocial Standards of Care Project for Childhood Cancer, interdisciplinary process involving paediatric cancer survivors and families[13]	▪Developed 15 evidence-based standards for cancer centres to identify essential psychosocial care services for children with cancer and their families
Quality of Cancer Survivorship Care Framework interviewed experts, policy makers, payers, advocacy groups, patients[14]	▪Survivor and advocacy input helped shape quality framework for life after treatment ▪Authority over the use of such input remained with the convening team throughout
Cystic Fibrosis Foundation, where people with CF and family members were included as members of CFF guideline committees.[15]	▪Contributed to defining clinical questions, helped draft recommendation statements, voted on final recommendations

- The Bright Spot cases provide examples of survivor leadership across governance models, where experts include people with lived experience with a recognized role who use their expertise to meaningfully shape an agenda, decision, output, service, standard, research program or policy (**Figure 2**).

Figure 2. Survivor leadership across governance models



Columns show where decision authority sits but are not a ranking of contribution. †'Community-led' means the community or advocacy organisation initiates and owns the agenda. ‡'Survivor leadership' does not require community ownership but does require a recognised role and meaningful influence.

- Across the Bright Spots, survivor leadership ranged from recognized expert roles within multidisciplinary structures and shared governance, to agenda-setting, co-leadership and community-led initiatives (**Table 2**).

Table 2. What other health communities reveal about how survivor leadership can operate across the stroke health ecosystem

Health ecosystem area	Observed forms of leadership	What the Bright Spots demonstrate
Healthcare planning, service design & long-term care[7,8,11–13]	▪Co-design ▪Service improvement ▪Peer/community leadership	Lived experience can move beyond feedback to shaping how services are designed, delivered and improved
Leadership, governance & policy[7,9]	▪Agenda-setting ▪Governance roles ▪Organizational leadership ▪Policy/regulatory influence	Leadership can occur through formal seats, shared governance, advocacy organizations, and direct participation in policy and regulatory processes
Clinical guidelines & standards[7,8,13,15]	▪Expert roles ▪Working-group membership ▪Consensus and recommendation development	People with lived experience can contribute as recognized experts alongside clinical, research and policy experts, rather than solely as consultees
Research, medicines & innovation[7,9,10,12]	▪Priority-setting ▪Co-research ▪Research governance ▪Community-generated evidence	Lived experience can shape what is researched, how research is conducted, which outcomes matter and how evidence is generated and used

Conclusions

- Across HIV, rare diseases, and cancer, survivor leadership succeeded where it was structurally enabled.
- Not all cases demonstrated leadership (e.g., Quality of Cancer Survivorship Care Framework); indicating that influence alone, without a structural role, does not constitute leadership.
- This targeted literature review provides an evidence-based blueprint for linking governance of acute clinical care and transition to communities with lived experience of life after stroke, enabling survivors to become more involved across the stroke health ecosystem.
- Bright Spot examples illustrate that there isn't one leadership model; different mechanisms could work in different parts of the stroke health ecosystem.
  - **Survivor leadership can be enabled and strengthened** through structured training, technical education, mentorship, and opportunities to apply learning.[9,10]
  - **Experienced patient leaders** can emerge through sustained involvement, building confidence, technical expertise, networks, and governance experience.[9,10]
  - **Influence can expand over time**, with a growing pool of experienced leaders broadening lived-experience representation across research, guidelines, services, and policy.[7]
- Framework developments emerging from this review include where leadership occurs, what form it takes, what enables it and what influence it has.
  - Establishment of this framework could help advance treatment and care innovations in stroke.

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Abbreviations

CFF, Cystic Fibrosis Foundation; EUPROMS, Europa Uomo Patient Reported Outcome Study; FDA, US Food and Drug Administration; HIT-CF, Human Individualized Therapy for Cystic Fibrosis; JLA, James Lind Alliance; NCFS, Dutch Cystic Fibrosis Foundation; NICE, National Institute for Health and Care Excellence; NIH, US National Institutes of Health; PAG, patient advocacy group; PSP, Priority Setting Partnership; QoL, quality of life.

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