Integrating digital peer support into stroke recovery

view Simon's video



I had a stroke! It was totally disorientating. After 40 years in IT governance and change, I saw a huge gap between what is easy and already possible in the stroke survivor world and what is used in delivery and research. The lack of vision for integration and improvement of this was frustrating, so I took on the challenge to make changes.

We started this community because survivors are capable of directing beneficial outcomes for everyone. This is about connection, empowerment and using what is possible to make real change.

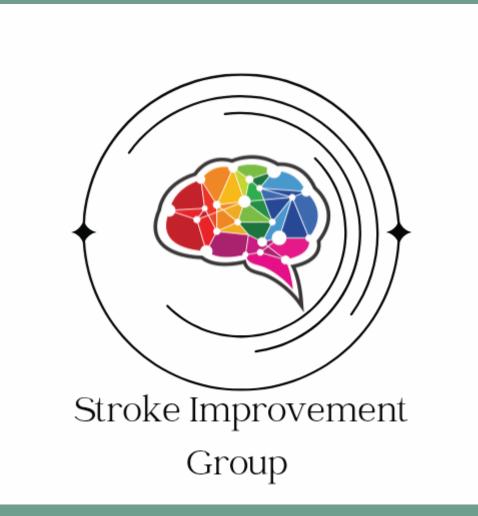
We are sharing this journey because when we all come together, we will all improve things for each other.

The Stroke Improvement Group (SIG): A New Approach

The Stroke Improvement Group is driving a paradigm shift in stroke recovery by integrating digital peer support with traditional care pathways.

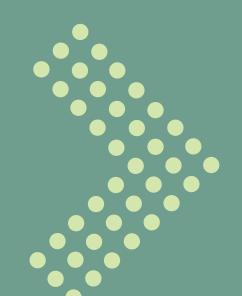
We are an affiliation of **#StrokeThrivers**, survivors and others, who have years of lived experience navigating the challenges of recovery. We advocate for **better care**, helping institutions understand our needs, embrace digital support and listen to survivor voices, voices made stronger through community.

SIG is co-chaired by a stroke survivor (Simon) and a Strategic Lead for Stroke Rehab Pathways (Charlie Chung, NHS Lothian), creating a unique collaboration between professional expertise, lived experience and academic research (via Queen Margaret University). This ensures that survivor-led insights shape future practice.



Scan to read our charter

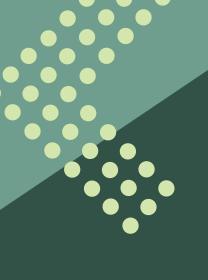


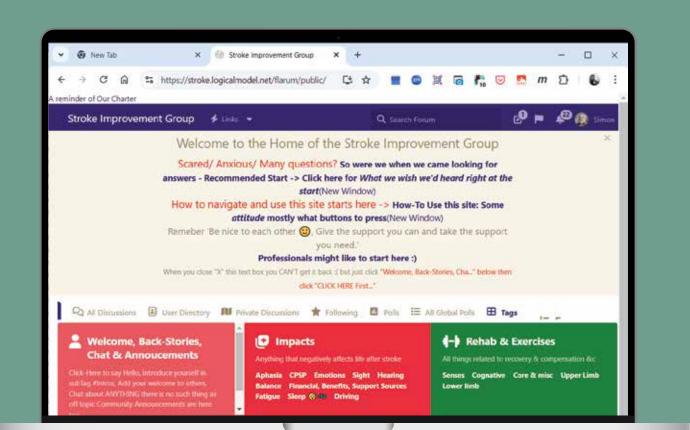


SIG wishes to enable those who can to advocate for us all, to evolve the integration of digital COMMUNITY with traditional pathways.

Be a voice with imagination

Help overcome a sometimes 'Not Invented Here Syndrome' and change resistance from some institutions with stroke-improvement goals





Life After Stroke (LAS): A New Normal

Recovery from stroke is a transition to a New Normal, from hospital to home, from formal rehab to independent living. Each stage is alien and tough, not just for survivors but for their close circle and those involved. The companionship of others on the same journey makes all the difference.

Stroke is impacting younger lives for longer and technology is unlocking new possibilities. Yet, traditional support systems are **lagging**. Services must adapt.

SIG helps curate this change, advocating for a hybrid model that fosters empathetic understanding and self-directed recovery, because survivors journeys can already be better than they are.

The Future of Stroke Recovery

The future of stroke recovery is hybrid, combining:

- Physical hubs for in-person interaction.
- Digital peer-led networks for 24/7 support.

Survivors are already connecting online, sharing experiences and improving recovery across emotional, psychological, cognitive and physical domains. Our medical services have yet to fully embrace and integrate these powerful, survivor-driven solutions.

The role of digital peer support

Digital peer support has already:

- Improved recovery by increasing our knowledge, setting expectations and demanding better care.
- Freed up therapist time, allowing professionals
- to focus on complex cases.
- Encouraged rehabilitation, supporting ongoing exercise and faster recoveries.

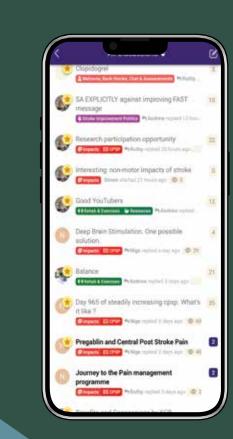
To truly integrate digital support, therapists must be trained to use these tools, embedding them into their professional practice through The Stroke Specific **Education Framework and Continuing Professional** Development (CPD) and equivalent undergrad syllabuses.

Technology and ethics: The next step

For digital rehabilitation tools to be effective, we need:

- Industry-wide data standards to support research and best practices.
- Ethical governance over data aggregation, ensuring that community-generated data benefits survivors, not just commercial interests.
- Unintrusive technology, creating new social norms for digital peer communities while avoiding the pitfalls of social media.





The impact we aim to achieve:

- Better recovery outcomes through hybrid peer support and formal medical pathways.
- Increased therapist job satisfaction by optimising care delivery.
- · A sustainable stroke care model that evolves policy, research and innovation.

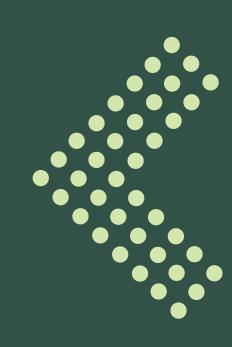
Stroke recovery is a 24/7/365 journey and community is key. By advocating for integration of our digital peer support with formal policies and to shape policies for the future, SIG is working to ensure that every stroke survivor gets the connected, effective support we are already capable of.



Community is a powerful sense-maker when life is blown apart by stroke. From that foundation, so much has emerged, but the journey of what will evolve has only just begun.

Digital platforms are transformational, enabling services that traditional models have yet to imagine. Training, education and professional development need a big slice of vision and change to fully support survivors.

This is disruptive, complex and unpredictable, but the scope for change is amazing. And we are only just starting on that journey.



Our long-term vision is a transformative impact on stroke care, empowering #StokeThrivers to live fulfilling lives.

