

Turning Lives Around; Using Lived Experience of Stroke in Research

Ann Bamford & Stephen Taylor on behalf of the RAP (Billy Ellison, Sanya Karim, Wendy Simms, Jav Rehman, Rudolph Edwards) & the WATERs-2 Research Team



After my stroke, I lost a sense of purpose.  
My skills and experiences were underused



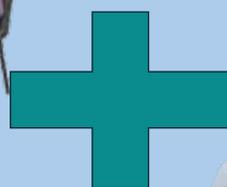
**1** I now lead Patient, Carer and Public Involvement (PCPI) on WATERs-2

Being part of the WATERs-2 Research Advisory Panel (RAP) helped me – and others – rebuild confidence

**2** Our “Core and cluster” model to involve people and communities

Our “core” Research Advisory Panel includes:

- stroke survivors and carers
- people underrepresented in stroke research including:
  - people from different ethnic backgrounds
  - people with communication difficulties
- Community leaders and health champions



The “clusters”  
We link into local groups and communities through outreach and community champions



We decided to meet every 2-3 months

**3**

We worked with the research team to:

- Apply for research **funding**
- Develop **study materials**
- Review the **data**
- **Develop** the final reports, making them **engaging** and **accessible**.
- Plan the **next steps** for the research

We had representation on the study management group and steering committee.

We reflected on our experiences of working together with the research team

**4**

KEY MESSAGES

Inclusive, respectful involvement is possible and powerful.

- It shapes **better research**
- gives **purpose** and
- **connection**

It allows people to **grow** from patients into **confident contributors**

Inclusive involvement **improves research quality** and supports **confidence, purpose and connection** after stroke

Resources are needed for quality involvement

- accessible formats
- one-to-one support
- proper payment
- inclusion



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