

Volunteering for Stroke Public and Patient Involvement Projects (PPI) to aid rehabilitation after stroke

By: Claire Angell

About me



A major basal ganglia stroke in 2014 aged 45 devastated my life overnight. With complete right-side weakness, expressive aphasia, difficulty with reading, writing and numeracy I found myself on a noisy geriatric ward with limited staff and no therapy offer.

Six months later I struggled to move forward with my recovery and rehabilitation. I was desperate to find a balance between therapy and using work skills that I could no longer apply. After a couple of months at a stroke peer

support group I found opportunities to get involved in stroke PPI projects and for me these were integral to my recovery.

It's inspiring for me to work alongside stroke clinicians and stress to them the importance of hearing the patient voice. I'm passionate about encouraging my peers to get involved and it's so much more interesting than conservative therapy.

PPI projects

UK Bristol, North Somerset and South Gloucestershire Stroke Programme 2016

Aim

To improve patient care after stroke. From emergency call out, to acute care and rehabilitation in hospital, to rehabilitation at home. Now fully operational across the region.

What I Did

- Attended meetings with stroke clinicians every month for 10 years
- Talked about my hospital experience and suggested ideas for improving care
- Made presentations to managers and decision-making bodies

How it helped my recovery

- Re-use work skills within my new limitations
- Improved my reading and writing
- Improved my aphasia and public speaking
- Gives me a feeling of achievement and self-worth

Stroke Health Integration Team funded by Bristol Health Partners UK Started and now Chair a Stroke Lived Experience Group Contact: hello@bristolhealthpartners.org.uk

What I do

- Plan Meetings
- Network with researchers and stroke clinicians to advise on written patient interactions
- Take part in recruiting new therapists
- Sit on Clinical Oversight Group meetings which holds stroke clinicians to account, ensuring that the new stroke service runs at it was designed to

How it helped my recovery

- Meeting new people
- Practise organisational skills
- Improves my self esteem
- Improves my aphasia
- Helps me To make sense of how my stroke has changed me



Attending Community Health Events

Aim

Talk about how to reduce the risk of stroke and how certain health conditions might put people more at risk.

What I do

- Talk about stroke services available locally
- Talk about how reduce the risk of stroke and how certain health conditions might put people more at risk

How it helped my recovery

- Improves my sense of compassion and emotional empathy which was affected after my stroke



Co-design of the Southwest Lived Experience Network for the UK Stroke Association

What I do

- Bringing the experience I had of setting up a lived experience group to a new group of friends and stroke professionals.
- Network with colleagues across the UK Southwest and sharing information about stroke events taking place in our stroke communities
- Opportunities to input into larger stroke projects on a national level E.g. UK Government 10-year plan for health services

How it helped my recovery

- Sharing stroke experiences with other stroke survivors
- Meeting socially online

UK Counselling Directory Complementary Therapy Colour therapy wheel

- Purple** – General colour for recovery and healing
- Violet** – Imagination, Self Knowledge, Artistic Qualities, Soothing
- Red** – Physical Energy, Stamina, Spontaneity, Stability
- Green** – Social, Nature, Acceptance, Renewal
- Indigo** – Self Responsibility, Inner Strength, Intuition, Creative Visualisation
- Yellow** – Fun, Lightness, Personal Power, Logic, Creativity
- Orange** – Productivity, Pleasure, Optimism, Enthusiasm, Emotional Expression
- Blue** – Calmness, communication, Self Expression

Research projects

Investigating how the use of a Lycra Sleeve as a medical aid on a person's stroke affected arm can improve movement and pain *Ref. Dr Praveen Kumar

What I did

- Talk to researchers about how my mobility problems affect my everyday life
- Offer ideas about how to access others with lived experience of stroke
- Attend planning meetings for PPI events to ensure that the needs of people living with stroke are met, accessibility toilets, parking etc.
- Design and make easy to read patient participation information sheets without technical jargon

How it helped my recovery

- Helps me to identify what areas of my mobility need to be targeted for improvement
- Provides opportunities to be honest about my own limitations
- Helps me accept my stroke and look for ways to improve things for myself and others

Development of an App for use by Occupational Therapists to assess cognition in people with stroke before they are discharged from hospital *Ref. Silvia Juan Link: tychomedlink.co.uk

What I did

- Use my understanding of how stroke can affect people to co-design games for people with stroke to play that show clinicians how an individual might be affected cognitively after their stroke e.g. telling the time, going shopping, dealing with money and actions to take in emergency situations

How it helped my recovery

- Fun and interesting to think of innovative methods to assess people's cognitive skills
- Helps me think about how my skills are improving
- Improving counting and use of numbers
- Opportunities for self-expression and acceptance



Development of a virtual reality game that could be used to improve shoulder pain after stroke *Ref. Avgi Christodoulou

What I did

- Liaising with other stroke affected people to consider what type of game could be used if people were exercising on their own at home
- Co-designing how the game appears to ensure it looks good aesthetically whilst meeting the technical requirements
- Working with robotics laboratory staff to assess measurements required for an upper arm exercise that addresses shoulder pain
- Attending test sessions of the prototype game to ensure it works and troubleshooting

How it helped my recovery

- Using my imagination for a physical purpose
- Learning about and understanding how shoulder pain after stroke can be addressed for myself and other stroke affected people



Developing an Algorithm for an Artificial Intelligence App that could be used for exercise videos for people with stroke *Ref. Dr Praveen Kumar

What I did

- Participating in the making of exercise videos that show people living with stroke how to carry out specific exercises when they are at home alone or with a carer
- Learning what exercises can target specific areas of the body to improve mobility and why

How it helped my recovery

- Improved my mobility, strength and physical recovery

Getting involved in wider projects that target people living with conditions that affect mobility, to improve opportunities for independent living Contact: thevivo.com

What I did

- Joining PPI sessions to discuss how everyday tasks could be made easier using robotics and new technology

How it helped my recovery

- Gives a new perspective to my own mobility problems
- Provides opportunities to be creative and innovative



References

Silvia Juan Lin Founder Empowering personalised Cognitive rehabilitation for accessible home recovery via augmented reality technology – www.tychomedlink.co

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Avgi Christodoulou Specialist neurological physiotherapist, University of West of England

In summary

Volunteering for PPI, at groups or for research offers stroke survivors opportunities for activity and improvement of individual skills. General wellbeing and avoiding isolation are paramount to stroke recovery. I found that it was better to use my time effectively than try (unsuccessfully) to get back to the person I once was. You can choose what projects you get involved in and you are usually compensated for your time and expenses (see UK National Institute for Health Research guidelines for PPI working). Grab opportunities to volunteer whenever they arise and use them to develop new skills that could help future survivors.