Students and stroke survivors working together in research: the Aphasia Research Collaboration (ARC)

Introduction

Speech & language therapy (SLT) students in undergraduate programmes need to learn about research[1]. Research should involve people who have personal experience of health conditions to prioritise, advise on or conduct research[2]. We therefore invited stroke survivors with aphasia – a communication disability – who were members of the Norfolk Conversation Partner (CP) trainers group, to join 3rd year SLT dissertation students in a research collaboration.

The aim was for students to get hands-on experience of Patient & Public Involvement (PPI), and to provide research opportunities for CP trainers.

Who was involved?

Thirteen people took part: SH, an experienced researcher led the initiative; 4 students and seven people with aphasia were co-investigators; AW acted as PPI mentor and consultant.

How we developed the collaboration

Two teams each worked to identify and develop a project: 1) Aphasia and internet access (ARCADIA); 2) Awareness of aphasia in schools (ACCESS). Each team developed research questions, protocols and applications for ethical permission, and carried out research. Ethical permission was granted for each project and for the study of the ARC initiative as a whole. Here we report on the study of PPI experience in the ARC.

How we studied PPI experience in the ARC

We made observations, and used individual notes & records of group work and meetings; one : one interviews conducted by SW and group members. We also used **A**mander's **L**evels of **P**atient and Public Involvement **S**ignificance (ALPS)[3] on three occasions to help reflect on our involvement as individuals and as a group.
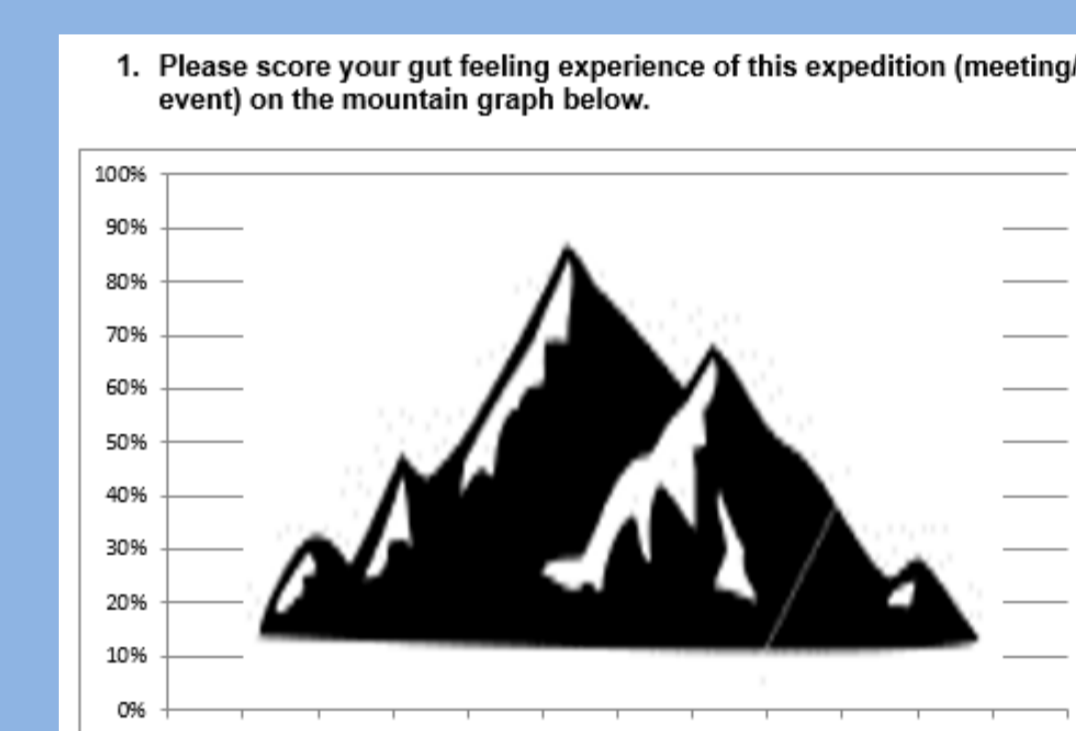
We brought together these sources of information and worked them into *four main topics*.

What we found

Main topics	Commentary	Illustrative quotes
Supporting inclusion	Positive partnerships were created through valued contributions, which enabled everyone to contribute. This was challenging but helped identify strengths in the group. Supporting communication in the team or in data collection was vital, but relationships and trust needed time to develop. Collaboration was a positive learning experience for all involved.	"I found it uplifting to work with people with aphasia as equals" (NC) "Working together strengthens quality" (LW) "one member seemed to be aware of another's tendency to keep on speaking and has struggled to be involved" (Notes) "Ensuring communicative accessibility at all times [is a challenge]" (SH) "having our voice heard can provide everyone involved with a learning experience" (DO)
Developing and growing	Listening to seldom-heard voices allowed ideas to be explored and developed, but opportunities for equality and collaboration had to be created. Team working and clear rules were essential for data collection, but more time was needed to practice research skills.	"when you are like us you worry that other people don't care or want to hear what you have to say" (DO) "CPs highlighted clear areas which they felt warranted further research" (NC) "This was the first time I've interviewed with CPs" (ALPS)
Support systems for involvement	Support systems need to be in place for all aspects of a project. A mentor was able to provide perspective and make ideas achievable. Equitable communication and inclusion were challenging – time was a significant factor, limiting opportunities for note taking and reflection on the process of co-production. Keeping it simple is good practice.	"we need to be attentive … enabling involvement and not letting collaboration drift" (SH) "[SH] has been busy organising car parking and access" (Notes) "external mentoring has been extremely helpful" (LH) "Problems with email as an inclusive strategy" (ALPS) "the most capable get heard" (Notes) "Inadequate minutes and reporting back to the group" (ALPS)
Making a difference	Group members reflected on the benefits and the challenges of collaborative research. ARC provided insights into the negative and positive realities of research. Members took part in a collective journey which gave valuable personal insights.	"we have collected valuable data and can make a difference" (ED) "Actually I feel I can help these young people achieve their objective" (DO) "We wouldn't have thought about doing this project…it gives more value" (LH) "I've been reined in … I want to change the world – need to start off with bite-sized chunks" (LW)

What we learned

*Time limitations affected the extent and quality of involvement *The scope of research is relative to the resources available *Involvement takes courage and tenacity *Time for reflection should be built-in to collaborative research projects such as these *Next time we would focus on one topic or project for the whole group

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References
1. The Royal College of Speech and Language Therapists (2010) *Guidelines for pre-registration speech and language therapy courses in the UK*. London: RCSLT
2. INVOLVE http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/ (accessed on 12 11 14)
3. **A**mander's **L**evels of **P**atient and Public Involvement **S**ignificance (ALPS) http://www.invo.org.uk/wp-content/uploads/2013/10/INVOLVE-Group-Minutes-May-2013.pdf