Experience of Public Patient Involvement in Aphasia Research; co-design of an ICT user feedback questionnaire.

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Overview

- PhD research aims
- Public Patient Involvement (PPI)
- Overview of the Co-design project
- Experience of all participants
- Results and implications
Research Aims for PhD “Use of Technology in Rehabilitation”

Investigate the **efficacy** of **self-administered aphasia rehabilitation** targeting **auditory sentence processing** using a **cross over design**

Explore **stakeholder perspectives on usability**:
- i. Speech and Language Therapists (SLTs)
- ii. Person with Aphasia (PwA)

Develop a **user feedback tool** – a mechanism to assist/support PwA provide feedback
Public Patient Involvement (PPI)

• “Public and patient involvement (PPI) occurs when individuals meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge” (MRCG, 2015)

• “.. research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (INVOLVE, 2015)
Co-design of an ICT User Feedback tool

- Purposeful sampling
- N=6
- Age range = 43 – 79 years
- Gender = 1 female & 5 males
- Time post stroke = 23 months – 12 years
- Aphasia = Mild – Severe
- Technology experience = varied from use of mobile to make calls only → online purchasing on laptops/tablets
- Initial Interviews; 6 group workshops; exit interviews
- Product = Online survey to facilitate reporting of feedback on use of computer in rehabilitation

<table>
<thead>
<tr>
<th>Workshop</th>
<th>Focus of Workshop</th>
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<tr>
<td>1</td>
<td>Introductions &amp; discuss good and bad points of technology</td>
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<tr>
<td>2</td>
<td>Review good and bad points of technology &amp; establish questions to ask and discover how best to answer questions</td>
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<td>3</td>
<td>Refine pictures to represent usability concepts</td>
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<td>4</td>
<td>Refine pictures further &amp; introduce NASA TLX</td>
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<td>5</td>
<td>Prototype questionnaire and refine</td>
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<td>6</td>
<td>Trial refined questionnaire</td>
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Co-designer exit interviews

Research Aim: explore the experience of PPI in a co-design activity

• 4 co-designers
• Aged range 43 - 65
• Time post CVA ranged from 23 months to 11 ½ years
• Mild – Severe Aphasia
• All four co-designers used mobile phones and tablet, smartphone, laptop or PC technologies
Methods

People with Aphasia
• Exit Interviews with independent SLT
• Question guide
• Video recorded & transcribed including notes on non verbal communication
• Nvivo 11
• Thematic Analysis (Braun & Clarke, 2006)

SLT researcher
• Reflective diary
  • After each workshop
  • After each review of workshop videos

“Critical gaze”
(Finlay & Gough, 2003)
Results

- Aspects of the group make up and interactions
- Reflecting on own and others’ abilities within the process
- Content and topics covered in an accessible manner
- Reporting satisfaction with process and the outcome
- Group Dynamics
- Balance of Complexities of Tasks
- Reflection on abilities
- Positive Experience
Group Dynamics

• Aspects discussed in all interviews
• All four spoke about the size of the group
• Social interaction was important
• Developing rapport & group familiarity

Sean*: “I have to, you have to get nobody, see you have to be, know, you have to know somebody before you say anything”

Ed*: there should be (pointing around him in a circle for each number) one, two, three, four, five, six, seven, eight
SLT: you want a bigger group?
Ed: f, group because how are you today?
SLT: OK
Ed: ah fuck it, to dah now eh the mo, the, the, there now and eh, how are you today?
SLT: OK
Ed: ta, ta, are you good?

*Pseudonyms

Today we had a full group and a much more positive experience for me. The group appeared to enjoy the social aspect of the tasks...X highlighted the positive aspect of talking to people after his stroke...
Balance of Complexities of Tasks

- No issues reported when asked about what was difficult
- Prompts and cues used helped e.g. images, prototypes
- Accessible information
- Supporting material e.g. name badges, large table
- Timing of workshops – cognitive load

Jim*: “no, no, no problems”

Ed*: the, the I forgot it
SLT: OK so the next week you kinda forgotten or
Ed*: yes, yeah

Boy this is hard work! Exhausted! I’m finding this very tough and I’m not sure if I’m on the right track at all.
Reflection on abilities

• Recognising own communication strengths and challenges
• Comparing abilities against other members of the group
• Identified prior learning/skills
• Continuing improvement and hopefulness for change

Sean*: “..was, four or five people, I was the only one who wasn’t talking right … you know the people better off, were better off with me... no not me ehm, (pause) ehm, I thought I was bad but….but I wasn’t too bad”

Ed*: yeah the, the what do you call it, the you know like ehm, I love the truth I can’t I can say it I’m fucking very bad
SLT: OK, OK with the computers is it?
Ed: yes, yes I’d love to be better

Sean*: when, I want to … I hope I’m (raising his hand up to his mouth) I hope I’m help, helping
........
SLT: is it that you want to see that what you are doing is of benefit? Is it? Or?
Sean no
SLT: for a purpose
Sean: no the other way I want to see my, myself
SLT: OK
Sean: getting better
Positive Experience

• Satisfaction and enjoyment in the process
• Feedback to enhance experience; more people, timing
• Suggestion for more
• Consider costs incurred

Sean*: “nothing”

Oliver*: ehm (hand up to his mouth) (pause) (shakes head and gestures thumbs up and indicates to the page he has just written on)
SLT: nothing
Oliver: yeah yeah
SLT: you can’t think of anything, no
Oliver: yeah

Jim*: again (shakes head side to side) {unintelligible utterance} worker
SLT: OK, there was nothing
Jim: no

Ed*: “tell the truth I liked everything”

Growing understanding of PPI, loved the experience!
Discussion

• **Shared goal** emerged throughout the development process

• **Iterative learning process** with accessible information (Worrell et al. 2005; Rose et al. 2012; Wilson et al. 2015)

• **Influence** of prior **skills, attitudes**, and **experience** of all participants (Byng & Duchan, 2005)

• **Satisfaction** in the process & end product having developed and tested the questionnaire function

• **Social interaction** provide opportunity for communication through out the sessions (Wallace et al. 2016) and supportive relationships (Harrison & Palmer, 2015)

• **Group dynamics & logistics** ideally smaller numbers 4-6 people, lots of preparation in terms of materials and aphasia accessible content and consider the environment
Limitations

• Small study
• Only four of six co-designers
• Technology users
• No female representation
• Experience of being involved in the design workshops versus research activity
• Need an expanded question guide
Maximising Impact - Key points

*Importance of including people with aphasia in research:*

• Social interaction opportunities
• Accessible and enjoyable
• Experts
• Relevant and meaningful outcome measures

*Implications:*

• Cost/funding
• Shared goals
Thank you for listening!

Call for participant recruitment for intervention study:
• Republic of Ireland (Munster based)
• People with Aphasia with auditory sentence comprehension deficits
• At least 6months post CVA

Call Áine on +353 89 2030594 or email 114224388@umail.ucc.ie,
Message on Twitter @AineKearnsSLT

Thank you to Ms Sarah Curran, Speech and Language Therapist, who carried out the interviews in this study!
References

• Wallace, S. J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., ... & Gauvreau, C. A. (2016). Which outcomes are most important to people with aphasia and their families? an international nominal group technique study framed within the ICF. *Disability and Rehabilitation*, 1-16.