



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

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**A TRADITION OF
INDEPENDENT
THINKING**



UCC

**University College Cork, Ireland
Coláiste na hOllscoile Corcaigh**

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**

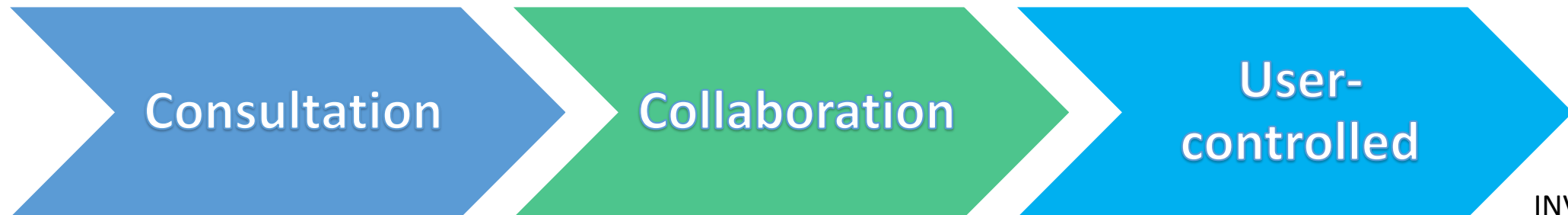
Explore **stakeholder perspectives** on **usability**:

- 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

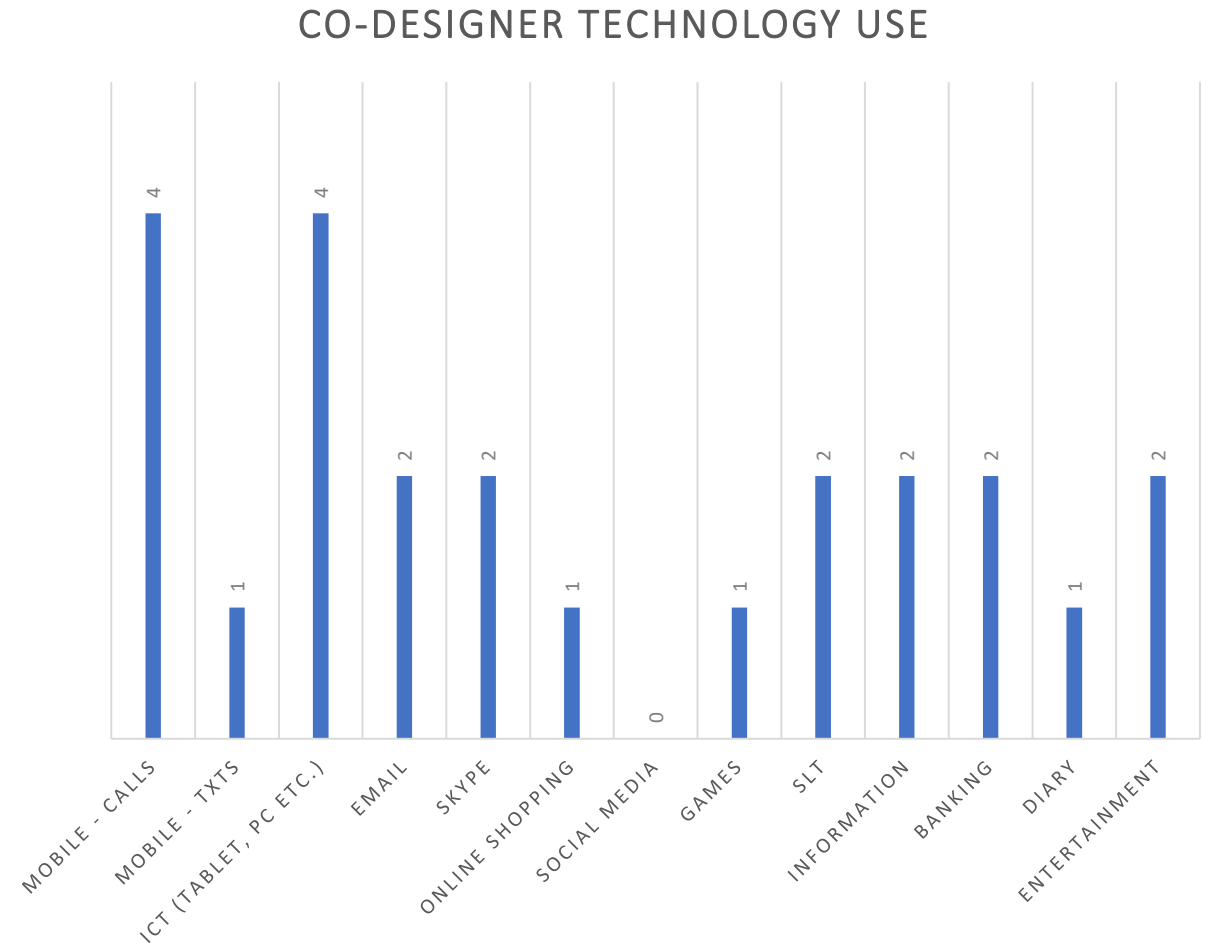
Workshop	Focus of Workshop
1	Introductions & discuss good and bad points of technology
2	Review good and bad points of technology & establish questions to ask and discover how best to answer questions
3	Refine pictures to represent usability concepts
4	Refine pictures further & introduce NASA TLX
5	Prototype questionnaire and refine
6	Trial refined questionnaire

- 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

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

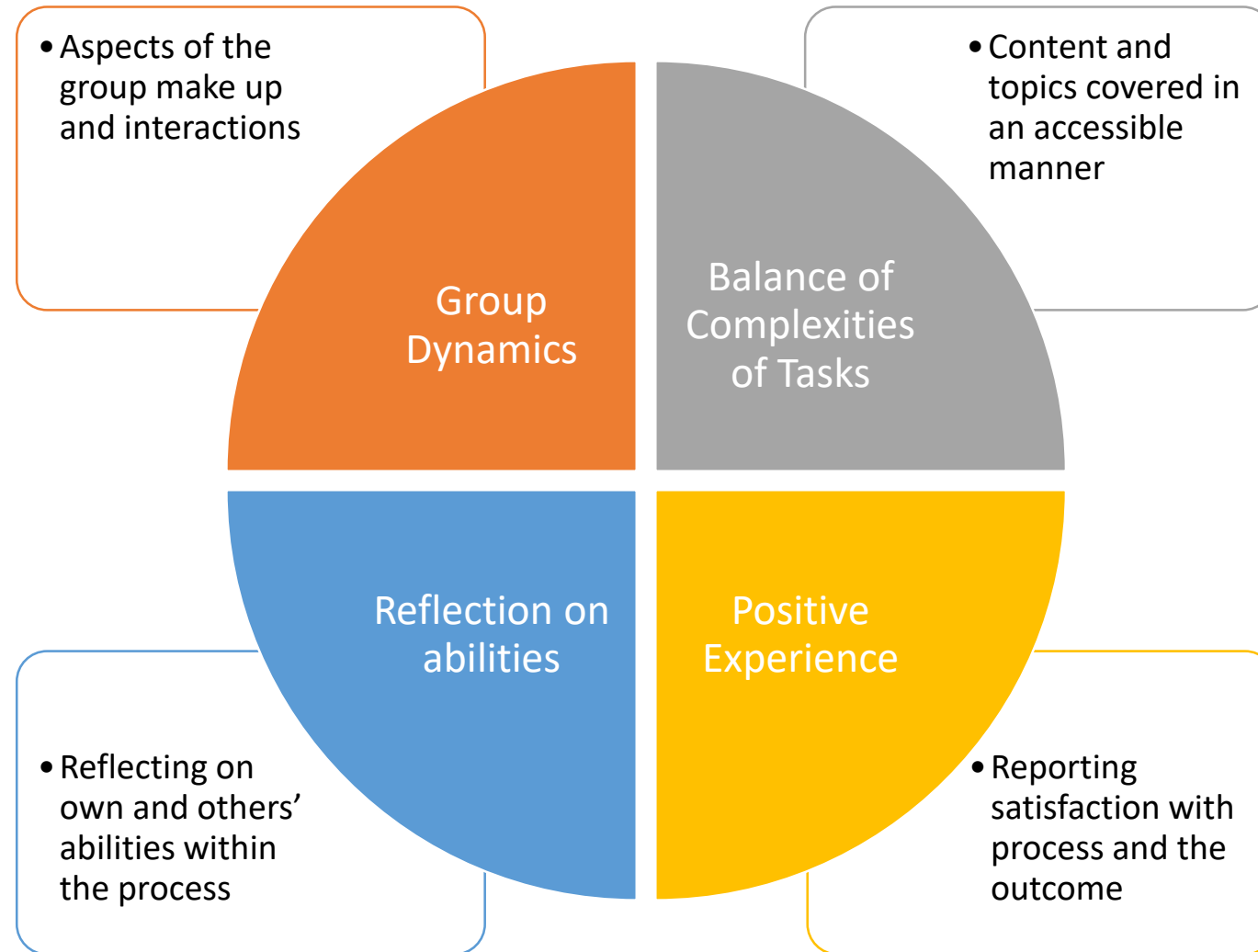
- Exit Interviews with independent SLT
- Question guide
- Video recorded & transcribed including notes on non verbal communication
- Nvivo 11
- Thematic Analysis (Braun & Clarke, 2006)

SLT researcher

- Reflective diary
 - After each workshop
 - After each review of workshop videos



Results



Group Dynamics

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

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...

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

Balance of Complexities of Tasks

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- 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

*Power imbalance...SLT as a
researcher*

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*

*Growing
understanding of
PPI, loved the
experience!*

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”

Discussion

- **Shared goal** *emerged though out 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!

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