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Rating Experience of ICT-delivered aphasia rehabilitation: co-design of a feedback questionnaire

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Abstract

Background: Speech and language therapy can provide beneficial outcomes in post-stroke aphasia rehabilitation, and intensity is a key component of a successful programme (Brady et al. 2016). Information and communication technologies (ICT) may offer an option for the provision of intensive rehabilitation but the views of those undertaking this mode of rehabilitation must be considered to ensure motivation and adherence with self-administered rehabilitation. There is no consensus measure for recording feedback from people with aphasia on user experience of ICT-delivered aphasia rehabilitation. This paper reports on the collaborative development of a feedback questionnaire *with* people with aphasia *for* people with aphasia.

Aims: There are three research aims (i) to develop a questionnaire to facilitate feedback on ICT-delivered aphasia rehabilitation by collaboratively working with people with aphasia in the design process, (ii) to describe the development process and the co-design techniques employed, and (iii) to explore the experiences of co-designers in the development process.

Methods and Procedures: Using public patient involvement (PPI) in health research, a co-design process was employed throughout 6 group workshops. Six people with aphasia (age 43 to 76 years of age) and with a range of aphasia severities (Western Aphasia Battery Aphasia Quotient range 24.4 – 83) engaged in the co-design process. The final product, an online user feedback questionnaire, was developed. Individual exit interviews were carried out with the co-designers after the workshops, and a thematic analysis of the interview data was completed.

Outcomes and Results: The final questionnaire provides an outcome measure that investigates: cognitive workload, satisfaction, programme functionality and ease of use, and

the level of assistance required when engaging in ICT-delivered aphasia rehabilitation. It is presented as an online survey in an aphasia-accessible format. Following the co-design experience, four themes were identified within the exit interviews: Group Dynamics, Balance of Complexity of Tasks, Reflection on Abilities and Positive Experience. The co-design process provided opportunities for social interaction with other people with aphasia and allowed co-designers to reflect on their own abilities. The workshops were considered accessible and facilitated their engagement in the co-design process. The process was inclusive and the co-designers reported feeling comfortable about contributing in the workshops and this was also noted in their feedback in the individual exit interviews. Conclusion: People with aphasia can, and should, be included in all stages of the aphasia research process and especially in the development and design of evaluation measures for use by people with aphasia.

Keywords: Collaboration, co-design, questionnaire development, aphasia, ICT

Introduction

Over the past two decades, stroke mortality rates worldwide have decreased but the absolute numbers of stroke survivors and people who have a stroke each year are increasing (Feigin et al., 2014). Flowers, Silver, Fang, Rochon, & Martino (2013) estimate the incidence of aphasia at 30% after first stroke, with the risk of aphasia increasing with age (Dickey et al., 2010). Aphasia can impact on a person's ability to engage in everyday social activities and stroke survivors with aphasia are less likely to return to work when compared with those without aphasia (Graham, Pereira, & Teasell, 2011). A recent Cochrane review reported that individuals with aphasia demonstrate positive outcomes following rehabilitation, and intensity is an important component of a successful intervention programme (Brady, Kelly, Godwin, Enderby, & Campbell, 2016). This presents a challenge to service providers striving to deliver an equitable and efficacious service to a growing number of individuals with long-term communication impairment. A notable increase in the percentage of dysphagia referrals within services (Enderby and Petheram, 2002) combined with a perceived prioritisation of new referrals and dysphagia clients (Foster, O'Halloran, Rose, & Worrall, 2016) can lead to people with aphasia receiving less than optimum levels of treatment. One potential solution is the use of technology in aphasia rehabilitation which is promoted as an efficient route for the delivery of intensive speech and language therapy (Code and Petheram, 2011). A recent systematic review suggests that computer-delivered therapy is effective when compared to no therapy, and may be as effective as clinician-delivered therapy for specific conditions (Zheng, Lynch, & Taylor, 2016). However, the authors conclude that the current quality of evidence is low due to the small number of studies available and highlight the need for further research in computer-delivered aphasia rehabilitation.

Self-management of chronic conditions post stroke has been proposed as one way of improving long term outcomes including quality of life, depression and activities of daily living (Jones et al., 2016; Jones and Riazi, 2011). Positive results have been reported for participants undertaking computer-delivered therapy, including a statistically significant improvement in naming ability after 5 months of therapy using a computer-based programme targeting word finding difficulties (Palmer et al., 2012) and statistically significant improvements in naming accuracy of treated items after exposure to a speech programme targeting apraxia of speech (Varley et al., 2016). These findings suggest there is scope for using information and communication technologies (ICT) to self-manage communication rehabilitation. In addition to treatment efficacy, it is important to investigate patient satisfaction of ICT-delivered rehabilitation to ensure high-quality health care provision. People with aphasia have been reported to identify unique factors, that differ from other populations, such as personalisation and relevance of care, that influence their satisfaction and dissatisfaction with health care provision (Tomkins, Siyambalapitiya, & Worrall, 2013). These factors could potentially impact their motivation for carrying out ICT-delivered rehabilitation tasks. There is a growing body of research supporting improved language outcomes with ICT-delivered aphasia rehabilitation that also reports participants' satisfaction, user experience, and engagement with this method of rehabilitation (Choi, Park, & Paik, 2016; Mortley, Wade, & Enderby, 2004). A range of data collection methods have been used to explore patient experiences of ICT-delivered aphasia rehabilitation including interviews, questionnaires and written narratives (Kearns, Kelly, & Pitt, 2019). Wade, Mortley, & Enderby (2003) provide one of the earliest reports investigating the views and experiences of people with aphasia who engaged in computer-delivered therapy for word retrieval difficulties. They used in-depth interviews and qualitative data analysis to explore the

"*expectations, experiences, effects and views*" of six participants engaging in remote-based computer therapy (Wade, et al., 2003, p. 1039). They suggest that one application of a qualitative approach to research is the identification of variables for further investigation using a quantitative methodology. The authors concluded that the data obtained from their small-scale study was potentially too limited to develop a self-rating scale which can provide a quantitative measure to investigate participants' views of this mode of intervention. They suggest that further qualitative investigations with a larger cohort would be required to develop such a tool. Despite an increase in research exploring this phenomenon, there is no consensus measure available for use in planning or evaluating ICT use in clinical practice or research.

Research exploring the perspectives of people with aphasia engaging in ICT-delivered aphasia rehabilitation report primarily positive experiences. These positive experiences include: perceived benefits of therapy (Marshall et al., 2013; Wade, et al., 2003), satisfaction with the programme and/or mode of rehabilitation (Cherney, Halper, & Kaye, 2011; Choi, et al., 2016; Galliers et al., 2017), and increased confidence (Cherney, et al., 2011; Palmer, Enderby, & Paterson, 2013). However, some negative aspects of engaging in ICT-delivered aphasia rehabilitation are also reported including: fatigue (Palmer, et al., 2013), frustration (Cherney, Halper, Holland, & Cole, 2008), and the time commitment for ICT-delivered rehabilitation perceived as time away from other activities (Amaya et al., 2018; Wade, et al., 2003) as well as minor usability and accessibility issues e.g. opening an iPad application and pairing Bluetooth devices (Brandenburg, Worrall, Copland, & Rodriguez, 2016). Cherney, et al. (2011) highlighted a challenge when examining negative experiences among people with aphasia and suggested that as participants in their study were interviewed by familiar people, they may have been less likely to provide negative feedback that might offend. The authors

suggest that it may also be more difficult for people with aphasia to formulate negative or neutral comments compared to positive comments (Cherney, et al., 2011). This poses a challenge for researchers aiming to explore both positive and negative aspects of ICT-delivered aphasia rehabilitation when obtaining feedback from participants with aphasia.

Despite an increase in research exploring user experience, there is currently no consensus measure available to evaluate ICT-delivered aphasia rehabilitation in clinical practice, and many questionnaires developed for individual studies make little reference to human-computer interaction theories, which are an essential feature of ICT use. Any system for ICT-delivered aphasia rehabilitation should be "*accessible, usable and acceptable to people with aphasia*" (Mortley, et al., 2004, p. 207). This reflects the principles of human-computer interaction and introduces the concept of usability to aphasia rehabilitation. Usability is defined as the "*extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use*" (ISO, 2018). Usability has multiple dimensions and can be systematically studied, measured and evaluated (Nielsen, 1994). Methods of usability testing can include logging usage data, observations, completing questionnaires, thinking aloud while performing tasks, interviews and focus groups. One such measurement tool is the Systems Usability Scale (SUS) which is a 10 item questionnaire that can be used to measure the usability of a product or system (Brooke, 1996). The SUS has been used to examine the subjective experience of undertaking Virtual Reality based telerehabilitation for balance recovery post stroke (Lloréns, Noé, Colomer, & Alcañiz, 2015) and also in a study on Internet-based anomia rehabilitation (Simic et al., 2016). Alternatively, the NASA Task load index (NASA TLX) is a subjective measure of workload and consists of six subscales: Mental, Physical, and Temporal Demands, Frustration, Effort and Performance (Hart and Staveland, 1988). It can facilitate subjective

feedback on the measure of task difficulty and is used in a range of arenas including aviation, teleoperation and health (Hart, 2016). This tool has been used in stroke rehabilitation research to evaluate an augmented feedback application in upper limb rehabilitation (Zimmerli et al., 2012) and with adults with Alzheimer's Disease to rate the degree of difficulty of mobile technology use to promote independence with activities of daily living (Zmily, Mowafi, & Mashal, 2014). The NASA TLX is more appealing than the SUS, with only six question domains, quicker administration, and provision of additional descriptors for each subscale to assist the responder. The NASA TLX could be combined with additional probing questions on usability and programme functionality for ICT-delivered aphasia rehabilitation. However, in its current format it is not aphasia-accessible.

There is an inherent challenge when using general language-based questionnaires with people with aphasia as modifications of existing tools may be required to incorporate additional visual stimuli (Simic, et al., 2016), or studies may simply exclude participants with severe aphasia (Zimmerli, et al., 2012). However, a more appropriate approach is to engage the users of ICT-rehabilitation programmes (i.e. people with aphasia) in the collaborative development of a feedback questionnaire. This questionnaire development should draw on their personal experiences and incorporate the findings from the literature on participant views of ICT-delivered aphasia rehabilitation as well as principles of usability. Public and Patient Involvement (PPI) in research incorporates meaningful engagement and active collaboration such that research is carried out by people with an understanding of the issue at the focus of the research e.g. aphasia (INVOLVE, 2012). Involving people with aphasia as co-researchers in the research process is not a new concept in aphasia research. Examples of participatory research include, the use of a Participatory Learning and Action approach to explore participants' experiences of a conversation partner programme (Mc Menamin,

Tierney, & Mac Farlane, 2015), and Community-Based Participatory Research to identify and incorporate views of people with aphasia on current research needs (Hinckley, Boyle, Lombard, & Bartels-Tobin, 2014). Participatory design has emerged as a viable method for people with aphasia to be involved in designing software intended for use by this population (Moffatt, McGrenere, Purves, & Klawe, 2004; Wilson et al., 2015), and in a recent study co-designing accessible and acceptable information material for and in collaboration with people with aphasia (Herbert, Gregory, & Haw, 2018). Wilson, et al. (2015) provide a comprehensive overview of techniques used in two design projects. These projects involved people with aphasia in all stages of the development of two computer-based therapy tools. The authors recognised that in order to facilitate the engagement of people with aphasia in the design process, new design techniques, and the adaptation of existing techniques, were required.

Harrison and Palmer (2015) employed qualitative research methods to explore the experience of being involved in PPI research with 11 stroke survivors and carers; two of the participants reported they had aphasia after stroke. Participants identified the supportive relationships that developed during the research process, and the intellectual stimulation acquired as part of it, as positive impacts of being involved in PPI research. They described how they felt they brought a different perspective to the research, though their lived experiences, and that the interaction between expertise from stroke survivors, clinicians and researchers benefitted the process. Some participants reported that they were "sceptical" about the true value placed on their involvement by researchers (Harrison and Palmer, 2015, p. 2180) although many felt that they had an equal relationship with the professionals. A number of potential barriers to participation were identified by participants and included transport and location issues, cognitive deficits, fatigue and communication difficulties. However, facilitators of

participation were also reported including the provision of transport, accessible environments, supportive group facilitators and supportive group dynamics.

As previously discussed, there is no consensus measurement tool for reporting feedback on user experience of ICT-delivered aphasia rehabilitation. There are three aims in this study:

1. To develop a feedback questionnaire, in collaboration *with* people with aphasia, *for* people with aphasia who undertake ICT-delivered aphasia rehabilitation.
2. To describe the collaborative co-design process to develop this questionnaire.
3. To explore the experiences of the co-designers in this collaborative design process.

The questionnaire developed in this process will focus on the accessibility, functionality and ease of use of an aphasia rehabilitation programme, taking into consideration usability attributes (Nielsen, 1994) and the cognitive load of engaging with the rehabilitation software programme.

Methods

This is a *collaborative* research activity (INVOLVE, 2012) which aims to bring people with aphasia and Speech and Language Therapist (SLT) researchers together in an equal partnership to develop a meaningful and relevant feedback questionnaire. This differs from *consultation* where lay people are asked for their views and opinions about a research project and researchers don't necessarily act on these suggestions and it is not *user-controlled* research, which gives patients or members of the public the power to set the research agenda (INVOLVE, 2012). In addition to utilising expert patient involvement within the design process, the study aims to explore the co-design researchers' experience in the PPI activities. Ethical approval was obtained from the local clinical research ethics committee. Participants were recruited through local speech and language therapy services for adults with aphasia. Individuals who were at least 6 months post stroke and with no known cognitive

comorbidities were invited to participate. Individuals were provided with an aphasia-accessible information sheet and consent form and given the opportunity to discuss the research before providing informed consent. As this study was unfunded, individuals were advised that they would not receive payment or compensation for attendance, when provided with information about the study.

Initial Session

The first author visited each participant in their own home prior to the workshops in order to establish the type and severity of aphasia (Western Aphasia Battery - Revised (WAB-R), Kertesz, 2007) and determine communication supports that each individual required to ensure full participation in the workshops. In addition, a technology screening questionnaire was completed (Czaja et al., 2006; Roper, Marshall, & Wilson, 2014) which provided information on current and pre-stroke use of a range of everyday technologies and facilitated discussion of individuals' experiences with technology.

Co-design Workshops

The workshops aimed to define and refine the questions and structure of the questionnaire being developed through a collaborative co-design process. Co-design refers to the shared creativity across the whole design process (Sanders and Stappers, 2008). Due to the iterative nature of this design process, the focus and aims of each workshop were established as the design process progressed. Initially, three weekly 90 minute workshops (with 30-minute tea break) were planned for the co-design process. However, three additional workshops were required in order to complete the research process, resulting in a 4-week break between workshop 3 and 4 while waiting for ethical approval for the additional workshops. Figure 1 provides an overview of the aim of each workshop.

[insert Figure 1 here]

Wilson, et al. (2015) implemented a co-design project with people with aphasia and used a range of techniques suitable for adults with aphasia to facilitate their engagement in the design process. Planned techniques for this study included: visual analogue scales, ranking tasks, photo-diaries, and use of prototypes. Supported conversation strategies were implemented throughout the workshops to facilitate engagement in the design activities (Kagan, 1998). Aphasia-accessible information was prepared before each workshop (Rose, Worrall, Hickson, & Hoffmann, 2011a; Rose, Worrall, Hickson, & Hoffmann, 2011b; Rose, Worrall, Hickson, & Hoffmann, 2012) and supplied in paper and/or online format depending on the target activity. Techniques such as visual analogue scales and ranking tasks were primarily used in the initial workshops and prototype testing was used in the final three sessions. Photo-diaries were suggested to the group as a means of recording ideas; however, they were not used by any individual. As questions and visual supports for the questionnaire were discussed in the workshops a measure of the agreement for each item was recorded during the session. This was achieved using ranking tasks where each co-designer indicated their preferences and the facilitator made field notes of all the decisions made in the sessions. When consensus agreement was reached this was recorded and the item was maintained for use in further iterations of the co-design process. When consensus was not reached, the percentage of agreement was recorded, and field notes were written. This noted the item and the issues in relation to the disagreement. A plan was devised following this discussion and this was also recorded in field notes. Such plans included reviewing the item from a new perspective at the next workshop or excluding the item from the process. All sessions were video-recorded and the recordings were reviewed after each workshop to ensure that no information was overlooked during the session and to cross-reference the field notes with the video recordings.

Co-designers

Six co-design researchers with aphasia (five male, one female) were recruited (see Table 1). The group ranged in age from 43 to 76 years with a mean of 60.7 years (SD = 11.3). The co-designers were between 1.9 – 11.4 years post-stroke with a mean of 5.8 years (SD = 3.8) and presented with mild to severe aphasia (WAB-R AQ range 24.4 - 83, mean 64.7 (SD = 23.05)). Individuals in the group differed in their technology use and ability. Five of the co-designers used ICT devices (smartphone, tablet, laptop or computer) whereas the sixth person used a Nokia phone, only to make phone calls. Of the five who used internet-enabled ICT devices, the most popular online uses included: information searches (n=3), entertainment (n=3) email (n=2), video-chat (n=2), banking (n=2), shopping (n=2), diary/reminders (n=2) and speech and language therapy (n=2). Only one co-designer used social media and gaming applications. One group member had previously worked as a computer programmer before his stroke but was not working in that role at the time of the research. During the initial individual sessions with the researcher, the co-designers outlined challenges they experienced when accessing ICT devices, sometimes experiencing frustration with the device. The primary causes of these difficulties included: anomia (n=2) e.g. word finding difficulties preventing the input of content for internet searches, acquired dysgraphia (n=2) resulting in spelling errors or an inability to spell words for text input, memory difficulties (n=1) when attempting to remember phone numbers etc., hearing aids (n=1) impacting on ability to use mobile phones, and hemiplegia (n=1) restricting the use of devices that require use of both hands.

The first author, a speech and language therapist experienced in working with people with aphasia and who has a research interest in ICT-delivered aphasia rehabilitation, facilitated the workshops (facilitator). Given the additional collaborative role with the co-designers with

aphasia in the development of the questionnaire, she is considered to have a role as a co-designer in the design process. Experience of these roles in the co-design process was recorded in a Reflective Diary and is reported in the Results section.

[Insert Table 1 here]

Exit interviews

After the final workshop co-design researchers with aphasia were invited to give feedback on their role in the research and explore their experience of the co-design process. The interviews were video recorded and facilitated by an independent speech and language therapist, experienced in working with adults with aphasia, who was not involved in the research. The interviews were directed by a question guide with supporting visual content (see Appendix 1). The first author transcribed the interviews and analysed the data using Braun and Clarke (2006) six steps of thematic analysis. In the initial step, the video data was reviewed alongside the written transcripts to ensure that all verbal and non-verbal information was recorded and the transcripts were read through for a sense of the whole. Next, the dataset was read and a process of familiarisation took place when initial codes, representing units of meaning, were written up and points of interest identified. When the initial coding was completed a list of codes was generated. Discussion of the codes with the second author occurred at this point and candidate themes and subthemes were identified. Following this phase, the themes were further reviewed and refined and subsequently, the scope and context of each theme was summarised before final analysis and write up of the thematic analysis (Braun and Clarke, 2006).

Reflexivity

The first author facilitated the workshops and completed the initial individual sessions. It was important that she remained conscious of bias throughout the whole process. In addition to reviewing the video recordings, a reflective journal was completed after each session and reviewed prior to the next session. This allowed the researcher to critically reflect on her role in the research and identify how her clinical background, position, behaviours and assumptions may have influenced the research process (Finlay and Gough, 2003). Any issues that emerged were discussed with the second author and recorded within the reflective journal.

Results

The collaborative co-design process will firstly be outlined, followed by a description of the co-design feedback questionnaire, and then the experiences of being involved in the co-design process.

Collaborative Co-Design Development Process

Workshop 1: Introductions and setting the scene

In order to set the scene two brainstorming activities were carried out in the first workshop: consider both the "good" and the "bad" aspects of technology. This built on the discussions from the individual sessions and the co-designers' references to ICT challenges. This concept of challenge and potential frustration was used as a scaffold to encourage the group to explore their views and opinions of ICT. The facilitator wrote each co-designer's contribution on post-it notes and stuck them onto a large whiteboard in front of the group. This allowed for ideas to be tracked and grouped during the discussion. Participation was encouraged with supported conversation techniques and multi-modal communication. These

activities allowed each co-designer to express their views about technology and allowed the group to identify accessibility issues that may be related to aphasia. For example, one co-designer reported that he was unable to spell, impacting on his ability to complete text messaging tasks. This discussion also highlighted accessibility issues not related to aphasia, e.g. poor Internet infrastructure impacting on smartphone function for speech to text. A summary of the discussion generated during the session is represented in Figure 2. The final task in the initial workshop explored the concept of questions and the structure of questions e.g. written question, visual stimuli and visual analogue scales. It was important to highlight the function of the design workshops i.e. the development of a questionnaire for people with aphasia to report feedback when engaging in ICT-delivered aphasia rehabilitation and re-orientate the co-designers to the aim of the research. The initial session drew on their combined views and experiences of ICT use. Subsequent workshops would develop questions for the feedback questionnaire while drawing on the co-designers' experiences and available literature that the facilitator brought to the process. Following the workshop, the facilitator prepared a set of sample questions based on the issues that emerged in this session, as a starting point for the design process in the next workshop.

[Insert Figure 2 here]

Workshop 2: Review brainstorm activities from Session 1 and introduce questions

A summary of the initial workshop activities was visually displayed at the start of the session, providing a reminder to participants about the previous workshop discussions and allowing for new ideas to be added. The facilitator introduced the idea of the questionnaire as a computer-based activity using PowerPoint on a laptop with examples of possible questions based on the previous workshop. A set of sample questions, prepared by the facilitator after

the previous session, were introduced. These related to aspects of usability of computer-based activities including concepts such as ease of use, frustration, satisfaction, and level of assistance required to complete ICT tasks. The group discussed the questions and ranked corresponding images that were intended to support comprehension of the questions. These were images that the facilitator had accessed online before the workshop and added to the initial sample questions. However, it became clear that the online images did not fully represent, or support comprehension for many of the question concepts related to ICT use. For example, images may clearly represent frustration but did not have a computer present to link the relationship between them. The group unanimously agreed that a clear representation of the relationship between the concept, e.g. an emotional response of frustration, and the precipitating action, using the computer, was essential for a person with aphasia. Therefore, before the next workshop, the facilitator was photographed while acting out these ICT-related scenarios, to be discussed and evaluated at the next workshop.

Workshop 3: Ranking images of the concepts

A range of photographs, with the facilitator acting out scenarios associated with computer usage were introduced to the group. These photographs related to an initial set of 16 concepts of usability that would be refined and explored in the questions e.g. satisfaction, frustration, tiredness, and needing help with the computer. See Figure 3 for the development of the question topics throughout the process. These images were intended to support respondents' understanding of the questions when completing the questionnaire. The co-designers first determined what aspect of usability the photograph might represent. Where there was more than one image to represent the concept, they were asked to rank their preferences of the most appropriate image. There was consensus agreement for 44% of the images with a minor suggestion for editing one of the agreed images. Five co-designers agreed on the suitability of an additional 25% of the images used to represent aspects of

usability. However, concepts such as anxiety, satisfaction, disinterest, the pace of tasks and remembering computer functions were challenging to represent in the images. The group discussed the use of a single image versus a binary choice of two images to support understanding of questions (see examples in Figure 4). The group was divided, some felt that only one image was required to express the concept and others felt that a binary choice aided understanding of the images. There was agreement among co-designers that an independent person rather than the facilitator should be in the images if she was using the questionnaire with people with aphasia. Following this recommendation, a model was recruited to re-enact the images which would be evaluated in the next workshop.

[Insert Figure 3 and 4 here]

Workshop 4: Ranking images with a new model

The four-week break between workshops 3 and 4 (while awaiting ethical approval to increase the number of workshops) provided the opportunity to engage a model to pose for photographs, as per the recommendations of Workshop 3. In Workshop 4, concepts of *mental, physical and temporal demands,* as well as *performance, effort and frustration* from the NASA TLX, were introduced. Some of these concepts had already emerged in the discussions about usability and technology use and the NASA TLX provided a neat structure to present these questions and refine them to single key concepts (see Figure 3). For example, using the NASA TLX construct of *mental demands* allowed for the inclusion of *thinking* and *remembering* and *confusion,* under one question heading. All potential questions and related visual stimuli to support communication were reviewed in Workshop 4. Nine of 20 images were agreed by all co-designers and an additional seven images were agreed with minor changes to aid understanding e.g. addition of an egg timer to indicate the concept of time. Following these discussions, it became apparent that some questions benefitted from the binary choice format. For example, when probing *satisfaction* on

performance, the visual stimuli accompanying the question presented two images on the screen. One image was a successful, cheering actor with the written cue "good" underneath it, representing *satisfied*; the second image depicted an actor with head lowered and the written cue "poor", representing *unsatisfied*. Other questions used a simple question structure with one supporting image to aid comprehension.

Workshop 5: Prototype testing

Between workshop 4 and 5, the facilitator refined the question statements and used an online survey tool to create a draft questionnaire which was introduced to the co-designers during Workshop 5. In order to trial the prototype, each co-designer completed a computer task of their choice. These tasks varied from online therapy activities targeting auditory memory, visual matching and auditory comprehension to online gaming and tic tac toe. After the task, each co-designer then completed the questionnaire with some assistance from the facilitator. The facilitator observed any issues that emerged and the co-designers gave feedback on the questionnaire as they used it. Feedback was documented and plans for final refinement were discussed.

Workshop 6: Final testing

The online questionnaire was further refined following the feedback generated in Workshop 5 and re-introduced to co-designers at Workshop 6. Again, each co-designer completed a computer task and then answered the questionnaire and provided feedback on it. A small number of minor edits were required after this session and the questionnaire was considered ready for use. Co-designers expressed satisfaction with their final product and the work they completed over the previous five workshops.

[Insert Figure 5 here]

Description of the Co-designed ICT feedback questionnaire

The finalised co-designed feedback questionnaire consists of 15 questions (see Figure 5.). Six questions relate to the NASA TLX, which probes features of cognitive workload and satisfaction on a sliding scale from low to high level of workload (see Figure 6). Seven questions relate to ease of use and function of the programme being tested as well as the level of assistance required (see Figure 7). Responses to these questions are presented on a 5-point visual analogue scale with graded 'smiley faces'- a large smile indicates "very easy" / "no help" and a large frown indicates "very hard" / "a lot of help" with a neutral face to represent a neutral or "OK" response. There is one identifier question, and one question relates to the time point which allows for easy tracking of questionnaire responses over a number of time points. The questionnaire will facilitate user feedback on usability and cognitive workload.

[Insert Figures 6 and 7 here]

Experience of Collaborative Co-design Research

The experiences of co-designers will be discussed with reference to the exit interviews of the co-designers with aphasia as well as the Reflective Diary of the Facilitator.

Exit interviews

Four of the six co-designers attended the exit interviews completed within 3 weeks from the final workshop. One co-designer was unable to attend due to illness and the other due to time constraints and other commitments; he had returned to work after his stroke. Four themes were identified within the interview data: Group Dynamics, Balance of Complexities of Tasks, Reflection on Abilities and Positive Experience. These are discussed individually below with supporting quotations.

Group Dynamics: Although not asked specifically about the group interactions during the interviews all four participants discussed the make-up of the group. Two reported that 4-5 people were optimum for this activity, one favoured 2-4 people and one preferred a larger group. Three spoke about "meeting people", "talking" and everyday social conversations as aspects they liked about the research process. One spoke about needing time to develop rapport to be able to give his views.

> *"I have to, you have to get nobody, see you have to be, know, you have to know somebody before you say anything" Co-designer C*

One co-designer suggested that consistency in attendance was best. This was not always the case in this design process as not all members were able to attend all 6 sessions.

Balance of Complexities: When initially asked about aspects of the workshops that were difficult all four responded that they had no problems with the content.

> *"no eh…I…pictures…and computers…happy with having how much was in it" Co-designer F*

One co-designer referenced the use of the large circular table, which was utilised following the first session, as well as the use of name badges as important for supporting interactions. Another pointed out that supporting visual materials were beneficial. One co-designer who presents with auditory comprehension difficulties on the WAB-AQ and also wore hearing aids reported that he could hear everything except one day when his hearing aids were not functioning. One co-designer commented on the timing of the group, suggesting that the time between one week and the next caused issues with remembering the content covered. This wasn't reported by others.

Reflection on Abilities: Three of the four co-designers commented on their own communication abilities, recognising their own strengths and challenges. One co-designer spent some time comparing himself to others in the group. He was 2.5 years post stroke, the earliest of all in the group, and this may have prompted him to consider his abilities against others with aphasia.

> *"..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,…*
>
> *ehm, I thought I was bad but….but I wasn't too bad" Co-designer C*

Another advised the interviewer of his prior knowledge of computers, which was utilised within the design process. Two discussed their own potential for continued improvement in both learning and communication skills.

Positive Experience: Each co-designer was asked what they did not like about the workshops and all indicated they enjoyed the process and didn't have anything negative to report.

> *"tell the truth I liked everything" Co-designer A*

They were also asked to suggest changes to consider for future research which reiterated previous comments on logistics such as, badges, larger table, and group size. One co-designer emphasised that there should be more opportunities like this and appreciated the optimum environment of the workshops e.g. room location was close to toilet facilities. He also noted one challenge in terms of the cost of a taxi in order to attend one workshop; this differed to his normal routine.

Reflexivity in Action

A review of the reflective journal written by the facilitator presents a number of recurring issues throughout the research process. The facilitator identified the importance of the social

interaction within the group from early in the process, noting that the coffee break was a powerful time for people to chat and support each other. In addition, she observed that some tasks allowed a diversion from established roles within the group e.g. testing the questionnaire on a game activity allowed one member to teach another how to complete tic tac toe on the iPad and provided some humour in the process. This appeared to further strengthen the relationship between co-designers. The facilitator was preoccupied with the level of difficulty of tasks and the abstract nature of some of the usability concepts and how these could be made accessible to all. There were frequent diary entries referring to the "tough" and "tiring" nature of the work involved in making the information accessible. A sense of relief was noted when reviewing the interview transcripts where co-designers reported no problems with accessibility of information. The facilitator was new to participatory research but was completing a university training module on community-based participatory research at the time of the study. This was seen as vital in appraising her own role and developing research skills within the PPI process. She identified the challenge of establishing an equal partnership working in a collaborative, rather than a user-controlled, research process. Here, the goal of the research process was defined at the outset by the facilitator. Through reflective questioning, she negotiated the challenges she faced of ensuring a collaborative rather than consultative process. This encouraged her to embrace the collaborative nature of the research and be ever mindful to avoid tokenism (Arnstein, 1969).

Discussion

The collaborative research outlined above identified the iterative nature of the design process for the development of this ICT feedback questionnaire, aimed to provide a greater understanding of the experience of a person with aphasia when engaging with ICT rehabilitation programmes. The questionnaire explores the accessibility, functionality and ease of use of an aphasia rehabilitation programme as well as the level of assistance required

as reported by the person with aphasia. It incorporates a measure of cognitive workload and satisfaction using an aphasia-accessible version of the NASA TLX (Hart and Staveland, 1988) and integrates usability principles (Nielsen, 1994) as relevant to ICT-delivered aphasia rehabilitation (Mortley, et al., 2004). It is presented as an online survey in an aphasia-accessible format with supporting visual aids (Rose, et al., 2011a; Rose, et al., 2011b).

Research exploring feedback from people with aphasia engaging in ICT-delivered aphasia rehabilitation has grown since Wade, et al. (2003) explored this topic and proposed the development of a self-rating scale. Despite this increase, there is no consensus questionnaire available and a range of data collection methods have been used to gather feedback from people with aphasia engaging in ICT-delivered aphasia rehabilitation including interviews (Marshall, et al., 2013; Palmer, et al., 2013) and questionnaires (Choi, et al., 2016; Mallet et al., 2016). Studies that employ questionnaires do not provide a description of the questionnaire development. The questionnaire development process in our research takes a somewhat different approach to that proposed by Wade, et al. (2003). Our research involved people with aphasia as part of a *co-design* rather than consultation process, grounded on *collaboration* between those with a lived experience of aphasia and an SLT facilitator with expertise in ICT-delivered aphasia rehabilitation. The final product reflects the output of this collaboration and the iterative nature of the co-design process in the production of, as far as we are aware, the first co-design measure available for use in planning or monitoring ICT-delivered aphasia rehabilitation.

The co-designers in this PPI research had a range of experience and views of ICT use that they brought to the design process. Reports of challenges when using ICT emerged in the initial individual sessions. This was a common narrative among the co-designers and has

been reported in studies of ICT use in aphasia rehabilitation (Brandenburg, Worrall, Copland, & Rodriguez, 2017; Galliers, et al., 2017) so it was discussed in the first workshop. The concept of *frustration* was identified by many of our co-designers irrespective of ICT experience and was therefore a good starting point to begin discussing usability and user experience of ICT devices and applications. The workshops provided a supportive environment for all co-designers to express their views on ICT and questionnaire development and each person was provided with the opportunity to give an opinion, rank preferences, etc. The process of consensus agreement was not always easy during the workshops. In many cases, a consensus was not obtained and the question was parked for a period of time and then returned to with new information and consensus attempted again. If consensus could not be achieved then a majority vote was considered a successful outcome. The need for accommodation was discussed and agreed within the group in order to progress the design process. Offering a comprehensive co-design process resulted in a time and labour intensive journey which has also been recognised in other research involving collaborative design with people with aphasia (Herbert, et al., 2018). Our final questionnaire was realised with the use of modified design techniques (Wilson, et al., 2015) and taking into account existing guidelines for aphasia-accessible information and supporting visual aids (Rose, et al., 2011a; Rose, et al., 2011b). The questions are presented in text format with bold font for keywords above a relevant, related photograph to aid comprehension. Throughout the design process, it became apparent that the supporting photographs needed to be bespoke for the questionnaire being developed, reflect realistic situations and accurately represent the concept addressed in the question. When attempting to probe feelings of success or satisfaction in the context of using an ICT device, the emotion and the context i.e. a person experiencing satisfaction when using a laptop computer, needed to be clearly identified in the image. This

preference for concrete images has also been identified by people with aphasia in other collaborative design activities (Herbert, et al., 2018).

The facilitator came to this design process with a very specific goal to collaboratively develop a questionnaire *with* people with aphasia for use *by* people with aphasia in future research. This was probably not the same for the co-designers in the process who were recruited from local SLT services. Despite the provision of the research information prior to recruitment, they were unlikely to have had the same goals as the SLT researcher. However, after a small number of sessions, there was a clear consensus of a shared goal: the aim to explore the challenges and benefits of ICT-delivered aphasia rehabilitation by developing the feedback questionnaire (INVOLVE, 2012). This cemented the working relationship and drove the development process. The facilitator's reflective journal entries note concern about the complex and abstract nature of concepts related to usability that were being explored. However, the use of aphasia-accessible information (Rose, et al., 2012), as well as simple ranking tasks and trialling prototypes (Wilson, et al., 2015), facilitated the iterative design process and became just part of the development process. Some co-designers had more experience of ICT use than others, each bringing their own shared, and varied, experiences to the group which also facilitated the research process. It was possible to recognise individuals' expertise, not just their lived experience of aphasia when considering the social model of disabilities (Byng and Duchan, 2005), but also their life experience.

The satisfaction of seeing an end product was important. Although this wasn't explicitly focused on in the exit interviews, this was obvious from the positive responses to the final product in the final workshop. Interestingly, the social opportunity the group provided for each member with aphasia was very apparent in the exit interviews. All four co-designers

identified the opportunity to talk with others with aphasia as a positive aspect of the process. This may echo people with aphasia's focus on improved communication and life participation as important outcomes in aphasia rehabilitation (Wallace et al., 2017). Alternatively, it may also reflect the development of supportive relationships as a key benefit of PPI research (Harrison and Palmer, 2015).

A number of key learning points emerged from this experience with respect to the logistics of running co-design workshops. It is important to be mindful of the workshop location in terms of ramps, accessible toilets etc. There is also a challenge with respect to balancing timing and frequency for all involved for example, one co-designer reported a preference for less time between sessions as he found it difficult to remember all the information from one week to the next. The facilitator needed to prepare a substantial amount of aphasia-accessible materials between workshops in order to facilitate workshop discussions. This was labour intensive and the time commitment cannot be underestimated (Herbert, et al., 2018). This preparation between sessions necessitated the weekly schedule. Reviewing the previous session at the start of each workshop helped to remind co-designers about the discussions and decisions made. The use of name badges and a large circular table for group activities within the workshops were considered beneficial. Although there was no consensus from the exit interviews, it would appear that a group with 4-6 people is ideal for this type of collaborative activity. A relaxed and lengthy coffee break during the workshops allows for social conversation and rapport building as well as a reprieve from workshop activities. The design process, including the interactions, the aims and the workload involved, may have been an engaging experience for the co-designers, reflecting a contribution that was valued and considered worthwhile (Byng and Duchan, 2005).

Future Work

The feedback questionnaire was developed for use as an outcome measure in a subsequent research study investigating ICT-delivered aphasia rehabilitation targeting auditory sentence comprehension in conjunction with other outcome measures. The questionnaire will provide relevant and meaningful feedback as reported by people with aphasia who engage in ICT-delivered aphasia rehabilitation and will provide a mechanism for reporting feedback on their experience of this mode of rehabilitation. Future work will involve psychometric testing of this co-designed feedback tool.

Limitations

The first author was an integral part of the co-design, execution and evaluation of the workshops, therefore it was important that she remained reflexive and recognise her role in the whole research process (Finlay and Gough, 2003) while attempting to minimise any potential bias. A reflective journal was completed and reviewed after each session. The facilitator completed the initial individual sessions, facilitated the workshops, transcribed and analysed the final exit interviews. However, an independent speech and language therapist not involved in the research completed the exit interviews and the thematic analysis was discussed at each step with the second author. Four of the 6 co-designers attended the exit interviews. Unfortunately, the only female co-designer was unable to be interviewed due to illness, therefore, the views expressed may not be representative of the group as a whole. The feedback questionnaire was not validated as part of the development process outlined above. The next planned phase will include testing the questionnaire within a pilot study exploring the feasibility of ICT-delivered aphasia rehabilitation. This will allow for further refinement of the questionnaire following feedback from a larger cohort of people with aphasia. This was an unfunded study and co-designers were not compensated for their time, however it is good practice to offer payment whenever possible (INVOLVE, 2012).

Conclusions

Information and communication technologies have become a fact of everyday living and can provide opportunities for cheap and easy access to communication, media and potential therapeutic activities. This opportunity should be considered in the context of the users' preferences to ensure optimal engagement. Currently, there is no consensus measure to record user feedback within research exploring ICT-delivered rehabilitation among people with aphasia. The development of a feedback questionnaire, in collaboration with people with aphasia, for use by people with aphasia, was an iterative process. The iterative design process was time and labour intensive but was an appropriate and feasible approach that was valued by all involved. The resultant questionnaire will provide feedback on usability, functionality and level of assistance required to complete ICT-delivered aphasia rehabilitation tasks and incorporates an aphasia-accessible version of the NASA TLX, providing a measure of cognitive workload and satisfaction. This product will be tested in a subsequent feasibility study. Our research illustrates that people with aphasia can, and should, be included in all stages of the aphasia research process and especially in the development and design of evaluation measures for use by people with aphasia.

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The authors report no conflict of interest.

References

Amaya, A., Woolf, C., Devane, N., Galliers, J., Talbot, R., Wilson, S., & Marshall, J. (2018). Receiving aphasia intervention in a virtual environment: the participants' perspective. *Aphasiology, 32*(5), pp. 538-558.

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of planners, 35*(4), pp. 216-224.

Brady, M. C., Kelly, H., Godwin, J., Enderby, P., & Campbell, P. (2016). Speech and language therapy for aphasia following stroke. *Cochrane Database of Systematic Reviews*(6)

Brandenburg, C., Worrall, L., Copland, D., & Rodriguez, A. D. (2016). Barriers and facilitators to using the CommFit™ smart phone app to measure talk time for people with aphasia. *Aphasiology, 31*(8), pp. 901-927.

Brandenburg, C., Worrall, L., Copland, D., & Rodriguez, A. D. (2017). Barriers and facilitators to using the CommFit™ smart phone app to measure talk time for people with aphasia. *Aphasiology, 31*(8), pp. 901-927.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), pp. 77-101.

Brooke, J. (1996). SUS-A quick and dirty usability scale. *Usability evaluation in industry, 189*(194), pp. 4-7.

Byng, S., & Duchan, J. F. (2005). Social model philosophies and principles: Their applications to therapies for aphasia. *Aphasiology, 19*(10-11), pp. 906-922.

Cherney, L. R., Halper, A. S., Holland, A. L., & Cole, R. (2008). Computerized script training for aphasia: Preliminary results. *American Journal of Speech-Language Pathology, 17*(1), pp. 19-34.

Cherney, L. R., Halper, A. S., & Kaye, R. C. (2011). Computer-based script training for aphasia: emerging themes from post-treatment interviews. *J Commun Disord, 44*(4), pp. 493-501.

Choi, Y.-H., Park, H. K., & Paik, N.-J. (2016). A telerehabilitation approach for chronic aphasia following stroke. *Telemedicine and e-Health, 22*(5), pp. 434-440.

Code, C., & Petheram, B. (2011). Delivering for aphasia. *International Journal of Speech-Language Pathology, 13*(1), pp. 3-10.

Czaja, S. J., Charness, N., Fisk, A. D., Hertzog, C., Nair, S. N., Rogers, W. A., & Sharit, J. (2006). Factors predicting the use of technology: Findings from the center for research and education on aging and technology enhancement (CREATE). *Psychology and aging, 21*(2), p 333.

Dickey, L., Kagan, A., Lindsay, M. P., Fang, J., Rowland, A., & Black, S. (2010). Incidence and profile of inpatient stroke-induced aphasia in Ontario, Canada. *Arch Phys Med Rehabil, 91*(2), pp. 196-202.

Enderby, P., & Petheram, B. (2002). Has aphasia therapy been swallowed up? *Clin Rehabil, 16*(6), pp. 604-608.

Feigin, V. L., Forouzanfar, M. H., Krishnamurthi, R., Mensah, G. A., Connor, M., Bennett, D. A., . . . Truelsen, T. (2014). Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. *The Lancet, 383*(9913), pp. 245-255.

Finlay, L., & Gough, B. (2003). *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*: Wiley.

Flowers, H. L., Silver, F. L., Fang, J., Rochon, E., & Martino, R. (2013). The incidence, co-occurrence, and predictors of dysphagia, dysarthria, and aphasia after first-ever acute ischemic stroke. *Journal of Communication Disorders, 46*(3), pp. 238-248.

Foster, A., O'Halloran, R., Rose, M., & Worrall, L. (2016). "Communication is taking a back seat": speech pathologists' perceptions of aphasia management in acute hospital settings. *Aphasiology, 30*(5), pp. 585-608.

Galliers, J., Wilson, S., Marshall, J., Talbot, R., Devane, N., Booth, T., . . . Greenwood, H. (2017). Experiencing EVA Park, a Multi-User Virtual World for People with Aphasia. *ACM Transactions on Accessible Computing, 10*(4), pp. 1-24.

Graham, J. R., Pereira, S., & Teasell, R. (2011). Aphasia and return to work in younger stroke survivors. *Aphasiology, 25*(8), pp. 952-960.

Harrison, M., & Palmer, R. (2015). Exploring patient and public involvement in stroke research: a qualitative study. *Disability and Rehabilitation, 37*(23), pp. 2174-2183.

Hart, S. G. (2016). Nasa-Task Load Index (NASA-TLX); 20 Years Later. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting, 50*(9), pp. 904-908.

Hart, S. G., & Staveland, L. E. (1988). Development of NASA-TLX (Task Load Index): Results of empirical and theoretical research *Advances in psychology* (Vol. 52, pp. 139-183): Elsevier.

Herbert, R., Gregory, E., & Haw, C. (2018). Collaborative design of accessible information with people with aphasia. *Aphasiology*, pp. 1-27.

Hinckley, J., Boyle, E., Lombard, D., & Bartels-Tobin, L. (2014). Towards a consumer-informed research agenda for aphasia: preliminary work. *Disability and Rehabilitation, 36*(12), pp. 1042-1050.

INVOLVE. (2012). Briefing notes for researchers: involving the public in NHS, public health and social care research. Retrieved Date Accessed, 21 July 2017 from http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf.

ISO. (2018). Ergonomics of human-system interaction — Part 11: Usability: Definitions and concepts ISO 9241-11:2018(en). Retrieved Date Accessed, 08 November 2018 from https://www.iso.org/obp/ui/#iso:std:iso:9241:-11:ed-2:v1:en.

Jones, F., Gage, H., Drummond, A., Bhalla, A., Grant, R., Lennon, S., . . . Liston, M. (2016). Feasibility study of an integrated stroke self-management programme: a cluster-randomised controlled trial. *BMJ Open, 6*(1), p e008900.

Jones, F., & Riazi, A. (2011). Self-efficacy and self-management after stroke: a systematic review. *Disabil Rehabil, 33*(10), pp. 797-810.

Kagan, A. (1998). Supported conversation for adults with aphasia: methods and resources for training conversation partners. *Aphasiology, 12*(9), pp. 816-830.

Kearns, A., Kelly, H., & Pitt, I. (2019). *Self-reported Feedback in ICT-delivered Aphasia Rehabilitation: a Literature Review* Manuscript submitted for publication

Kertesz, A. (2007). *Western Aphasia Battery (Revised)* San Antonio: PsychCorp.

Lloréns, R., Noé, E., Colomer, C., & Alcañiz, M. (2015). Effectiveness, Usability, and Cost-Benefit of a Virtual Reality–Based Telerehabilitation Program for Balance Recovery After Stroke: A Randomized Controlled Trial. *Archives of Physical Medicine and Rehabilitation, 96*(3), pp. 418-425.e412.

Mallet, K. H., Shamloul, R. M., Corbett, D., Finestone, H. M., Hatcher, S., Lumsden, J., . . . Dowlatshahi, D. (2016). RecoverNow: Feasibility of a Mobile Tablet-Based Rehabilitation Intervention to Treat Post-Stroke Communication Deficits in the Acute Care Setting. *PLoS ONE, 11*(12), p e0167950.

Marshall, J., Roper, A., Galliers, J., Wilson, S., Cocks, N., Muscroft, S., & Pring, T. (2013). Computer delivery of gesture therapy for people with severe aphasia. *Aphasiology, 27*(9), pp. 1128-1146.

Mc Menamin, R., Tierney, E., & Mac Farlane, A. (2015). Addressing the long-term impacts of aphasia: how far does the Conversation Partner Programme go? *Aphasiology, 29*(8), pp. 889-913.

Moffatt, K., McGrenere, J., Purves, B., & Klawe, M. (2004). *The participatory design of a sound and image enhanced daily planner for people with Aphasia.* Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI 2004), Vienna, Austria.

Mortley, J., Wade, J., & Enderby, P. (2004). Superhighway to promoting a client-therapist partnership? Using the Internet to deliver word-retrieval computer therapy, monitored remotely with minimal speech and language therapy input. *Aphasiology, 18*(3), pp. 193-211.

Nielsen, J. (1994). *Usability Engineering*: Morgan Kaufmann.

Palmer, R., Enderby, P., Cooper, C., Latimer, N., Julious, S., Paterson, G., . . . Hughes, H. (2012). Computer therapy compared with usual care for people with long-standing aphasia poststroke: a pilot randomized controlled trial. *Stroke, 43*(7), pp. 1904-1911.

Palmer, R., Enderby, P., & Paterson, G. (2013). Using computers to enable self-management of aphasia therapy exercises for word finding: the patient and carer perspective. *Int J Lang Commun Disord, 48*(5), pp. 508-521.

Roper, A., Marshall, J., & Wilson, S. M. (2014) *Assessing technology use in aphasia*. Paper presented at the Proceedings of the 16th international ACM SIGACCESS conference on Computers & Accessibility (ASSETS'14), (pp. 239-240), Rochester, New York, USA.

Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffmann, T. C. (2011a). Aphasia friendly written health information: content and design characteristics. *Int J Speech Lang Pathol, 13*(4), pp. 335-347.

Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffmann, T. C. (2011b). Exploring the use of graphics in written health information for people with aphasia. *Aphasiology, 25*(12), pp. 1579-1599.

Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffmann, T. C. (2012). Guiding principles for printed education materials: design preferences of people with aphasia. *Int J Speech Lang Pathol, 14*(1), pp. 11-23.

Sanders, E. B. N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign, 4*(1), pp. 5-18.

Simic, T., Leonard, C., Laird, L., Cupit, J., Höbler, F., & Rochon, E. (2016). A Usability Study of Internet-Based Therapy for Naming Deficits in Aphasia. *American Journal of Speech-Language Pathology, 25*(4), pp. 642-653.

Tomkins, B., Siyambalapitiya, S., & Worrall, L. (2013). What do people with aphasia think about their health care? Factors influencing satisfaction and dissatisfaction. *Aphasiology, 27*(8), p 982.

Varley, R., Cowell, P. E., Dyson, L., Inglis, L., Roper, A., & Whiteside, S. P. (2016). Self-Administered Computer Therapy for Apraxia of Speech: Two-Period Randomized Control Trial With Crossover. *Stroke, 47*(3), pp. 822-828.

Wade, J., Mortley, J., & Enderby, P. (2003). Talk about IT: Views of people with aphasia and their partners on receiving remotely monitored computer-based word finding therapy. *Aphasiology, 17*(11), pp. 1031-1056.

Wallace, S. J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., . . . Gauvreau, C. A. (2017). 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, 39*(14), pp. 1364-1379.

Wilson, S., Roper, A., Marshall, J., Galliers, J., Devane, N., Booth, T., & Woolf, C. (2015). Codesign for people with aphasia through tangible design languages. *CoDesign, 11*(1), pp. 21-34.

Zheng, C., Lynch, L., & Taylor, N. (2016). Effect of computer therapy in aphasia: a systematic review. *Aphasiology, 30*(2-3), pp. 211-244.

Zimmerli, L., Krewer, C., Gassert, R., Müller, F., Riener, R., & Lünenburger, L. (2012). Validation of a mechanism to balance exercise difficulty in robot-assisted upper-extremity rehabilitation after stroke. [journal article]. *Journal of NeuroEngineering and Rehabilitation, 9*(1), p 6.

Zmily, A., Mowafi, Y., & Mashal, E. (2014). Study of the usability of spaced retrieval exercise using mobile devices for Alzheimer's disease rehabilitation. *JMIR Mhealth Uhealth, 2*(3), p e31.

Tables

Table 1 Co-designer Details

Co-design researcher	Age	Gender	Time post CVA (years)	Location of CVA	WAB AQ	Aphasia Type	Aphasia severity	Summary of ICT ownership and use
A	65	m	11.4	(L) parietal lobe	24.4	Global	Severe/ very severe	Newly acquired tablet computer used for gaming, rarely uses mobile phone and for calls only, no text messaging. Requires assistance from family to set up.
B	43	m	4	(L) MCA	51.8	Broca's	Moderate	Independently uses laptop, iPad daily and smartphone daily for electronic schedule, information searches, speech and language therapy applications and communication including emails, text messenger applications e.g. Viber, phone calls and text messages. Sometimes uses internet banking.
C	64	m	1.9	(L) MCA	67.1	Broca's	Moderate	Independently uses an iPad and smartphone daily for entertainment and phone calls, does not use text messages.
D	53	m	6	(L) MCA	83	Conduction	Mild	Independently uses a smartphone and laptop daily for information searches, online entertainment, phone calls and text messages. Uses social media and online shopping occasionally.
E	76	f	9	(R) temporo-parietal lobe	79	Anomia	Mild	Owns a Nokia phone which is used on a daily basis for phone calls only. Does not own any other ICT device.
F	63	m	2.4	(L) MCA	82.6	Anomia	Mild	Owns a laptop, PC, iPad and smartphone and independently uses his phone to make calls daily, never used text messages. Frequently uses email, online information searches, speech and language therapy applications and occasionally uses internet banking.

Figures

Figure 1. Workshop topics and primary focus

Workshop	Focus
1	Introductions & discussion on “good” and “bad” aspects of technology
2	Review discussion on technology from session 1; establish key questions and determine how best to ask and answer questions
3	Refine questions, consider aphasia-accessible format and create supporting visual stimuli
4	Further refine visual stimuli for each question
5	Prototype questionnaire and refinements based on feedback from trialling it within the group
6	Trial final draft questionnaire and finalise

Figure 2. Summary of discussions in the initial workshop

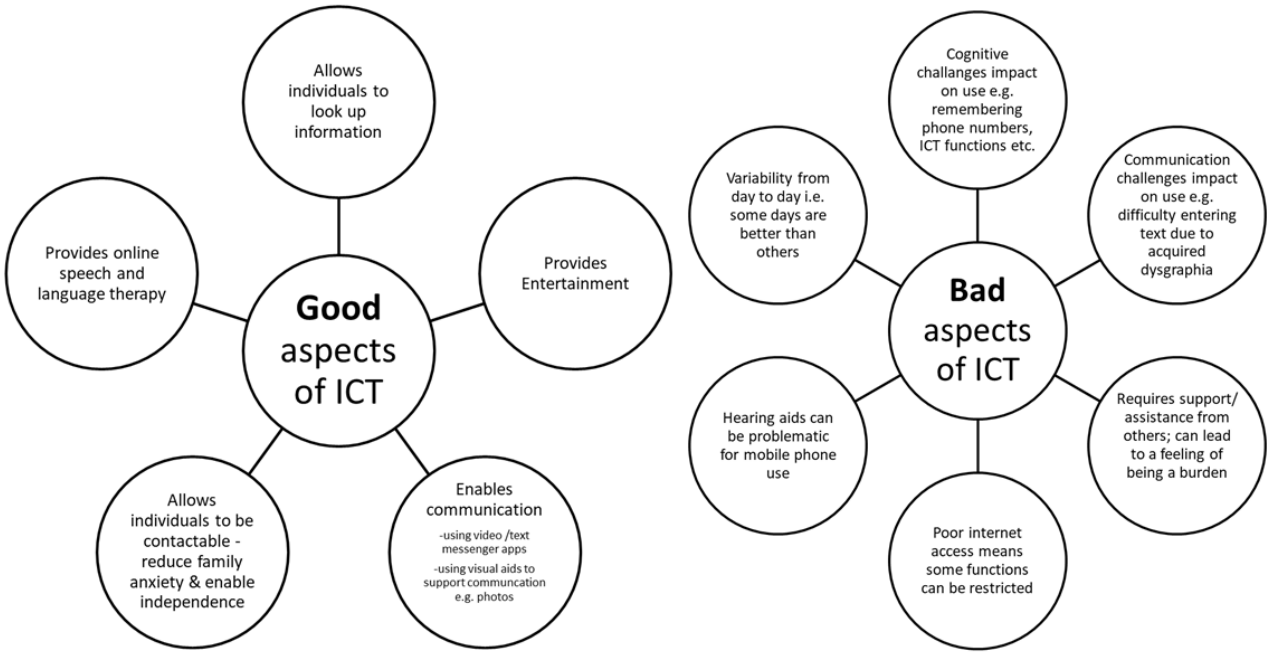


Figure 3 Question Topic Development

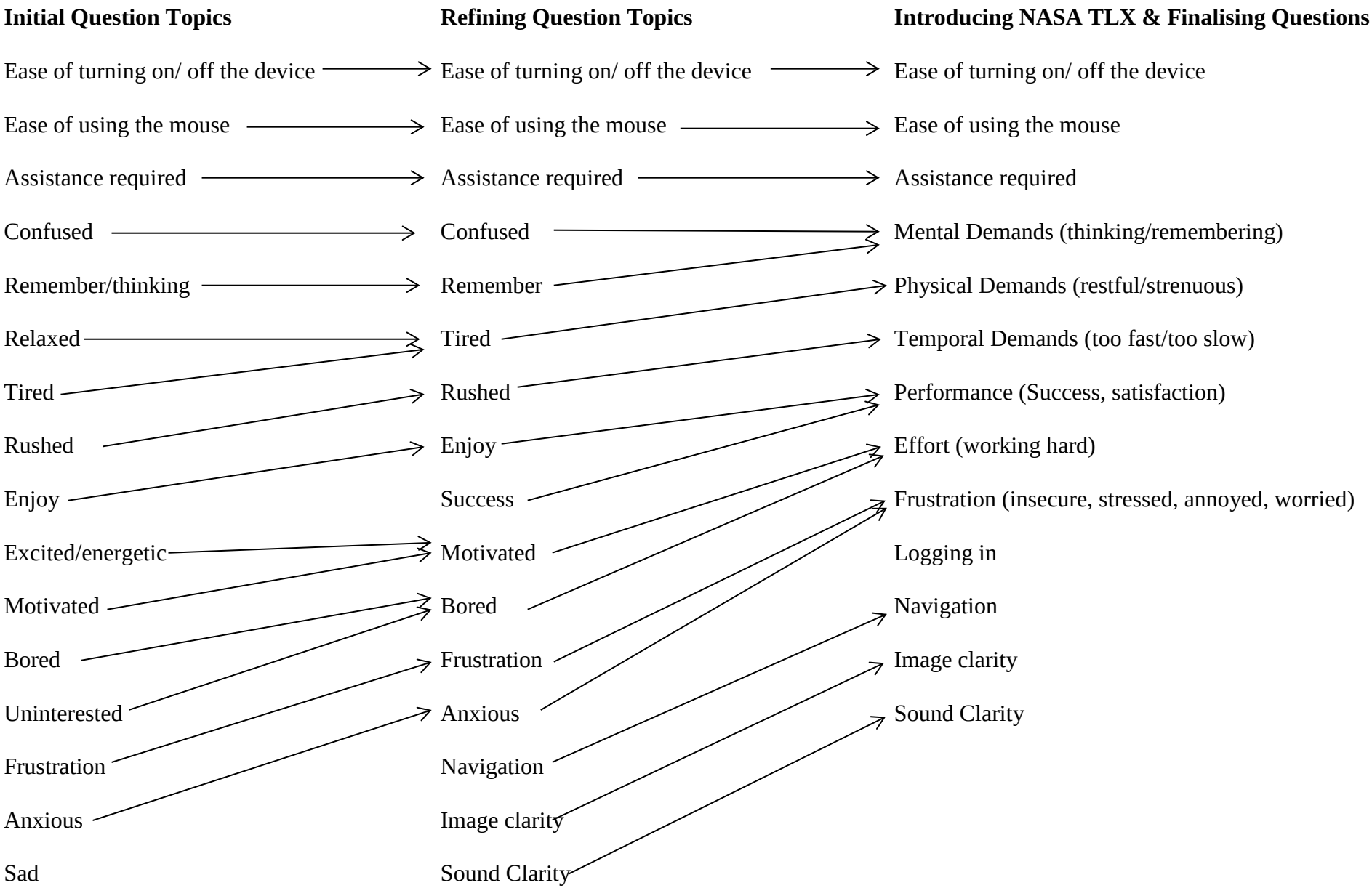


Figure 4 Single versus binary choice question images

I feel **frustrated** using the computer



I feel **frustrated** using the computer





Figure 5. Overview of final questionnaire

Ease of Use and Functionality items	**NASA TLX items** **Subscale, question and additional prompt in italic font**
1. *Identifier* 2. *Timepoint* 3. How much help did you need when using the computer/laptop? 4. How easy was it for you to turn on/off the computer/laptop? 5. How easy was it for you to use the mouse? 6. How easy was it for you to log into the programme? 7. How easy was it for you to find the right level? 8. How easy was it for you to understand the pictures? 9. How easy was it for you to hear the sentences?	10. Mental Demand: How mentally demanding was the task? *How much thinking/ remembering was involved?* 11. Physical Demand: How physically demanding was the task? *How restful or strenuous was the task?* 12. Time Demand: How hurried or rushed was the pace of the task? *Was it too fast or two slow?* 13. Performance: How successful were you in achieving your goals? *Were you satisfied with your work?* 14. Effort: How hard did you have to work to achieve your goals? *How much effort did you have to put in?* 15. Frustration: How insecure, discouraged, irritated, stressed and annoyed were you?

Figure 6. Example of NASA TLX Question

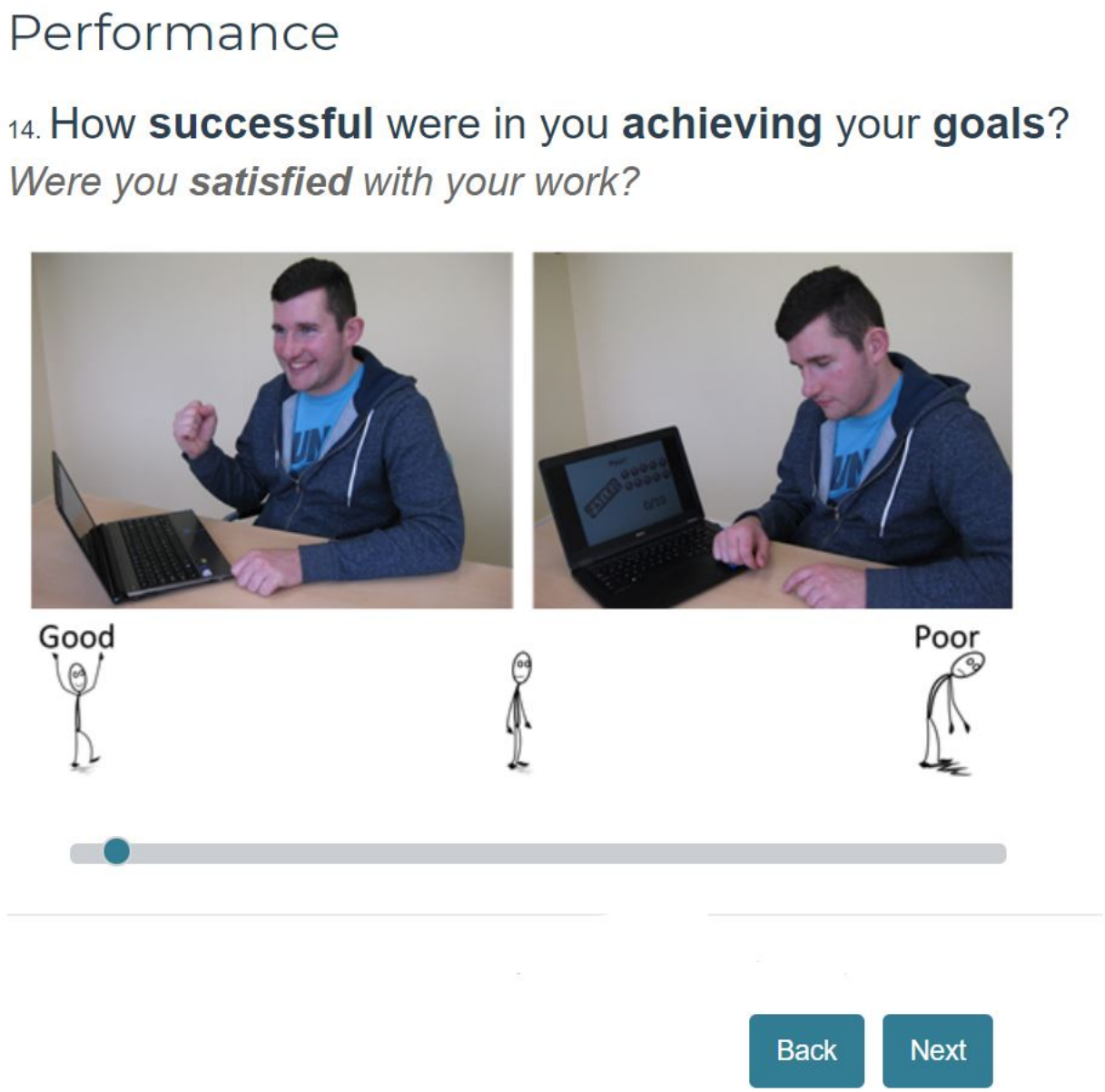


Figure 7. Example of required level of assistance question

