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Codesign for People with Aphasia Through Tangible Design Languages

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Codesign techniques encourage designers and end-users to work together in the creation of design solutions, but often make assumptions about the ways in which participants will be able to communicate. This can lead to the unwitting exclusion of people with communication impairments from the design of technologies that have the potential to transform their lives. This paper reports our research into codesign techniques for people whose communication skills are impaired. A variety of codesign techniques were explored on two projects; some were adaptations of existing techniques, others were created specially. In both cases, the emphasis was on creating tangible design languages. The results illustrate how people with communication impairments can be given a voice in design and demonstrate the benefits of doing so.

Keywords: codesign; aphasia, participatory design; tangible design language

1. Introduction

Codesign techniques encourage designers and end-users to work together in the creation of design solutions, thus blurring the boundaries between traditional stakeholder roles in user-centred design. However, many codesign techniques use design representations and processes that assume effective communication skills on the part of participants. We are interested in enabling the participation in design of people with aphasia, a communication impairment causing difficulty with spoken and written language, and report research into the development of aphasia-accessible codesign techniques.

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A number of codesign techniques were conceived and employed in the development of two therapy tools for people with aphasia. The first tool, GeST, provides gesture therapy (Galliers et al, 2012; Marshall et al, 2013). The second, EVA Park, offers a virtual world for practising speech. At the heart of the codesign techniques lies what we have termed 'tangible design languages'; these are manipulable, non-verbal design representations. We describe the techniques and reflect on what we learned through their application. Three key themes emerge: the importance of tangibility, relevance and level of challenge.

2. Background

The benefits of involving future users in the design of new technologies are well-reported. Notably, giving users a voice in design should result in better products, help to avert adverse consequences of innovations (Cross, 1972, cited in Sanders and Stapers, 2008) and foster common ground between stakeholders. User involvement is also advocated for ideological reasons. For example, it chimes with beliefs about the value of democracy in the workplace and the need to empower underprivileged groups (Muller, 2003). In the context of disability, codesign is consistent with the changes in attitudes that have occurred in the last 30 years, particularly the uptake of the social model of disability (Oliver, 1996). This model views disability as arising not from the medical impairment, but from disabling barriers and attitudes within society. Adherents to the model argue that the problems of disability should be tackled by seeking changes to social policies and practices, rather than medical cures. Critically, the social model also casts people with disabilities into a new role. Rather than being passive recipients of care, as was the case with the medical model of disability, they are experts who are leading the demand for change. If change is to be sought through technology, people with disabilities should be at the heart of that endeavour, and this in turn should be achieved through their participation in the design process.

The options for users to participate in design span a continuum. At one end, users are 'subjects' and play a largely passive role, e.g. to trial products while being observed by the designers. At the other end of the continuum, users are 'partners' or 'codesigners' who participate actively in the whole design process, including what Sanders and Stappers (2008) describe as the 'fuzzy front end'. As an example they cite a project to explore the unmet needs of people living with Type 2 Diabetes. Here, users participated while the potential outcomes of the project were still to be determined, thus enabling them to shape those outcomes.

A further question relates to the methods that best enable user participation in design. If the user's role is to be that of codesigner, then creative and open-ended techniques are required. It has long been recognised that simply asking users what they want is unlikely to be effective. Rather, 'generative' tools are needed: tools that engage imagination, invite personal and emotional reflection, encourage speculation and dreaming (Sanders, 2000). Muller (2003) argues that such tools stimulate a fertile 'third space' between the different members of the design team, in which new insights and plans for action become possible.

The literature is replete with examples of co- and participatory design techniques. For example, workshops where participants speculate about a given scenario or envision the uses of a device in their home or work setting (Buur et al, 2000) or games where a board represents the floor plan of a work place and players are invited to position pieces on the board, thus stimulating discussion about different work practices (Pederson and Buur, 2000), (Huyghe et al, 2014). Many of these techniques employ non-verbal artefacts such as photographs, drawings, 3D models and game boards. However, these artefacts are typically embedded within processes that rely heavily on language. It has been argued that a 'new language' is needed for codesigning, much of which is visual (Sanders, 2000). This

argument is of particular relevance when participants have communication impairments such as aphasia.

Aphasia is a language disorder, typically caused by a stroke. It can affect a person's ability to speak, read and write. When the problem is severe, the person may be entirely unable to speak or able to speak only one or two words, such as 'yes' and 'no'. Comprehension impairments can affect the understanding of both words and sentences. In some cases, the person may be able to use alternative communication modalities, such as gesture or drawing. Aphasia is not a disorder of thought or memory. People with the condition are orientated in time and space, recall events in their life, have opinions and detailed knowledge, and can solve problems (Varley et al, 2005).

A number of computer-based aphasia therapy tools have been developed, (Palmer et al, 2012; Cherney, 2010). However, users were not typically involved in the design process. There are limited reports of the participation of people with aphasia in the design of other, non-therapeutic, technologies. For example, Moffat et al (2004) involved one user with aphasia in the design of the ESI (Enhanced with Sound and Images) Planner, Kane et al (2012) report the participation of five adults with aphasia in the design of TalkAbout, a system that provides communication support through context-sensitive word lists and Al Mahmud et al (2014) observed people with aphasia using computers as input to the development of a multimodal email tool and later evaluated the tool with 5 people with aphasia. Although guidelines for involving people with aphasia in design have been reported, e.g. Daeman et al (2007), Moffat et al (2004), none of these projects have reported codesign techniques specifically for people with aphasia.

3. Case Studies: GeST and EVA Park

Muller (2003) argues that hybridity lies at the heart of participatory design, that is, hybrid

practices that lie between the technology developers' domain and the users' domain, and lead to the creation of fertile third spaces. The same holds true when involving people with communication impairments in design, but the practices to foster hybrid third spaces need to change. We explored a number of codesign techniques that contribute to hybridity for people with aphasia in the development of GeST and EVA Park.

The design processes for both tools were structured around a series of codesign workshops. Each workshop lasted between one and two hours and involved two to five people with aphasia (referred to here as 'consultants'), one software developer, one human-computer interaction (HCI) researcher and one speech and language therapy (SLT) researcher. The consultants were employed by the projects and received payment for their time.

GeST

GeST (Figures 1 and 2) supports users with severe aphasia in practising a set of communicative gestures, e.g. gestures to represent "book" or "drink", which may be used to compensate for language deficits. GeST demonstrates gestures to the user, invites the user to produce the same gesture and monitors their attempt using a computer vision-based gesture recognition technique. It incorporates a virtual world where the user makes gestures in order to progress a character through a story.

Five consultants were involved in the design of GeST: 3 women and 2 men, ranging in age from 22 to 69. All had moderate to severe aphasia affecting their use of spoken and written language. Three had very limited vocabulary and spoke only a few words; the other two had more vocabulary and could speak in short sentences. All had difficulty reading: some could read single words or short sentences; the others were unable to read.

Eighteen codesign workshops were held over a nine month period. The workshops explored the accessibility of gesture recognition technologies, feedback, interaction and navigation paradigms, and evaluated a series of GeST prototypes.

EVA Park

EVA Park (Figure 3) is an online virtual world where users, represented as avatars, can practise conversations with remote partners. Designed for people with moderate aphasia who are able to produce single words and short sentences, EVA Park is a serene space with a variety of functional and fantastical locations where conversations can develop grounded in contexts such as a restaurant or tree house (Figures 4 and 5). Five people with moderate aphasia affecting their spoken and written language participated in this project: 2 women and 3 men, with ages ranging from early twenties to late fifties. One had previously worked on GeST.

Ten codesign workshops were held over a one year period. There was greater emphasis on creativity and co-construction than there had been in the GeST workshops. The workshops explored potential conversation settings, conversation topics, interaction and navigation and evaluated a series of prototypes.

4. Codesign Techniques

Although we made the decision to involve people with aphasia in both projects from the outset, the approach evolved with experience. In particular, we did not have a clear vision of how to facilitate effective participation when we embarked upon GeST. The starting point was a user-centred design process with codesign techniques introduced largely through serendipity. The codesign techniques for the later EVA Park were an evolution of those early approaches but with the goal of facilitating greater generative participation of people with aphasia. We selected techniques that either already made use of non-verbal design

representations or could be adapted to do so. Some techniques were created specifically for the projects. We report a selection of the codesign techniques, organised in approximately design-process order (Table 1), and reflect on their successes and limitations for people with aphasia.

4.1 Ice Breaker Games

The workshops started with ice-breaker activities. A "gesture-picture" lotto game was created for this purpose in designing GeST by adapting a conventional lotto game (Figure 6). The game used gestures and images in place of words and numbers. Players were introduced to a series of pantomime gestures, each of which was linked to a photograph of an object or a person. Each player had a board containing six of these photographs and took it in turns to demonstrate a correct gesture for one of the photographs. The other players judged whether the gesture had been produced correctly. A correctly produced gesture was ticked off on the player's board. Players took turns to produce and judge gestures until somebody had ticked off all six pictures from their lotto board. This successfully created a shared focus that was not dependent upon conversational capacity and also introduced all participants to the gestures that would be used subsequently within the session.

A game-based approach was explored during the first EVA Park workshop as a means of breaking the ice. Members of the codesign team were organised into small groups and asked to build a tower using marshmallows and dried spaghetti. This was not a success. The most obvious problem was that, as a consequence of their strokes, the consultants did not have the manual dexterity needed to assemble the marshmallows and spaghetti. However, it appeared that the lack of engagement went deeper than this. There was a disconnect between the game and the design activity: the game lacked relevance.

4.2 Photo Diaries and Scenarios

We wanted to involve users early in the design of EVA Park to inspire the choice of virtual spaces that would be created and to ensure they were grounded in meaningful communication situations. A photo diary technique was chosen for this purpose because of its simplicity and visual nature; the basic technique was then adapted by the addition of communication scenarios.

Everyone was asked to use their smart phones to take photographs of situations they encountered in their daily lives where communication may be challenging. The photos were then shared in codesign workshops where the participants reflected upon and generated oral scenarios about the communication involved in each situation. The diaries included photos of people's homes, places of work and places they socialised. The resultant communication scenarios were used to generate conversational spaces within EVA Park and they culminated in the emphasis shifting from functional environments (e.g. a post office) to social environments (e.g. a nightclub). The photo diaries enabled people to contribute possible conversation settings even if they did not have the language to describe them and provided concrete representations for the workshop discussions; the diary element had the additional advantage of supporting memory which is sometimes affected following a stroke.

4.3 Story Grids

Another technique, which we called *Story Grids*, was also used to understand potential settings for conversations in EVA Park. This was an adaptation of Talking Mats ^{TM} (Murphy et al, 2005), an SLT technique whereby individuals with limited ability to express themselves verbally allocate symbols or photographs to one of a number of categories in order to convey their opinions.

A grid structure was created to map out a communication space; an example can be seen in Figure 7. The vertical dimension of the grid gave attributes of communication spaces such as "noisy environment" while the horizontal dimension rated the degree of challenge and/or enjoyability presented by communication in this setting. Photographs of specific settings, such as a busy restaurant, were presented to workshop participants, and then - through discussion and gesturing - placed on the grid to define how challenging this would be for someone with aphasia. This was very successful. It generated a lot of discussion about peoples' daily lives, what they found difficult and why. The grid provided a tangible, manipulable representation of the classification of settings.

4.4 Tangible Avatars

Tangible Avatars was a technique developed specifically for EVA Park and which epitomised our approach. Avatars are normally created by selecting options from complex pick lists, an activity not accessible to people with aphasia because of its reliance on comprehension of written words. Drawing inspiration from children's paper "dressing-up" dolls, we created tangible body parts and clothes by printing and laminating hundreds of options (Figures 8a, 8b): everything from faces, eyes and hair to shoes, trousers and skirts. Users readily manipulated these to create their avatars. This simple example illustrates our approach of transforming a design activity that usually requires verbal skills into something more visual and tangible; it could easily be extended to other aspects of design.

4.5 Prototypes

Prototypes were used extensively in both projects. User-centred design commonly advocates low-fidelity prototypes; in contrast, we used only high-fidelity prototypes in a bid to reduce the amount of abstraction required on the part of the user to understand what the final experience would be like. In some cases, the prototypes were incomplete versions of the

actual tools; in other cases, they were different systems that embodied interactions which we wanted to explore. For example, in developing GeST we used prototypes to explore a range of gesture input methods, including a Wii-remote in both hand-held and wrist-mounted form. In the later codesign workshops, the consultants had the opportunity to experience full prototypes of the therapy tools. They were asked to use each tool as if they were using it for therapy themselves; in essence, this was a variation of usability testing where participants were neither presented with narrative task scenarios nor asked to produce thinkalouds.

The prototypes were particularly valuable for people with more severe language impairments. Other members of the design team observed use of the prototypes to supplement oral reports where aphasia prevented individuals from fully explicating their experiences verbally. The precedence given to prototyping within this model of codesign relates closely to the increased levels of demonstration reported in section 5, enabling people with reduced language capacities to effectively engage with and influence the design process.

4.6 Visual Usability Measures

The interview and questionnaire techniques often used in usability evaluation were modified to use visual representations in the evaluation of GeST. Consultants used prototypes that embodied various design alternatives and then reviewed their experiences with an SLT researcher. Spoken questions were challenging, therefore topics were supported both by photographs (e.g. screen grabs and photographs of computer equipment) and by simplified written versions of the questions with keywords highlighted in bold. These tangible representations facilitated understanding of the topics being discussed. Consultants could respond by pointing to specific features of the images and then using gestures or single spoken words to elaborate. The SLT researcher then rephrased the response verbally to check and amend her understanding.

Visual representations were used to a lesser extent in evaluating EVA Park. The consultants had slightly less reliance upon tangible representations to stand in for spoken language. Additionally, the use of a virtual environment replete with virtual objects and locations stood well as a substitute for the tangible pictures that supported evaluation in GeST.

4.7 "Someone Who Isn't Me"

The final technique is one that was used throughout the design of EVA Park. The communication difficulties faced by people with aphasia can vary greatly from one individual to another. To design not just for those participating in the project, but for a broader constituency, we used a customised "someone who isn't me" (or SWIM) technique. Each consultant was asked to identify another person with aphasia whom they knew. At various times, consultants were first asked to report their own responses to a given scenario or question and then to report how they thought their chosen friend would respond. For example, when considering a potential mayoral election story for EVA Park, one consultant reported, 'Yes, friend would find the story interesting. He would vote for Noah. The mayor thing is fantastic.'. This individual was an enthusiastic supporter of another candidate in the election story yet he was able to report that his friend would vote for Noah. In this tangible way, the consultants were able to envision how another person with aphasia might respond to specific aspects of EVA Park, thus broadening the constituency beyond those users represented in the design team.

The choice to use the SWIM technique for EVA Park followed a less successful attempt to broaden constituency when developing GeST. In that case, the consultants were sometimes asked to reflect upon how they would have answered specific questions immediately after they had had their stroke and were more severely affected by their aphasia.

They were reluctant to respond to these questions; although we cannot be certain, this might have reflected a reluctance to focus on a distressing personal experience. They were also asked to imagine how they thought someone else with more severe aphasia might respond. This was equally unsuccessful: the consultants were universally unwilling to provide an answer, reporting that everybody with aphasia is affected differently and that they found it too challenging to comment on how a non-specific, imagined person with severe aphasia would respond in the same situation. The decision to employ a more concrete means of broadening constituency for EVA Park proved to be more successful. It should be noted, however, that these consultants had less severe aphasia and may therefore have found it easier to offer such speculations. Reflecting on this technique, one of the consultants said 'So I think it's good to think about myself but also another person that's different from me.'

5. Tangible Design Languages

The establishment of common ground within the design team hinged on the use of tangible, rather than verbal, design languages that were accessible to all participants. In this section we summarise how we partially substituted other modalities (images, gesture, demonstrations and physical artefacts) for verbal language to create these tangible design languages. In so doing, we drew on an extensive literature about how to make information accessible to people with aphasia e.g. Rose et al (2011). There are also parallels here with Total Communication (Fawcus and Fawcus, 1990) which is commonly used in SLT with people with aphasia. This incorporates a range of modalities to support communication but still includes verbal expression as one of the modalities.

Images

Images were central to creating tangible design languages. Concepts that might otherwise have been presented verbally were presented visually. Photos and sketches were used in

story grids and photo diaries to understand the design space, to ground co-creation, to support evaluation. Photos were used as games pieces in the gesture-picture lotto game and manipulable images were at the heart of the Tangible Avatars. Again, their purpose here was to support understanding and expression without the need for spoken labels.

Gesture

GeST is a gesture therapy tool and therefore the introduction and use of gestures were integral parts of the codesign process. Basic principles of gesture were introduced early on during the workshops, specific gestures were trained and the suitability of a large number of possible gestures to be used in the final tool was discussed and reviewed throughout the design process.

Demonstration

Both the GeST and EVA projects frequently used demonstration as a means of explanation. To reduce demands on expressive language whilst explaining, and receptive language whilst being explained to, many of the activities within workshop sessions were explicated as a physical demonstration of what to do. For instance, the SLT researcher modelled target interactions with a piece of software or hardware before they were trialled by consultants. Similarly, during feedback discussions, consultants used demonstration in combination with gesture and varying amounts of spoken language to report thoughts and views. Within the design space created by both projects, demonstration proved an integral facet of the mutual communication environment.

Physical Artefacts and Spaces

Physical artefacts included the prototypes, Tangible Avatars and Story Grid. These representations could be manipulated by participants to co-create design outcomes.

6. Impact of Codesign

In line with other reports, there were beneficial outcomes from the codesign approach, notably co-constructions and mutual learning. Codesign helped to shape the tools and had an impact on all those who participated.

Impact on Tools

It is clearly impossible to quantify the impact on the tools: we cannot know what GeST and EVA Park would have been like had we not undertaken codesign. However, we can point to features of GeST and EVA Park that arose directly from the codesign activities. For GeST, these included using videos of people, rather than avatars, to demonstrate gestures, providing a simplified keypad for input, increased accessibility and incorporating fun elements such as a simple virtual world. For EVA Park, the codesign activities influenced the conversational settings, simplified interactions, provided story themes and led to a strong shift from the functional (e.g. a clinic) to the playful (e.g. elephants and mermaids). For example, one person commented 'Ugh! Don't like it!' when presented with a clinic in EVA Park. The codesign activities also impacted on the design of the tools in more subtle ways. The increased understanding of aphasia and of how people with aphasia can and cannot access technology was immensely valuable for the software developer and HCI researchers and led to them taking informed design decisions outside of the workshop settings. A follow-up trial of GeST with 9 participants who had severe aphasia provided evidence of its accessibility (Marshall et al, 2013); a similar study is ongoing for EVA Park.

More generally, the codesign process resulted in products that are strikingly different from previous computerised aphasia therapy tools. Many other tools effectively mimic paper-based therapy exercises; i.e. users carry out typical therapy tasks such as building sentences. GeST and EVA Park are radically different. For example, GeST presents targets

for gesture practice in a virtual world or in real world video scenarios. EVA Park abandons exercises altogether, in favour of a navigable world that can be used for conversation, role-play or pure exploration. As a result, each user's experience of EVA Park is individualised and self-determined.

Impact on Participants

There was mutual learning between all members of the design teams. The 'designers' learned about each other's disciplines. Everyone learned about designing interactive technologies for people with aphasia. The consultants engaged with technologies that were largely unfamiliar to them. The consultants were interviewed at the conclusion of the projects. They reported that they had helped shape the tools (e.g. 'it's really good now. It was different. It wasn't so good. But it's good now.') and several reported improvements to their confidence in general and in using computers ('I think EVA, yes, a lot. First time, didn't know, you know. But practise, practise. And now flying is easier. And dancing.'). They also reported other personal benefits from participating: 'I feel like I'm speaking out.' and 'I just like that... because I know about aphasia and so, [if] people who have aphasia want to use it then I'm glad that I've helped people.'

Relevance to other communication impairments

Many of the techniques described in this paper might enable people with other communication impairments to become co-designers. For example, the persistent nature of the visual representations may be of value to people with memory impairments. However, differences between diagnoses means that generalisation cannot be assumed. For example, the SWIM technique would be challenging for people with autism, who struggle to reflect on the thoughts and feelings of others; and people with dementia might be confused if asked to trial several alternative prototypes. Conversely, if problems are confined to speech with no

language involvement, fewer adaptations may be needed. Further studies, involving people living with other conditions, would illuminate this question.

7. Conclusion

We have given an account of our experience using a range of codesign techniques with people who have aphasia. We made a decision to involve people with aphasia in the development of both GeST and EVA from the outset, but the techniques evolved with experience. Some techniques were more successful than others. It was not always apparent which techniques would work best, but the severity of aphasia was clearly one determining factor. Techniques that are appropriate for people with moderate aphasia may be inaccessible to those with more severe aphasia and, vice versa, techniques for severe aphasia run the risk of being perceived as patronising by people whose language is less impaired. The relevance of the technique to the design activity and the level of challenge were other factors impacting upon success.

In summary, the codesign activities reported here demonstrate that it is both feasible and desirable to involve people with aphasia in design. We argue that one key to success is a clear focus on creating tangible design languages, customised for specific codesign activities, using images, gestures, demonstrations, physical artefacts and spaces. Tangible design languages enable participation when verbal language is impaired, thus fostering creative design spaces.

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Table 1: Overview of codesign techniques used for GeST and EVA Park

Purpose	**GeST: Gesture Therapy**	**EVA Park: Conversation Therapy**
Ice-breaking, introducing session content	Ice-breaking game: Picture Lotto	Ice-breaking game: Marshmallow Towers
Generating design options	–	Picture Diaries and Scenarios
Generating design options	–	Story Grids
Generating design options	–	Tangible Avatars
Exploring design alternatives, accessibility of hardware, accessibility of navigation and interaction options	High-Fidelity Prototypes	High-Fidelity Prototypes
Evaluating designs	Visual Usability Measures	Visual Usability Measures
Broadening constituency	–	SWIM

Figure 1: GeST running on laptop with customised keypad for input.

Figure 2: Virtual world in GeST.

Figure 3: Panorama of EVA Park.

Figure 4: Virtual coffee and cakes in EVA Park.

Figure 5: Treehouse (and elephants) in EVA Park.

Figure 6: Breaking the ice with a gesture-picture lotto game.

Figure 7: Story Grid.

Figure 8: Tangible Avatars (a) body parts, (b) assembling an avatar.