Use of an Agile Bridge in the Development of Assistive Technology

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ABSTRACT

Engaging with end users in the development of assistive technologies remains one of the major challenges for researchers and developers in the field of accessibility and HCI. Developing usable software systems for people with complex disabilities is problematic, software developers are wary of using user-centred design, one of the main methods by which usability can be improved, due to concerns about how best to work with adults with complex disabilities, in particular Severe Speech and Physical Impairments (SSPI) and how to involve them in research. This paper reports on how the adoption of an adapted agile approach involving the incorporation of a user advocate on the research team helped in meeting this challenge in one software project and offers suggestions for how this could be used by other development teams.

INTRODUCTION

Traditionally designers and developers of assistive technology have not engaged with users with limited communication abilities due to perceived issues with vulnerability and difficulties in gathering feedback from users who are unable to speak or who have intellectual impairments [12]**.** Many developers are concerned that by working with adults who have these complex disabilities there is the potential risk for participants in research to not fully understand their rights as participants and to become distressed when working with complicated new software. Concerns have also been raised regarding how feedback can be elicited from participants with complex communication impairments and how to ensure that participants think about other potential users other than themselves. Software developers have instead used proxy users and have tended to restrict engagement with end users to the summative evaluation stage of system development [21]. One reason behind software developers making these decisions can often be their lack of experience in communicating and working with adults with Severe Speech and Physical Impairments (SSPI). However, given the high rates of abandonment of assistive technology and in particular technology for adults with SSPI there is a need to consider how existing methodologies can be adapted to help facilitate the inclusion of adults with SSPI in the development of technology.

One challenge researchers can face when attempting to develop assistive technology for adults with SSPI is the need for a multidisciplinary team (often consisting of software developers, speech and language therapists and experts in the theory behind the software). A difficulty for multidisciplinary teams can be how to ensure close communication between team members and that team members are working productively on tasks to best help the team as a whole. Agile methodologies designed to help team work may offer a solution.

This regular contact combined with the ability for team members to work independently while still being aware of each other's tasks means that the SCRUM framework could potentially solve some of the problems found in other development projects when multidisciplinary teams attempt to work concurrently on tasks.

The Agile software development approach is based on iterative incremental cycles of software production [14]. Agile development places an emphasis on self-organisation and motivation, meaning that the team can be dispersed geographically during the day provided that daily contact is maintained. Agile methods promote close teamwork collaboration and a focus on rapidly producing the end products of a project. The SCRUM framework is one of the various agile methodologies. In a SCRUM framework, the time for the project is divided into unit of time known as sprints; these are usually between 1 week and 1 month. At the beginning of a sprint, the entire development team will meet together to identify the tasks and goals that are to be completed in the sprint. These decisions are based upon task priority and team availability. At the end of the sprint, a review meeting is held to examine progress made and to plan for the next sprint. In addition to these planning meetings, in a typical SCRUM implementation there will be regular team meetings (usually daily) in which team members share about the activities they completed the previous day, as well as their plans for the coming day. This is also an opportunity for team members to share about the problems they are facing.

The ability for the team to function despite being geographically dispersed using the agile methodology provides the opportunity to address the challenge of conducting user-centred design with adults with SSPI. In the project discussed in this paper, a user advocate role was developed within the research team who acted as a bridge between the software developers and the end users. By working in short sprints the user advocate was able to work with both the development team and the users in tandem to achieve rapid codesign and feedback on prototypes.

BACKGROUND

Severe Speech and Physical Impairments

Severe Speech and Physical Impairments (SSPI) is an umbrella term used to describe a set of impairments that affect the motor and communication abilities of an individual [23]. A number of different disabilities can contribute to someone having SSPI. Congenital disabilities are the major reason for children having SSPI and originate either before, during or shortly after birth, the most common congenital cause of SSPI is cerebral palsy [12] which is thought to occur in 1 in 500 births [16].

Individuals with SSPI may experience a physical inability to speak. They may also have additional language and cognitive difficulties. These difficulties can impact on their ability to use technological devices known as Augmentative and Alternative Communication (AAC) aids which allow users to communicate [9]. AAC is the general term for the methods used to aid communication by those for whom the usual form of communication through speech is not sufficient. Additional impairments such as sensory (e.g. hearing) or cognitive impairment can further affect the receptive processing of communication [9]. Receptive processing refers to how a person interprets or understands what is being said to them [6]. Without access to communication it is incredibly difficult for a person to be able to share their needs and preferences.

The mobility Assistive Technology research field and commercial market are large [7] with much work being undertaken into improving physical mobility. By contrast, AAC forms a small niche market. AAC is an area of practice which attempts to compensate for loss of verbal communication through a variety of techniques [9]. The term Speech Generating Devices (SGD) is used to describe technological AAC devices which allow users to use voice synthesis to speak words or phrases.

User-Centred Design (UCD) and AAC

Sadly many assistive technologies, especially SGDs, have high rates of abandonment. Abandonment can be an indication of poor usability and for SGD devices it can be as high as 53.3% [24]. Typing or accessing words or phrases using AAC is extremely slow and frustrating with rates seldom exceeding 15 words per minute [28]. Engaging in extended interactions, e.g., sharing stories and relating narratives, is therefore a particular challenge for people with SSPI for whom communicating verbally is difficult or impossible.

A major means of improving usability is through user- centred design (UCD). UCD aims to include end users in the planning, design and development of products. The level of user involvement can range from projects in which end users become researchers and developers to projects in which end user involvement is restricted to the evaluation of the final project. End users can also have varying levels of input into the design and formative evaluation of iterative prototypes.

Although the involvement of end users with disabilities in the design of assistive technology is on the increase, proxy users are still too often considered a 'valid' alternative to users with complex disabilities in the design process e.g. [3]. When people with complex disabilities are involved, this tends to be in the end stages of projects and they are seldom employed

early on in the design process because they have difficulties with communication and with the physical manipulation of design artifacts.

Studies on the topic of involving end users with complex disabilities, in particular those with SSPI, in UCD have discussed the problems that can occur when attempting this.

When conducting UCD the participants are likely to only be a small sample of the entire user group; it is therefore important to make sure that the sample is representative of the user group. For example, if the software was being designed for use in a school one would expect that the participants would include teachers and pupils with a range of ages and a mixture of both genders [20]. No two people with SSPI will have an identical set of impairments or needs, and there is a great variety of user characteristics, so there are problems in finding representative users [9].

One important task in UCD is to specify the characteristics of the user group and their abilities and needs [25]. This variation of impairments and characteristics of the population with SSPI can make the task of specifying the characteristics of the user group difficult [18].

Ensuring that a purposive sample of participants is involved is one way to improve the validity of decisions - another challenge to achieve agreement between all the participants on a decision. One risk when working with adults with SSPI is that those participants who are most adept at using their AAC device will be able to provide the most information on their preferences. This means there can be a tendency to pay too much attention to *the articulated needs of one user* [18, (p. 41)].

While there can be the risk of paying more attention to participants who can communicate the most effectively, even with these participants it can be very challenging to hold a conversation with them which goes into more detail than simple phrases, and delves into opinions and feelings [15]. It is important particularly when gathering requirements or conducting design that the participants can provide good feedback and explain why they hold an opinion [13].

Newell suggests that participants may struggle to communicate their thoughts [18], meaning that a participant may not be able to offer suggestions for how features of a design or discuss their views on the way a design is progressing.

Enabling participants to communicate their thoughts can be especially challenging when creating new technology [5]. AAC research is frequently at the forefront of technology and often focuses on technology that has not previously been envisaged [19]. Careful consideration must be given to methods centring around new technology to ensure that they are suitable and ethical for use with adults with SSPI.

There are a wide variety of methods used in the development of software; however when working with participants with SSPI, some of the traditional methods used to uncover thoughts may be unethical [4]. For example, one of the traditional methods for evaluating the usability of software is for a researcher to watch a participant attempt to use the software and monitor the mistakes they made. It could be deemed unethical to do this with a user with SSPI as they may not fully understand the aims of the method, and become distressed when feeling that they are making mistakes [18].

Prior [21] demonstrated how different existing design and evaluation methodologies could be adapted for use with adults with SSPI. Prior [21] provides a set of guidelines describing how different user-centred design principles can be adapted for use by severely disabled individuals. These guidelines highlight the need for training software developers aiming to work with adults with SSPI. However, a theoretical form of training can take up to two weeks, while the practical training may take much longer. Prior suggests that the practical training may last many weeks as the developer becomes embedded in the participants' environment and begins to understand how the environment operates and how participants communicate.

Despite progress in increasing training for software developers, involving multiple stakeholders and experts from different backgrounds continues to prove a challenge. A particular challenge is how to bridge the gap between usability engineering specialists and technical experts, e.g., in Natural Language Generation (which is increasingly found in modern AAC research), and the end users with SSPI and their support staff. The use of the Agile methodology and the development of the role of the user advocate could be of benefit to development teams trying to meet these challenges. This paper reports on how an adapted agile methodology was used in a project to develop a piece of AAC software known as CHRONICLES.

CHRONICLES
Technology and Narratives
CHRONICLES was developed as part of a larger study looking at how storytelling can be best supported in the adult care environment. The CHRONICLES software took inspiration from other narrative project [2; 22] to support adults with SSPI to share narratives in an interactive conversation.

Narrative has been demonstrated to shape identity and a sense of personal continuity across the life span [17]. Being able to integrate one's narrative life story enables one to adapt to changing circumstances throughout life. An inability to tell one's own story makes the building of relationships and community difficult and may negatively impact self concept and identity formation, exacerbating social isolation [17]. As people move into adulthood, their narratives become richer in meaning and include more interpretive accounts of their daily life than they shared in earlier years [10]. In adulthood narratives are used to shape social identity and to form bonds with new acquaintances.

Current AAC devices are well suited to supporting the expression of needs and wants (such as *I am thirsty*) but more complex interactions such as conversational narrative (e.g. *Did I tell you about the time I went to Spain?*) and social dialogue (e.g. pub chats about football) are not well supported [15]. Important information and experience can be stored and retrieved as chunks of reusable text in AAC devices, but this is problematic on several levels: it is difficult to identify narrative, create and store written dialogue; the user cannot easily embellish/extend narrative within interactive conversation; and narratives tend to be transient, i.e., they are lost when devices are reprogrammed or replaced and when people transition to new settings where carers do not know their stories. The CHRONICLES system, which provides the context for this paper, aims to harness existing research technology to support users in formulating, editing and retrieving their narratives.

Previous Research into Narratives and AAC
Related work includes story sharing for adults with dementia, story based communication aids, and Natural Language Generation (NLG) support for AAC. The development of AAC systems to support narrative has, until recently, focused on either children with little or no literacy skills, or adults who are literate. At their most basic, these systems provide users with a library of fixed "conversational texts" which can be selected and spoken using a speech synthesizer. The Talk system [26] implements a retrieval system in which the user is supported to make conversational moves. Based on a pragmatic conversational model, these moves allow users to navigate through a conversation in which the progression of conversation is seen as a series of gradual shifts of perspectives. Waller [27] developed a storytelling tool for AAC users, which included ways to introduce a story, tell it at the pace required and give feedback to comments from listeners; but again this tool was based on a library of fixed texts and templates. NLG has been used in more recent AAC projects to support the automatic availability of experiential data for conversation. The How was School Today…? project [2] uses sensor data to provide information about a disabled child's day at school. This data (location, interaction with people and objects, deviations from routine and voice recordings) are transformed into a narrative using data-to-text technology.

The aim of this project was to use techniques from many previous projects in narrative and combine them while attempting to tackle one of the major challenges in AAC: the poor usability of devices and technology.

The CHRONICLES software enables adults with SSPI to retrieve their narratives using a facility which searches for stories based on a keyword and its synonyms. The narratives are stored as individual utterances and when a user selects one, the system will search for extra information which is stored in a user's profile that may provide embellishments or context for the utterance such as information about a place or person. The system also provides the ability for a user to evaluate an experience within an utterance using statements relating to the information within an utterance (e.g. an utterance about food would offer evaluations about the food tasted).

The system uses Artificial Intelligence technology to search utterances for people or places known to the user. Extra information on the person or places is then provided for the user to select as embellishments. For example, the system would know the users relationship to people in thier narratives and be able to automatically say "Emma is my support worker." Natural Language Generation technology automatically generates evaluations for a phrase. For example the phrase: "Then we went to a restaurant for a meal" would automatically provide the option for the user to select either "it tasted nice" or "it tasted awful".

Challenges in CHRONICLES Design
While the sharing of narratives was derived from existing communication sharing interfaces, we faced a particular challenge in developing a system for the retrieval of stories. A user could potentially have in excess of one hundred stories within the

system and developing a retrieval system which was efficient, intuitive and suitable for use by adults who may have severe cognitive impairments was not a straightforward task.

An additional constraint to this aspect was that the developer who was assigned the task of creating a navigational tool was only available for a relatively short period of time (6 months) and on a part time basis. This is a common problem in research projects, particularly in assistive technology, when the main researchers are often specialists in accessibility and complex assistive technology, but may not have strong software development skills. Software developers are often brought in for a short period of time to assist in the complex programming of the technology and there is a need to ensure the best use of their available time.

The development of a navigation tool required the input of a usability engineer, an expert in Natural Language Generation, a Speech and Language therapist and the project manager. The input of end users would be relied upon extensively when creating a tool that had not existed prior to this project. These challenges forced us as researchers to examine new methods of working.

AGILE SOLUTION
A particular challenge in this project was how to bridge the gap between the software and NLG experts and the end users with SSPI and their support staff which included a speech and language therapist. We piloted an agile approach to the development of the navigational feature of CHRONICLES and developed the role of a "user advocate" for a member of the research team.

SCRUM Team
For this project we adopted the SCRUM branch of agile methodology. The sprint time blocks allow for flexibility in workloads for individual team members which is again important when groups in which some team members may have roles outside of academia. Agile methods allow for the adaptation of the process to best meet a development team's requirements and so the adoption of an adapted framework was used in this project.

Within a SCRUM team there are three core roles: the product owner, the development team and the SCRUM master. These clearly defined roles ensured that everyone in the team was aware of their responsibilities. The product owner should advocate what the customer will be looking for in the software and within our team they became a "user advocate". The user advocate had previously studied a module within the University of Dundee which gave her a theoretical understanding of both the end users of assistive technology and the various aspects of assistive technology, in particular AAC devices. Topics covered in this module included the everyday challenges associated with a variety of physical disabilities and in particular cerebral palsy. Technical features of assistive technology were also covered, including switch scanning and eye scanning as a means of selection in software, the different symbol languages used in AAC and how input prediction can be used to increase the speed of text input. This module also provided an awareness of current research in this area. Prior to this project, she had spent the last 3 years working with adults who had SSPI in a separate software development project and in an exploration of methodological adaptations required to conduct UCD with this population.

The user advocate met with the end users on a weekly basis at their care centre to work with them in ensuring that their points of view were being gathered and brought back to the SCRUM team. Meetings were held in the main leisure room at the care centre and participants would gather around a table on which prototypes could be laid. These meetings lasted for 2 hours with a break in the middle. On the occasions where it was not possible to meet all the participants together due to timetabling problems the user advocate would meet with participants in two separate sessions, one in the morning and one in the afternoon. The user advocate initially used a Dictaphone and ethnographic note taking to record sessions with participants. These ethnographic notes would highlight quotes given by participants and challenges and issues that occurred during the sessions. At the end of the day in the care centre the user advocate would add more detail to these basic notes along with a reflective account of how she felt the sessions had progressed. However, due to the challenges in accurately recording the key non-verbal communication used by adults with SSPI a video camera was later used to capture the sessions. The user advocate would produce a summary of the sessions with participants and bring this back to the development team through an oral report which often incorporated the use of the prototype to recreate the issues that participants had faced.

The development team comprised the sole software developer and the expert in NLG who worked together to develop technical solutions to the challenge of navigation and how to implement the users' wishes into the solution.

All members of the development team had at some point met at least one adult with SSPI, although they did not all directly work with them. In the United Kingdom there are ethical and legal issues which may mean it is not possible for the entire

team to work in a care home. Every researcher who works in a care home must have had a criminal background check which the project will need to pay for. In addition many care centres or charity organisations may need to carry out their own approval procedures before a researcher can enter the environment. There are also security concerns in bringing a large number of "strangers" to a care centre and often it is important that all staff are personally introduced to any researcher in the environment. Finally, as meeting new people or having their environment disrupted can be confusing and upsetting for adults with complex disabilities it is best to minimize the disruption as much as possible.

Sprint Measurements

The regular sprint and scrum meetings were adopted in this project. This was of significant benefit in this project as it ensured that participants were always aware of what they would be designing or evaluating in the coming week. Adults with SSPI, particularly those with cognitive impairment can become unsettled by surprises and this helped to reduce uncertainty for participants. The development of CHRONICLES as a whole took nine months and throughout this project each sprint lasted for three weeks.

SPRINTS

Pre-Sprint: Recruitment and Informed Consent

Traditionally participants would be recruited through adverts in the local press or University, or by being contacted directly from researchers who have been given their contact details by organization [11]. These methods are not best suited to working with adults with SSPI who may have literacy problems which limit the opportunity for them to see such adverts. Additionally we were aware that people with SSPI are often excited by the opportunity to work with people from outside their care centre. We did not want to cause distress for potential participants who would apply to take part in our research only to find out that they do not meet all of our participation criteria.

Contact was made with a local centre for adults with a variety of complex disabilities including SSPI. The centre management was provided with details of the study. The management then provided a site-specific study coordinator to be the liaison on the project. We met with the study coordinator and gave further study details and asked them to consider potential participants. The study coordinator met with potential participants and with their consent arranged a meeting between them and the user advocate.

The user advocate had experience in the informed consent process when working with participants with SSPI and other complex disabilities. It was important for us to ensure that participants were aware of their rights as study participants and that they understood what the project would entail. We developed a written consent form that was read out to participants individually by the site-specific study coordinator. Where the study coordinator deemed it to be appropriate she incorporated the use of symbols to support the information being given. Following the reading of the information sheet, the study coordinator would encourage the participants to ask questions about the study. Initially the study coordinator found that participants were reluctant or hesitant to ask questions and that they simply wanted to begin work on the study.

The study coordinator had been fully briefed on the importance of the participants being fully confident about what they were signing and so prompted them by asking questions such as *"but what about the timing? Do you know how long you would be working with the researchers for?"*. This often resulted in questions being asked by participants. The study coordinator then would read out the consent form to participants using the methods described in [1]. Participants were asked questions such as "Do you have to give a reason if you want to stop taking part?".

Once the study coordinator was confident that the participant was fully briefed on the study they would ask them to sign the consent form. In the case of two participants guardianship orders were in place and so letters were sent to their legal guardians, asking for their additional consent to the participant taking part in the study.

Participants

The end users in this study were comprised of 4 adults (female:2, male:2) with SSPI aged between 22 and 60. All of the participants had cerebral palsy and in addition to their communication impairment had mobility impairments and some level of cognitive impairment (ranging from mild to moderate). Motorised wheelchairs were used by all of the participants to travel around the centre. Three participants used AAC as their main method of communication; the remaining participant used it in addition to severely dysarthric speech. Two participants had no functional literacy and used a combination of symbolic language to access language. Three participants used touch to select options on their AAC device while the other used a switch device to scan through the user interface. Switches are typically physical buttons which a user

can press when the option they are searching for is highlighted. This provides an alternative input method for those for whom a mouse or touch screen is not appropriate.

Sprint	Objective	Team Members Tasks*
#1	Storytelling ability assessment	UA – Sessions understanding particpants' current level of story telling SLT – Assisted in evaluating storytelling ability
#2	Gathering of participants personal narratives	UA – Sessions to gather narratives from participants SLT – Examination of narratives NLG – Assisted in holding narrative conversations
#3	Requirements gathering for navigation of stories	UA – Conducted requirements gathering with participants SD– Developing understanding of project
#4	Paper mock ups	UA – Developing and evaluating mock ups SD – Background code NLG – Assisting in mock ups
#5	Mid fidelity prototype produced using accessible PowerPoint	UA – Developing and evaluating prototypes SD – Developing navigational code
#6	Mid fidelity prototype concentrating on layout using C#	UA – Evaluating prototype and adapting requirements SD – Creating voice output integration and keyword searching
#7	High fidelity prototype in C# with keyword searching integrated	UA – Continuing evaluations and gathering of further user narratives to compare stories SD – NLG integration with retrieving and sharing stories NLG – Assisted with NLG integration, particularly retrieval
#8	High fidelity prototype with basic NLG integrate into retrieval	UA – Testing of NLG with users, examining how software could be deployed on participant's equipment SD – Ensuring integration across

	and telling of story	devices NLG – Assisted with how NLG could be used for advanced story retrieval
#9	Software deployed on end devices with advanced NLG	UA – Evaluated use of software on end devices SD – Worked with UA to deploy software
#10	Completed software used with participants, error testing	UA – Completed work with users at centre SD – Final error testing
#11	Evaluation with expert users	UA – Evaluation with expert users NLG – Assisted evaluation
#12	Examination of evaluation results	UA – Data analysis SLT – Data analysis

*UA – User Advocate (full time throughout project), SLT – Speech and Language Therapist (part time throughout project), NLG – NLG expert (part time throughout project), SD – Software Developer (part time, sprints 3-10)

Table 1 - Timeline of Sprints

First and Second Sprint - Becoming embedded in the environment

The user advocate was aware of the challenges that can occur when a stranger enters a closed environment such as a care centre and that this can alter the information that we as researchers can gather. The team was concerned that participants might be reluctant to give negative feedback on design suggestions or software if they were not comfortable with the researcher. Prior [21] advises that the researcher spend time in the environment, getting to know participants and slowly working towards a level of understanding where they will feel comfortable in being honest and sharing their views and concerns regarding ideas with her.

The user advocate spent a month in the environment working on small research projects, assisting with activity sessions, e.g. a drama group, and allowing participants to get to know her and become comfortable with her. This extended period was needed due to the unpredictability of a care centre environment, in which activities may be cancelled at short notice or participants are taken somewhere else during the time the researcher plans to spend with them.

The user advocate also worked with participants to understand their level of storytelling abilities through several 'storytelling' activity sessions. In the first session the focus was on helping the participants feel comfortable in the group and to assess their storytelling skills. Members were introduced to each other and asked to describe a story they were shown in a photograph, for example a man at the stove cooking. Participants were then guided through a storytelling conversation based upon the picture e.g. "Why is the man cooking?". This provided prompts for stories to be shared without relying upon participants thinking about their own personal narratives at this early stage.

With the assistance of the SLT, the user advocate encouraged participants to share stories and noted the degree to which the participant led the conversation, asked questions of the listener and were able to change the way they told the story based upon the responses of the listener. This revealed that all participants struggled with at least some aspects of storytelling, particularly the interactive elements. Two participants had significant problems in sharing stories and had to be prompted throughout the storytelling session for information and to continue with the story.

In the following sessions participants were encouraged to begin sharing narratives about recent events; for some participants this was based upon information the user advocate and the centre's communication worker had about trips out that participants had been on.At the end of the second sprint, a sprint review was held with the full SCRUM team. The software developer highlighted that one of his key concerns was how the stories would be organised visually. The team discussed possible methods and the user advocate was asked to explore these with participants.

Third Sprint – Initial Ideas Gathering and Mock Ups
By the time of the third sprint, the four participants involved in the project had become aware of the aims of the project and what the software could potentially achieve. The user advocate held two discussion groups with the participants thinking about how they could retrieve stories. The participants felt that they would prefer to see all the stories linearly. There was always a member of care centre staff in the group when the user advocate worked with participants and they helped to ensure that the user advocate was capturing the participants' views correctly.

At the sprint review the user advocate presented this feedback to the SCRUM team and suggested that they could start on initial prototypes. There were concerns by the rest of the SCRUM team that linear stories would prove confusing when a large number of stories were entered into the system. While the user advocate was clear that this was what the users had requested she agreed to the team's request that this issue was carried into the next sprint and paper mock-ups were produced to ensure that this method would really work for the users.

Figure 1 - First Paper Mock-Up

Fourth Sprint – Paper Mock-ups
Three different forms of paper mock-ups were produced; one based on a categorisation system, one based on stories being displayed linearly (see Figure 1), and one based on a time line (see Figure 2). The time line allowed participants to select a time period and see stories from that time period displayed on a road.

Using her experience in working with adults with SSPI the user advocate worked with participants in using the paper mock-ups, asking them to retrieve a set of stories using each of the different systems. Following this a focus group was held in which participants discussed and examined each of the possible systems. Participants expressed a change of opinion about their preferred system and instead preferred the time based interface.

The user advocate was then able to return to the development team with data from the evaluations of the paper mock-up, including the time required to find a given story. This information was used by the development to produce the first basic computer interface version of the navigation system.

Figure 2 – Second Navigation Mock Up

Fifth – Tenth Sprints

Following the major design decision the sprints continued with the software development team producing small pieces of additional functionality every three weeks and the user advocate working with the end users to evaluate it and provide feedback. One benefit that was found in using a user advocate to work with the users was that she was able to listen to any criticism by the users impartially and not rush to defend the software.
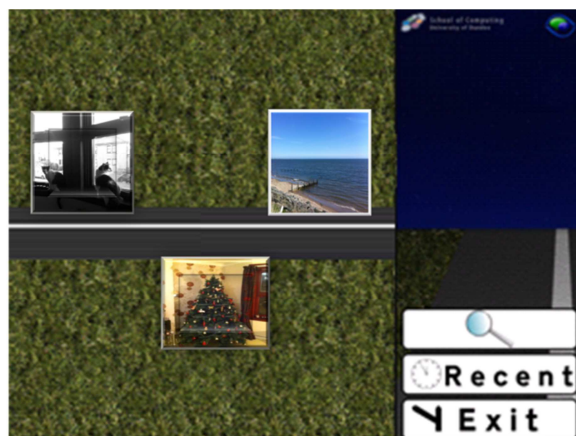

Figure 3 - Later Prototype of Navigation

As the project progressed the user advocate became aware of the importance of being able to clearly explain to the software development team why the users had particular concerns or issues that needed to be addressed. A video camera was then used in sessions with participants.

Eleventh and Twelve Sprints

The final two sprints were centred on the evaluation of the navigational tools (see Figure 3). Rather than use the existing participants we decided to work with a group of expert users: five adults with SSPI who use AAC and who have been trained in the evaluation of software. This decision was made as the original participants had helped to tailor the navigational system and while it worked well for them, it was important that we could be sure if would work for other users of AAC as well.

The expert evaluators rated the navigational software highly and were overall impressed with its design and functionality.

RESULTS

All of the adults in the study made contributions to the eventual design and functionality of the system. Care had to be taken to ensure that participants were given sufficient periods of time to compose answers to questions or to share their views on a feature of the software. We found participants to be respectful of each other and in general were very patient in waiting for one another to share views. Initially one participant tended to dominate the group discussion but over the

course of the sprints we witnessed other participants gaining in confidence and standing up for their opinions and their right to speak in a conversation.

The users were all involved on a weekly basis and worked as a group to identify challenges and issues in using the system. Several significant features in the end software came as a direct result of participant involvement, including the use of a rapid answer button designed to generate stock answers to questions that could be asked of an utterance and the design of the story navigational features. Users held discussions with one another and attempted to find solutions that would work for all participants in the group.

At times the user advocate faced problems when users attempted to agree on everything and would not raise issues with a suggestion that may have been made by a more dominant member of the group. The user advocate sought to work around this by quickly mocking-up the suggested solution and asking the quieter members of the group to use it. By asking them to use prototypes in 'real time' any problems that could come from a solution were identified quickly and in a way that did not cause direct conflict.

The users involved in the study all reported enjoying their sessions with the user advocate. Before completion of the study the user advocate held a meeting with staff at the care centre to explain the work that users had undertaken and discussed with them the possibility for the group to continue to meet to address other problems with technology happening in the centre.

DISCUSSION

Agile has not typically been associated with development projects with one or two software developers. The use of Agile has also tended to be focused on the software development and the functionality and code that is being produced. Working with users throughout the sprints is not traditional, nor is such a heavy focus on design.

The advantages in this approach lie in the ability to give end users a greater level of involvement in the development of the software than would have been possible without the user advocate and for each member of the research team to play to their own strengths. The use of the agile methodology means that all members of the team can work concurrently and ensures that each member of the team is constantly aware of the progress being made by other team members, meaning that there is less potential for problems to occur due to a lack of communication between team members.

We found that using Agile in the development of CHRONICLES allowed the user advocate to have a degree of freedom in exploring the users' wish list for the software without delaying the progress of the software.

One clear example of this was how the navigational tool should be structured; the user advocate listened carefully to the opinions of the participants who in turn felt that they were being heard. By using a SCRUM approach, the team was able to work together to quickly ascertain that the best decision was being made in this fundamental aspect of the design.

This approach was of benefit to the software developer who could focus on the technical challenges in this software. In a more traditional design, by focussing on technology there is a high risk that the developer could forget about usability and the end user. This methodology ensured that this did not happen, the daily meetings with the user advocate helped to keep the software developer aware of the usability without having to devote large periods of time to it.

This highly structured approach was also of benefit to our participants who can become anxious when they are not kept informed of what the next steps in a process would be. The other advantage to participants is that by having the user advocate work closely with participants they are able to build up a working relationship with them and we found that our user advocated began to understand participants' different gestures and vocalisations, as well as recognizing when they were becoming tired.

A disadvantage in this approach is the challenge in accurately describing how a participant used the software and why participants faced difficulties to the rest of the development team. The various physical impairments that participants had meant that they all accessed the software in different ways. We found that videoing these sessions helped the user advocate greatly when presenting feedback to the rest of the team. The other disadvantage in this approach is that relying on the one user advocate to travel to a care centre caused problems when the user advocate could not attend on the day due to transport difficulties or ill health.

As a team we found that the SCRUM approach worked well in the CHRONICLES development helping us to bridge the gap between end users and the technologists. It is possible that if this method was applied more widely to AAC development some of the usability issues that contribute to the high levels of abandonment could be prevented. This methodology

allows users to have their opinions heard and listened to by someone with training in SSPI, meaning that it is not necessary for the software developers to devote large periods of time to working with the users. This has been a concern amongst researchers when considering working with adults with SSPI.

Generalizability

Some constraints that we faced in the CHRONICLES project are highly specific to the AAC engineering field (e.g. the need for NLG experts alongside usability engineers) however other challenges in this project can also be seen in other fields. While relatively few other projects are likely to require such in depth work with adults with SSPI there are many other challenging populations which could benefit from involvement in the design of technology, for example patients in hospitals, children both with and without disabilities, older adults and occupations which require an in depth understanding of complex issues (for example navel engineering). By including a user advocate on the research team who has knowledge of a specific population there is the opportunity for the research team to gain a better understanding of the needs of the target users. We would recommend other teams look to recruit a user advocate with experience of HCI and usability as well as experience of working with the target population. This then allows the team to recruit software engineers who may have less understanding of the specific usability issues but who have the necessary technical skills to produce the end software.

Industry has piloted the use of advocates for the end users [8] in agile approaches and we believe there is scope for other research fields to work with industrial companies using an agile approach in order to learn from one another.

CONCLUSION

This study has discussed how a user-centred design and development project can be managed to involve adults with SSPI as active participants. We have demonstrated how the SCRUM methodology can be adapted to support decision making by end users while balancing the needs of the software developers. The core of Agile methodology is the intrinsic role of the client/end user in the development process [14].

By its very definition, the adaptability of the Agile methodology makes it suitable when designing systems for and with hard to reach populations. We would therefore highly recommend the exploration of this methodology by others in the field of HCI and assistive technology who have concerns about working with end users.

ACKNOWLEDGMENTS

REFERENCES

1. Balandin S, Berg N, Waller A. 2006. Assessing the loneliness of older people with cerebral palsy. *Disability & Rehabilitation* 28:469 - 79
2. Black R, Reddington J, Reiter E, Tintarev N, Waller A. 2010. Using NLG and sensors to support personal narrative for children with complex communication needs. In *NAACL HLT 2010 Workshop on Speech and Language Processing for Assistive Technologies*, pp. 1-9. Los Angeles, California: Association for Computational Linguistics
3. Boyd-Graber J, L. , Nikolova S, S. , Moffatt K, A. , Kin K, C. , Lee J, Y. , et al. 2006. Participatory design with proxies: developing a desktop-PDA system to support people with aphasia. In *Proceedings of the SIGCHI conference on Human Factors in computing systems*. Montreal, Quebec, Canada: ACM
4. Braun J, Al Mahmud A, Martens J-B. 2010. Capture Me! Helping People with Aphasia to Capture and Share Life Experiences. In *BCS HCI 2010*. Dundee, Scotland
5. Carmichael A, Newell A, Dickinson A, Morgan M. 2005. Using theatre and film to represent user requirements. In *Proceeding of Include Conference Royal College of Art*. London
6. Demchak M, Rickard C, Elquist M. 2002. Using Cues to Enhance Receptive Communication. ed. NDSI Project. Nevada: University of Nevada
7. Enders A, Hall M. 1990. *Assistive Technology Sourcebook*. Washington: Resna Press. 576 pp.
8. Fox D, Sillito J, Maurer F. 2008. Agile Methods and User-Centered Design: How These Two Methodologies are Being Successfully Integrated in Industry. In *Proceedings of the Agile 2008*, pp. 63-72: IEEE Computer Society
9. Glennen S, Descoste D. 1997. *The Handbook of Augmentative and Alternative Communication*. Thomson Delmar Learning. 795 pp.
10. Hoyt T. 2009. The development of narrative identity in late adolescence and emergent adulthood: the continued importance of listeners. *Developmental Psychology* 45:558-74
11. Krueger RA, Casey MA. 2009. *Focus Groups A Practical Guide for Applied Research*. California, United States of America: SAGE Publications
12. Larsson M, Sandberg A, Smith M. 2009. Reading and Spelling in Children with Severe Speech and Physical Impairments. *Journal of Developmental and Physical Disabilities* 21:369-92
13. Lazar J, Feng JH, Hochheiser H. 2010. *Research Methods in Human-Computer Interaction*. United Kingdom: Wiley

14. Lukanuski M, Milano M, Bruin Jd, Rochford M, Bosman R. 2008. Agile or awkward: surviving and flourishing in an agile/scrum project. In *CHI '08 Extended Abstracts on Human Factors in Computing Systems*, pp. 2253-6. Florence, Italy: ACM

15. Luo F. 2009. *Personal narrative telling by individuals with ALS who use AAC devices*. http://gradworks.umi.com/33/42/3342143.html

16. MacDonald BK, Cockerell OC, Sander JWAS, Shorvon SD. 2000. The incidence and lifetime prevalence of neurological disorders in a prospective community-based study in the UK. *Brain* 123:665-76

17. McLean KC. 2008. Stories of the young and the old: Personal continuity and narrative identity. *Developmental Psychology* 44:254-64

18. Newell A, Gregor P. 2000. "User sensitive inclusive design"; in search of a new paradigm. In *Proceedings on the 2000 conference on Universal Usability*. Arlington, Virginia, United States: ACM

19. O'Keefe BM, Kozak NB, Schuller R. 2007. Research priorities in augmentative and alternative communication as identified by people who use AAC and their facilitators. *AAC: Augmentative & Alternative Communication* 23:89-96

20. Preece J. 1993. *A guide to usability - human factors in computing*. Addison Wesley Publishing Company. 144 pp.

21. Prior S. 2011. *Towards the Full Inclusion of People with Severe Speech and Physical Impairments in the Design of Augmentative and Alternative Communication*. University of Dundee

22. Prior S, Betzler H, Waller A. 2010. The Participatory Design of a Talking Photo Album for Adults with Severe Speech and Physical Impairments. In *RaATE Conference*. Coventry, UK

23. Redmond SM, Johnston SS. 2001. Evaluating the Morphological Competence of Children With Severe Speech and Physical Impairments. pp. 1362-75

24. Riemer-Reiss ML, Wacker R. 2000. Factors Associated with Assistive Technology Discontinuance among Individuals with Disabilities. *The Journal of Rehabilitation* 66:44-50

25. Sharp H, Rogers Y, Preece J. 2007. *Interaction Design: beyond human-computer interaction*. Chichester: John Whiley & Sons Ltd. 759 pp.

26. Todman J, Alm N. 2003. Modelling conversational pragmatics in communication aids. *Journal of Pragmatics* 35:523-38

27. Waller A. 2006. Communication Access to Conversational Narrative. pp. 221-39

28. Waller A, Dave OM. 2002. Aided communication and the development of personal storytelling. In *Augmentative and Alternative Communication: Developmental Issues*, ed. S van Tetzchner, N Grove. London, UK: British Library. Number of.