The Design and Field Evaluation of PhotoTalk: A Digital Image Communication Application for People who have Aphasia

by

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Abstract

PhotoTalk is a software application for a mobile device that allows people with aphasia to capture and manage digital photographs in order to support face-to-face communication. Aphasia is an acquired language impairment which can affect speaking, auditory comprehension, reading and writing. Individuals with aphasia often find it challenging to communicate verbally, although they generally retain their ability to recognize images. Unlike any other augmentative and alternative communication device, our application focuses *solely* on image capture and organization and is designed to be accessible to people with aphasia.

The PhotoTalk project used a streamlined research process that consisted of 4 phases: (1) a participatory design phase involving speech experts, (2) an informal usability study, (3) the primary evaluation of PhotoTalk, a 1 month field study with 2 people who have aphasia, and (4) a secondary field study with 1 individual who has aphasia.

Two speech-language pathologists acted as representative users in the participatory design phase in order to rapidly design and develop PhotoTalk and to move quickly to the evaluation stage with individuals who have aphasia. The informal usability study with 5 participants caught usability problems and provided preliminary feedback on the usefulness of PhotoTalk before we moved forward with the field studies.

Our 1 month field evaluations with 3 users demonstrated the application's promise in terms of both its usability and usefulness in *real life* situations. Both participants in the primary field study used PhotoTalk regularly and fairly independently throughout the field study, although not always for its intended communicative purpose. The participant in the secondary study was able to use PhotoTalk completely independently for specific communicative purposes.

In this thesis we describe the streamlined research process we used, the PhotoTalk application, the informal usability study, and the two field studies, as well as provide preliminary guidelines for involving domain experts in assistive technology research.

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Co-Authorship Statement

The work on involving domain experts in assistive technology research, in Section 2.4, all of Chapter 5, and parts of Chapter 6 (hereafter referred to as the co-authored thesis sections), is largely based on a co-authored paper written by myself, Rock Leung, Joanna McGrenere, and Barbara Purves that is currently under submission. I was the lead author for the co-authored paper; however, significant portions of the material were written and edited by Leung, McGrenere, and Purves. The co-authored thesis sections include only slight modifications from the co-authored paper. All authors have given permission to include material from the co-authored paper in this thesis.

The identification of the research problem discussed in the co-authored thesis sections occurred during a meeting between myself and McGrenere, who is my academic supervisor.

In the co-authored thesis sections, we draw heavily on PhotoTalk (my master's thesis project reported in this thesis) and the ALEX Project [32, 33, 37], which is Leung's master's thesis project. I was not involved in the ALEX Project research.

No data analysis is reported in the co-authored thesis sections.

The core work on the PhotoTalk project described in this thesis will be submitted as a paper co-authored by myself, McGrenere, and Purves. Purves has been involved in a co-supervisory capacity since the outset of this project.

Chapter 1

Introduction

PhotoTalk is an application for a mobile device that allows people with aphasia to easily capture and manage digital photographs in order to support face-to-face communication. PhotoTalk supports communication by providing a platform for users to capture personally meaningful images and share them with their communication partners. The ease of sharing images allows for communication that would otherwise be more difficult or impossible verbally or gesturally. Someone with aphasia can use PhotoTalk to share important personal information with others, such as photographs of her family, pets or hobbies or to show her husband photographs captured during daily events, taken while he was at work.

In this chapter we provide a brief introduction to aphasia, the motivation and objectives of this research project, a summary of our contributions, and a research overview.

1.1 What is Aphasia

Aphasia is an acquired language impairment which can affect speaking, comprehension of spoken language, reading and writing [48]. Aphasia is most often caused by a stroke, although other brain damage such as a tumour or injury can also be a cause [42]. The incidence of stroke increases with age, so the majority of people with aphasia are older; however, aphasia can affect individuals of any age. It is estimated that 1.1 million North Americans have aphasia [26]. Since aphasia is an acquired disorder, people are suddenly unable or less able to communicate after having successfully communicated for their entire lives. People with aphasia can participate in speech and language therapy and often improve their speech and language skills over time. It is rare for a person with aphasia to fully recover the communication abilities they had before they acquired aphasia - usually it is a lifelong impairment.

Individuals with aphasia present different patterns of symptoms. In addition, the severity of symptoms can vary across individuals. Some people with aphasia struggle to find certain words, usually nouns, while others may only be able to produce a very small set of words. There are a number of different types of aphasia; each individual will fit roughly into a category, although each person will likely have slightly different symptoms even if they have the same type of aphasia. Although people with aphasia often have difficulty communicating with written or verbal language, they generally retain their ability to recognize images [53].

Aphasia is primarily a communication impairment; it affects the information coming into and going out of the brain [48]. However, aphasia also affects the underlying cognitive processes of language [9]. In particular, aphasia has been linked to several cognitive challenges involving memory, attention, perception, and resource capacity and allocation [18].

1.2 Motivation

One of the motivations for PhotoTalk was to provide a means for social communication for people with aphasia. The National Joint Committee for the Communication Needs of Persons with Severe Disabilities defined communication as:

> Any act by which one person gives to or receives from another person information about that persons needs, desires, perceptions, knowledge, or affective states. Communication may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or nonlinguistic forms, and may occur through spoken or other modes. [43]

In 1988, Light created a taxonomy that classifies communication into four categories: needs and wants, information transfer, social closeness, and social etiquette [35]. Messages from each of these categories of communication have different goals and the content of the messages is of varying degrees of importance. The goal of expressing your needs and wants is to affect the behaviour of your communication partner in some desired way. The content of these messages is very important. Messages for information transfer are more involved than messages for expressing basic needs and wants, and include information content such as a description of a social event. The goal of information transfer is to share information with your communication partner. The content of these messages is also very important. Social closeness is a vital form of communication as its goal is to establish, maintain, or develop personal relationships. In this type of communication, the content of the message is less important than the feelings invoked by the communication. Social etiquette communication, such as saying please and thank you, allows people to conform to social standards.

The goal of augmentative and alternative communication (AAC) is to enable an individual to effectively participate in a variety of communication interactions [6]. Many AAC systems address the necessity of expressing needs and wants - communication books (described in Section 2.1.1) are often designed solely for this purpose. Most AAC systems have focused entirely on the expression of needs and wants, with a smaller amount of work done on information transfer. As discussed by Beukelman and Mirenda, the lack of research and technical developments in the area of AAC for social closeness reflects not only the concentration of the field on the communication of needs and wants, but also the difficulty of successfully creating AAC systems which allow the type of communication necessary for social closeness [6]. Our aim was to develop a tool that could be used for information transfer messages as well as social closeness messages.

An additional motivation of PhotoTalk was to provide an AAC device that is developed on standard commercial technology. The aesthetics of an AAC system can be extremely important; even if an AAC system is useful, adults may not want to use it if it is aesthetically unpleasing [23]. PhotoTalk had to be implemented on a standard device; the aesthetics of traditional communication devices often draw immediate attention to the users deficit, which is one reason why some people with communication impairments choose not to use them. The development of PhotoTalk on a standard device ensured that users would be able to use the system without drawing attention to their impairment, and by using cutting-edge technology, subtly demonstrate their significant cognitive abilities despite their difficulty communicating.

The PhotoTalk research is being conducted within the Aphasia Project, which is a multi-disciplinary research project with the objective of designing technology to support people with aphasia in their daily lives [45]. A long term goal of the Aphasia Project is to design a digital remnant (life) book for people who have aphasia. A traditional remnant book is physical in nature, often a three ring binder with pages containing text, images, and other artifacts. The items included are meaningful to the individual and convey information about their past life events [24]. The act of sharing this book creates a feeling of closeness between the communication partners, thus fufilling the communication need of social closeness. The goal of a *digital* remnant book is to allow the user to collect personally meaningful multimedia files such as photographs, movies, and sound clips that they can share with others on a portable device. Traditional remnant books tend to be static, whereas the digital variant could be considerably more dynamic given the potential ease of capturing multimedia data. In addition, a digital remnant book developed for a small mobile device could be significantly more portable than a traditional remnant book.

As a first step towards a digital remnant book, Davies, Marcella, McGrenere, and Purves investigated the feasibility of using a PDA given its portability and cachet. They performed an ethnographically informed field study with a single aphasic user to determine which aspects of a PDA were most effective and most troublesome for the participant [14]. They discovered that PDA file access was the most challenging, and together decided to focus on the file system. Davies and the participant used participatory design (PD) to create a file system called FileFacility, which was designed for this user to manage and access his files. One of the findings from that research was that it remained difficult to manage images in FileFacility. PhotoTalk was designed to address this limitation as a further step towards creating a digital remnant book.

1.3 PhotoTalk Research Objectives

The key objectives of PhotoTalk were: (1) to design an application for a mobile device that would allow people with aphasia to independently capture and manage digital photographs to support face-to-face communication, and (2) to evaluate this application in a field study. Many current communication systems require someone other than the end user to import and organize the contents of the system (for example, [4, 56]). The objective of independent use by the end user was crucial for PhotoTalk. We planned on implementing PhotoTalk for a mobile device so that users could capture and share their pictures anywhere, thereby supporting face-to-face communication in all contexts that are useful for the user. Evaluating PhotoTalk in a field study was vital to determine *how* individuals would use PhotoTalk in their daily lives.

A secondary objective of the PhotoTalk research was to use a streamlined design approach and to document the merits of this approach. We conducted a PD phase with two speech-language pathologists, clinically trained experts in aphasia. Including these experts in the design team instead of target users allowed us to very quickly complete the design phase. We wanted to investigate the advantages and disadvantages of working with speech-language pathologists instead of target users when designing assistive technology for people with aphasia.

1.4 Contributions

The contributions from the PhotoTalk research project are: (1) the design of the first application for a mobile device that is *solely* focused on image capture and organization and is accessible to people with aphasia, (2) a 1 month field evaluation with 3 users demonstrating the application's promise in terms of both its usability and usefulness in *real life* situations, and (3) preliminary guidelines for working with domain experts when designing assistive technology.

1.5 Research Overview

Our streamlined design approach began with a PD phase with two speech-language pathologists. We then conducted an informal usability study with 5 participants who have aphasia to identify usability problems. As our main evaluation of PhotoTalk, we ran a 1 month field study with 2 individuals who have aphasia to understand how they would incorporate PhotoTalk into their daily lives. We found that both individuals used PhotoTalk fairly independently and used it regularly throughout the field study, although not always for its intended communicative purpose. We then ran a second field study with the aphasic individual who was involved in the 4 month ethnographically informed field study and PD of FileFacility [14]. This individual was able to use PhotoTalk completely independently for specific communicative purposes. Overall, our results indicate that PhotoTalk shows promise as a communication tool for individuals who have aphasia.

This thesis consists of six chapters, including this chapter. Chapter 2 covers previous research that is relevant to PhotoTalk. Chapter 3 explains the PD process we used and describes the PhotoTalk system in detail. Chapter 4 describes the three evaluation phases and discusses the results of the two field studies. Chapter 5 presents guidelines for involving domain experts in assistive technology research, and Chapter 6 is our conclusions and plans for future work.

Section 2.4, all of Chapter 5, and parts of Chapter 6 are under submission as a paper co-authored by Meghan Allen, Rock Leung, Joanna McGrenere, and Barbara Purves. All of Chapter 3, Section 4.1, Section 4.2, Section 4.4, and parts of Chapter 6 are under submission as a separate paper co-authored by Meghan Allen, Joanna McGrenere, and Barbara Purves.

Chapter 2

Related Work

> In a fair society, all individuals would have equal opportunity to participate in, or benefit from, the use of computer resources regardless of race, sex, religion, age, disability, national origin or other such similar factors. [17]

In 2000, Shneiderman proposed a research agenda based on three challenges to providing universal access to technology: user diversity, gaps in user knowledge, and technology variety [50]. The user diversity challenges he presented included accommodating users with disabilities. Providing equal access to technology is an important current goal for the HCI community. The Aphasia Project focuses on creating technology that is accessible to people who have aphasia, and the PhotoTalk research focuses specifically on creating an image based communication system.

In this chapter we review previous research that is relevant to our work. We focus on five areas that are most relevant - augmentative and alternative communication techniques and devices, field evaluations of AAC devices, communicating with images in the broader population, involving experts in assistive technology research, and the adoption of assistive technology.

2.1 Augmentative and Alternative Communication (AAC)

The American Speech-Language-Hearing Association (ASHA) defined Augmentative and Alternative Communication (AAC) as

> An area of clinical practice that attempts to compensate (either temporarily or permanently) for the impairment and disability patterns of individuals with severe expressive communication disorders (i.e., the severely speech-language and writing impaired). [2]

The goal of AAC is to enable an individual to effectively participate in a variety of communication interactions [6].

2.1.1 Low Tech AAC Techniques

There are many examples of low tech AAC techniques. Some of the techniques, such as gesture and drawing, are used in everyday conversation by people who do not have communication impairments. However, people with aphasia rely more heavily on these techniques as they may be less able to verbally communicate. Each individual who has aphasia is likely to only use the subset of techniques and strategies that she finds most useful.

Written choice communication is a technique in which the communication partner asks a question of the person with aphasia and presents her with some written choices [54]. This technique is based on the fact that people with aphasia will better understand information that is presented in multiple modalities, such as a combination of speech and writing, than information that is presented in a single modality [24]. A useful variant of written choice communication presents a scale to the person with aphasia for them to use in their response. For example, ASHA created the Quality of Communication Life Scale in 2004 for use with people with aphasia [44].

Gestures can be an extremely valuable AAC technique. Gestures can be intuitive for communication partners because many people use gestures to convey needs and wants, feelings, and directions. However, since aphasia is often caused by a stroke, people with aphasia may also have physical impairments which can make gesturing challenging. Although gestures are often intuitive to communication partners, this is not always the case. Gestures can be confusing, especially when many different gestures are used in one communicative interaction [24].

A physical remnant book is an artifact which contains items that are meaningful to the individual and convey information about her past life events [24] (described in Section 1.3). Sharing these personally meaningful items with others fulfills more than just an information transfer communication need: remnant books can be used to fulfill the communication need of social closeness. Individuals may share the same item with the same partner multiple times. Remnant books are an important AAC technique because there are few AAC systems that can fulfill the communication need of social closeness. However, a drawback of physical remnant books is that they must be continuously updated, often by someone other than the aphasic user. The PhotoTalk research builds on the FileFacility research [14] as a further step towards creating a digital remnant book.

Drawing is a common technique that can be used by a person with aphasia and her communication partner to convey information. There are two main approaches to drawing in this context [49]. The first approach trains the person with aphasia to create recognizable drawings so they can become an independent communicator. Using this approach, the communication partner receives the message from the drawing and does not add to the drawing. The second approach uses drawing as an augmentative tool and the focus is on the exchange of ideas between the person with aphasia and their communication partner, rather than on the quality of the drawings. With this approach, both the person with aphasia and their communication partner can add to the drawings in order to make their ideas understood.

Communication books contain pages of pictures, symbols, and words that someone who has aphasia can point to in order to express her needs and wants. Communication books can be extremely useful for people who are only able to produce limited amounts of speech or who have severe word-finding difficulties [24]. Personalized communication books include additional information such as information about hobbies or photographs of family members [24].

Instruction cards can be handed to new communication partners by someone who has aphasia to explain how to best communicate [24]. The cards explain what aphasia is, and give specific instructions on how to successfully engage in communication.

2.1.2 High Tech AAC Devices

Many high tech AAC systems have been developed for people with cognitive disabilities. This section will focus on the high tech solutions that are most relevant to the PhotoTalk research.

Devices Developed by the Aphasia Project Team

The PhotoTalk research was largely guided by previous projects conducted by the Aphasia Project team which provide insight into how to best create technology for people who have aphasia. The Visually Enhanced Recipe Application (VERA) was developed to help people with aphasia cook more independently

[52]. VERA is a multi-modal recipe book which uses a visual language for cooking instructions plus the ability to play the instruction via digitized speech. The results of the evaluation with 4 users were mixed; however, the most severely impaired individuals benefited the most from the multi-modal cookbook.

The Enhanced with Sound and Images Planner (ESI Planner) is a multimodal day planner for a mobile device which incorporates sounds and images so people with aphasia can more easily make and keep appointments [39, 41]. A lab study was conducted with 9 participants who have aphasia comparing ESI Planner to a text only daily planner. Participant preferences were split between ESI Planner and the text only planner. Moffatt et al. hypothesized that the reading ability of the participants was the cause for the split preferences, with the more severely impaired individuals preferring ESI Planner.

More recently, ESI Planner II and LgLite [7] were developed to provide a combined portable communication device and daily planner for people with aphasia. LgLite is a simpler version of Lingraphica (described below) that was designed to have a more modest learning curve. The combined ESI Planner II and LgLite system allow people who have aphasia to create digital speech communication on a desktop computer and download this speech to a mobile device to support communication away from the desktop computer. The speech can be associated with specific appointments, such as a doctor's appointment. A 4 week long field study was conducted with 7 aphasic individuals to evaluate ESI Planner II and LgLite. The evaluation revealed some usability problems with the system, but 6 of the 7 participants were able to independently use it by the end of the field study showing its promise.

As described in Section 1.2, Davies et al. conducted an ethnographically-informed field study on how one individual with aphasia used a PDA and then used participatory design to create FileFacility [14].

Devices for People who have Aphasia

Lingraphica is a dedicated AAC device that allows people to construct phrases and sentences by dragging corresponding images into the correct order on the screen [25]. These phrases are then spoken with digitized speech and animations are displayed on the screen for verbs. Lingraphica comes with 2,200 images, which supplies a large vocabulary for users to express their thoughts. The system also comes with many preloaded phrases as well as extensive practice materials. Lingraphica can be personalized to include the names of friends and family or other personal items. To our knowledge, there have been no recent evaluations of Lingraphica reported in the literature; however, evaluations have been performed on C-VIC, which is the precursor to Lingraphica. For example, Weinrich et al. conducted a study that showed some individuals with aphasia were able to understand and produce C-VIC phrases [58].

EasySpeaker provides a icon-based communication aid for people who have aphasia on a laptop or desktop computer [47]. The 800 pre-loaded items are organized into hierarchical screens according to topic, and personal content can be added for each user. For 20% of the items an appropriate icon could not be found, so text was displayed instead. Digital photographs are not used in this communication aid. The user can select items sequentially, which are then concatenated together and spoken with a recorded voice. Rostron, Ward, and Plant report a 4 week field study with one individual who used EasySpeaker in his own home [47]. Nine structured meetings were held during the study. They found that although the participant was able to perform most of the tasks he was given, he did not use EasySpeaker for communicative purposes outside of the structured meetings. Rostron et al. suspected that one of the reasons for this was because EasySpeaker was deployed on a physically large device that took some time to turn on before it could be used. PhotoTalk, by contrast, is small and easily portable and starts quickly with the touch of a button.

Beukelman, Hux, McKelvey, Dietz, and Weissling are creating a commericial application that an individual who has aphasia can use to share personal, communicative messages with their communication partners [4, 5]. Preliminary information indicates that the application is organized into themes, such as *introductions* and *family*. Each theme contains personal photographs and 'speak buttons', which play a sound when they are pressed. A therapist, with input from the user, personalizes the application for each user by collecting personal photographs and determining appropriate themes. By contrast, PhotoTalk is intended to be populated by the user herself.

TalksBac is an AAC system designed for people with aphasia to help communicate pre-loaded stories and sentences [56]. Caregivers enter specific phrases, sentences, or stories into the system and the individual with aphasia is then able to play back the sentences. An evaluation of TalksBac with 4 aphasic participants compared their conversations with and without TalksBac after 9 months of use [56]. For 2 of the 4 participants, TalksBac improved their control of conversations by allowing them to initiate and expand on conversation topics more than they were able to without the use of TalksBac [56]. The TalksBac system can be used for all four of the communication needs defined by Light [35], which makes it a valuable AAC system.

The Predictive Retrieval Of Story Extracts (PROSE) contains a set of stories that can be searched and played for conversation partners [57]. The system uses artificial intelligence for predicting the most relevant stories based on frequency and recency, as well as information from past conversations. PROSE was developed to integrate with the TalksBac system. Waller and Newell performed an initial evaluation of PROSE with a single non-fluent aphasic user, HM, who had previously used the TalksBac system. Stories were entered into the PROSE system by HM's family members and the story book was a printed version of the same stories. HM was observed communicating with the PROSE system, with the story book, and unaided. During the evaluation, single conversations with each method were observed. HM contributed the most to the conversation when using PROSE. Although this is only a small study, the results are encouraging. The social interaction between HM and her family was positive, even if the stories had previously been heard by her family members. This suggests that PROSE is useful for fulfilling the communication need of social closeness.

A multi-disciplinary team created PCAD (a Portable Communication Assistant for people with Dysphasia[1]), a portable communication device intended for people with aphasia to communicate using pictures, sound clips, digitized and synthesized speech, and written text [55]. A therapist must customize PCAD for each user by selecting from the seven modules that are provided and inputting a vocabulary of words, images, and sounds. A multiple case study involving 22 individuals who have aphasia was conducted. First, each participant met with a therapist to set goals for his use of PCAD, then the therapist configured PCAD for each participant, and finally, each participant spent several therapy sessions learning how to use PCAD. The participants subsequently used PCAD at home for an unspecified amount of time, after which the therapists conducted structured interviews to learn how PCAD was used. All participants were able to use PCAD in therapy sessions, and the majority of participants (77%) successfully used PCAD in a real life situation for one of their pre-determined communication goals. This study shows that individuals with aphasia are able to use mobile computerized communication devices to communicate.

TalksBac, PROSE, and PCAD all require therapist or caregiver involvement for data input, whereas all the data input in PhotoTalk is performed by the

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[1] Dysphasia is defined as *an impaired ability to communicate* and aphasia as *a total inability to communicate*, but the term aphasia is generally used to describe both impairments [1].

user himself. The independence of data input is one factor that may positively influence the adoption of PhotoTalk (see Section 2.5).

Devices for Language Impairments in General

In this section, we describe AAC devices designed for a range of communication impairments. We focus on six devices because of their similarity to PhotoTalk.

The Cyrano Communicator is a device designed to aid individuals to communicate through customized images, text, sound, and synthesized speech [11]. Cyrano is built on a mobile device and allows users to use the built in camera to capture personalized images. The Cyrano interface uses considerably more text and is also more complex than PhotoTalk; each page can contain up to 35 elements, and each element can be a photograph, text, a sound clip, a link to another Cyrano page, or a shortcut to launch another application. The amount of text and interface complexity would likely be too difficult for many individuals who have aphasia.

Gus Communications has developed a variety of software designed for people with communication impairments. The Gus! Multimedia speech system can be installed on a desktop or laptop computer and contains five modules, including a talking word processor and a talking calculator [20]. The Gus! Pocket Communicator [21] and Gus! Easy Talk for Pocket PCs [19] are both designed for mobile devices, and appear to be targeted towards individuals who have relatively unimpaired reading ability.

To our knowledge, no evaluations of the Cyrano Communicator or any of Gus Communications' products have been reported in the literature.

Phrase-it is a commercial Danish communication aid for individuals who have severe linguistic impairments, such as aphasia [8]. Users navigate through contexts such as *house*, *kitchen*, and *kitchen cupboard* to select icons or words from a specific context to build up sentences which can then be played or written. Unfortunately, very little information about this product is available in English. To our knowledge, no evaluations of Phrase-it have been reported in the literature.

Hine and Arnott created a multi-media storytelling service that allows non-speaking users to collect photographs, video clips, and audio clips in a database and present them in sequences via a web browser [22]. The interface visually displays each story with a photograph and a single word or short phrase. The storytelling service can be used to present stories in face-to-face communication and via videoconferencing. In initial studies, the multi-media storytelling service was found to be more effective than a text only storytelling interface, and the multi-media storytelling service with videoconferencing was found to be more effective than a text/symbol/speech presentation. Whereas the multimedia storytelling service requires a full-sized web browser to be viewed properly, PhotoTalk is designed for a small mobile device which allows it to be used in many different contexts. In addition, the multi-media storytelling service interface contains more complex navigation than PhotoTalk, which may be difficult for some people who have aphasia.

A preliminary report suggests that Leroy, Chuang, Huang, and Charlop-Christy are developing a mobile communication tool for children who have autism [31]. The report indicates that the design process will include creating a digital library of images and that the subset of these images that each child finds useful for communication will be stored on her mobile device. To our knowledge, no further information about this project has been published.

2.2 Field Evaluations of AAC Devices

To our knowledge, very little field work has been conducted to evaluate AAC devices with individuals who have aphasia. The TalksBac [56], EasySpeaker [47], and the combined LgLite and ESI Planner II [7] projects are notable exceptions. As described earlier in this chapter, EasySpeaker and the LgLite and ESI Planner II system were each evaluated with 4 week field studies, and TalksBac was evaluated with a 9 month field study. Although Davies et al. conducted a field study to learn how an individual with aphasia used a PDA, they only did a very preliminary and casual evaluation of their FileFacility prototype in the field [13].

Garrett and Kimelman describe many studies where participants were able to successfully use AAC systems in therapeutic contexts, but were unable to generalize those skills to other contexts without specific, intensive training [18]. A study by Purdy, Duffy, and Coelho suggests that people with aphasia may have difficulty intuitively switching between communication modalities when verbal communication is insufficient [46]. Accordingly, we believe it is important to conduct field studies to assess the usability and usefulness of AAC devices in real life situations.

A field evaluation of PhotoTalk that demonstrates its usability as well as usefulness in *real life* situations is a contribution of this thesis.

2.3 Communicating with Images in the Broader Population

AAC is obviously not unique in its use of photographs and images for communication; most people from the broader population use images and photographs to communicate on a regular basis. Here, we highlight two studies that have specifically investigated the use of digital images for communication.

Mäkelä, Giller, Tscheligi, and Sefelin conducted two field studies, each with 4 participants, of digital-image use for leisure-related communicative activities, such as joking, storytelling, and expressing affection [38]. Although the participants in this study had unimpaired communication, some of their findings are likely relevant for our population. In both studies, all participants were given a mobile device that could capture, edit, and share digital photographs. Mäkelä et al. found that supporting communication was one of the ways the participants used the digital images. We speculate that their photo capture and management application would be too complex for individuals with aphasia.

Balabanović, Chu, and Wolff created StoryTrack, which is software for a tablet computer designed for organizing photographs into stories and subsequently sharing them with others [3]. The images must be imported into StoryTrack, because the tablet computer does not contain a digital camera. An initial evaluation showed that participants were able to use StoryTrack with little instruction, demonstrating that people can effectively tell stories with digital photographs. Although this system is intended for individuals with unimpaired communication skills, their findings show promise for the use of PhotoTalk in communication because all participants successfully used digital images for communication.

2.4 Working with Domain Experts

In the past, HCI assistive technology research projects have usually involved domain experts to some degree (for example, [12, 27, 51, 59]). However, publications arising from these projects generally have not discussed the specifics of how these experts were involved in the projects or reflected on their involvement. We note a recent trend where HCI researchers are beginning to reflect on collaborations with domain experts (for example, [7, 10, 16, 39]). Many of these collaborations have involved participatory design, so we briefly expand on it next.

Participatory design (PD) is a mainstream HCI design method that has seen some success in assistive technology research. This is often partially due to the involvement of domain experts. PD is generally recognized as an effective approach for designing technology because target users and other stakeholders are involved as equal participants (i.e., team members) in the process, which ensures that their needs are considered from the outset. Carrying out PD effectively is challenging, even in ideal situations with ordinary participants. This is because it can be difficult for target users and system designers to effectively communicate their ideas given their diverse backgrounds and perspectives [28]. This challenge can be exacerbated when working with users with impairments [14, 41, 62].

PD traditionally relies on strong written and oral communication between the design team members. However, these abilities cannot always be assumed with special needs populations, necessitating modifications to accommodate their needs. Domain experts are often recruited to help reduce the challenges that arise due to the impairments of the target users. For example, the experts can help modify the PD process so that target users can participate. Members of the Aphasia Project have successfully modified PD in past projects. Moffatt et al. involved four aphasic individuals in PD sessions to develop ESI Planner [39, 41]. Similarly, Davies et al. designed File Facility together with a person with aphasia [14]. In both the ESI Planner project and the File Facility project, a university researcher who is also a certified speech-language pathologist provided detailed input into how to modify PD sessions to accommodate persons with aphasia. For example, the PD sessions were shortened, based on her recommendations, because people with aphasia tend to tire quickly. In addition, aphasic participants were provided with visual feedback mechanisms to elicit their input which would have been difficult for them to provide verbally.

When target users have special needs, it is often necessary to include other people in the PD process. These individuals may participate in the design process along with target users, or they may act as representatives and participate instead of target users.

Cohene, Baecker, and Marziali included both the target user, a woman who has Alzheimer's Disease, and her family members in the design phase of a multimedia life story system. They used a PD approach [10] and needed the family members because the target user was only able to minimally participate.

Wu, Baecker, and Richards also used an adapted PD approach to develop a portable system that helps people with anterograde amnesia orientate themselves [60, 61, 62]. Their PD team consisted of six people with anterograde amnesia, one HCI researcher, and one neuropsychologist who specializes in the assessment and treatment of severe memory disorders. Wu et al. recognized that the typical PD process needed to be adapted for their population due to their participants' amnesia. For example, they emphasized structured review of past sessions each time the design team met [62]. Wu et al. used their experiences to create a framework that researchers can use to adapt PD methods to make them more appropriate for a population with cognitive disabilities [62].

Leung, Lumsden, and Fritz used participatory design to create an assistive handheld application for adults with limited literacy skills [32, 33, 37]. Leung et al. involved literacy facilitators and tutors as experts in focus groups and during the participatory design phase of the project because of their expertise working with adults who have limited literacy skills and with literacy resources. The domain experts provided input based on their perception of the needs and desires of adults with limited literacy skills from their years of experience working with these adults.

Boyd-Graber et al. included speech-language pathologists as representatives in the participatory design stage of LgLite and ESI Planner II [7]. A domain expert in this representative role has been called a *proxy* [7, 10, 16]. We raise some concerns about the use of this term in Chapter 5 of this thesis.

2.5 Adoption of Assistive Technology by Individuals who have Cognitive Disabilities

Adoption is a crucial issue for assistive technology; on average, 33% of all assistive technology devices are abandoned after they are purchased [30].

Lasker and Bedrosian proposed an AAC Acceptance Model for adults with acquired communication disorders based on factors related to the milieu, the person (user), and the technology, where acceptance is defined as the degree to which the technology is integrated into the life of the user [30]. The communication partner and funding options are factors related to the milieu, or environment, which affect the acceptance of AAC systems. Attitude, skills, needs, and emotional state are some of the factors related to the user that affect acceptance. Lastly, durability, reliability, ease of use, size, and cost are some of the technology factors affecting acceptance.

Dawe recently conducted semi-structured interviews with teachers and parents of cognitively disabled students to determine which types of technology the students were using, how they were using it, and what technology they had tried in the past and abandoned [15]. Although, Dawe's study focused on young adults with various cognitive disabilities, we believe that many of her findings are likely relevant to people with aphasia. Dawe found that ease of use, not only of the technology but also of the configuration and documentation, affected adoption. Increased independence, social interaction, and safety were cited as reasons for adopting technology. Dawe found that some level of out-of-the-box usefulness prior to the configuration of an AAC device, and the ability to back-up, restore, and upgrade the software of an AAC device are important to maximize the likelihood of assistive technology being adopted.

Chapter 3

PhotoTalk Design and Implementation

In this chapter, we describe the participatory design (PD) process involving experts that we used in the PhotoTalk project. We then describe the PhotoTalk application, first by listing its requirements and subsequently describing the application in detail.

3.1 Participatory Design with Experts

The original design of PhotoTalk was achieved through PD, done by a team comprising two speech-language pathologists (SLPs) and a computer science graduate student specializing in human-computer interaction (author of this thesis). We chose to involve the two speech experts instead of target users for several reasons. They are clinically trained in aphasia and provide speech therapy to adults who have aphasia on a daily basis. Thus, they have a broad knowledge and understanding of many different adults with aphasia and can envision the needs of our target users. We also chose to work with experts instead of target users because it is easier and thus more efficient. Recruiting adults with aphasia can be extremely challenging. Since aphasia is most often due to a stroke, many aphasic adults have physical limitations that reduce their ability to participate in research (for example, reliance on other people for transportation to and from a study held in a fixed location). People with aphasia are often socially isolated, which makes contacting a wide pool of participants difficult. Additionally, the Aphasia Project focuses on individuals with mild to moderate impairments, further reducing the participant pool.

We recognize that there are advantages and disadvantages to working with experts instead of target users. Target users should ideally be involved in all stages of assistive technology research; however, this is not always practical or feasible, particularly when the users have cognitive disabilities such as aphasia. We expand on the best practises for involving domain experts in assistive technology research in Chapter 5. The specific advantages of working with the SLPs were that they clearly understood the goal of the project and were able to use their knowledge of aphasia to contribute strong design ideas. Their communication skills are unimpaired, which significantly eased the process, allowing us to quickly develop a system which could be tested with target users. The main disadvantage of this approach was that we had a hi-fidelity system developed before we tested it with real users, introducing the risk that our design vision was off base. We note, however, that because PhotoTalk leveraged the FileFacility prototype, that risk was mitigated. Nonetheless, it was crucial for us to assess usefulness as well as usability in our field studies.

Each SLP brought different perspectives to the design process. One of the SLPs works in a hospital setting and therefore sees patients who have recently acquired aphasia; the other SLP, who also works primarily with people who have recently acquired aphasia, works with them in their own homes. One of the SLPs has a moderate amount of experience designing software applications and was able to use her past experiences to give useful and practical suggestions. The other SLP, by contrast, had never worked with a technology design team before, so she brought a fresh perspective to the design process.

Initially, the PD team met to discuss the high level goals of the project. The computer scientist brought the idea of PhotoTalk to the design team, and the SLPs were enthusiastic that such a system would be useful for their patients. The design team met approximately once per week over a 5 week period to iteratively develop the design for PhotoTalk. Each design meeting lasted approximately 75 minutes. At first the team generated the requirements for the application, and then the computer scientist created paper prototypes based on those requirements. The rest of the meetings were spent evaluating and discussing the paper prototypes and changing and improving the design of the system. Between meetings, new paper prototypes were created based on the decisions the team made. Once the team was satisfied with the paper prototypes, the computer scientist developed a medium-fidelity prototype of PhotoTalk. The team met one additional time to evaluate the medium-fidelity prototype and to once again evaluate and improve its design. At this stage, only minor changes were made, which included changing some of the icons.

3.2 PhotoTalk

3.2.1 Requirements

The PD team worked together to determine system requirements before PhotoTalk was designed. Two important aspects of the form factor were identified: (1) it had to be mobile so that users could capture and access their images anywhere; and (2) it had to be implemented on a standard device. With respect to tasks, PhotoTalk had to support the capture and automatic import of images to avoid the confusion that could occur if users had to explicitly import their photographs from the file system. Users had to be able to sort their photographs into five or six categories, display them in a sequence of their choice, and add captions, as well as remove them from PhotoTalk.

We limited the number of photographs that could be stored in the system for both technical reasons (limited storage), and design reasons. Unlimited capacity could lead to a volume of images that would eventually become too difficult or impossible to manage with a simple user interface, negating the communicative purpose of PhotoTalk. To balance flexibility of use with ease of management, we chose 100 photographs as an initial target. We decided to create a folder for each category of photographs - the exact number of folders would be decided in the design phase based on space constraints. The categories New, People, Places, Things, and Events were suggested by the SLPs; Personal was added during the design phase. Each folder, excepting New, could be associated with only one screen of photographs to minimize navigation. We did not want to limit the number of photographs that the user could take before sorting, so New had to be able to contain more photographs.

PhotoTalk could not contain menus and could only use limited text. Menus were avoided to keep the system as simple as possible; because people with aphasia are often older, they may not have experience with mobile technology and may find it difficult to learn how to navigate through a complex system. Text was obviously limited due to reading impairments. We used images in place of text wherever possible because, as mentioned previously, individuals who have aphasia often maintain their ability to recognize images [53].

3.2.2 Description of the Application

This section describes the PhotoTalk application as it was used in Field Study I and Field Study II, which includes small modifications that were made after the usability study (described in Section 4.1). PhotoTalk is built on the HP iPAQ rx3715 Pocket PC with a built in 1.2 megapixel digital camera and a 240x360 pixel screen. PhotoTalk consists of six folders labelled New, People, Places, Events, Things, and Personal (see Figure 3.1). Newly captured photographs are automatically imported into the New folder, and the user may sort her photographs by moving them to another folder if she wishes (described below). PhotoTalk is designed to be simple to navigate; the folder buttons are always visible and are tapped to open the folder (using a stylus or finger). In addition, the current folder selection is shown with a black box around the folder button, and is redundantly encoded with a coloured bar above the folder buttons. The colours selected for the folders are loosely based on the colour-category mapping that is used in other augmentative and alternative communication (AAC) devices because the target users may be familiar with this mapping. The colours used for the People, Places and Things folders are the standard AAC mapping, and the colours for the New, Events and Personal folders were recommended by one of the SLPs.

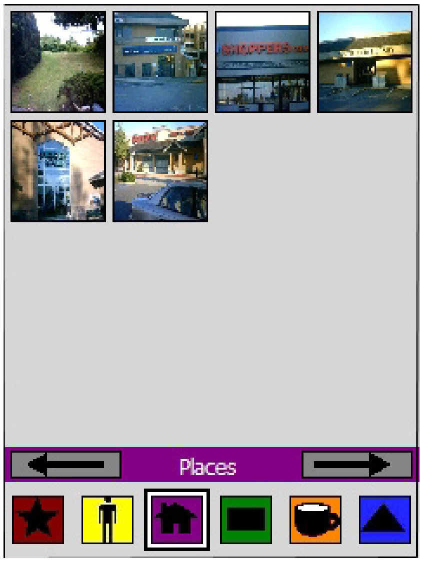

Figure 3.1: PhotoTalk in the folder view. The Places folder is currently selected.

Each folder, except New, is limited to contain no more than 16 photographs, each 55x59 pixels in size. Sixteen is the maximum number of photographs that can be displayed on the screen simultaneously while keeping the images recognizable. This allows for 80 photographs in the category folders. The New folder supports up to 5 screens, which contains a total of 72 photographs[1] (see Figure 3.2). Thus PhotoTalk holds 152 photographs.

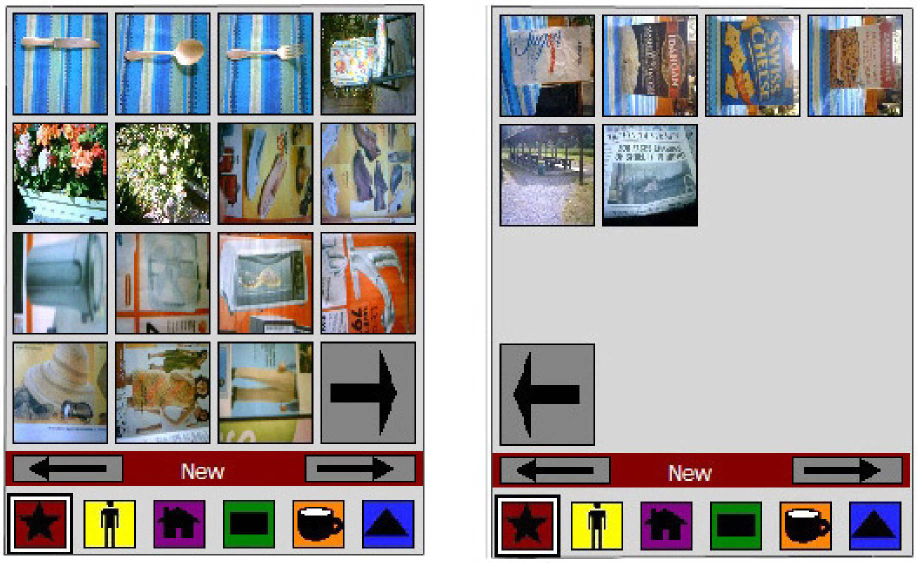

Figure 3.2: Two screens in the New folder (here, the remaining three screens are empty). The large arrow buttons at the bottom open the next and previous screens.

When a user taps a photograph, that photograph becomes selected. The selected photograph is enlarged to 82x88 pixels and the delete button appears, shown as a 36x36 pixel trash can (see Figure 3.3). To delete a photograph, the user must tap the delete button. A full-screen delete dialog confirms the operation with the user (see Figure 3.4).

Users can control the arrangement of photographs within a folder by moving them within that folder; photographs can also be moved to a different folder. A move operation occurs by dragging the photograph to a new position. Visual feedback is given through an orange arrow that indicates the drop target when moving within the same folder (see Figure 3.5), or by highlighting the target folder with an orange box when moving to a different folder (see Figure 3.6).

When a photograph is selected, a user may tap it to bring it to a 240x256 pixel full-screen view (see Figure 3.7). The user may then add a caption to the photograph by clicking the caption button, shown with an ABC icon, in the

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[1] Initially, we wanted the New folder to contain 10 screens of photographs, but the iPAQ did not have sufficient memory capacity.

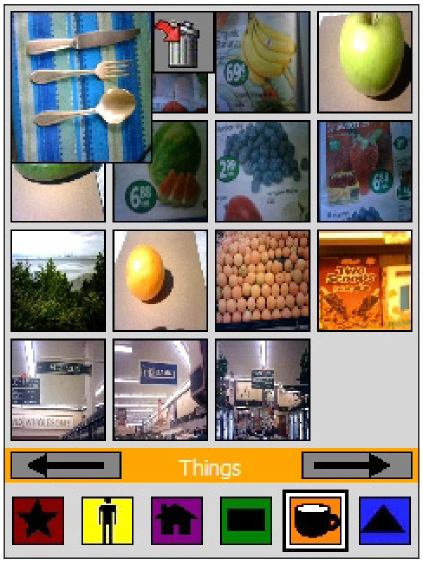

Figure 3.3: On selection, the photo is enlarged and the delete button is shown. Here, the top left photograph is selected.

Figure 3.4: The full-screen delete dialog confirmation dialog.

Figure 3.5: An orange arrow provides visual feedback demonstrating where the photograph will be moved.

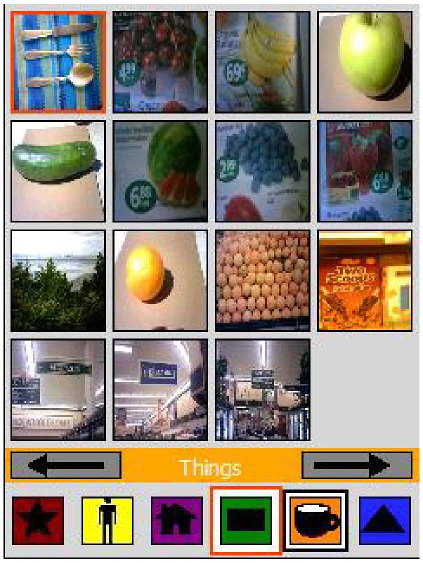

Figure 3.6: An orange box provides visual feedback demonstrating the different folder to which the photograph will be moved.

top left corner. A custom alphabetic soft keyboard is displayed for the user to enter text (see Figure 3.8). A custom keyboard with 35x35 pixel softkeys was implemented because the HP default soft keyboard was too small for our user population. As many people with aphasia are older or stroke survivors, they often have motor impairments that make selecting small targets difficult. The custom softkeys are approximately four times larger than the softkeys on the default soft keyboard.

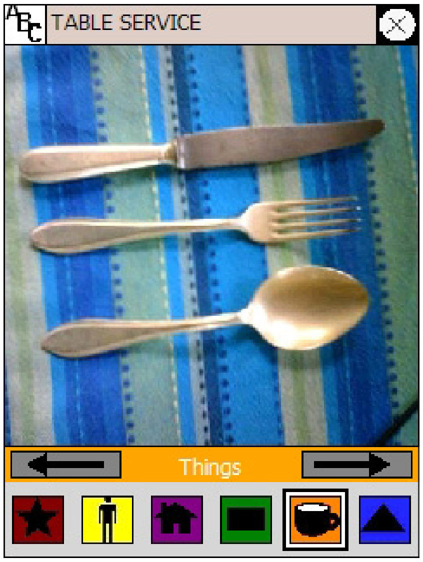

Figure 3.7: A full-screen view of a photograph.

PhotoTalk has built-in logging to capture user interactions. It logs when a photograph is taken, moved (and where it is moved to), deleted, and when navigation is performed, as well as when captions are created or changed. The log does not store the actual photograph for privacy reasons; the usage data is solely associated with image filenames. This logging was developed to enable rich and objective data about system usage during the planned field studies.

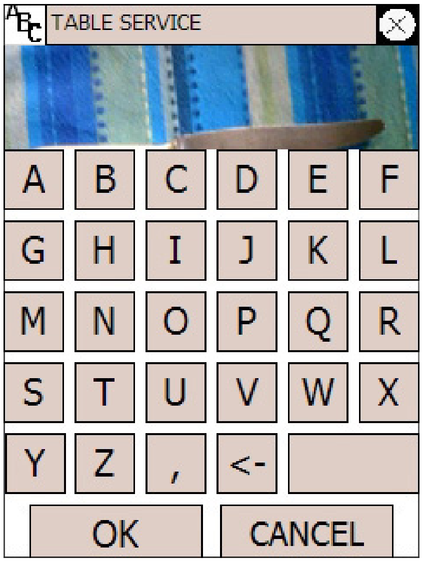
TABLE SERVICE

Figure 3.8: The custom keyboard for entering caption text. Here, the user has just finished entering the caption “TABLE SERVICE”.

Chapter 4

PhotoTalk Evaluation and Discussion

In this chapter, we describe the informal usability study and the two field studies that were conducted to evaluate PhotoTalk. The chapter concludes with a detailed discussion of the field studies.

4.1 Usability Study

We ran an informal study to identify usability problems, as well as assess the perceived usefulness of PhotoTalk before conducting our field studies. In this section, we describe the study and explain the changes to PhotoTalk that arose from this study.

4.1.1 Participants

Five adults over the age of 50 who have aphasia participated in the usability study. Four were male (P1, P2, P3, and P4) and one female (P5). All 5 participants acquired aphasia because of a stroke at least 2 years prior to the study and all were recruited through stroke and aphasia groups with the assistance of the group facilitators. All 5 participants regularly used computers prior to their strokes, but only P3 continued to use computers (including a PDA) regularly, both for communication and other purposes. P3 participated in the ethnographically informed field study and participatory design (PD) of the FileFacility (described in Section 1.2). Participants were paid $10 for their time.

4.1.2 Procedure

Each participant met with the experimenter once for up to 1 hour at a place convenient to the participant. The participant was asked to sign an aphasia friendly consent form that contained images illustrating each section (see Appendix A.1), which were also explained verbally in detail. The experimenter asked the participant some brief questions about his technology use, both before and since his stroke, and provided a short explanation of the goals of PhotoTalk and a quick demo of the software.

The experimenter then went through a series of tasks with the participant: taking a photograph, moving a photograph within the same folder, moving a photograph to a different folder, adding a caption to a photograph, changing the caption of a photograph, and deleting a photograph. Each task was first explained then a brief demo was given. The participant was then asked to perform the task. If the participant made a mistake, the experimenter intervened with a suggestion of how to complete the task successfully. The participant continued until he was successful or it became clear that he would be unable to perform the task. Before introducing the caption tasks, the participant was asked if he was comfortable spelling; if he was not, he was not asked to perform those tasks to minimize any feeling of embarrassment.

After the participant finished the tasks, the experimenter asked questions probing his opinions of PhotoTalk, including what he liked best, what he liked least, and how, if at all, he thought he would use PhotoTalk in his daily life.

4.1.3 Results

No major usability issues were discovered in this study. All of the participants were able to successfully complete all of the tasks with one exception. P1 had not regained his ability to spell since his stroke and was not asked to perform the caption tasks. Although all the participants were able to successfully move photographs, it was clear that the interaction sequence was challenging for many of them. Accordingly, the interaction for move was changed to the current drag and drop style (described in Section 3.2.2) from the previous style, which required a button press before the photograph could be dragged to a new location.

P1 suggested several modifications to PhotoTalk, all of which involved making parts of the interface bigger. This was not surprising, given that P1 has large hands and preferred interacting with his fingers rather than the stylus.

Each participant had a different and interesting way that they envisioned using PhotoTalk. P1 thought he would use it to take pictures of his garden. P2 thought he might use it to work on his language skills by taking photographs and using the captions to practice his spelling and pronunciation. P3 thought he might use it to help him remember the names of his co-workers because remembering names was difficult for him since his stroke. P4 thought he would use it to take pictures of items while he was shopping to bring home and show his wife. Finally, P5 thought she would use it to ask for directions (for example, show the image of the female symbol when asking for help locating the restroom).

Based on the results of the usability study, we were confident in the basic usability of PhotoTalk and were able to move forward with the planned field study.

4.2 Field Study I

The main goal of our primary field study was to learn how and if individuals with aphasia would incorporate PhotoTalk into their daily lives. We chose the field study format to discover actual use of the system, rather than anticipated use, which we gathered in our usability study. We chose a 1 month duration to balance the need for our participants to have sufficient time to identify key strengths and weaknesses of PhotoTalk with our expectation that further design iteration would be required before investing the resources required for a longer study. We restricted the study to 2 participants for similar reasons.

We expected the primary field study to reveal that our participants would use PhotoTalk independently, incorporate it into their lives to some extent, and use it for some aspects of communication. We were particularly interested to learn if the participants would use PhotoTalk on a regular basis, and for what purposes they would use it.

4.2.1 Participants

We recruited P1 and P2 from the usability study to be the two primary participants in the field study. A close family member of each aphasic participant was also recruited to attend a small subset of the interviews. PhotoTalk was designed to be used independently; however, given that communication naturally occurs between pairs of people, we anticipated learning additional information about the use of PhotoTalk and the participant's communication strategies by including a family member. The aphasic participants and their family members were each paid $75 and $25 respectively for their time.

A certified speech-language pathologist administered the Western Aphasia Battery (WAB) to each participant. The WAB is a standardized assessment that is widely used to assess language impairments in aphasia [29]. Abilities are assessed in the areas of speech, auditory comprehension, reading, and writing. The severity of language impairments reflect the WAB scores as follows: mild (8–10), moderate (4–7), and severe, (0–3). P1 completed the WAB approximately halfway through the field study and P2 completed the WAB after the conclusion of the field study. An individual's language skills are considered stable 1 year after they acquire aphasia and both P1 and P2 acquired aphasia at least 2 years prior to the study, allowing us to administer the WAB at a time convenient to both the participant and the speech-language pathologist.

We administered the Quality of Communication Life Scale (QCL) [44] at the end of the field study to gain a deeper understanding of the impact of P1 and P2's aphasia on their quality of communication life. The QCL is an 18 item scale completed by the person with aphasia; each item is presented visually, and we helped the participants understand the questions. An example item in the QCL is "Even though I have difficulty communicating, I like talking to people". Each item is scored from 1–5 where 1 corresponds to *no* and 5 corresponds to *yes*. A copy of the QCL is provided in Appendix B.3.

We also administered the Communicative Effectiveness Index (CETI) [36] during the field study. The CETI measures the communicative effectiveness of the person with aphasia; it is a 16 item scale completed by a close family member of the person with aphasia. An example item from the CETI is "Please rate your spouse's/father's ability at: communicating his/her emotions". For each item, the close family member makes a mark on a 10 centimetre line indicating the degree to which they think the person with aphasia is able or unable to effectively communicate in the given situation. A list of the CETI questions is provided in Appendix B.4.

P1 is an adult male (approximately 65 years old), who is unable to speak more than a few words and has difficulties reading and writing. P1 lives with his wife and spends a lot of time with his two adult children and many close friends. P1 ran a consulting business, but has been unable to return to work since his stroke 10 years ago. P1's WAB showed that he has severe speech and writing impairments and moderate auditory comprehension and reading impairments (see Table 4.1). Although P1 speaks very few words, he is comfortable performing many activities independently; for example, P1 goes to the grocery store, the bank, the doctor, and the coffee shop by himself. He uses limited speech, gestures, props, drawings, and occasionally notes written by his wife to communicate in these situations. P1 attends a stroke club once a week.

Table 4.1: Western Aphasia Battery (WAB) scores for P1 and P2.

	P1	P2
speech	severe	moderate
auditory comprehension	moderate	moderate
reading	moderate	mild
writing	severe	moderate

The version of PhotoTalk that P1 used during the field study was slightly modified from the system described in Chapter 3. Minor suggestions that P1 made during the usability study were implemented specifically for him before he began the field study: larger pictures in the folder view and some larger buttons, both needed to support interaction with his fingers. P1's version of PhotoTalk only displayed nine photographs per folder, allowing 76x80 pixel photographs instead of the default size of 55x59 pixels. P1's version of PhotoTalk also had only five folders so that the folder buttons could be larger and easier for P1 to press; the Personal folder was dropped because we deemed it the least important. The size of the delete button was increased from 36x36 pixels to 60x60 pixels and the caption box was increased to from 24 to 40 pixels.

P1's wife (P1_w) also participated in the field study. She works part-time and is quite busy due to her job and household responsibilities. Both P1 and P1_w spend a lot of time working on their substantial and well cared for garden.

P2 is an adult male (approximately 75 years old). P2 speaks with a fluent pace, but often makes word-choice errors. Most often, he mistakenly says another word with the same first letter instead of the target word. Sometimes he recognizes that he has made a mistake and will keep trying to say the correct word until he is successful or until someone guesses what word he is trying to say. Other times he does not notice that he has made a word-choice error and will continue with his sentence. P2's WAB showed that he has a mild reading impairment and moderate speech, auditory comprehension and writing impairments (see Table 4.1). P2 lives with his adult daughter; his wife has been in full-time hospital care for many years. P2 visits his wife at the hospital three times a day at meal times. These daily visits keep P2 very busy. P2 retired before his stroke occurred 2.5 years ago. P2 is comfortable performing many activities independently, for example, he goes shopping and visits his wife in the hospital by himself. P2 uses speech, gestures, writing, and newspapers and other written material to communicate in these situations. P2 also attends a stroke club once a week. P2 used the version of PhotoTalk that was described in Chapter 3 without any personal modifications.

P2's daughter (P2_d) participated in the field study. She is quite busy with full-time work as well as regularly scheduled activities during most evenings.

Despite the differences in the severity of P1 and P2's aphasia, they both scored 3.75 out of 5 on the QCL which indicates that although they are aware of their communicative difficulties, they both have a relatively high quality of communication life. The CETI scores were consistent with the WAB and QCL scores, and did not provide any additional insight into the communicative abilities of our participants.

4.2.2 Procedure

The researcher met with each aphasic participant twice per week for 4 weeks during the field study. The family member was involved in the first and last meeting, and one meeting in the middle. We planned a large number of meetings in order to maintain awareness of the study progress, to allow us to quickly fix any software or hardware problems should they occur, and to collect log data throughout the study mitigating the potential of total data loss.

At the beginning of the first meeting, both the aphasic participant and the family member were asked to sign consent forms. The consent forms are provided in Appendix B.1 and Appendix B.2. The particular communication skills and strategies of the person with aphasia were then discussed with the aphasic participant and the family member. To refresh each participant's memory, the researcher also re-taught PhotoTalk to the person with aphasia using the *demonstrate followed by trial* approach that was used in the usability study. Both participants quickly remembered how to use each feature. Participants were also told that their interactions with PhotoTalk would be logged by the system but that the information collected would not include any actual images.

At each subsequent meeting, the researcher asked the person with aphasia questions about how they had been using PhotoTalk since the previous meeting. These discussions often involved looking at captured images. The participants were aware that the researcher may be viewing their images at each meeting and could delete any images in advance. Participants were also asked if they had experienced any problems, and the researcher briefly looked at the log data.

The log data was copied and briefly checked between meetings. As one of our research goals was to see how these two individuals would use PhotoTalk, we did not dictate how or when they should use PhotoTalk. We told the participants to use PhotoTalk whenever and however they wanted and not to feel obligated to use it. The researcher did however ask each participant on two or three occasions about specific situations, such as “Would it be useful for you to take PhotoTalk to your stroke club?”.

At the last meeting, we conducted a semi-structured interview with both the aphasic participant and the close family member about PhotoTalk. The planned questions for the interview were:

- If you could keep using PhotoTalk, would you? For what purposes would you continue to use it?
- What was the most useful feature of PhotoTalk?
- What was the most frustrating feature of PhotoTalk?
- What feature of PhotoTalk did you like the best?
- What feature of PhotoTalk did you like the least?

4.2.3 Results

We first describe the quantitative usage results. This is followed by the qualitative findings from the interviews, which augment the quantitative data and reveal the purposes for which the participants used PhotoTalk. Finally, we describe the usability problems uncovered.

The quantitative usage results captured from P1 and P2’s logs are given in Table 4.2. The data show that both participants used PhotoTalk regularly during the study and on approximately half of the days that they did not meet with us. Photographs were deleted by both participants outside of PhotoTalk (using File Explorer or HP Image Zone, the built-in photo viewing software on the iPAQ), when their New folders became full and the most recent photographs were not automatically imported. Due to a software limitation discovered during the field study, photographs taken when the New folder was full could never be accessed via PhotoTalk. P1 and P2 each viewed a variety of photographs in full-screen mode suggesting its utility. P2 made extensive use of captions, while P1 only used this feature once. Both participants relied heavily on the move operation, both within a folder and between folders. Figure 4.1 shows accesses

Table 4.2: Quantitative usage results from Field Study I.

	P1	P2
Field study duration (in days)	28	30
Days PhotoTalk was used	20	21
Meetings with researcher	9	8
Photographs taken	151	218
Photographs deleted within PhotoTalk	64	101
Photographs deleted in other software	30	42
Photographs remaining at end of study	57	75
Delete operations cancelled	6	4
Full-screen mode enabled	59	243
Different photographs shown in full-screen mode	39	91
Captions entered or changed	1	117
Photographs moved within the same folder	13	66
Photographs moved to a new folder	63	125

and manipulations of the five photographs that P1 and P2 used most often on unique days. Overall the log data suggest that PhotoTalk was used considerably by both participants and regularly throughout the study.

The interviews provide significant insight into the logging data. P1 only used the folders when we prompted him to do so. It was necessary to suggest that he sort his photographs into other folders when his New folder was almost or completely full. P2, however, regularly and independently sorted his photographs into folders. Neither participant used the folders exactly as we had anticipated. P1's version of PhotoTalk had five folders and he kept photographs of his garden in both the Events and Things folders, photographs of people in the People folder, the Places folder was empty and the New folder was used for all the unsorted photographs. P2's version of PhotoTalk had six folders and he used the Places folder for photographs of places, the Things folder for photographs of produce, both the Events and People folders for household items, the Personal folder was empty and the New folder contained all other photographs. Within the New folder, P2 had organized a tools section by moving all the photographs of tools to the beginning of the first screen and the rest were unsorted.

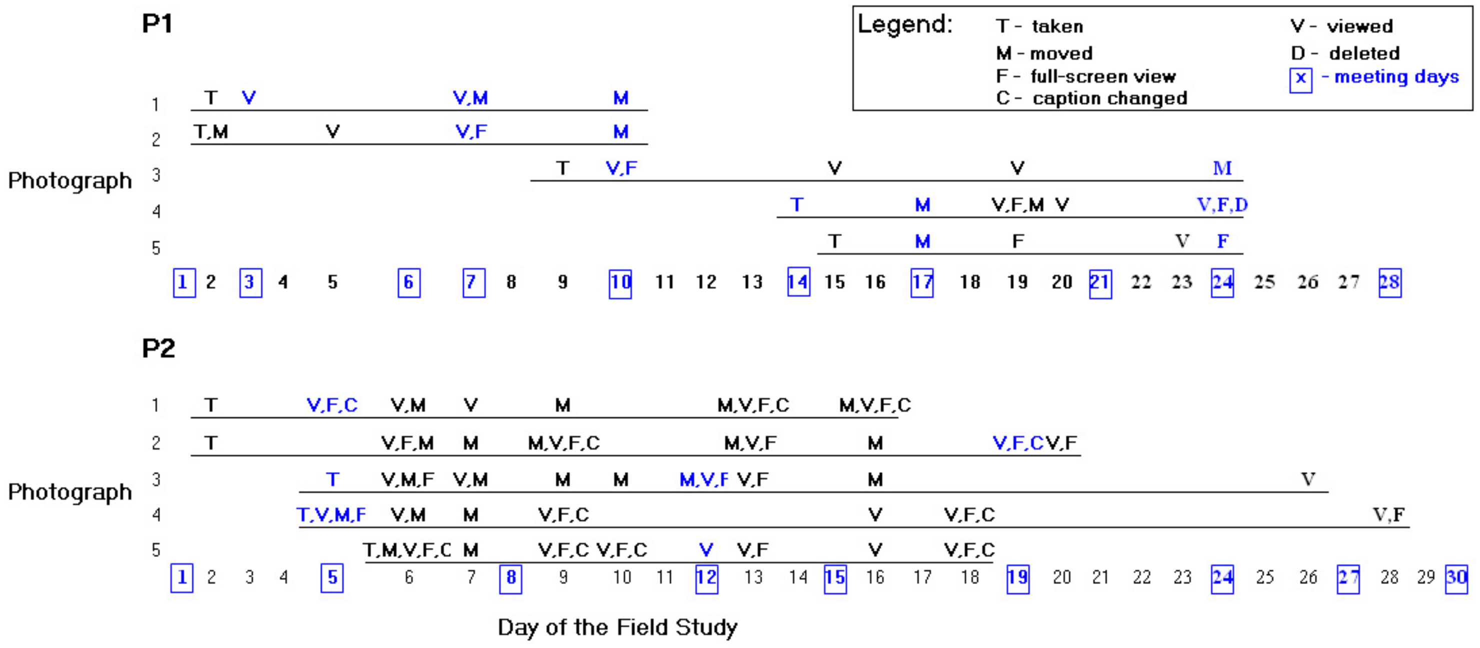

Figure 4.1: This figure displays a timeline of the accesses and manipulations for the five most frequently used photographs by each of P1 and P2.

Both participants reported using PhotoTalk to communicate. P1 and P1_w reported that P1 used PhotoTalk about three or four times per week to show P1_w what he had done in the garden while she was at work or something that still needed to be done with a specific plant. P1 also took PhotoTalk to his stroke club once, and was able to show the other members of the group photographs of his garden, which he had never done before. This communicated a large part of his life that had previously remained hidden from the stroke club. P2's use of PhotoTalk for communication was more limited than P1's. P2 used PhotoTalk once towards the end of the study to ask for a specific tool in a hardware store. P2 also took PhotoTalk to his stroke club once to share his photographs with the group. When asked at the end of the study "What was most the most useful feature of PhotoTalk?", both participants identified communication: for P1 it was his ability to show P1_w photographs of the garden, and for P2 it was his use of a photograph to ask for a tool in the hardware store. We note that neither of these uses were suggested to the participants by the researcher.

P2 remarked that it would be difficult to fully populate PhotoTalk with all of the specific items that you may need to ask people for. For example, P2 mentioned that he could take a picture of a light bulb, but that there are so many different types of light bulbs that it would be hard to have pictures of all the different types that he might need. P2 also said that it would be hard to use PhotoTalk to ask for something that you did not already have; if you could find it in a store yourself, you would not need a picture, and if you could not find it, then you could not take a picture.

When asked, P1 said that if he had continued access to PhotoTalk that he would continue to use it in the same way he used it during the field study. P2's response was more mixed and not fully interpretable. He said that at this time he would not continue to use PhotoTalk, although he thought that PhotoTalk could be "tremendous". P2 felt that given how busy he is, he did not have enough time to work on his language in this manner. P2 used PhotoTalk predominantly as a language rehabilitation tool. This use was not surprising given his comments in the usability study; however, we had been optimistic that he would also find it useful for communication. P2 spent considerable time taking pictures, especially of produce and other household items, and entering captions with the aim of improving his language skills.

P2 mentioned that it can be difficult for individuals with aphasia to communicate with strangers, regardless of the medium they are using to communicate. Often, strangers are impatient and are not willing to spend the time to understand what the person who has aphasia is trying to communicate. P2 thought that he may have the same problem with PhotoTalk. However, we note that this was not the case when P2 successfully communicated with a stranger using PhotoTalk in a hardware store. P1_w also mentioned a concern that people might see her husband taking photographs and wonder what he was doing. Since he is only able to speak a few words, it would be challenging for him to explain himself if he was questioned. One possible solution is that concerned users could carry a pre-printed card with a brief description of aphasia and PhotoTalk to give to strangers if needed.

A few usability problems were uncovered during the field study. Both P1 and P2 had suggestions for the improvement of the form factor of the iPAQ and the design of PhotoTalk. Both participants mentioned that the most frustrating aspect of the study was that it was hard for them to hold the camera steady. This often resulted in fuzzy photographs that had to be retaken. The high number of retakes accounts for many of the photographs that were deleted for both participants. P1 would have preferred a slightly bigger device (1–2 inches wider and longer), although we have been unable to locate any commercial devices of this size. P1 also commented that it would have been easier to use if the on-screen buttons were bigger, indicating that our modifications for P1 may not have been sufficient.

Both participants got confused if they accidentally ran other, built-in software on the PDA, for example if they restarted the iPAQ or pressed one of the soft buttons on the initial screen before starting PhotoTalk. Occasionally, the iPAQ would make a sound as if it had recognized a tap, but PhotoTalk did not react to the tap, which caused confusion for the participants. We were not able to determine whether the unrecognized taps were a hardware, HP software, or PhotoTalk issue. P1 had more difficulties with unrecognized taps than P2 did. Both participants had to be reminded how to move photographs at least once during the study, although they remembered how to use all the other features of PhotoTalk. Finally, the software limitation that prevented newly taken photographs from being imported when the New folder was full is an obvious usability problem.

4.3 Field Study II

After completing the primary field study we conducted a less formal, secondary field study in order to get feedback from a particular participant.

4.3.1 Participant

The participant, P3, was involved in the 4 month ethnographically informed field study and participatory design of the FileFacility [14]. P3 also participated in the PhotoTalk usability study. We chose to run an additional study with this individual because he has had considerable involvement in previous Aphasia Project research, which brings a unique perspective to the evaluation of PhotoTalk. Additionally, since P3 was involved with the FileFacility project, he would be able to comment on our team's progress towards the goal of a digital remnant book.

P3 is an adult male (approximately 55 years old). He speaks very few words, but is an expert communicator and uses a variety of strategies to communicate including writing single words, gesturing, using props, sharing digital photographs, and email. P3 regularly uses a PDA and a laptop computer, and many of his communication strategies involve some type of technology. P3's extensive experience with technology provided a different perspective to the evaluation of PhotoTalk, since neither P1 nor P2 regularly use technology.

We administered the Quality of Communication Life Scale (QCL) [44] at the beginning of the field study (the QCL is described in detail in Section 4.2.1). P3 scored 4.18 out of 5 on the QCL which indicates that although he is aware of his communicative difficulties, he has a fairly high quality of communication life. Since we did not find the Communicative Effectiveness Index (CETI) [36] results useful in Field Study I (discussed in Section 4.2.1), we did not administer it here, nor did we administer the Western Aphasia Battery [29].

We did not involve any of P3's family members in this field study. The researchers are all familiar with P3 and felt confident that they could communicate effectively with P3, and therefore would not gain any additional knowledge from also interviewing a close family member. Also, we were confident that he would be able to use PhotoTalk completely independently and would not benefit from a family member who was familiar with the system.

4.3.2 Procedure

The researcher met with P3 five times over a 7 week period. The study was initially planned as a 1 month field study so as to be consistent with Field Study I, but it was extended because P3 became unexpectedly unavailable for several weeks in the middle of the study. At the first meeting, the researcher taught P3 how to use PhotoTalk with the same *demonstrate followed by trial* approach that was used in the usability study and Field Study I. Since P3 regularly uses a PDA and participated in the usability study, he quickly remembered how to use all the features of PhotoTalk. At each subsequent meeting, the researcher asked P3 about how he had been using PhotoTalk. At the final meeting, the researcher and P3 discussed his opinions of PhotoTalk, including his thoughts about PhotoTalk in relation to FileFacility [14] for managing and sharing images.

4.3.3 Results

The quantitative usage results are presented in Table 4.3. P3 did not use PhotoTalk regularly throughout the field study, but this is largely because of unexpected circumstances that arose midway through the study.

Table 4.3: Quantitative usage results from Field Study II.

	P3
Field study duration (in days)	48
Days PhotoTalk was used	9
Meetings with researcher	5
Photographs taken	43
Photographs deleted within PhotoTalk	13
Photographs deleted in other software	0
Photographs remaining at end of study	30
Delete operations cancelled	6
Full-screen mode enabled	64
Different photographs shown in full-screen mode	26
Captions entered or changed	8
Photographs moved within the same folder	4
Photographs moved to a new folder	17

Additional information was obtained during the interviews with P3. Not surprisingly, he was easily able to learn how to use PhotoTalk and used PhotoTalk completely independently throughout the field study. Although P3 did not regularly use PhotoTalk, he did find it useful for two specific purposes. P3 took photographs of his damaged motorcycle and found PhotoTalk useful for sharing these photographs. P3 also used PhotoTalk to share photographs of his pets.

P3 suggested including the captions in the folder view (see Figure 3.1) as well as showing them in full-screen mode (see Figure 3.7). He also mentioned that it is difficult to take photographs with the built-in digital camera if the lighting is not ideal.

P3 said that he preferred using PhotoTalk for photographs to FileFacility [14]. His main reason for preferring PhotoTalk was because the resolution of the photographs was higher, and therefore, the photographs were of better quality. PhotoTalk is implemented on more recent hardware than FileFacility, so it is not surprising that PhotoTalk produced better quality photographs. When asked, P3 said that he also preferred the PhotoTalk software for managing and accessing his digital photographs.

P3 said that if he had continued access to PhotoTalk, he would continue to take it with him on a daily basis as long as he was carrying a backpack. If he was not carrying a backpack, he would only carry PhotoTalk in his pocket on days when he was specifically planning on using it. In particular, he thought that PhotoTalk would be useful for capturing and sharing photographs of vacations.

4.4 Discussion

Our results indicate that PhotoTalk is a promising tool for people with aphasia, but that the hardware form factor and design of PhotoTalk need further improvement. Here we discuss the findings of the field studies and briefly reflect on the research process that we used.

4.4.1 Merit of Concept

P1 and P3 used PhotoTalk for its intended purpose, that is, to support face-to-face communication. P2 primarily used PhotoTalk as a language rehabilitation tool, and only once to support communication in a hardware store, although at the end of the study P2 indicated that its communication potential was PhotoTalk's most valuable aspect. All 3 participants were able to use PhotoTalk quite independently, and incorporate PhotoTalk into their daily lives to some extent. Although P1 needed support sorting his photographs and both P1 and P2 needed support with the move operation, the rest of their use was independent, and P3 used PhotoTalk completely independently. All 3 participants were able to use PhotoTalk in a meaningful and personal way, which shows that the tool provided some benefit to these three individuals. Although none of the participants used the folder-category mapping exactly as we had designed it, all 3 participants were easily able to create their own folder-category mapping based on their photographs, showing the flexibility of the design.

P2 viewed PhotoTalk largely as a rehabilitation tool, even though it was not described to him in this way in either the usability study or the field study. We believe that this perspective led to his comment that it is difficult to populate PhotoTalk. He took many photographs so that he could practice his spelling and pronunciation with the captions rather than just taking photographs that he planned to use to meet specific communication goals. By contrast, P1 and P3 used it exclusively to capture images to communicate. The difference in approach could be due to the dissimilar types and severity of aphasia among the participants and the differing lengths of time they have been coping with this impairment. P1 and P3 have had aphasia for 10 and 5 years respectively, and have well developed coping and communication strategies. P2 has only had aphasia for 2.5 years and is still working on rehabilitating his language skills. P1's well developed coping strategies are a likely explanation for why he only used PhotoTalk for a very specific communicative purpose when he was at home. He is already able to effectively communicate with his wife, and only needed PhotoTalk to communicate specific information about the garden to her. P3's excellent communication skills are likely why he also used PhotoTalk for only a specific communicative purpose. P2, however, is actively working on rehabilitating his language skills and was excited to incorporate PhotoTalk into his language practice.

Overall, our findings suggest that the concept of easily capturing and managing photographs using a mobile device has merit, although further study will be required to assess the extent of its usefulness.

4.4.2 Patterns of Use

Although each of the 3 participants found PhotoTalk useful for a particular communicative purpose, P1 and P2 used PhotoTalk far more regularly than P3 (see Table 4.2 and Table 4.3 for more information). We believe that this is because P1 and P2 were exploring different scenarios of use, while this was not necessary for P3 because of his previous experience using a mobile device with a digital camera [14]. P3 had already explored different scenarios and knew prior to participating in the PhotoTalk study the communicative situations in which PhotoTalk would be most useful for him. This may indicate that once a user is familiar with PhotoTalk, its use becomes less time-consuming (as mentioned by P2, see Section 4.2.3) because he is aware of the situations in which it will be useful.

4.4.3 Customizability

Several issues that emerged from the field studies could be rectified with customizable options. P1 wanted almost all elements of PhotoTalk to be bigger, including the PDA, the photographs, and the buttons, but P2 and P3 were happy with the elements' default sizes. The different preferences could easily be accounted for if the size of the GUI elements in PhotoTalk was customizable. P1 had more difficulty with the screen-sensitivity than P2 and P3. This indicates that a customizable level of screen-sensitivity would be useful (although this is not possible on the current iPAQ hardware). P2 created captions on 73% of the photographs that remained at the end of the field study, and P3 created captions on 33% of his photographs, while P1 only created one caption. The caption feature should be customizable so that if captions are not desired the extra space could be devoted to the photographs. P3 suggested including the captions in the folder view as well as in full-screen mode, but this was not desired by P1 or P2. The presence of captions in the folder view is another feature that could be customizable. In order to keep the use of PhotoTalk as simple as possible, these customizations should be made before the user receives the system, possibly with a simple text-based configuration wizard that a family member could complete.

4.4.4 Improvements to PhotoTalk

We found problems with the form factor and design of PhotoTalk during the field studies. Some of the problems mentioned in Section 4.2.3 could be easily avoided. PhotoTalk should prevent users from starting native Pocket PC applications to alleviate the confusion that the participants faced when they accidentally started software other than PhotoTalk. Also, the iPAQ is designed to be used by a right-handed user. Many people with aphasia have motor impairments in their right arm and hand (hemiparesis), which makes physical operation of the PDA challenging. Left-handed models would be a significant improvement to PDA accessibility.

Even though P3 was consistently able to move photographs, both P1 and P2 needed reminders of how to do this, which indicates that this feature still requires improvement. A simple solution could be to add a visual reminder that photographs are moved by drag and drop, such as a drag handle in the corner of each photograph.

4.4.5 Adoption

Although adoption is a key issue for assistive technology, it was not a core goal at this stage of the PhotoTalk project; the current software is far too young to be adoptable as a shrink-wrapped application. However, based on the AAC Acceptance Model developed by Lasker and Bedrosian for adults with acquired communication disorders [30], we are encouraged that PhotoTalk has many of the attributes that suggest its eventual likelihood for adoption: PhotoTalk is relatively simple, provides a platform for increased independence and social interaction, and is small and portable. Although our field studies were short and provided support to the participants, we are cautiously interpreting P1 and P2's regular use of PhotoTalk and P3's expressed desire to continue using PhotoTalk as positive indicators for future adoption. A longer field study with less regular support from the researcher would be required to identify whether or not users will be willing and able to adopt PhotoTalk and continue to use it for an extended period of time.

Due to shifting demographics, a larger percentage of older people, and therefore, a larger percentage of people acquiring aphasia, will have prior experience with PDAs. This is another factor that should positively influence the adoption rate of a PDA based application like PhotoTalk.

4.4.6 Research Process

The streamlined research process we used was mostly effective. Involving SLPs in the participatory design phase rather than target users expedited the process. It worked in our project because our team had worked closely with target users in the past and because the PhotoTalk concept originated from someone with aphasia. We do not suggest that it would work well for all research projects. Unless one is building on previous work (here, the FileFacility [14]) or is extremely confident about the target users' need, moving a design forward before involving target users is very risky.

Conducting the informal usability study before running the primary 1 month field study caught basic usability problems before our field study participants invested a month of their time using the system. The additional usability problems that emerged in that field study, however, may have been caught had we run another usability study first.

The field study protocol worked reasonably well. The frequent meetings ensured that we were constantly aware of the study progress. We discovered one bug in P1's version of PhotoTalk which was quickly fixed. Two participants in Field Study I were sufficient to get informative results from this initial evaluation of PhotoTalk. The involvement of the close family members was most beneficial at the outset of the study; the participants seemed more comfortable knowing that their family members would be present to assist in communication with the researcher if necessary. Once the participants and the researcher gained more familiarity with one another, the family members had much less involvement in the discussions. (Both family members were extremely busy and hardly spent any time interacting with P1 and P2 and PhotoTalk.) Conducting the secondary field study with P3 was an effective way to evaluate our team's progress towards the goal of creating a digital remnant book.

We discovered a glitch with our field study protocol at the end of Field Study I. Both P1 and P2 had used PhotoTalk for communication, but despite being asked about their use at every meeting neither participant mentioned this until the last meeting. At the meetings throughout the study they typically described when and what they had taken pictures of. It was only at the end that they both mentioned communication as being PhotoTalk's most useful feature. Although the communicative exchanges they described are exactly what we had in mind when designing PhotoTalk, perhaps because our usage instructions at the outset were intentionally vague, the participants did not consider these uses to be significant enough to mention earlier on. Another possibility is that, due to the participants' communication impairments, the researcher was not effectively communicating with them. It is possible that P1 and P2 did not completely understand the researcher, although, during the earlier meetings it seemed otherwise. This raises the concern that we may have missed other pertinent information because of unknown difficulties communicating with the participants. This confusion highlights the challenge of performing field evaluations with people who have communication impairments.

All 3 participants' relatively high QCL scores could be one of the reasons that they both used PhotoTalk only for a very specific purpose. They are all reasonably confident in their coping strategies and ability to communicate, so they may have a lesser need for an AAC device. We speculate, however, that it may be hard to recruit users with low QCL scores because they may be more socially withdrawn.

Chapter 5

Guidelines for Involving Domain Experts in Assistive Technology Research

The secondary objective of our research was to use a streamlined design approach in the PhotoTalk project and to document the merits of this approach. Reflecting on our experiences using this approach caused us to consider the broader issues underlying the involvement of domain experts in assistive technology research. This chapter[1] presents our analysis and is intended to lay a preliminary foundation of best practices for involving domain experts in assistive technology research.

5.1 Introduction

Human-computer interaction (HCI) is an inherently multi-disciplinary field of research. It is common, for example, to include computer scientists, psychologists, sociologists, and designers on a research project, to name just a few. It is widely accepted that no single discipline provides sufficient expertise and breadth of perspective for any given project involving the design of interactive technology. Nowhere is the need for such multi-disciplinarity more evident than in the design of assistive computer technology for *users with special needs.*

There are substantial challenges involved in assistive technology research. Some of these challenges, such as familiarizing the whole research team about

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[1] A version of Section 2.4, Chapter 5, and Chapter 6 are under submission as a paper – Allen, M., Leung, R., McGrenere, J., Purves, B. Involving Domain Experts in Assistive Technology Research.

the domain of the impairment, are universal in assistive technology research, while other challenges, such as communicating with a user who has a language impairment, are more specific to a particular target population. The involvement of domain experts can help to mitigate those challenges. The required expertise can take on many different forms – from a clinician's educated understanding of the disability to a spouse who has personal knowledge of the specific abilities of a particular individual who is intended to use the technology. Target users can also be considered one type of domain expert, as they often have considerable expertise in the impairment themselves, and should always be included in the research where possible. However, target users may not always be capable of or comfortable communicating their expertise to others. In these cases, domain experts other than target users can be involved as intermediaries, providing increased access to users through their existing relationships and established trust with both the community and specific individuals. Our focus in this chapter is on domain experts other than the target users themselves.

Although domain experts can greatly help HCI researchers in assistive technology research, our experiences have revealed that unexpected problems can sometimes arise from this collaboration. For example, differences in expectations between the HCI researcher and domain experts that are not addressed can negatively impact the research outcomes. Guidelines on how to best involve domain experts in assistive technology research will be instrumental to mitigating these kinds of problems before they arise. Although many research teams have documented their involvement of domain experts in designing assistive technologies (for example, [7, 10, 16, 62]), there has been little reflection on how to best involve these experts in the research process, on the various types of domain experts that can be included, or on the roles they can play. This chapter is a first step towards filling that void. The material is drawn from both our own experiences working with domain experts as well as chosen accounts published in the literature. The analysis presented is intended to be useful to anyone in the assistive technology community, especially those who are in the early stages of assistive technologies research.

We begin by highlighting the ALEX Project [32, 33, 37] (described briefly in Chapter 2). We draw heavily on both the PhotoTalk and ALEX projects in the remainder of this chapter. We then begin to discuss how to best work with domain experts, by identifying and discussing the different types of domain experts and the roles that they can play in an assistive technology research project. Finally, we present five guidelines for working with domain experts.

5.2 ALEX Project

The aim of the ALEX (*A*dult *L*iteracy support application for *EX*periential learning) project [32, 33, 37] was to design an assistive handheld application for adults with limited literacy skills. *Adults with limited literacy skills* were defined as

> individuals, aged 18 and over, whose current literacy skills in their native language limit their ability to understand, use, find, produce, and benefit from printed information required in daily activities at home, at work and in the community [32].

The project had three objectives: 1) identify ways that handheld computers could assist adults with limited literacy skills; 2) identify appropriate and effective design processes given the needs of the target population; and, 3) design a handheld application to assist this population. The researchers used a three phased approach (focus groups, participatory design, and evaluation) that involved target users and domain experts in order to produce an ecologically valid design (described in detail in [37]).

Both literacy facilitators and tutors were involved as domain experts in this research because of their experience with adult literacy students and with adult literacy resources; they support their students by individually assessing their abilities, locating suitable learning resources, and helping them work through learning activities, rather than providing direct instruction. The literacy facilitators are employed by a literacy organization to support a *group* of students. By contrast, the tutors are volunteers assigned to help an *individual* student.

In the first phase of the research, three literacy facilitators and six literacy students participated in the focus groups. In the second phase, one literacy facilitator and four literacy students were involved in the participatory design of the prototype. In the third phase, one literacy facilitator as well as three tutors helped in recruiting some of their literacy students to participate in the evaluation and were also easily accessible during the evaluation in case any problems arose.

5.3 Types of domain experts

In this section we present five types of domain experts that can be involved in a research project, in addition to the actual target users themselves. Again, wherever possible, actual target users should be involved in the design process.

A *spouse* or other *close family member* of a target user can be a key domain expert to involve in a research project. The family member is aware of the specific strengths and weaknesses, interests, personality, motivation, sources of confusion, and energy level of the target user and can help facilitate communication between the user and the researcher.

A *clinician* is a trained professional who supports the target user by providing objective assessments and appropriate intervention. It can be useful to involve clinicians in research because they have worked extensively with many users in the target population and have been trained to help these individuals improve their condition. Examples of clinicians include medical doctors and speech-language pathologists (SLPs).

A *facilitator* is someone who may not have specific training in relation to the special need, but who organizes groups or facilitates other types of interactions with target users. Although facilitators are not clinically trained, their experiences and regular contact with target users provide them with insights that can be very valuable to a research project. Examples include stroke club facilitators and literacy facilitators.

A *university researcher* who is an expert in one or more domain areas related to the special need can provide another point of view. Their background and experience helps in planning and carrying out the research.

A *formal caregiver* is employed to assist the target user with his daily needs and therefore has detailed information about the daily life as well as the functional abilities of the target user. An example of a formal caregiver is a nurse in a hospital or care facility.

We have personal experience working with the first four types of domain experts; formal caregivers have been involved in other projects reported in the literature (for example, [10]). This list is not exhaustive; we recognize that there may be other types of domain experts that have been involved in HCI research projects.

5.4 Roles of domain experts

In this section, we describe roles that domain experts have played both in our projects and in other research projects reported in the literature. A particular domain expert is not limited to playing a single role, and in our experience domain experts often play multiple roles. The roles that domain experts can play are illustrated by Figure 5.1 and fit into three broad categories: *researcher*, *liaison*, and *representative*. We discuss each of these in turn.

Researcher

Domain experts in the researcher role can both inform the design of the research and/or assist in executing the research.

Domain experts can provide valuable input on how to best carry out research with people who have special needs. A domain expert has in depth knowledge of the abilities of one or more target users with special needs, so she can act as an advocate for the target user while the research is being planned. For example, she may be aware of certain cognitive or physical limitations that must be taken into account during the study that the HCI researchers would not be aware of. Specifically, there may be aspects of the consent process, the tasks the participant will perform during the study, and any follow-up after the study that may need to be modified based on the disabilities of the participants.

As HCI researchers, we are always concerned that our studies are ethical and comfortable for the participants. By soliciting input on study design from domain experts, HCI researchers can help ensure that the needs of the target users will be taken into account. People who have special needs are often more vulnerable than the average person. University and other research ethics boards need to ensure that research participants are not exposed to a risk of harm beyond what they encounter in their daily lives. The involvement of domain experts as researchers, as well as liaisons (described below), may reduce the risk of harm to the participants who have special needs.

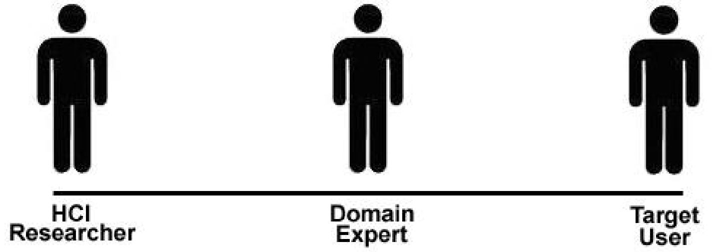
In a project between the University of Toronto and the Baycrest Centre for Geriatric Care, a portable memory tool was developed for people with amnesia [60, 61, 62]. This tool was successfully developed using a participatory design approach that Wu et al. adapted to suit the constraints and needs of their target users who had anterograde amnesia. Close collaboration between HCI researchers and a memory expert from the Baycrest Centre was instrumental in creating a process within which the target users could contribute. For example, the HCI researcher and memory expert collaborated to carefully choose the composition of the participatory design team [60].

Not surprisingly, the depth of the domain experts' roles in the research will depend on their background and experience. A university researcher, in the field

Researcher

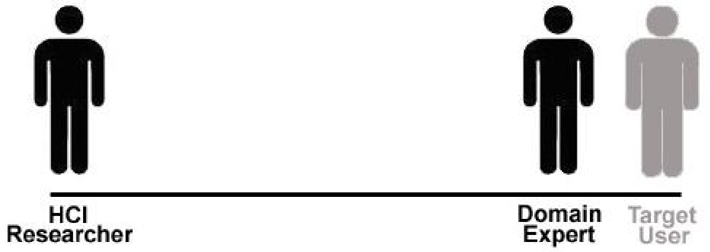
A domain expert works closest with the HCI researcher when acting in a *researcher* role.

Liaison



A domain expert works between the HCI researcher and the target user when acting in a *liaison* role.

Representative



A domain expert participates in the research instead of the target user when acting in a *representative* role.

Figure 5.1: Various roles that domain experts can play in assistive technology research.

of the special need, may be extremely involved in the planning of the research because she understands the mechanics of research, whereas a spouse will likely only provide feedback on aspects of a study design that will be problematic for their loved one.

In addition to informing research, domain experts often conduct parts of the research. For example, some domain experts have the expertise to suggest and perform functional assessments or standardized testing. People who have special needs can have widely varying abilities, which can make obtaining meaningful results of a study challenging. This challenge is exacerbated by the fact that the sample size of these research studies is often small. Standardized and detailed information about each participant's abilities can help researchers learn to interpret the results. For example, one of the researchers of the Aphasia Project is also a certified SLP, and she is aware of the tests that are most appropriate to assess the language ability of people with aphasia. She also administers and scores these tests for the Aphasia Project team. The results of these tests have been found to be very valuable for analyzing the data and providing meaningful results [41, 52]. Without language assessments, the results would have been more difficult to analyze and interpret.

Liaison

Another role domain experts can perform is to act as a liaison between the team and the target users. Liaisons act as communication intermediaries, establish trust with the target population, facilitate subject recruitment, and assist subjects in understanding and completing consent forms.

As communication intermediaries, the domain experts facilitate communication between the researchers and target users, whose disabilities (for example, aphasia) make it difficult for them to communicate. The liaison may teach the researchers strategies for communicating with the target users. At times, the liaisons may be present while the researchers and target users are interacting to directly facilitate communication.

Domain experts can also help establish trust in the community or with a specific individual for the research project, which is very important in recruiting participants. Before taking part in the project, many domain experts are already closely connected with a community of target users or with a specific individual who has special needs. Often, these connections allow the experts to access the community more easily than the HCI researchers alone. If an expert who has ties to the community of the target population demonstrates trust in the project, the target users are more likely to trust the project. For example, in the PhotoTalk project, the community ties of an SLP allowed us to easily recruit participants for the usability study. The SLP was able to identify appropriate individuals from her group and invite them to participate in the study.

Involving domain experts with close connections to a specific individual (for example, a spouse) as liaisons can be crucial when working with users who have communication impairments. The target users are not always able to perfectly understand what the researcher is explaining to them, but if their family member has trust in the project, the target user feels more comfortable participating.

Existing relationships are important to our research because recruiting participants who have special needs is a major challenge. The population is often relatively small, and many people who have special needs have additional impairments or disabilities that make it difficult or impossible for them to participate in research. For example, some of these individuals have physical disabilities that make getting from their home to the place of the study a substantive challenge. The disabilities of the target users often lead to social isolation, so it can be difficult to even identify potential participants.

In addition, domain experts can help ensure that the target users provide informed consent before they participate in research by helping them understand and complete consent forms. For example, in the ALEX project, the researchers gave literacy students consent forms to fill out. The consent forms were worded using relatively simple language and contained images to augment the written language. However, the researchers were not sure whether the literacy students would be able to fully understand the form on their own. To address this, researchers asked each literacy student's facilitator (or in some cases, the student's tutor) to go over the consent form with the student and co-sign the consent form.

Representative

Target users should ideally be involved in all aspects of assistive technology research. However, the involvement of target users is not always practical or feasible, particularly when the users have special needs. Domain experts can initially take part in the design process as representatives of the target users when the target users themselves cannot participate. Domain experts can act as representatives in multiple ways. They may represent one target user (for example, their spouse), they may represent many individual target users (for example, a group they work with), or they may be an expert on a particular aspect of the target population as a whole (for example, how to improve literacy skills). For example, in the ALEX project, four literacy students and one literacy facilitator were recruited to form the participatory design team and represent a range of target users in design decisions. The literacy students who participated had varying levels of literacy skills; each contributed to the design in the role of a potential target user. The literacy facilitator represented other potential users, such as her students, and provided input based on her perception of their needs.

In the literature, experts who represented target users in research have been called *proxies* [7, 10, 16]. The definition for proxy is "a person authorized to act for another; an agent or substitute" [34]. Recent discussion at a CHI workshop suggested that this term may be problematic and potentially misleading for this role [40]. The term proxy implies that the expert acts as a full substitute for the target user. In the field of HCI, it is standard practice to involve the target user in the research process, as users are most familiar with their current work processes and their needs for the system. It is not recommended to substitute someone else, like their boss, in the design process because even though that person may be familiar with the work, she cannot act as a substitute for the target user as she is not as intimately acquainted with the details of the work as the target user. The target user cannot be accurately substituted by someone else and we argue that this is especially true for a user with special needs. Therefore we suggest that the term *representative* be used instead as it does not imply that the expert can provide a full substitute for the target user.

5.5 Guidelines for Working With Domain Experts

We next present five guidelines for involving domain experts in assistive technology research. Although they may appear to be common sense at first glance, we, as members of the Aphasia Project and ALEX Project, would have benefited from having such guidelines available to us at the outset of our various research endeavours. Thus, we expect others engaged in assistive technology research, especially those who are just starting to work with domain experts, will find them beneficial. These inter-related guidelines are not meant to be followed sequentially and we recommend giving them consideration at each phase of the research.

1. **Anticipate the necessary domain expert roles and match the available experts to the roles**

The roles that domain experts can fulfill to cover the necessary expertise and skills must be determined during the planning stage. There may be many potential roles; however, it is not always possible to find a suitable expert for each role. Appropriate experts may not be available or the personalities or other traits of available domain experts may make them unsuitable for certain roles. We should match the experts to the required roles based on their abilities, personalities, and interests.

In the PhotoTalk project, the researchers worked with two SLPs who were acting in representative roles during the design phase of the prototype. One of the SLPs had previous experience designing technology and the other did not. Having these two experts act as representative users worked well because it brought two very different perspectives to the team. The SLP with experience designing technology was more aware of the technical possibilities and was often able to give concrete suggestions on how to implement her ideas. The other SLP was less aware of the technological constraints, which allowed her to think more freely about a range of design possibilities. This example shows that domain experts, even if they bear the same professional title, can have varying backgrounds and bring different skills to the research process. It is important to match potential experts to roles based on their full skill set.

In the ALEX project, three literacy facilitators were involved in the focus groups as representatives, but only one literacy facilitator was needed to act as a representative for the participatory design phase. The researchers got to know the literacy facilitators during the focus groups and were able to invite the most suitable literacy facilitator to participate in the participatory design phase. This assignment was based on the literacy facilitators abilities and personality.

Boyd-Graber et al. [7] involved SLPs as representatives in their project. They noted that the SLPs they worked with had difficulty analyzing paper prototypes because they could not envision the problems target users would have when interacting with the system. Boyd-Graber et al. suggested that providing the SLPs with training on usability evaluation techniques may have helped them better evaluate the paper prototypes. This demonstrates that researchers must continuously evaluate the abilities of the domain experts to assess whether they are a good match for the roles that they are being asked to play.

2. **Recognize the lack of expertise in a particular domain related to the design or target user**

In relation to Guideline #1, it is crucial to recognize any potential gaps in the necessary expertise and abilities of the research team due to a lack of available domain experts. If possible, this lack of expertise should be compensated for. Even if these gaps cannot be addressed, it is essential to recognize the risks that occur due to lack of expertise.

For example, Cohene et al. involved family members as representatives in the design process for their multi-media life story of the target user [10]. Unfortunately, the family members they involved were at least 20 years younger than the target user. This large age gap created the risk that the first 20 years of the target user's life would not adequately be covered in the multi-media life story. As Cohene et al. stated, "it is not the risks that impede design, but the failure to recognize such risks". Because they identified this risk early in the research project, they were able to compensate by making an extra effort to gather stories from the first 20 years of the target user's life and ensure that these years were adequately documented in the life story. If they had not recognized the risk until the end of the project, it would have been too late to adequately address the lack of the domain experts' knowledge.

As another example, the ALEX project worked extensively with adults with limited literacy skills, but no one on their team was able to administer standardized testing. The researchers realized this lack of expertise early in the research project and were able to plan a self-assessment of reading and writing levels in their evaluation. In other words, the subjects assessed their own literacy without the involvement of domain experts. Although their data analysis may have been stronger if they had been able to correlate the results from their evaluation with the participants' actual literacy skills, they were able to compensate by using the self-assessment scores. If they had failed to realize that this aspect of their research team was missing until after the evaluation was complete, it would have been too late to include the self-assessments. There may not always be an adequate way of compensating for the missing skill set, but even if this is the case, it is crucial to recognize the missing skills at the beginning so that you are clear about how it will impact your research.

3. Anticipate and mitigate possible interference between roles when a domain expert plays multiple roles

Having a domain expert play multiple roles in your project can be an efficient and beneficial way to incorporate their expertise. However, if the same person plays more than one role, the roles may interfere. Each team member's previous experiences will influence the way he approaches each aspect of his involvement in the project, and this is true of his previous experiences in the same project. It may not be possible to anticipate all of the potential interference, but it is advantageous to consider and address potential problems that may arise.

For example, in the PhotoTalk project, the two SLPs who participated in the design phase as representative users were also asked to act as liaisons by helping to recruit participants for the evaluation phase which involved a 1 month field study. The SLPs had an unstated expectation that the prototype would be fully developed by the evaluation phase, which became problematic during recruiting. Once the SLPs realized that PhotoTalk was a research prototype, not a finished application that the clients could keep and use permanently, they felt uncomfortable recommending that their clients participate in the study. These mismatched expectations arose in part because the SLPs participated in the design phase, and were very keen about the envisioned design and quite optimistic about its potential impact. The HCI researchers should have been more aware of the potential for increased optimism from the SLPs due to their participation in the design of the tool and tried to mitigate this problem before it arose through very clear communication at each stage of the project about the expected outcomes (see Guideline #5 for more about communication).

4. Consider the domain expert's interest in research, perspectives and expectations

The perspectives, expectations, and level of interest of the domain experts should be taken into consideration throughout the research project. It is easy for researchers to plan and implement a project entirely from their own points of view. However, it can be problematic if the motivations and expectations of some domain experts are not in harmony with the project goals. Understanding each domain expert's perspective will help the team to proactively minimize any negative effects that may occur.

For example, family members may be particularly sensitive when discussing the special needs of loved ones. In Cohene et al.'s project, family members of individuals suffering from Alzheimer's Disease were involved in research as representatives [10]. Cohene et al. found that they needed to consider the needs of the family members as they became more involved in the participatory design stage of the research. The experts participated in reminiscing activities about their family member's life, which was emotionally difficult at times because the person with Alzheimer's Disease did not necessarily remember important events or people from her life. Thus, it was crucial that the researchers recognized and planned for the needs of the experts. Cohene et al. were aware of how difficult the reminiscing could be, and referred the family members to social workers for support.

Another example is that there can be a disparity in the perspectives between the domain experts and the researchers; sometimes domain experts may not realize what information is important for the research project. Boyd-Graber et al. noted that much of the relevant information they learned from the SLPs who were acting in representative roles was not revealed in their formal, semi-structured interviews [7]. The researchers overheard the SLPs having a casual conversation in which they were discussing pertinent information which had not arisen in the formal interviews. The information had not been shared by the SLPs during the formal interviews because it was tacit, that is, embedded in the context of their work. Once the researchers realized that their interviews had not exposed all of the relevant information they were able to employ a different interviewing technique, which revealed further information from the SLPs and changed the direction of the research.

Compensating domain experts appropriately also requires understanding their motivation for participating in the research project. In the PhotoTalk project, the research team thoroughly discussed the expectations the SLPs might have for compensation before we began recruiting SLPs. We were uncertain of their exact motivations for participating in the research. It is important to think about what motivates domain experts to get involved in a project, and how their motivation will affect how they contribute to the project. Domain experts may expect to be compensated for their time based on an hourly rate or the rendering of a particular deliverable. They may also be happy to volunteer their time because of their belief in the good of the project. In part, this may be a cultural difference and is also likely dependent on the time commitment required. We have found that it is useful to discuss the goals of the research project at the outset with the domain experts playing certain roles and ask for their feedback. An open conversation about the goals of the research project can help to identify the experts' motivations.

5. **Clearly communicate roles and research goals to involved domain experts**

The more clearly the researchers understand the domain experts' perspectives (Guideline #4), the easier it is to effectively communicate the experts' roles and the research goals to them. Extremely clear and explicit communication between the researchers and domain experts will help ensure that everyone participating in the research understands their expected involvement.

The need for clear communication can be exemplified by comparing the approaches taken to involve domain experts in the ALEX project and in the PhotoTalk project.

In the ALEX project, the literacy facilitators were officially considered participants in the focus group and participatory design phases. Therefore, the documented description of their involvement and required consent forms had to be passed through the university ethics board. This forced the researchers to carefully think through how the literacy facilitators would be involved in the project and document it clearly on consent forms. Due to this explicit approach, no misunderstandings arose between the researchers and the domain experts.

In the PhotoTalk project, the SLPs were considered part of the research team. Their involvement was only informally documented, was not passed through the university ethics board, and they did not fill out consent forms. In this project, problems arose because of misunderstandings between the researchers and the SLPs (as described earlier in the example for Guideline #3). These problems may have been avoided if the researchers had followed the approach taken by the ALEX project. The extra clarity required for ethics procedures may be a valuable way to ensure the domain experts' expected involvement is clearly communicated to them.

Related to communication, it is important that the researchers ensure that the domain experts who are performing recruitment in their liaison roles communicate clearly with potential target users. If the domain experts clearly understand the goals and requirements of the project, it is more likely that they will be able to convey the correct information to target users when they are recruiting for participation or just discussing the research project. If possible, it is useful for a researcher to be present when the communication is taking place. Although this may be more time consuming for the researcher, being present makes it easier to correct any inaccurate statements made by the domain expert.

In the ESI Planner project [39, 41] Moffatt et al. found that an SLP who was acting in a liaison role was unintentionally misrepresenting the system when she was recruiting participants. She was describing the system to potential participants as rehabilitative, even though the HCI researchers had clearly explained to her that it was not intended as a rehabilitative tool. Because of this miscommunication, the participants in the evaluation expected a rehabilitative tool; their expectations created awkward situations for the researchers when the participants realized that ESI Planner was not rehabilitative. As noted by Moffatt, it is important to confirm with each participant that the purpose of the research is understood [39].

5.6 Summary

In this chapter, we have identified five types of domain experts who can contribute to assistive technology research projects: *spouse or other close family member*, *clinician*, *facilitator*, *university researcher* and *formal caregiver*. We have described three broad categories for roles that a domain expert can play: *researcher*, *liaison* and *representative*. Each domain expert can play one or more role in a research project. We also presented five guidelines on how to best involve domain experts in assistive technology research:

1. Anticipate the necessary domain expert roles and match the available experts to the roles
2. Recognize the lack of expertise in a particular domain related to the design or target user
3. Anticipate and mitigate possible interference between roles when a domain expert plays multiple roles
4. Consider the domain expert's interest in research, perspectives and expectations
5. Clearly communicate roles and research goals to involved domain experts

This chapter is an initial step towards comprehensively documenting the involvement of domain experts in assistive technology research projects.

Chapter 6

Conclusions and Future Work

In this chapter, we present our conclusions and identify future work both for the PhotoTalk project and for documenting best practises for involving domain experts in assistive technology research.

6.1 Conclusions

A key objective of the PhotoTalk project was to design an application for a mobile device that would allow people with aphasia to independently capture and manage digital photographs to support face-to-face communication. The results from our field studies indicate that we successfully achieved this objective; all three field study participants found PhotoTalk useful for a specific type of face-to-face communication. Even though neither P1 nor P2 regularly used computers before the field study, and had never used a PDA before, they were both able to learn how to use PhotoTalk successfully. Due to his prior experience with PDAs, P3 was easily able to learn how to use PhotoTalk. P1 and P3 had positive impressions of the software, although P2's feedback was mixed and difficult to interpret. P1 and P2 both needed some reminders of how to use PhotoTalk throughout the study, indicating that some level of support would be necessary if they were to continue using the application in its current form. Creating an accessible, image based application that supports communication is one of the contributions of this research.

Another key objective was to evaluate this application in the field. To our knowledge, little field work has been done to evaluate AAC devices with individuals who have aphasia. Although conducting field studies with aphasic participants is challenging, it is important to evaluate AAC devices in *real life* situations instead of solely in therapeutic or laboratory settings. Our field evaluation of PhotoTalk is an additional contribution of this thesis.

The PhotoTalk project was a positive step towards the Aphasia Project's goal of creating a digital remnant book – individuals who have aphasia were able to fairly independently use our image capture and management application. PhotoTalk could be a base for a digital remnant book once its usability problems are rectified; additional functionality, such as digitized speech and support for multimedia files, could be added. This would necessitate considerable design work and naturally shift the application in the direction of some of the more complex AAC devices (for example, [11]) that cannot be used independently by the person who has aphasia. The tradeoff between the power of the application and the users' abilities to independently operate the application would have to be considered.

A secondary objective of the PhotoTalk project was to use a streamlined design approach and reflect on the merits of this approach. We found that our design approach worked well for this project. Involving the two speech-language pathologists in the design phase of PhotoTalk was an effective way to rapidly design and develop a prototype. Although not originally an objective of this project, our work with domain experts led us to consider their role more broadly in the design and evaluation of assistive technology. We have made a preliminary step towards comprehensively documenting the involvement of domain experts based primarily on our reflections on both the PhotoTalk project and the ALEX project [32, 33, 37]. In particular, we have outlined roles and guidelines for involving domain experts in assistive technology research, which is the third contribution of this thesis. Considerable work remains to be done to build upon this foundation, both by our team and by the assistive technology community.

6.2 Future Work

The next steps for the PhotoTalk project involve further development and evaluation. We plan to investigate customizability broadly, using GUI element size, caption bar presence, and the presence of captions in the folder view as our starting points. Eventually, we hope to compare PhotoTalk to Cyrano Communicator [11] (described in Section 2.1.1) in a lab study. We hypothesize that people with mild aphasia may prefer the power of Cyrano Communicator, while more moderately or severely impaired individuals may require the simplicity of PhotoTalk. If this proves true, we could create a more complex and powerful layer within PhotoTalk, providing a full-featured system that allows users to choose the layer they will work with.

Longer term, we expect to conduct another field study to determine how individuals with aphasia will integrate PhotoTalk into their daily lives over a period of 6 months or more. Many social interactions occur infrequently and a longer field study would span more events in our participants' lives. Such a study would shed significant light on the level of support necessary for PhotoTalk's independent operation as well as its overall potential for adoption.

With respect to involving domain experts in assistive technology research, we have identified several open questions that would benefit from future work. In terms of traditional research methods, such as participatory design (PD), how should they be modified when involving domain experts as representatives? Should domain experts, for example, be given some training to help them assume the role of the target users, such as role-playing? We have also reported hybrid approaches where domain experts are used as representatives in addition to the target users themselves. Sometimes they are used together at the same point in the design cycle (for example, users and representatives in a PD session) and other times it is at different points in the cycle (for example, representatives in a PD session, and target users in subsequent usability testing). It would be helpful to identify best practices of *when* to involve domain experts as representatives in the design cycle. Finally, do the answers to these questions depend on the particular impairment under investigation, and if so, how do the guidelines presented need to be adapted to account for different disabilities?

It is our hope that these questions and issues related to the involvement of domain experts will spark discussion within the community and that others will revise and evolve our guidelines based on their own experiences in this field.

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[59] S. Wilcox, J. Scheibman, D. Wood, D. Cokely, and W.C. Stokoe. Multimedia Dictionary of American Sign Language. In *Proceedings of the ACM conference on Assistive technologies*, pages 9–16. ACM Press, 1994.

[60] M. Wu. The Participatory Design of an Orientation Aid for People with Amnesia. Master's thesis, The University of Toronto, 2004.

[61] M. Wu, R. Baecker, and B. Richards. Participatory Design of an Orientation Aid for Amnesics. In *Proceedings of the SIGCHI conference on Human factors in computing systems*, pages 511–520. ACM Press, 2005.

[62] M. Wu, B. Richards, and R. Baecker. Participatory Design with Individuals who have Amnesia. In *Proceedings of the Participatory Design Conference*, pages 214–223. ACM Press, 2004.

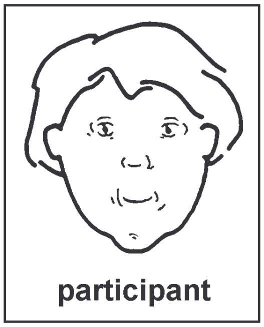
Appendix A

Usability Study Forms

A.1 Consent Form

We asked each participant to sign a consent form prior to participating in the usability study. To help the participants understand the consent form it was illustrated with images wherever possible. The following pages show an example of this form.

INFORMED CONSENT
For
RESEARCH



Participant: ________________________________

Investigators: Peter Graf, Ph.D. (604-822-6635)
Joanna McGrenere, Ph.D. (604-827-5201)
Barbara Purves, M.Sc. (604-822-2288)

Project Title: Designing Technology for People with Aphasia

Adapted from Kagan, A. Winckel, J. & Shumway, E. Pictographic Communication Resources. Aphasia Centre – North York, 1996.

Computer Technology

computers

Designing computer technology for people with aphasia.

We want to know if you can use it.

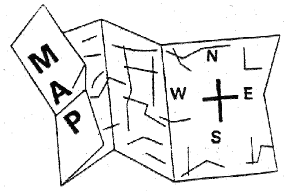
Can you use it? **YES** 👍 **NO** 👎

25/07/2006 Version 1.0 2

How often?

1 session

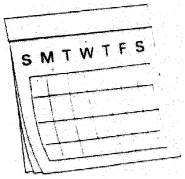
Where?



where?

Island Aphasia Project

When?

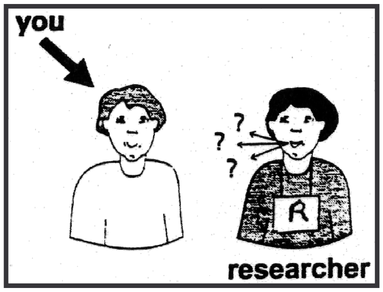


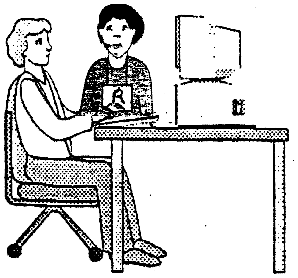
Tuesday, April 4

What ? can you expect?

Session 1

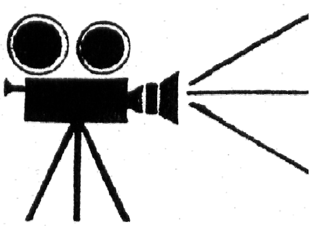
Meeting with a
researcher
= 1 hour

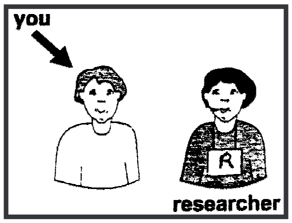




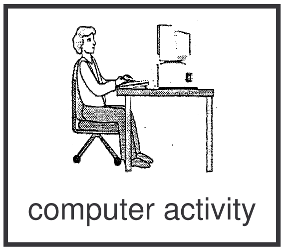
The researcher will show you some computer activities.

We will make a **videotape**.

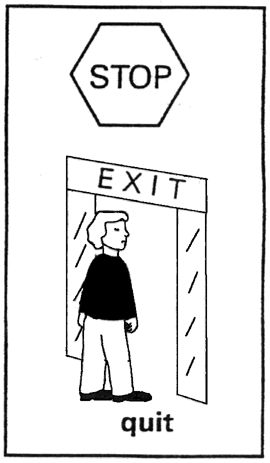




+



Right to Withdraw

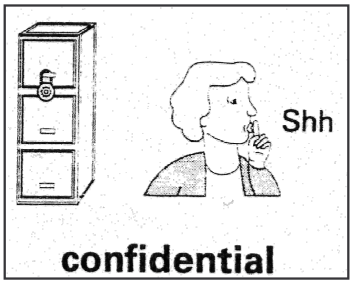


- ✓ You **can stop** at any time
- ✓ It is **your choice**
- ✓ It is **ok** to quit

Potential Risks:

✗ There is **NO** danger in participating in this study

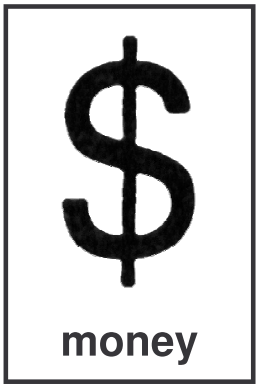
✓ Everything is **confidential**



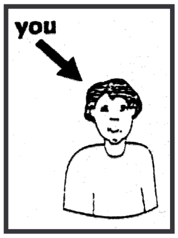
Will this **harm** you? **NO**

Thank you

We will pay you
$10.



You can call the researchers to ask questions.

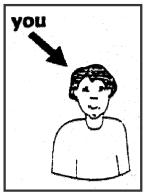


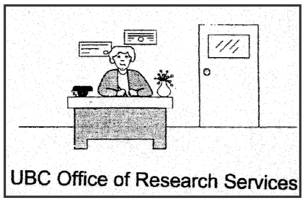
Barbara Purves, M.Sc., S-LP(C)	604-822-2288
Meghan Allen	604-827-3924
Joanna McGrenere, Ph.D.	604-827-5201

Concerns

not satisfied

If you have concerns about your treatment or rights, you can call the UBC Office of Research Services.





Research Subject Information Line: 604-822-8598

Project Title: Designing Technology for People with Aphasia

Project Consent:

The information on the previous 10 pages has been **explained** to me.

YES 👍 ____________

I **agree** to participate in this research project.

YES 👍 ____________ NO 👎 ____________

I have been given a **copy** of this form.

YES 👍 ____________ NO 👎 ____________

____________________ ____________

Signature of Participant Date

____________________ ____________

Signature of Witness Date

Appendix B

Field Study Forms

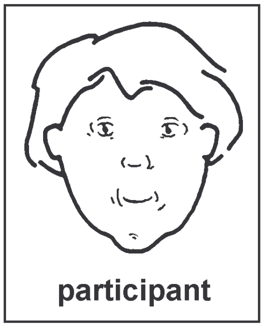
B.1 Consent Forms for the Participants who have Aphasia

We asked each participant who has aphasia to sign a consent form prior to participating in the field studies. To help the participants understand the consent form it was illustrated with images wherever possible. The following pages show an example of this form.

INFORMED CONSENT

For

RESEARCH



Participant: ______________________________

Investigators: Peter Graf, Ph.D. (604-822-6635)
Joanna McGrenere, Ph.D. (604-827-5201)
Barbara Purves, M.Sc. (604-822-2288)

Student Investigator: Meghan Allen (604-736-4213)

Project Title: Designing Technology for People with Aphasia

Adapted from Kagan, A. Winckel, J. & Shumway, E. Pictographic Communication Resources. Aphasia Centre – North York, 1996.

Computer Technology

computers

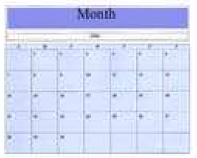
Designing computer technology for people
with aphasia.

We want to know if you can use it.

Can you use it? **YES** **NO**

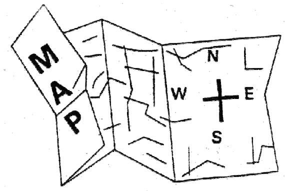
How often?

2-4 Sessions each week for 1 month.



At least 2 hours per week with the researchers

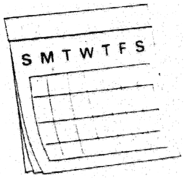
Where?



→

Your House

When?

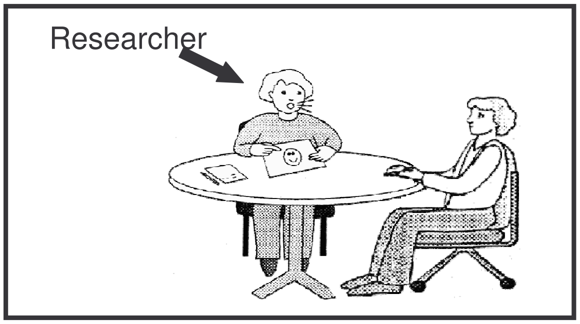


→ to be arranged

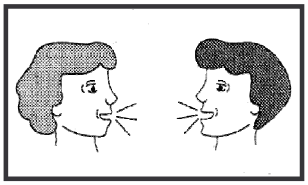
What ? can you expect?

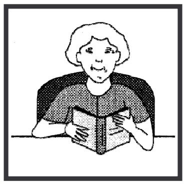
Week 1: A researcher will:

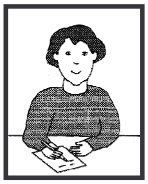
- Assess your language skills
- Talk about your communication with you



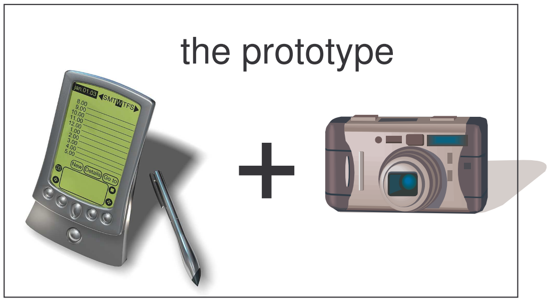
Communication

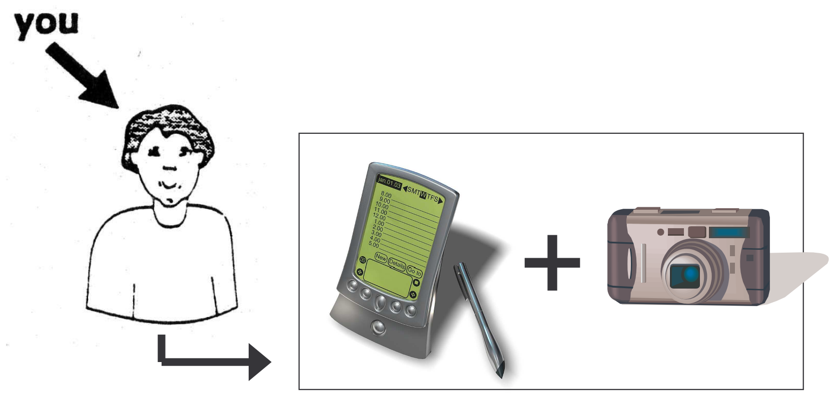

conversing


reading

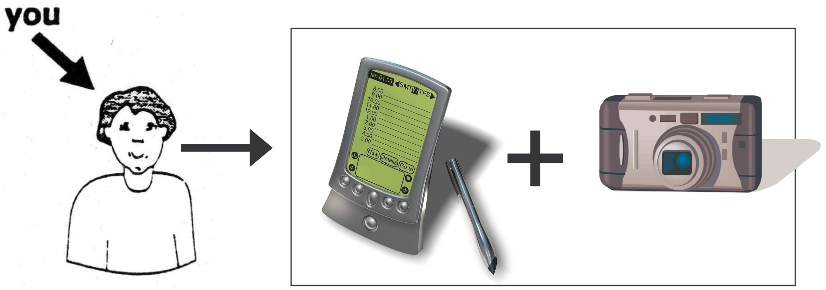

writing

- Teach you how to use the prototype



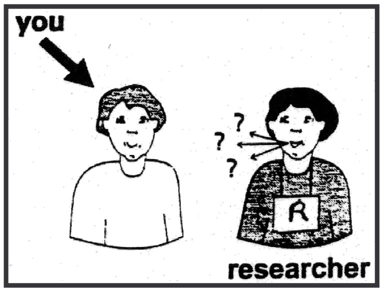


Weeks 2-4: You will use the prototype on your own and talk with the researchers about your experiences

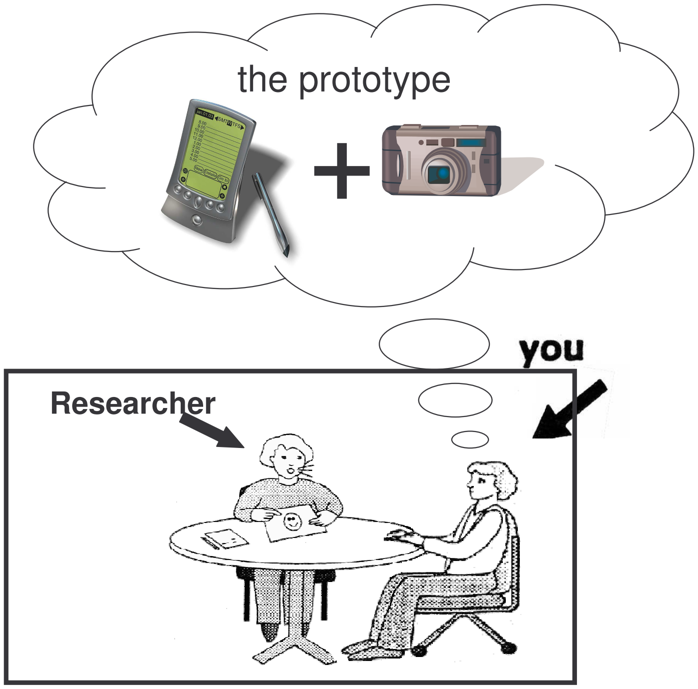


You will use the prototype.

The researcher will talk with you about how you are using the prototype.

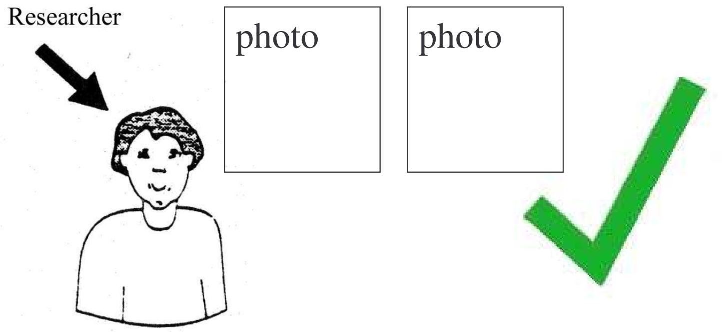


End of Week 4: The researcher will ask you some questions about your experience with the prototype.

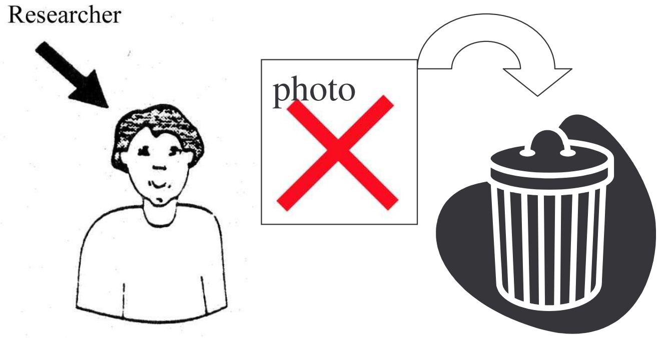


Privacy

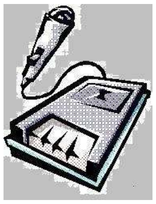
The researcher can see all the photographs that you take

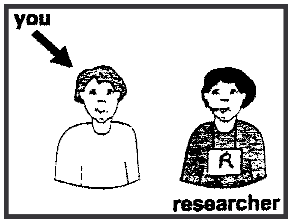


But, if you **delete** a photograph, the researcher **cannot** see it

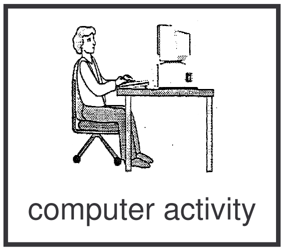


The researcher may **audiotape** some sessions.

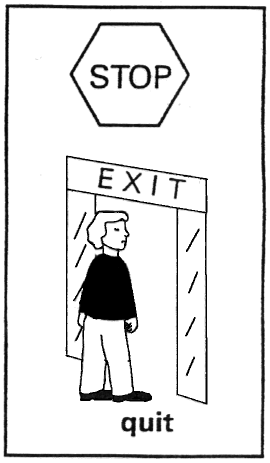




+



Right to Withdraw

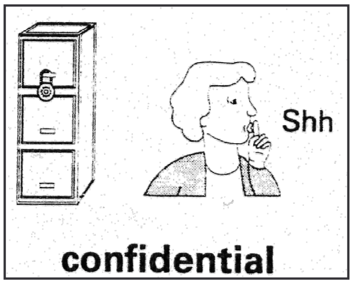


- ✓ You **can stop** at any time
- ✓ It is **your choice**
- ✓ It is **ok** to quit

Potential Risks:

✗ There is **NO** danger in participating in this study

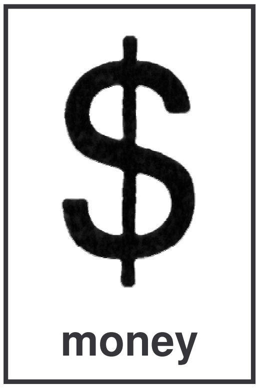
✓ Everything is **confidential**



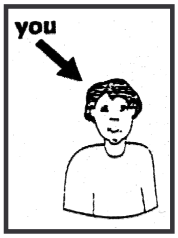
Will this **harm** you? **NO**

Thank you

We will pay you
$75.



You can call the researchers to ask questions.

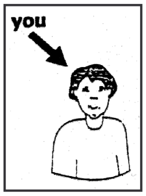


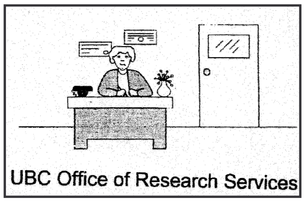
Barbara Purves, M.Sc., S-LP(C)	604-822-2288
Meghan Allen	604-827-3924
Joanna McGrenere, Ph.D.	604-827-5201

Concerns

not satisfied

If you have concerns about your treatment or rights, you can call the UBC Office of Research Services.





Research Subject Information Line: 604-822-8598

Project Title: Designing Technology for People with Aphasia

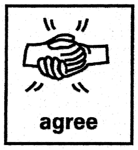
Project Consent:

The information on the previous 14 pages has been **explained** to me.

YES 👍

____

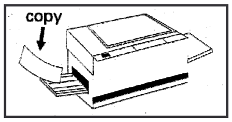
I **agree** to participate in this research project.



YES 👍 NO 👎

__________ __________

I have been given a **copy** of this form.



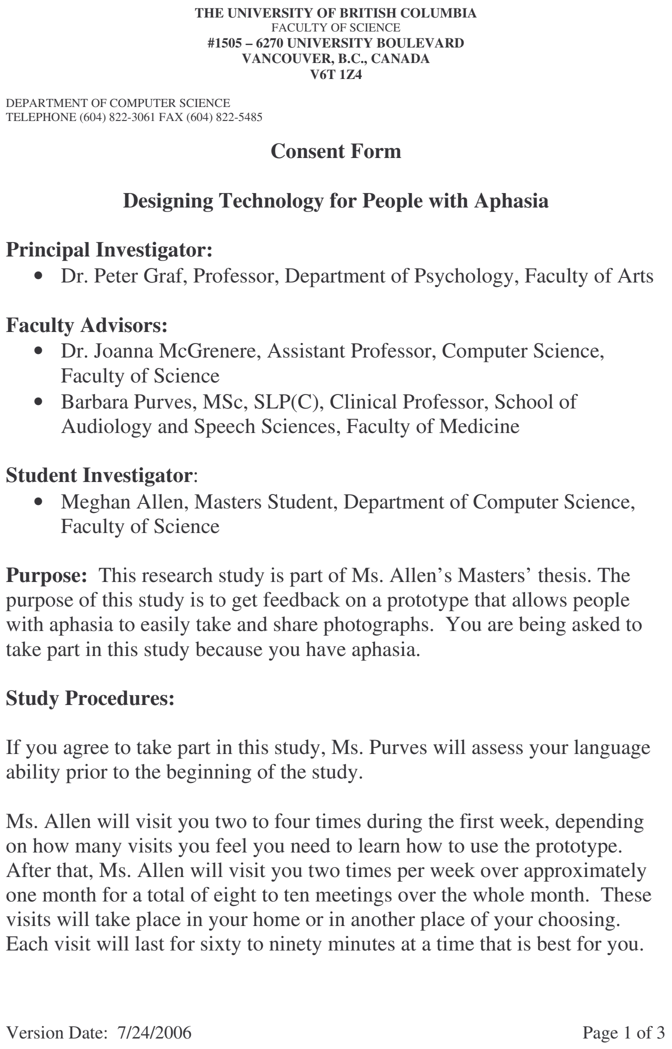
YES 👍 NO 👎

__________ __________

______________________________ __________

Signature of Participant Date

A text version of the consent form for the participant who has aphasia was also provided. A copy of this consent form follows.



THE UNIVERSITY OF BRITISH COLUMBIA
FACULTY OF SCIENCE
#1505 – 6270 UNIVERSITY BOULEVARD
VANCOUVER, B.C., CANADA
V6T 1Z4

DEPARTMENT OF COMPUTER SCIENCE
TELEPHONE (604) 822-3061 FAX (604) 822-5485

Consent Form

Designing Technology for People with Aphasia

Principal Investigator:
- Dr. Peter Graf, Professor, Department of Psychology, Faculty of Arts

Faculty Advisors:
- Dr. Joanna McGrenere, Assistant Professor, Computer Science, Faculty of Science
- Barbara Purves, MSc, SLP(C), Clinical Professor, School of Audiology and Speech Sciences, Faculty of Medicine

Student Investigator:
- Meghan Allen, Masters Student, Department of Computer Science, Faculty of Science

Purpose: This research study is part of Ms. Allen's Masters' thesis. The purpose of this study is to get feedback on a prototype that allows people with aphasia to easily take and share photographs. You are being asked to take part in this study because you have aphasia.

Study Procedures:

If you agree to take part in this study, Ms. Purves will assess your language ability prior to the beginning of the study.

Ms. Allen will visit you two to four times during the first week, depending on how many visits you feel you need to learn how to use the prototype. After that, Ms. Allen will visit you two times per week over approximately one month for a total of eight to ten meetings over the whole month. These visits will take place in your home or in another place of your choosing. Each visit will last for sixty to ninety minutes at a time that is best for you.

During the rest of the month, you will have the opportunity to use the prototype in your daily life to take photographs and share them with people.

During the second and third weeks, Ms. Allen will meet with you to ask questions about your use of the prototype. Ms. Allen will be asking questions that will help her determine which parts of the prototype are working well for you and which parts of the prototype need to be improved. Ms. Allen will also be asking about how you use the prototype, who you use it with and how often you use it.

Ms. Allen will meet with you at the end of the month long period and ask questions about the prototype and how it worked for you.

Everything you do with the prototype will be logged. Only Ms. Allen and members of her research project will have access to this data. The only exception is that if you delete a photograph, Ms. Allen will not be able to view the photograph that you have deleted. However, she will be able to determine when you took the photograph, how many times you shared it with someone, and when it was deleted.

For some of the visits, Ms. Allen will ask for permission to record the conversation with a tape-recorder. Everyone who takes part in the conversation will be asked for their permission to be recorded. These recordings will be for the purposes of this study only and only members of the research project will have access to the recordings.

In total, this study will require approximately twelve to sixteen hours of meeting time with researchers over a one month period.

Compensation: You will receive $75 as compensation for participating in this study.

Confidentiality: Any information obtained from you or your conversation partner will be kept strictly confidential. This consent form will be kept in a locked place separate from all other study data, accessible only to Ms. Allen and her faculty advisors, Ms. Barbara Purves and Dr. Joanna McGrenere. Your name will not be used in any document. Your name will not be used in any report about this research. All documents and recordings will be identified by a pseudonym and will be kept in a locked office in a locked filing cabinet and/or on a password-protected computer. Only Ms. Allen and members of the research project will have access to the information.

Contact: If you have any questions or if you want further information about the study, you may contact Meghan Allen at (604) 736-4213, Joanna McGrenere at (604) 827-5201, Barbara Purves at (604) 822-2288, or Peter Graf at (604) 822-6635.

If you have any concerns about your treatment or your rights as a research subject, you may contact the Research Subject Information Line at the University of British Columbia at (604) 822-8598.

Consent: I understand that my consent in this study is entirely voluntary and that I may withdraw from the study or refuse to participate at any time.

I have received a copy of this consent form for my own records.

I consent to participate in this study.

________________________	____________________
Subject Signature	Date

B.2 Consent Forms for Participants who do not have Aphasia

The close family members of the participants who have aphasia were also asked to sign a consent form prior to participating in the field studies. The following pages show an example of this form.

THE UNIVERSITY OF BRITISH COLUMBIA
FACULTY OF SCIENCE
#1505 – 6270 UNIVERSITY BOULEVARD
VANCOUVER, B.C., CANADA
V6T 1Z4

DEPARTMENT OF COMPUTER SCIENCE
TELEPHONE (604) 822-3061 FAX (604) 822-5485

Consent Form

Designing Technology for People with Aphasia

Principal Investigator:
- Dr. Peter Graf, Professor, Department of Psychology, Faculty of Arts

Faculty Advisors:
- Dr. Joanna McGrenere, Assistant Professor, Computer Science, Faculty of Science
- Barbara Purves, MSc, SLP(C), Clinical Professor, School of Audiology and Speech Sciences, Faculty of Medicine

Student Investigator:
- Meghan Allen, Masters Student, Department of Computer Science, Faculty of Science

Purpose: This research project is part of Ms. Allen's Masters' thesis. The purpose of this study is to get feedback on a prototype that allows people with aphasia to easily take and share photographs. You are being asked to take part in this study because you communicate regularly with someone who has aphasia.

Study Procedures: If you agree to take part in this study, Ms. Allen will visit you four times over approximately one month. These visits will take place in your home or in another place of your choosing. Each visit will last for sixty to ninety minutes at a time that is best for you. If you wish, you may also choose to additionally attend some or all of the meetings between Ms. Allen and the person with aphasia, but this is not required.

During the first visit, Ms. Allen will ask you to complete a questionnaire about communicating with the person who has aphasia. She will also ask you questions about what it is like to converse with the person with aphasia and about the communicative abilities of the person with aphasia.

In the first week of meetings, Ms. Allen will be training the person with aphasia how to use the prototype. You will be required to be present during one of the training sessions. Also, during this time, you and the person with aphasia will work out with Ms. Allen when she can visit over the next three weeks.

During the second and third weeks, Ms. Allen will be meeting with the person with aphasia to ask questions about the prototype. You will be expected to attend one of these sessions during each of these two weeks. You may attend additional meetings between Ms. Allen and the person with aphasia if you wish. Ms. Allen will meet with you at the end of the study and ask questions about your experiences with the prototype in communication with the person with aphasia. You will also be required to complete the questionnaire done at the beginning of the study again.

For some of the visits, Ms. Allen will ask for permission to record the conversation with a tape-recorder. Everyone who takes part in the conversation will be asked for their permission to be recorded. These recordings will be for the purposes of this study only and only members of the research project will have access to the recordings.

In total, this study will require approximately four to six hours of meeting time with Ms. Allen over a one month period.

Compensation: You will receive $25 as compensation for participating in this study.

Confidentiality: Any information obtained from you or the person with aphasia will be kept strictly confidential. This consent form will be kept in a locked place separate from all other study data, accessible only to Ms. Allen and her faculty advisors, Dr. Joanna McGrenere and Barbara Purves. Your name will not be used in any document. Your name will not be used in any report about this research. All documents and recordings will be identified by a pseudonym and will be kept in a locked office in a locked filing cabinet and/or on a password-protected computer. Only Ms. Allen and members of the research project will have access to the information.

Contact: If you have any questions or if you want further information about the study, you may contact Meghan Allen at (604) 736-4213, Joanna

McGrenere at (604) 827-5201, Barbara Purves at (604) 822-2288 or Peter Graf at (604) 822-6635.

If you have any concerns about your treatment or your rights as a research subject, you may contact the Research Subject Information Line at the University of British Columbia at (604) 822-8598.

Consent: I understand that my consent in this study is entirely voluntary and that I may withdraw from the study or refuse to participate at any time.

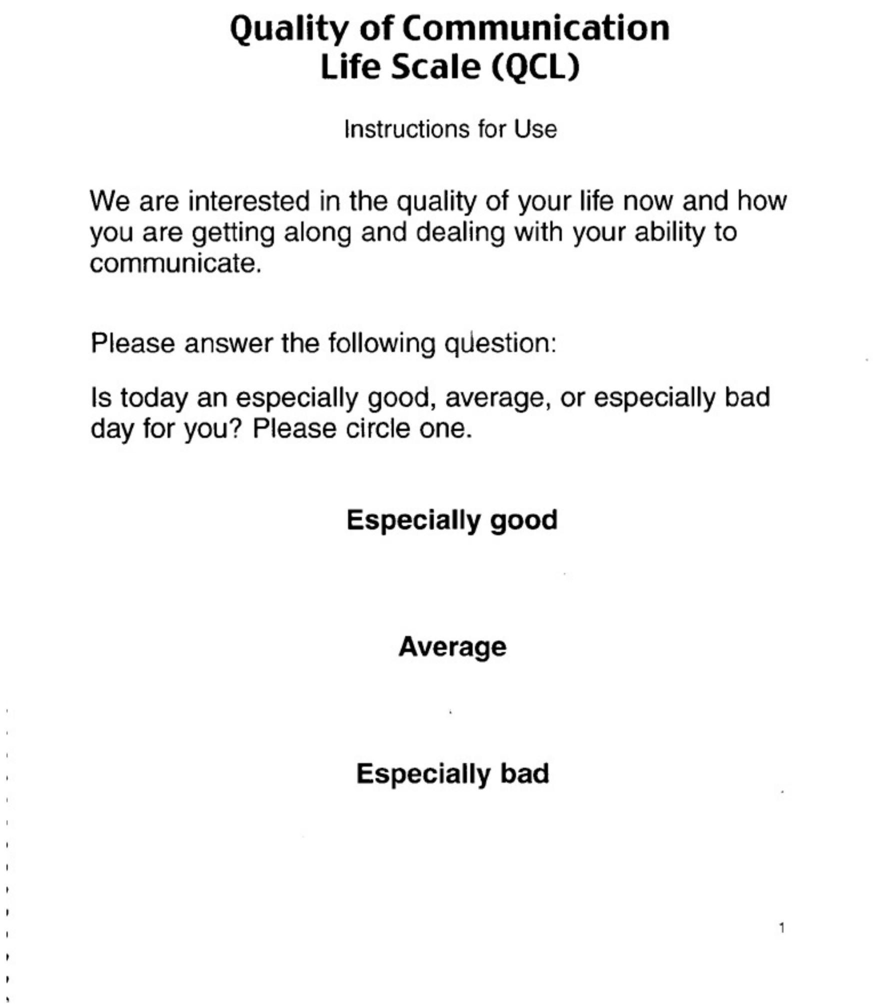
I have received a copy of this consent form for my own records.

I consent to participate in this study.

______________________	______________________
Subject Signature	Date

B.3 Quality of Communication Life Scale

We administered the Quality of Communication Life Scale (QCL) to P1, P2, and P3. The QCL was developed by the American Speech-Hearing-Language Association (ASHA), and copyright for the QCL is held by ASHA (©ASHA, [44]). The QCL is included in this appendix with permission from ASHA and the primary author, Dr. Diane Paul.



Quality of Communication Life Scale (QCL)

Instructions for Use

We are interested in the quality of your life now and how you are getting along and dealing with your ability to communicate.

Please answer the following question:

Is today an especially good, average, or especially bad day for you? Please circle one.

Especially good

Average

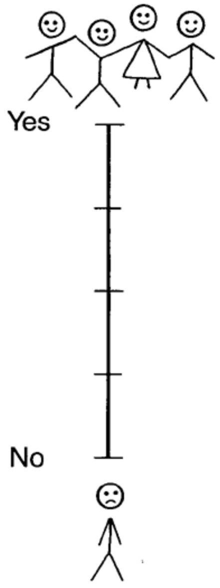
Especially bad

Now we want you to complete this scale about the quality of your life. Please follow these instructions:

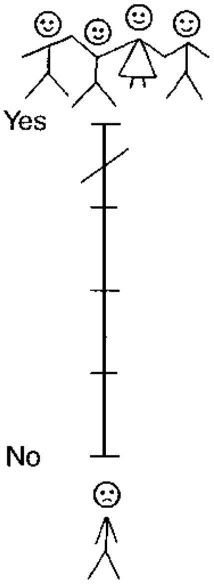
- Read each statement
- Mark the line at a point that describes you best.
- If the statement DOES describe you, put your mark as close to the top as you see fit. If the statement DOES NOT describe you, put your mark closer to the bottom. Mark the place that describes you the best.
- Remember, these statements are about you and your ability to communicate.
- Before each item, ask yourself “Even though I have difficulty communicating…”

Here is a sample item:

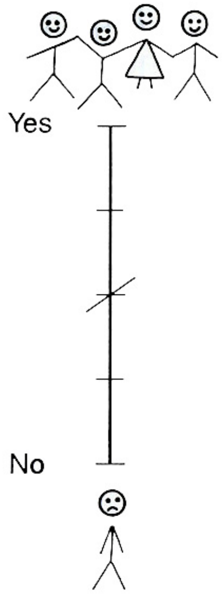
Even though I have difficulty communicating,
"I like to be with people."



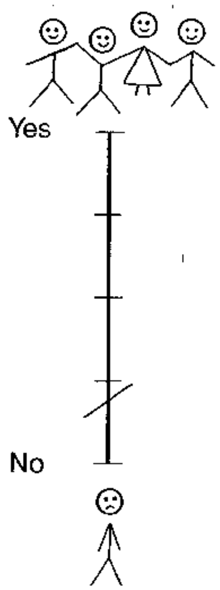
If you like to be with people a lot, even though you have difficulty communicating, then your mark goes close to the top, like this.



If you like to be with others sometimes, then your mark should be nearer the middle of the line, like this.



If you do not like to be with people then put your mark closer to the bottom, like this.

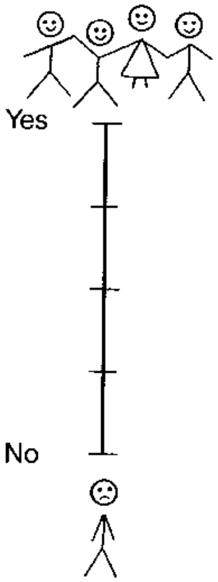


Your mark can go anywhere on the line that seems okay to you.

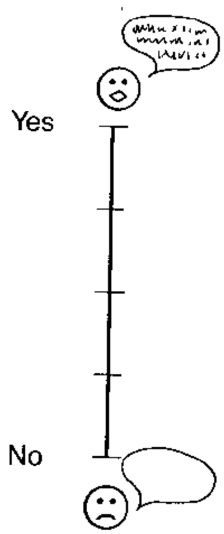
Practice Item:

Now you try one.

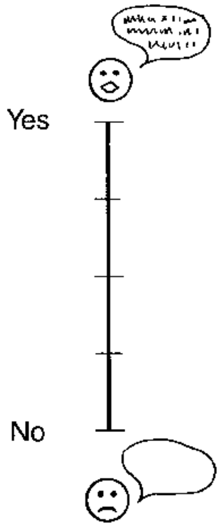
Even though I have difficulty communicating,
"I like to be with people."



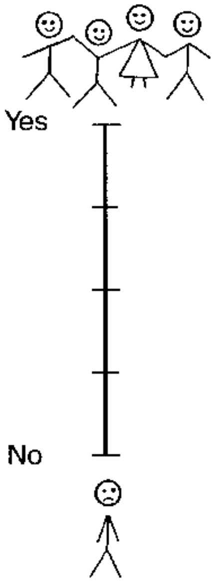
1. I like to talk with people.



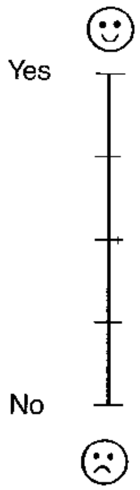
2. It's easy for me to communicate.



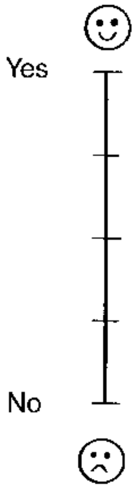
3. My role in the family is the same.



4. I like myself.

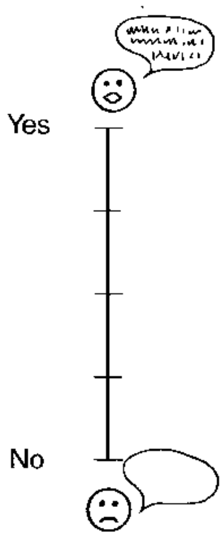


5. I meet the communication needs of my job or school (such as: typing, giving and following directions, reading).

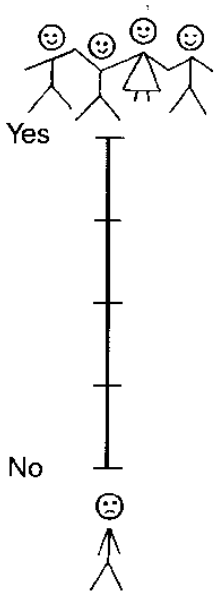


☐ **Does not apply**

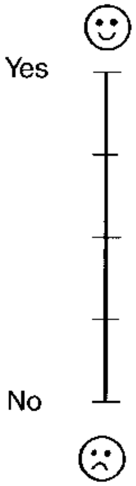
6. I stay in touch with family and friends.



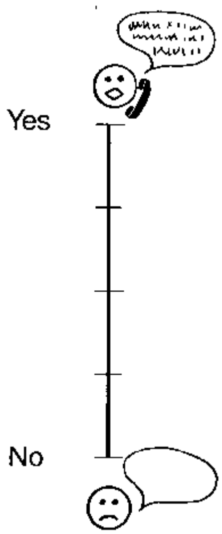
7. People include me in conversations.



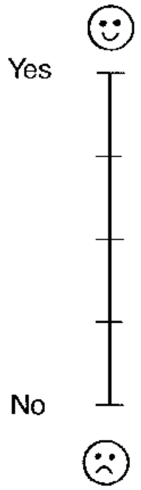
8. I follow news, sports, and stories on TV/movies.



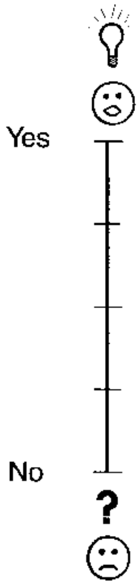
9. I use the telephone.



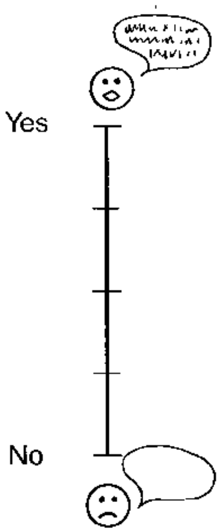
10. I see the funny things in life.



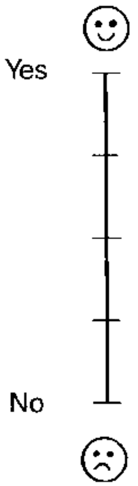
11. People understand me when I talk.



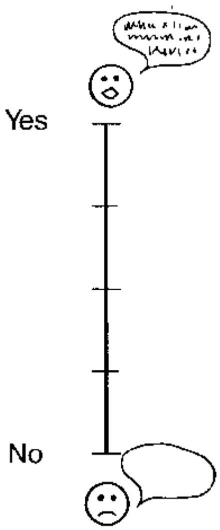
12. I keep trying when people don't understand me.



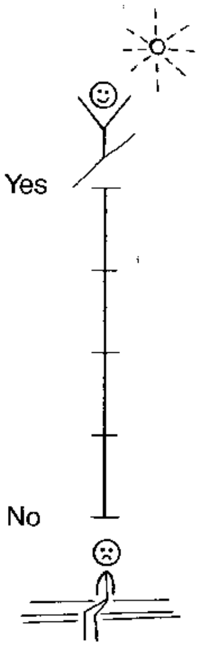
13. I make my own decisions.



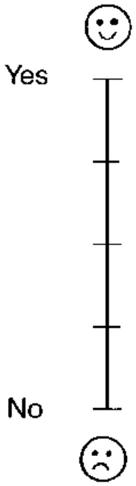
14. I am confident that I can communicate.



15. I get out of the house and do things (such as: sports, dinner, shows, parties).

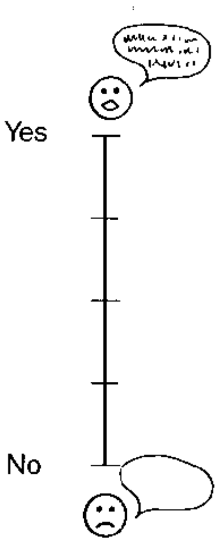


16. I have household responsibilities (such as: shopping, cooking, home repairs).

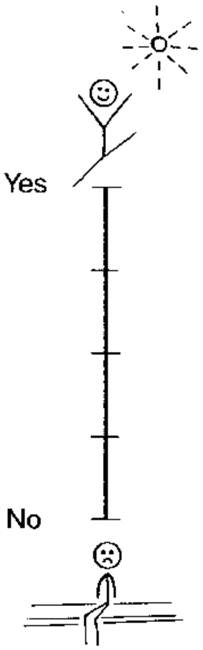


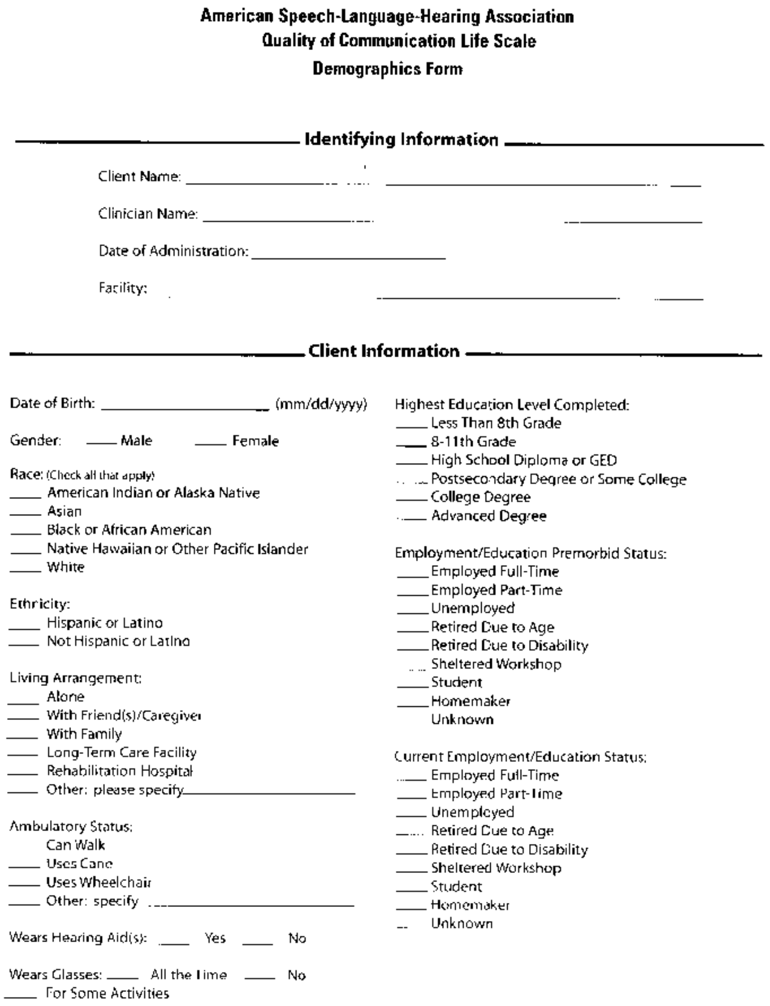
☐ **Does not apply**

17. I speak for myself.



18. In general, my quality of life is good.





American Speech-Language-Hearing Association
Quality of Communication Life Scale
Demographics Form

Identifying Information

Client Name: ____________________

Clinician Name: ____________________

Date of Administration: ____________________

Facility: ____________________

Client Information

Date of Birth: ____________________ (mm/dd/yyyy)

Gender: ____ Male ____ Female

Race: (Check all that apply)
____ American Indian or Alaska Native
____ Asian
____ Black or African American
____ Native Hawaiian or Other Pacific Islander
____ White

Ethnicity:
____ Hispanic or Latino
____ Not Hispanic or Latino

Living Arrangement:
____ Alone
____ With Friend(s)/Caregiver
____ With Family
____ Long-Term Care Facility
____ Rehabilitation Hospital
____ Other: please specify____________________

Ambulatory Status:
Can Walk
____ Uses Cane
____ Uses Wheelchair
____ Other: specify ____________________

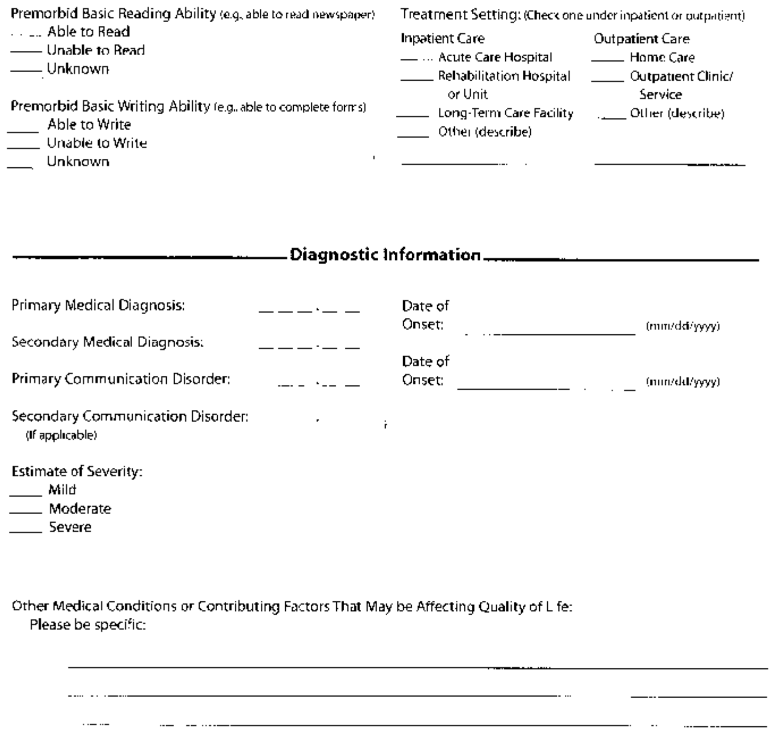
Wears Hearing Aid(s): ____ Yes ____ No

Wears Glasses: ____ All the Time ____ No
____ For Some Activities

Highest Education Level Completed:
____ Less Than 8th Grade
____ 8-11th Grade
____ High School Diploma or GED
____ Postsecondary Degree or Some College
____ College Degree
____ Advanced Degree

Employment/Education Premorbid Status:
____ Employed Full-Time
____ Employed Part-Time
____ Unemployed
____ Retired Due to Age
____ Retired Due to Disability
____ Sheltered Workshop
____ Student
____ Homemaker
Unknown

Current Employment/Education Status:
____ Employed Full-Time
____ Employed Part-Time
____ Unemployed
____ Retired Due to Age
____ Retired Due to Disability
____ Sheltered Workshop
____ Student
____ Homemaker
____ Unknown



Premorbid Basic Reading Ability (e.g., able to read newspaper)
____ Able to Read
____ Unable to Read
____ Unknown

Premorbid Basic Writing Ability (e.g., able to complete forms)
____ Able to Write
____ Unable to Write
____ Unknown

Treatment Setting: (Check one under inpatient or outpatient)

Inpatient Care
____ Acute Care Hospital
____ Rehabilitation Hospital
or Unit
____ Long-Term Care Facility
____ Other (describe)
____

Outpatient Care
____ Home Care
____ Outpatient Clinic/
Service
____ Other (describe)
____

Diagnostic Information

Primary Medical Diagnosis: _ _ _ . _ _

Secondary Medical Diagnosis: _ _ _ . _ _

Primary Communication Disorder: _ _ _ . _ _

Secondary Communication Disorder:
(If applicable)

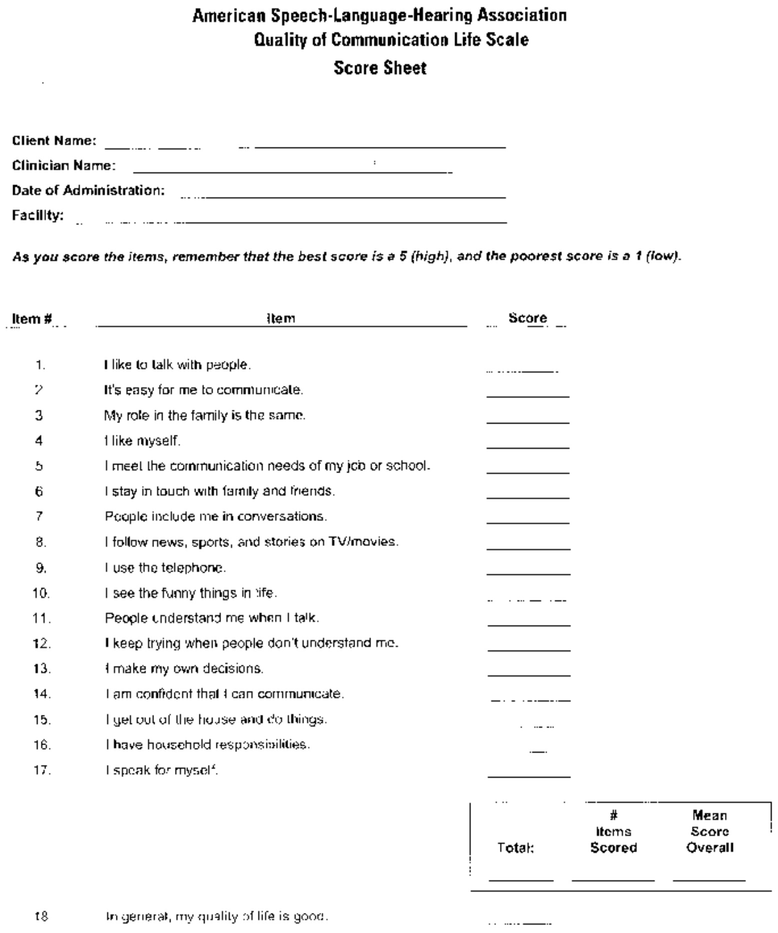
Date of
Onset: ____________________ (mm/dd/yyyy)

Date of
Onset: ____________________ (mm/dd/yyyy)

Estimate of Severity:
____ Mild
____ Moderate
____ Severe

Other Medical Conditions or Contributing Factors That May be Affecting Quality of Life:
Please be specific:

____
____
____



American Speech-Language-Hearing Association
Quality of Communication Life Scale
Score Sheet

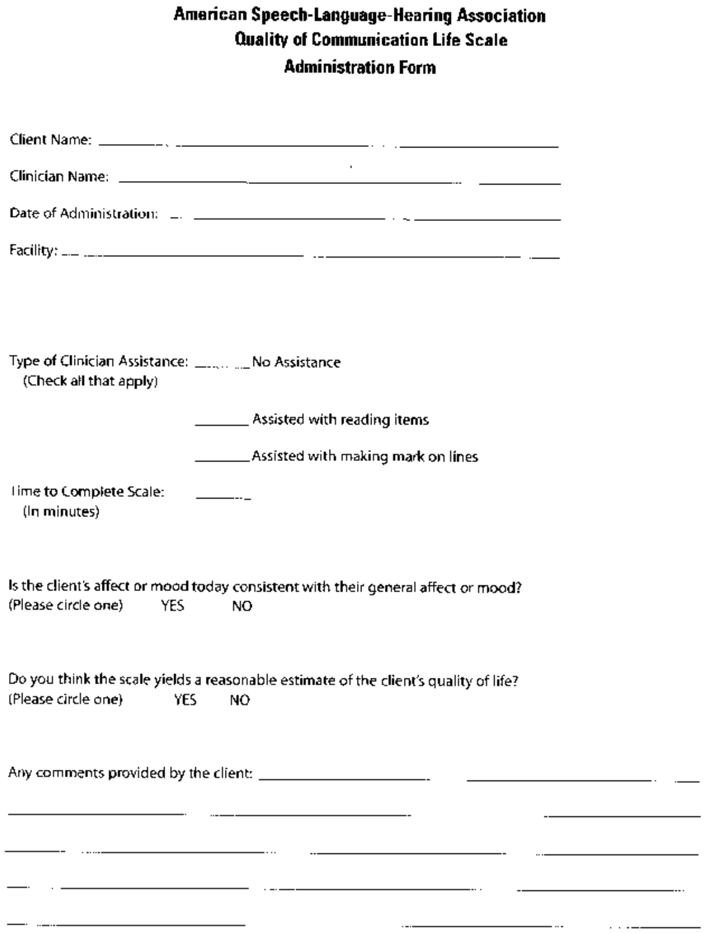
Client Name: ____________________
Clinician Name: ____________________
Date of Administration: ____________________
Facility: ____________________

As you score the items, remember that the best score is a 5 (high), and the poorest score is a 1 (low).

Item #	Item	Score
1.	I like to talk with people.	
2	It's easy for me to communicate.	
3	My role in the family is the same.	
4	I like myself.	
5	I meet the communication needs of my job or school.	
6	I stay in touch with family and friends.	
7	People include me in conversations.	
8.	I follow news, sports, and stories on TV/movies.	
9.	I use the telephone.	
10.	I see the funny things in life.	
11.	People understand me when I talk.	
12.	I keep trying when people don't understand me.	
13.	I make my own decisions.	
14.	I am confident that I can communicate.	
15.	I get out of the house and do things.	
16.	I have household responsibilities.	
17.	I speak for myself.	

	# Items Scored	Mean Score Overall
Total:		

18	In general, my quality of life is good.	



American Speech-Language-Hearing Association
Quality of Communication Life Scale
Administration Form

Client Name: ______________________________

Clinician Name: ______________________________

Date of Administration: ______________________________

Facility: ______________________________

Type of Clinician Assistance: ________ No Assistance
(Check all that apply)

________ Assisted with reading items

________ Assisted with making mark on lines

Time to Complete Scale: ________
(In minutes)

Is the client's affect or mood today consistent with their general affect or mood?
(Please circle one) YES NO

Do you think the scale yields a reasonable estimate of the client's quality of life?
(Please circle one) YES NO

Any comments provided by the client: ______________________________

____

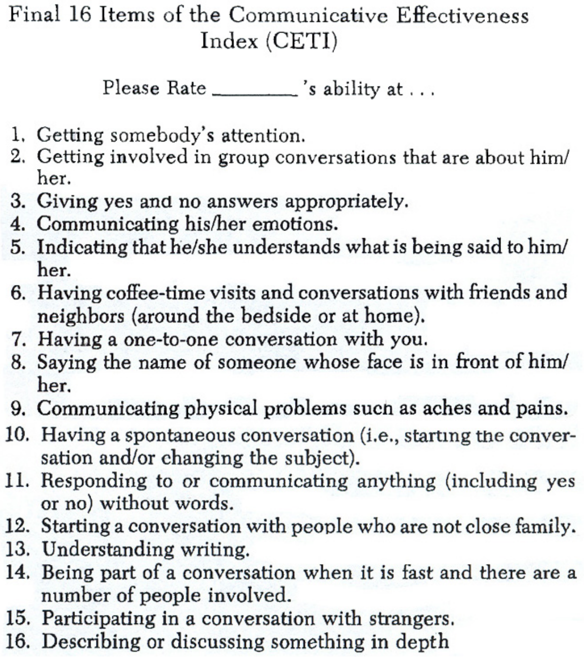
____

____

____

B.4 Communicative Effectiveness Index

We administered the Communicative Effectiveness Index (CETI) to P1 and P2. The CETI was developed by Lomas, Pickard, Bester, Elbard, Finlayson, and Zoghaib, and copyright for the CETI is held by the American Speech-Hearing-Language Association (ASHA) (©ASHA, [36]). The CETI questions are included in this appendix with permission from ASHA and the primary author, Dr. Jonathan Lomas.



Final 16 Items of the Communicative Effectiveness Index (CETI)

Please Rate ________ 's ability at . . .

1. Getting somebody's attention.
2. Getting involved in group conversations that are about him/her.
3. Giving yes and no answers appropriately.
4. Communicating his/her emotions.
5. Indicating that he/she understands what is being said to him/her.
6. Having coffee-time visits and conversations with friends and neighbors (around the bedside or at home).
7. Having a one-to-one conversation with you.
8. Saying the name of someone whose face is in front of him/her.
9. Communicating physical problems such as aches and pains.
10. Having a spontaneous conversation (i.e., starting the conversation and/or changing the subject).
11. Responding to or communicating anything (including yes or no) without words.
12. Starting a conversation with people who are not close family.
13. Understanding writing.
14. Being part of a conversation when it is fast and there are a number of people involved.
15. Participating in a conversation with strangers.
16. Describing or discussing something in depth

Appendix C

Ethics Approval Certificates

The Aphasia Project has ongoing ethics approval, which was last approved by the University of British Columbia Behavioural Research Ethics Board on October 27, 2005. A copy of the certificate is included on the following page.

The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

PRINCIPAL INVESTIGATOR Graf, P.	DEPARTMENT Psychology	NUMBER **B03-0147**

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
UBC Campus ,

CO-INVESTIGATORS:
Allen, Meghan, Computer Science; Klawe, Maria, Dean's Office - Science; McGrenere, Joanna, Computer Science; Moffatt, Karyn, Computer Science; Purves, Barbara, Audiology & Speech Sciences; Riley, Jeff,

SPONSORING AGENCIES
Humanities and Social Sciences Federation of Canada

TITLE :
Cognitive Demands of an Assistive Communication Device

APPROVAL RENEWED DATE	TERM (YEARS)	AMENDMENT:	AMENDMENT APPROVED:
OCT 2 7 2005	1	Oct. 18, 2005, Co-PI	OCT 2 7 2005

CERTIFICATION:

The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval of the Behavioural Research Ethics Board by one of the following:
Dr. Peter Suedfeld, Chair,
Dr. Susan Rowley, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures

We submitted the field study consent forms as an amendment to our ongoing project with the University of British Columbia Behavioural Research Ethics Review Board. The amendment was approved on May 11, 2006. A copy of the amendment approval certificate is included on the following page.

The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

PRINCIPAL INVESTIGATOR Graf, P.	DEPARTMENT Psychology	NUMBER **B03-0147**

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT

UBC Campus ,

CO-INVESTIGATORS:

Allen, Meghan, Computer Science; Klawe, Maria, Dean's Office - Science; McGrenere, Joanna, Computer Science; Moffatt, Karyn, Computer Science; Purves, Barbara, Audiology & Speech Sciences; Riley, Jeff,

SPONSORING AGENCIES

Humanities and Social Sciences Federation of Canada

TITLE :

Cognitive Demands of an Assistive Communication Device

APPROVAL DATE 05-10-27 (yr/mo/day)	TERM (YEARS) 1	AMENDMENT: May 8, 2006, Consent form	AMENDMENT APPROVED: MAY 1 1 2006

CERTIFICATION:

The request for continuing review of an amendment to the above-named project has been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approved on behalf of the Behavioural Research Ethics Board
by one of the following:
Dr. Peter Suedfeld, Chair,
Dr. Susan Rowley, Associate Chair
Dr. Jim Rupert, Associate Chair
Dr. Arminee Kazanjian, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures