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Factors and challenges when designing an ICT-tool for people with dementia

Master's Thesis in Interaction Design

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Report number: 2017:16
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Abstract

This thesis explores challenges when designing a software based photo diary tool for people with early stage dementia. The project was initiated by Semcon AB, to investigate the problem domain consisting of caregivers, relatives and persons with dementia. The study takes a user centered design (UCD) approach and applies existing design guidelines. Applying the three stages of UCD; research, design and evaluation, the project culminates in an interactive prototype that allows individuals with dementia to singlehandedly compile a tablet based photo diary. The tool is intended as creative support for caregivers when compiling life stories used in personalized care, as well as reminiscence support for the individual with dementia. The thesis concludes with a series of factors and guidelines to consider when designing for the aforementioned target group. Factors were identified as: access to participants, need identification, communication barriers, domain expert predisposition, validity of research data and interface design clarity.

Keywords: dementia, ICT, interaction design, UCD, interface design

Abbreviations

GUI = Graphical User Interface

ICT = Information and Communications Technology

PWD = Persons with dementia

UCD = User Centered Design

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1. INTRODUCTION

Dementia is a chronic syndrome that affects the brain and causes severe deterioration in cognitive functions. Since it affects mainly older people, it is often mistaken as a normal part of ageing. However, dementia is a genetically predisposed disease that usually manifests during later stages of life (Prince & Jackson, 2009).

Common symptoms for dementia patients are *memory loss, difficulty performing familiar tasks, problems with language, disorientation to time and place, poor or decreased judgement, and problems with keeping track of things*. Unfortunately, there is no cure for dementia as of today (Alzheimer's Disease International, 2017).

Dementia affects more than 50 million people worldwide (Alzheimer's Disease International, 2017) and is considered a growing global challenge. Between 2010 and 2015 the cost of dementia increased from 604 billion USD to 818 billion globally. Rising life expectancy is one major reason for the rapid increase in the number of dementia patients (Prince et al., 2015). Sweden is no exception. As of 2012, the total cost related to dementia was estimated to around 63 billion Swedish Kronor (Socialstyrelsen, 2014a), roughly 7 billion USD. Conclusively, dementia has tremendous economic impact on society – but most importantly it impairs quality of life for many people.

This study describes the design process of a software based photo diary tool for persons with dementia (henceforth referred to as PWDs). The project takes a UCD (User Centered Design) approach in which the user is placed in the center of the design process. This report describes the design process from early ideas to a rudimentary prototype and concludes with a series of factors and challenges when designing for people with dementia.

The study was carried out in Sweden together with PWDs and caregivers.

1.1 About Semcon

The project was carried out together with Semcon Sweden AB. Semcon is an international technology company with over 2000 employees operating all over the globe. The company is specialized in developing user friendly products in a wide variety of fields. Besides product development, research is an important part of the company effort in which health care products is a major segment (Semcon, 2017). ICT (Information and Communications Technology) has proven successful in the past for reminiscence support and for facilitating communication with PWDs. Semcon, as a technology company invested in health care, was therefore a prominent initiator for this project.

1.2 Aim and research question

The aim of this study is to investigate important factors when designing an ICT-based tool for persons with dementia. The desired outcome of this study is to provide insights and possible guidelines valuable when designing an ICT-tool for PWDs. The research question for this study is:

What factors should be considered when designing an ICT-based tool for persons with dementia?

The ICT-tool should be designed in such way that the PWD with little to no help can use the tool independently.

1.3 Delimitations

The target group for this study are persons with early stage dementia. At middle to late stage dementia verbal skills are often severely deteriorated (Prince & Jackson, 2009), requiring special training of those attempting to communicate with the PWD (Farran & Keane-Hagerty, 1989). The study will therefore involve PWDs not yet living in retirement homes, as these individuals usually suffer from middle to late-stage dementia.

The study was carried out in the Gothenburg area in Sweden, thus only accounting for Swedish conditions in regard to health care procedures and cultural circumstances.

Low fidelity prototypes were used as mediating tools, rather than fully implemented applications.

1.4 Stakeholders

PWD	Person with dementia. The primary end user. The design should be easy to use and comprehensible for this user. Also, ethical considerations must be taken into account when involving this user in the design process (see 3. Ethical considerations).
Caregiver	A person responsible for the care and wellbeing of the PWD. Nurses and healthcare providers can be attributed to this stakeholder. The design should accommodate for their needs as it most likely will be used in healthcare environments.
Relative	This stakeholder may be the most emotionally connected to the PWD and may have opinions on how the study should be performed as well as the final design.
Semcon	Semcon is interested in developing assistive technology for individuals with dementia. The company has commercial interests in the study, as the results may provide a framework for the development of future products.

2. THEORY AND BACKGROUND

This section accounts for relevant theory and previous work that was found during literature studies.

2.1 Dementia

Dementia is not a single disease, but a *descriptive umbrella term* for several types of cognitive afflictions. Despite common belief, dementia is not a natural part of ageing, but a genetic impairment that typically surfaces during later stages of life. Although deterioration of cognitive functions is a common characteristic during normal ageing, dementia is an organic disorder due to physical changes in the brain (Gustafson, 1996; Prince & Jackson, 2009).

Dementia affects every person differently as there are many factors that contribute to the impact of the disease. Personality, lifestyle, relationships, physical health and how the person was like before the disease are all factors that influence the symptoms. Dementia is therefore hard to specify, but can be best described in three major stages; early stage, middle stage and late stage (Table 1). These stages should be considered as guidelines as cognitive functions may deteriorate in different ways and in different rates (Prince & Jackson, 2009).

Early stage	Middle stage	Late stage
<ul style="list-style-type: none"> • Have problems talking properly (language problems) • Have significant memory loss – particularly for things that have just happened • Not know the time of day or the day of the week • Become lost in familiar places • Have difficulty in making decisions • Become inactive and unmotivated • Show mood changes, depression or anxiety • React unusually angrily or aggressively on occasion • Show a loss of interest in hobbies and activities 	<ul style="list-style-type: none"> • May become very forgetful – especially of recent events and people’s names • Can no longer manage to live alone without problems • Is unable to cook, clean or shop • May become extremely dependent on their family and caregivers • Has increased difficulty with speech • Shows problems with wandering and other behaviour problems such as repeated questioning and calling out, clinging and disturbed sleeping • Becomes lost at home as well as outside • May have hallucinations (seeing or hearing things which aren’t really there) 	<ul style="list-style-type: none"> • Have difficulty eating • Be incapable of communicating • Not recognise relatives, friends and familiar objects • Have difficulty understanding what is going on around them • Be unable to find their way around in the home • Have difficulty walking • Have bladder and bowel incontinence • Display inappropriate behaviour in public • Be confined to a wheelchair or bed

Table 1. The course and outcome of dementia (Prince & Jackson, 2009, p.18)

Alzheimer’s disease

Alzheimer’s disease is the most common type of dementia, accounting for 50-60% of all dementia cases (Alzheimer’s Disease International, 2017). Dementia is hard to quantify as lines are blurry, not just between different stages of the disease, but also between different dementia types (Prince & Jackson, 2009). It was found during the literature study that that the terms “Dementia” and “Alzheimer’s disease” are used interchangeably in most literature. As shown in Table 2 below, the classification of Alzheimer’s disease by Alzheimer’s Association (2016b) is very similar to the overall description of dementia presented in Table 1. Therefore, a differentiation between dementia and Alzheimer’s disease was considered unwarranted in this study.

Early stage Alzheimer’s disease	Middle stage Alzheimer’s disease	Late stage Alzheimer’s disease
<ul style="list-style-type: none"> • Problems coming up with the right word or name. • Trouble remembering names when introduced to new people. • Challenges performing tasks in social or work settings. • Forgetting material that was just read. • Losing or misplacing a valuable object. • Increasing trouble with planning or organizing. 	<ul style="list-style-type: none"> • Forgetfulness of events or about one’s own personal history. • Feeling moody or withdrawn, especially in socially or mentally challenging situations. • Being unable to recall their address or telephone number or the high school or college from which they graduated. • Confusion about where they are or what day it is. • The need for help choosing proper clothing for the season or the occasion. • Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand wringing or tissue shredding. 	<ul style="list-style-type: none"> • Need round-the-clock assistance with daily activities and personal care. • Lose awareness of recent experiences as well as of their surroundings. • Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow. • Have greater difficulty communicating. • Become increasingly vulnerable to infections, especially pneumonia.

Table 2. The three stages of Alzheimer’s disease (Alzheimer’s Association, 2016b, p.15-17)

2.2 Distributed cognition

Dementia is a cognitive impairment that makes the affected person dependent on external support (Prince & Jackson, 2009). The syndrome calls for cognitive offloading, especially when memory is affected. Tools intended to offload cognitive functions, such as memory, can therefore be described as cognitive prosthesis (Alm et al., 2007). ICT-based tools have been proven to work in this regard, hence it is relevant to discuss ICT-based assistive technology in terms of *distributed cognition* (Alm, 2015).

Distributed cognition means that cognitive functions (e.g. memory) can be distributed from the mind to the physical environment, such as artefacts and other people (Clark & Chalmers, 1998). In the famous paper *The Extended Mind*, Clark and Chalmers ask the question "Where does the mind stop and the rest of the world begin?". They include a story about Otto who has Alzheimer's. Otto manages his daily life by writing down memos in a notepad, a tool he carries with him at all times. By using the notepad, Otto offloads his cognitive resources (memory) into a physical artefact. The notepad is an extension of Otto's mind. The mind can therefore be distributed outside of the boundaries of the skull and into the physical world (Clark & Chalmers, 1998).

Hutchins (1995) describes the relationship between the individual mind and the world as deeply intertwined. Looking at knowledge structures as being separated from a sociocultural world (i.e. only happening in our minds) is misleading because of the interplay between individual minds and the physical world. This connection was stressed by Kirsh and Maglio (1994) who observed individuals playing Tetris. In this study, participants either rotated blocks by manipulating them physically, or by rotating them in their mind. Kirsh and Maglio found that the time it takes to rotate a block 90 degrees physically is about 300 milliseconds. Mental rotation takes about 1000 milliseconds. The physical rotation is therefore performed in order to relieve cognitive resources of the strain of doing a mental rotation, thus making real world tasks easier to compute (Kirsh & Maglio, 1994).

As Clark and Chalmers (1998) argue, cognition is not only distributed through physical artefacts, but through other human beings as well. In elderly couples, it is not uncommon that when a spouse dies, the survivor suddenly exhibits symptoms related to dementia. The deceased spouse likely compensated for reduced cognitive functions in the surviving spouse, such as remembering dates, procedures and knowledge (Alm, 2015).

In summary, cognitive functions are not isolated to solely mental activities, but rather distributed across systems of neural, bodily, social, and technological resources (Michaelian & Sutton, 2013). Hollan, Hutchins, and Kirsh (2000) support this view. They list cognitive functions as distributed through:

- Time, such as learning from previous experiences.
- Across members of a social group, for example between caregivers, individuals with dementia and relatives.
- Offloading of mental resources to external, physical sources and artifacts in one's environment (e.g. notepads, calendars, counting on hands, and diaries).

2.3 General design principles

Before discussing design for PWDs, this section will account for general design principles. These principles will provide a starting point for early stages of prototyping. However, utilizing established frameworks requires consideration. There is no such things as a general user, as all users have specific goals and needs (Cooper et al., 2014). Thus, in interaction design, "the user" cannot be regarded as a faceless entity (Tidwell, 2011). As Gaver (2012) points out, many successful aspects of design cannot be fully captured by simply following theories or frameworks, as design is suggestive rather than verifiable and falsifiable. Moggridge (2006) argues that the only way to determine whether a design is good or not is by asking the user. Cooper et al. (2014) emphasizes that there is no avoiding the process of fully understanding the people who will interact with the product. Good design is when the user expresses excitement, motivation and satisfaction (Cooper et al., 2014; Moggridge, 2006).

Schneiderman's eight golden rules of interface design

One attempt to create a summarizing set of rules is that of American researcher professor Ben Shneiderman. In *The Eight Golden Rules of Interface Design* (Shneiderman, 2016; Shneiderman et al., 2016) Schneiderman lists the following design advices:

1. Consistency

Similar sequences of actions should be consistent in its execution. Terminology should be identical for menus, help sections, prompts etc. The same evenness should be applied for visual information, such as color, layout, capitalization, and fonts, as well.

2. Universal usability

Design for different user profiles such as backgrounds, age, experience levels etc. Provide guides and help sections for beginners, and shortcuts for faster pacing for professional users. Strive for plasticity.

3. Provide feedback

User actions should be followed with informative feedback. For minor actions, the feedback can be moderate. For major actions, the feedback should be more substantial.

4. Convey closure

Sequences of actions should be organized in such way that they convey a beginning, a middle and an end. When the user has completed a set of actions, for example a transaction on an e-commerce website, the user should receive a confirmation that the sequence is completed. This will give users a sense of accomplishment, a feeling of closure, thus preparing them for the next group of actions.

5. Error prevention

The interface should prevent the user from making serious errors. Menu items can be greyed out and input fields should be formatted in such way that the correct input is used – for example not allowing alphabetic characters in a numeric field. If such errors occur, the interface should provide polite feedback and suggestions. Also, the interface should remain as unchanged as possible, prompting the user to only correct the faulty part.

6. Allow undo actions

Actions should be reversible. This provides users with a sense of safety, thus encouraging further exploration of the interface.

7. Keep users in control

Provide users with the feeling that they are in control of the interface - particularly experienced users. The interface should respond to the user's actions in a consistent manner. Surprises and changes in familiar behavior should be avoided.

8. Unload short-term memory

Design the interface in such way that users don't have to remember large amounts of information. For example, cell phones should remember the last dialed number and websites should always display its URL and the location of sub-pages.

Gestalt laws

Organizing interface elements is very important as it guides the user's attention and conveys meaning as well as points of interaction (Tidwell, 2011). People do not perceive objects, such as interface elements, as a set of individual features, but rather as a unified whole in relationship with other objects (Cooper et al., 2014). Gestalt laws are helpful in this regard. The gestalt laws are a set of principles developed by German psychologists Max Westheimer, Kurt Koffka, and Wolfgang Kohler during early twentieth century as an attempt to describe human pattern recognition. For an original text, see Koffka (1935). American data visualization researcher Colin Ware (2012) discusses these laws in his book *Information Visualization* (2012) as fundamental principles when designing for information display. This section will account for gestalt principles commonly used in design, as described by Ware (2012):

Proximity

Things that are close to each other are perceptually perceived as connected. Figure 1 demonstrates this by showing a collection of dots with proximity relationships. By using proximity as a gestalt principle, the dots are perceived as two separate groups rather than an overall collection. Symbols and other idioms representing related information should therefore be placed together (Ware, 2012).

Similarity

Objects with similar visual and physical attributes are perceptually grouped together. In Figure 2 this is demonstrated as similarity in color (brightness) makes the perception of rows dominate. The collection of dots in Figure 2 is therefore perceived as five rows (three black and three grey rows) rather than five columns. This is a useful technique when designing grid based data sets, as it makes it easier to distinguish rows and columns (Ware, 2012).

Connectedness

Connecting elements with a line is a very strong way of showing relationships (Figure 3). This gestalt principle is a more powerful gestalt principle than proximity and similarity (Ware, 2012).

Continuity

This principle states that humans perceive relationships between objects much easier if the objects are connected with smooth, continuous lines (Figure 4a) rather than straight lines with sharp angles (Figure 4b). This principle should be considered when there is a need to visualize the connection between sources and destinations (Ware, 2012).

Closure

When shapes and contours are closed, humans tend to perceived them as individual objects as Figure 5 demonstrates. The figure is interpreted as three separate entities (A, B and C) rather than a tangle of lines. Information placed within a closed contour is therefore perceived as related (Ware, 2012).

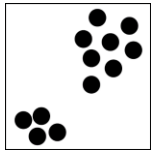


Figure 1.
Proximity

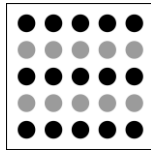


Figure 2.
Similarity

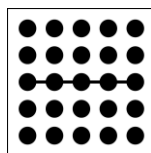


Figure 3.
Connectedness

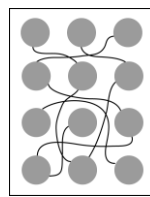


Figure 4a.
Continuity using
smooth lines

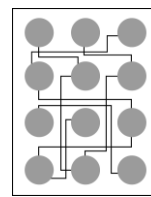


Figure 4b.
Straight lines
with abrupt
changes in
direction

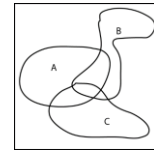


Figure 5.
Closure

Tidwell (2011) applies four of the above gestalt laws as layout properties for graphical user interfaces as shown below (Figure 6). She argues that, when designing interfaces, these principles are best used in combination with each other.

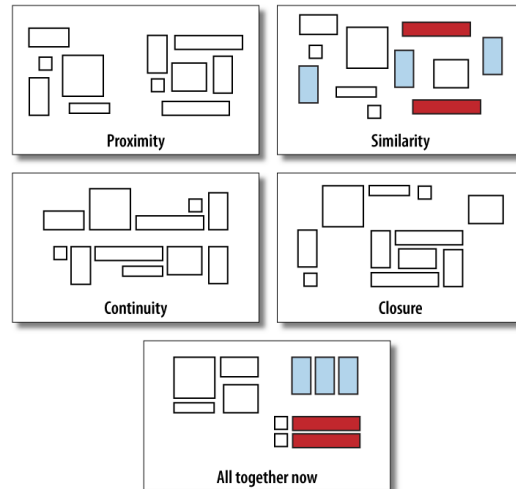


Figure 6. Four Important Gestalt Principles (Tidwell, 2011, p.139)

2.4 Interface design for people with dementia

When designing for PWDs it is imperative to focus on their specific needs, in which the interface plays a vital role (Wallace et al., 2010). In many cases, the designer faces structural challenges in the interface design. For example, too many options may disorient the user, however, too few will force the user to navigate through sub-menu structures and cause confusion (Burns et al., 2008).

Pang and Kwong (2015) discuss several considerations, design issues and principles regarding app design for elderly people with mild-to-moderate dementia. They conclude that the interface should provide a straightforward design and careful instructions. The interface should therefore utilize easy-to-use layout, bigger fonts and large buttons, as well as clearly labeled objects. Furthermore, color should be used to emphasize functionality such as buttons or regions. The following list is a set of principles to consider when designing for elderly with mild-to-moderate dementia as concluded by Pang and Kwong:

Reduce complexity

Functions that are rarely used should be removed. Also, minimize the number of items per view to between 2 and 5. The interaction should be simple and straightforward, this applies to written text as well. If the interface is tablet based, multi/touch gestures should be avoided due to diminished motor skills.

Tasks should be clearly structured

If a specific function is connected to a key, strive for unity. One key should represent one function consistently. The same principle should be applied for views; one page is for one task. To guide the user, wizards should be provided, especially for complex tasks.

Information consistency

Colors should be used to emphasize meanings of a button or a region. However, it should be considered that colors may be interpreted differently in different cultures. Make sure to label objects and items. If new versions of the software are made, make sure the interface is consistent.

Feedback should be rapid and straightforward

Feedback should be provided continuously and should be distinctly connected to specific actions. The user must be immediately informed when problems occur, and what is required to solve the problem.

Support the user

Errors should be minimized as much as possible by providing undo functions and on screen help. Also, limit the range of operations.

Interface optimization

The graphical appearance should be as simple as possible. Design the interface so that it appears less cluttered. Avoid fancy fonts and use static text. Making use of the proper size is also important, both for text and for graphical objects. The focus of attention should be placed on the center of the page.

2.5 User involvement when designing for persons with dementia

Orpwood et al. (2004) conducted a design project that culminated in a series of assistive technology products for people with dementia. The project applied a traditional user-led design approach that included PWDs during the design process.

It was found that products that have been developed together with care professionals are likely to be successful because caregivers can provide intimate understanding of the user's difficulties. Common dementia symptoms are sudden mood changes, paranoia, lack of motivation and confusion (Prince & Jackson, 2009), which makes it challenging when including PWDs in the design process (Orpwood et al., 2004). User evaluation with PWDs often leads to confusion and anxiety, consequently resulting in dropouts. Caregivers and care professionals should therefore be included and consulted throughout the whole design process (Orpwood et al., 2004).

Orpwood et al. also found that using early prototypes require special consideration. As crude prototypes usually don't provide full functionality and require varying degrees of abstraction (Rogers et al., 2011), they may be particularly troublesome for PWDs. People with dementia can become very upset and confused if the design they are trying out fails or requires abstract thinking (Orpwood et al., 2004). Therefore, if user testing is carried out together with PWDs, prototypes should be as close to fully implemented as possible. If low fidelity prototypes are used, they should be tested together with caregivers rather than people with dementia. In this way, the person with dementia does not have to be exposed to the design until it is more mature (Orpwood et al., 2004).

The study by Orpwood et al. (2004) concludes with a summary of key design recommendations for user involvement when developing products for persons with dementia:

- Caregivers and care professionals should be included and consulted throughout the whole design process. Preferably, the source of ideas early on in the project should be caregivers with understandings of the problems faced by PWDs.
- Prototypes tested with PWDs must be mature enough so that no abstraction is needed.
- In regards to user interaction with the product:
 - No extensive learning should be required
 - The design should keep users in control
 - The user should interact as little as possible with the new design
 - The design needs to be reassuring
- When involving PWDs in the design process, an intimate understanding and a trusting relationship between the designer and the PWDs should be established in beforehand. Caregivers should be present, acting as supervisors.

- The wellbeing of the PWDs must be prioritized. Confusion and anxiety often leads to dropouts, but most importantly, constitutes ethical problems. If the test induces anxiety or stress, consider using a professional caregiver as a ‘proxy user’ instead as they are able to understand the way the person they are caring for is likely to react.

2.6 Related work

Using ICT-based tools as support for people with dementia has been proven successful in the past. Below are two previous projects that resembles this study. The first example (CIRCA) describes an ICT-tool with similar structure to the prototype developed in this project. The second example (Talking Mat) is a tangible tool that shows the effectiveness of using pictures as a means of expressing emotions.

CIRCA, an ICT-based conversation support tool for people with dementia

CIRCA stands for Computer Interactive Reminiscence and Conversation Aid and is a communication support system for people with dementia developed during a study by Alm et al. (2007). The system was created to help individuals with dementia communicate and interact more successfully with relatives and caregivers using a multimedia platform structure. Using a touch screen interface, CIRCA displays photos, music, videos and other media from public archives to help people with dementia access long term memory.

A typical session would include dementia patients, caregivers and relatives. Pictures and music was presented through the CIRCA interface, during which caregivers asked questions that the person with dementia answered. These conversations appeared to stimulate long-term memory, demonstrating the benefits of using visual imagery and music as stimuli. Using CIRCA as support for conversation proved engaging also for the person asking questions. The platform was therefore positively received by caregivers and relatives.

The CIRCA-system was developed in a longitudinal study and with continual involvement of individuals afflicted with dementia as well as with caregivers and relatives. Following an iterative design process the interface was gradually improved building on user’s experience of previous iterations. The developers focused on designing a *friendly looking* system, focusing on low contrast, inviting color schemes and less cluttered interface. The study concluded that hypermedia (images, music, audio etc.) serves as an effective support tool during reminiscence sessions for dementia patients, especially during conversations. Also, CIRCA demonstrated the advantages of using a computer-based system over traditional material, as it makes it easy to incorporate a wide variety of media (Alm et al., 2007).

Thus CIRCA utilizes distributed cognition (as discussed by Holland et al., 2000) in the following ways: 1) through familiar historic events to anchor conversation 2) social help (relative or caregiver) for support in conversation 3) a mediating artefact supporting memory.

Talking Mat

Talking Mat was developed by Murphy et al. (2010) and is a tangible communication method that helps users organize their thoughts in terms of likes and dislikes. Using the principles of distributed cognition, Talking Mats help individuals with difficulties communicating to express themselves more effectively. Development was carried out together with the intended end user. This involved different types of conversational impairments: physical, cognitive as well as emotional.

The setup consists of a mat, about the size of an A3 paper sheet, on which users attach pictures using hooks and loop tape. A scale displaying emotions is placed at the top of the mat. The scale makes use of arbitrary symbols representing different feelings, ranging from positive to neutral to negative. When a topic is discussed, pictorial representations of the discussion content are placed under the emotion symbols. This eventually forms cluster of topics, grouped in accordance to emotional response

Talking Mat received positive response from user's afflicted with dementia as it helped them clarify and confirm their views on topics, as well as helping them gain confidence when expressing themselves. Expressing opinions can be hard for individuals with cognitive impairments, such as dementia, autism or mild cognitive impairment. Talking Mat was successful in this regard, as it allows users to express internal emotions externally with the help of images (Murphy et al., 2010).

3. ETHICAL CONSIDERATIONS

When doing research that involves humans, ethical considerations must be practiced. According to Swedish law, research must be conducted in respect to human dignity¹. To ensure that this study did not violate ethical requirements, the Swedish Central Ethical Review Board (Etikprövningsnämnden) was consulted. It was determined that the project did not need to undergo an ethics review as long as laws and legislations are obliged².

3.1 Laws and legislation

The following ethical principles, as recommended by Vetenskapsrådet (2002), were obliged in this study:

- **Information requirement:** researchers shall inform participants about the purpose of the study.
- **Consent requirement:** participants have the sole right to decide the extent of their participation.
- **Confidentiality requirement:** any data on participants must be treated with utmost confidentiality. Any personal information must be stored in such way that it cannot be compromised. Photographs must not reveal the identity of participants. Photographs must be edited so that faces and other means of identification, such as jewelry, trinkets or special garments, are not visible.
- **Utilization requirement:** any data gathered on individuals may only be used for research purposes.

All participants were informed verbally about the purpose of the study as well as their role in it. Participants were then informed that they may discontinue their involvement at any time without further explanation. Participants gave their consent by signing a written consent form (Appendix I).

Persons with dementia participating in this study are individuals that are aware of their impairment. These individuals are therefore considered able to give an informed consent to participating in the study. All participants taking part in the study were guaranteed anonymity.

A caregiver was always present during interviews with PWDs for assurance. Recordings, such as audio recordings, were stored on external hard drives and later transcribed. Codes like “Participant 1”, “Interviewee 2”, “Expert 3” etc. were used so that no other than members of the research team would be able to link the information to a specific individual.

¹ SFS (Swedish Statute Book) 2003:460. *Lag om etikprövning av forskning som avser människor.* (Law on ethical considerations in research involving human beings.) Stockholm: Utbildningsdepartementet. 2003.

² Catharina Wennardt, Etikprövningsnämnden, (Personal communication, Gothenburg: 16th February, 2017)

3.2 Moral standpoint

Aside from legislative requirements, there are other ethical considerations to observe. Anxiety is a common symptom of dementia (Prince & Jackson, 2009) and involving PWDs in research such as product evaluation may result in confusion and stress (Orpwood et al., 2004).

Therefore it was deemed necessary to formulate a moral guideline that extends beyond legislation and laws, a moral ethos for the project.

Friedman and Kahn (2002) argue that holding out human values is an important design criterion and essential when designing with an ethical stance. Frauenberger et.al (2016) take this argument further by coining the phrase *project ethos* - a moral statement on which a project stands.

The following project ethos was formulated:

When involving PWDs, measures must be taken in order to reduce potential stress, confusion and anxiety connected to unfamiliar interview and test situations.

Project ethos as a list of concrete requirements:

- Reduce time involving PWDs during eventual evaluations.
- Be vigilant for signs of anxiety and confusion that may occur during interviews or testing. Abort when necessary.
- Carry out research methods together with caregivers with sufficient knowledge about the PWDs.

The above ethos, together with recommendations, laws and legislation, composed a moral guidance for selection of methods as well as method execution.

4. METHODOLOGY

This section accounts for methods considered suitable for this study. These methods are well established in interaction design (Rogers et al., 2011) and compose the design framework for this project. This chapter provides a description of each method, pros and cons and why each method were considered appropriate.

4.1 User centered design

When designing for PWDs it is of uttermost importance to focus on their specific needs (Wallace et al., 2010). For this reason, this study takes on a User Centered Design (UCD) approach.

The term UCD started to surface in the 1986 publication *User Centered System Design: New Perspectives on Human Computer Interaction* (Norman & Draper, 1986). UCD has its foundations in usability engineering and human-computer interaction. Methods, research practices, and theory used in UCD can be traced back to these fields (Williams, 2009). In UCD, the user is placed in the center of the design process.

UCD concerns the functional needs of a product based on who the users are as well as the context of use (Williams, 2009). Pivotal to UCD is the designer's understanding of who the users are and their needs, desires and preferences for different aspects of a product. When having gathered information and achieved an understanding of the users the designer then makes informed design decisions based on this (Williams, 2009).

UCD processes consist of three phases: research, design and evaluation (Williams, 2009). During the research phase, users are identified as well as user needs. The research phase consist of several smaller steps. Common deliverables of the research phase are personas, written reports of findings and recommendations or process flows. During the design step, designers conduct brainstorming, conceptualization and sketching.

A related design approach is Goal Directed Design (Cooper, 1998). The goal directed design (GDD) approach aims to help users to as quickly as possible achieve their goals when using a product. The differences between GDD and UCD are minimal. While GDD focuses on the goals of the users, UCD focuses on the users themselves, and while doing so, also taking goals and tasks into consideration (Williams, 2009). Another difference between GDD and UCD is that while the user is taken into consideration in both approaches, UCD better accommodates for users' level of knowledge, their context of use and their reasons for using the product (Williams, 2009). Therefore, UCD was considered a more suitable approach for this project.

4.2 Unstructured interviews

Unstructured interviews are exploratory and open-ended. They are more like conversations about particular topics rather than scripted interviews. Both the interviewer and the interviewee can steer the conversation as the interviewee is free to answer in any fashion. Unstructured interviews are recommended when attempting to obtain a deeper understanding of the topic as it allows for boundless exploration. As was the case in this study, the design domain was unknown and in order to explore it, unstructured interviews with individuals well-read and educated in the field of caregiving for PWDs were hypothesized to yield a good foundation for the design process. However, the interviewer must have an agenda, a purpose with the unstructured interview. Without some kind of plan, the interview can drift off to irrelevant topics (Rogers et al., 2011).

The benefit of an unstructured interview is the amount of qualitative data it provides. Due to its exploratory nature, new unexpected insights are gained that were not originally anticipated. However, the amount of data is time-consuming to analyze. Furthermore, when interviewing a large number of participants, the generated data will not be consistent, as each interview is unique (Rogers et al., 2011).

4.3 Semi-structured interviews

Semi-structured interviews are in-depth interviews as the researcher may use interest areas and pre written questions, but is not obliged to follow a script (Howitt, 2010). In contrast to unstructured interviews, they rely on a script that ensures the same topics are covered for each interviewee (Rogers et al., 2011).

Semi-structured interviews aim to capture rich and extensive information about the intended target group (i.e. intended users). The interview should be flexible and feel natural, but not to the extent of an unstructured interview. The interviewer should encourage “rambling”, as the goal is capturing rich content. Probing and follow up questions are vital in this regard. Open questions and probing allows for wider perspectives to emerge. A certain lack of standardization is therefore inevitable, especially since answers given by the interviewee should be elaborated with follow up questions (Howitt, 2010).

This kind of interview is suitable when seeking information on individual and personal experiences on a certain issue or subject. Information extracted using this method may include: individual’s decision making, beliefs and perceptions, motivation for various behavior, feelings and emotions, pervasive information on sensitive issues and context about people’s lives (Howitt, 2010).

Compared to unstructured interviews, the semi-structured approach provides structure and makes it easier to compare data between interviewees. Furthermore, they retain the flexibility offered by unstructured interview by allowing follow up questions. However, this method requires careful consideration. It can be tempting for the interviewer to try and guide the interviewee in a certain direction. The interviewer must therefore not try to preempt an answer by asking questions that would suggest that a particular answer is expected. Also, semi structured interviews, like unstructured, require much longer time to analyze than closed question approaches (Rogers et al., 2011).

4.4 Personas

A persona is a fictional character created to represent a typical user of the final product (Rogers et al., 2011). Personas are archetypes of real users and commonly take shape in the form of a set of goals, a biography of varying length and a character photo (Goodwin, 2010).

The concept of personas was first introduced by Alan Cooper (1999) in his book *The Inmates are Running the Asylum*. Since then, personas has been an established method widely used within the field of UCD (Williams, 2009). Personas are based in qualitative research, primarily from data gathered from interviews and contextual observations. Personas are used to model user behavior and goals (Cooper et al., 2014). Cooper et al. further describe personas as archetypes compiled from behavioral patterns, grounded in qualitative research, used to inform product design. Personas are a good method of modeling user goals, needs and behaviors (Goodwin, 2010). According to Cooper et. al (2014), personas help designers to 1) determine a product's function and behavior 2) communicate the function and behavior of the product to stakeholders as well as motivate these decisions 3) create a common ground in understanding the design 4) evaluate and measure the effectiveness of a design.

By creating and using personas, designers are able to make decisions with a shared image of the user in mind. Having a shared image of the user is important to ensure involved parties in the design process doesn't pull in different directions. Designers can be tempted to fit their own opinions rather than the actual users', thus bending user needs to accommodate their own needs, creating an imagined *elastic user* (Cooper et al., 2014). The elastic user can be troublesome in design as it encompasses an unlikely range of needs and behaviors (Goodwin, 2010). Personas are useful for resolving this issue (Cooper et al. 2014).

Aside from helping designers void elastic users, personas also minimize the risk of self-referential design (Cooper et al., 2014). Self-referential design is when the designer create something with themselves as a reference for whether the design will work or not. Very often this leads to designs that work for people who think in the same way as the designer, but doesn't work for people who don't think in the same way. Considering the primary user of the design developed in this paper are PWDs, self-referential design would be likely to cause a lot of problems.

Personas are based on research. According to Cooper et al. (2014), the primary source of data when creating personas should be contextual interviews with actual users as well as potential users. The quality of the interviews leading up to the synthesising of the personas impacts the effectiveness of the resulting personas ability informing and directing design activities. Aside from contextual interviews and observations, Cooper et al. (2014, p.66-67) list the following data gathering methods as suitable for the creation of personas:

- Interviews with users outside of their use contexts
- Information about users supplied by stakeholders and subject matter experts
- Market research data such as focus groups and surveys
- Market-segmentation models
- Data gathered from literature reviews and previous studies

Doing the research for personas and the creation of personas can be a time consuming activity, but seen in relation to how useful personas can be in a design process it is well worth it (Goodwin, 2010). A risk in this is stressing through the research phase, ending up with sub-par data to ground the personas in. Cooper and Goodwin share a similar approach on how to create personas.

4.5 Prototyping

A prototype is a form of design manifestation that allows stakeholders and design teams to explore its suitability (Rogers et al., 2011). It is a preliminary representation of a product that usually lacks full functionality and is suitable for mediating purposes during the design process (Cooper et al., 2014).

Low-fidelity prototypes

Low-fidelity prototypes do not look like the final design and are usually constructed using other materials than the final product. Common types of low fidelity prototypes are paper sketches, storyboards and cardboard mockups. Low fidelity prototypes are useful since they are simple, cheap and quick to produce. They are best suited during early stages of development and should be considered rough mediating tools used for exploration. Low fidelity prototypes require a great degree of abstraction and should not be integrated into the final product. They are intended primarily for exploration (Rogers et al., 2011).

High fidelity prototypes

High-fidelity prototypes use materials that mimic the final product to a much greater degree than a low-fidelity prototype and usually incorporate functionality. Interactive prototypes constructed using mockup software are generally considered high-fidelity. The major benefit with using high-fidelity prototypes is that they closely resemble the final product. Because they offer functionality and interaction they are suitable for user testing and evaluation. However, they are time-consuming to develop and require technical skills to implement (Rogers et al., 2011).

In many cases the line between low fidelity and high fidelity is somewhat blurry. A prototype developed in for example PowerPoint is considered higher fidelity than a paper mockup, but may still lack full functionality. When to use what type is arbitrarily as the best choice of prototype is case specific. Designations aside, the intention with a prototype is allowing the design team to answer key issues about the design at hand. The designer is the arbitrator in this regard (Rogers et al., 2011).

4.6 Usability testing

Usability testing is an umbrella term for a range of methods used to assess and measure characteristics of a user's interaction with a design or artefact where the goal is to understand the product's usability (Cooper et al., 2014). Usability testing consists of testing whether users are able to perform specific, standardized tasks, and what problems arise when they perform these tasks. In usability tests, the object of evaluation is the service or prototype, if many users struggle with a feature of the design, this probably means that the feature needs to be reworked (Cooper et al., 2014). During usability tests, a range of methods are used to study the interaction, such as observations, audio/video recordings and think aloud protocols. The results of usability tests usually give designers an idea of what features of a product needs to be improved and what features are working.

Cooper et al. (2014) further argue that when performing usability tests the designed artifact needs to be complete and coherent since the goal of the test is to validate the product's design. Usability tests are as such often placed later in a design cycle when the bits and pieces of the design start to fall into place and more coherent and complete prototypes are possible.

Usability testing is most often done with the intended user groups in order to understand possible pitfalls in the design. There are however cases when primary users are hard to get into contact with or unable to perform usability tests. Such is the case with user's afflicted with dementia. PWDs are prone to confusion and anxiety when involved in usability testing (Orpwood et al., 2004). Usability tests with PWDs require a fully functional prototype that do not demand abstraction (e.g. pretend that a camera is working when the prototype actually shows an image of a camera view). When evaluating low-fi prototypes, Orpwood et al. (2014) recommend testing these with caregivers and professionals with extensive knowledge about the needs and typical behaviors of PWDs rather than with PWDs themselves. This variant of evaluations are sometimes referred to as *usability inspections* (Rogers et al., 2011).

4.6.1 Cognitive walkthrough

Walkthroughs are alternative evaluation methods during which the designer tries to predict user's problems without doing user testing (Rogers et al., 2011). A *cognitive walkthrough* is performed by evaluators taking on the role of a user and consists of a series of tasks and questions focused on identifying problems with a design (Mahatody et al., 2010). Originally used to evaluate walk-up-and-use systems such as ATMs or interactive exhibits, cognitive walkthroughs have also proven successful with more complex systems, especially when dealing with new users (Blandford et al., 2011). The method is recommended if users are inaccessible or hard to coordinate (Rogers et al., 2011).

Cognitive walkthroughs require some consideration. Since the actual user does not participate in the evaluation, a deep understanding of the user is essential. Using *personas* for this purpose is recommended (Blandford et al., 2011). In order to reduce bias in the outcome, walkthroughs should be carried out together with a usability or domain expert who is role-playing as the user the product is designed for (Rogers et al., 2011).

In a cognitive walkthrough, one first identifies tasks that need to be evaluated (e.g. *How the user takes photographs*). After extracting a set of tasks, these will be evaluated with four questions to form a credible story. The following list (Wharton, Rieman, Lewis & Polson, 1994) was written as a practitioners guide:

1. Will the user try to achieve the right effect?
2. Will the user notice that the correct action is available?
3. Will the user associate the correct action with the effect they are trying to achieve?
4. If the correct action is performed, will the user see that progress is being made toward the solution of the task?

These questions will then be answered yes or no during the cognitive walkthrough. A ‘no’ then needs to be followed by a design suggestion to improve on the design. Wharton, Rieman, Lewis and Polson (1992) suggest 1-4 tasks per cognitive walkthrough session depending on the complexity of the tasks.

4.7 Think aloud

Think aloud is a method where participants of an evaluation (or other form of testing) describe their actions out loud. These verbal descriptions concern motivations or reasoning for doing one thing or another (Nielsen, 2012). This is usually paired with video or audio recordings as well as some form of observation of the interaction.

Using the think aloud method, designers are able to understand user’s thoughts and misconceptions about a design. This information can then be turned into design recommendations. If an element of the design is commonly misinterpreted, it needs to be changed. Think aloud provides direct exposure to how users perceive a design, allowing designers to learn *why* users misinterpret or appreciate aspects of a design (Nielsen, 2012).

In this study, cognitive walkthroughs were carried out together with caregivers as domain experts. During walkthroughs, think aloud was used as a complement to gain further insights about the design. Also, experts were roleplaying as PWDs during walkthroughs. Think aloud made it easier for the design team to understand how the expert interpreted the personas.

4.8 Pilot study

A pilot study is a small trial of the main study with the aim to make sure that proposed methods are viable. It is recommended to perform a pilot study before any larger data gathering takes place. The pilot study is a great way of identifying shortcomings and possible confusion with interview questions. However, anyone involved in the pilot study should not be involved in the main study, as they hold preexisting knowledge about the study that may distort the results (Rogers et al., 2011).

5. DESIGN PROCESS

This section accounts for major steps during the design process, from idea to prototype. Initially, the design idea was to investigate relations between technology acceptance and graphical user interfaces. After contact was established with Semcon, the project instead refocused to encompass a entire design process when designing for people with dementia. This chapter describes methods and design rationales applied throughout the project, as well as findings from the different stages of the design process. The project followed a user centered design process that can be divided into three major phases; research design and evaluation.

5.1 Initial idea

Before contact was established with Semcon, the project was focused on designing a GUI (Graphical User Interface). The intention was to research what role GUIs play in regards to technology acceptance. A target group was not yet defined at this point.

Research on general GUI design was carried out by studying literature such as *About Face* (Cooper et al., 2014), *Information Visualization* (Ware, 2012) and the Technology Acceptance Model (Davis, 1989). Articles and design frameworks were obtained through Google Scholar.

Examples of the most used search words:

- GUI + Framework
- GUI + Design principles
- Technology Acceptance Model

Shortly thereafter, contact was established with Semcon. During an initial telephone conversation³ with Semcon, the proposal was positively received. During this conversation it was suggested that the project would focus on people with dementia.

5.2 Pre-study

During an initial meeting with Semcon⁴, Francoise Petersen, project manager at Semcon, expressed interest in developing some kind of communication tool for people with dementia. Petersen, who had personal experiences with affected relatives, pointed out communication challenges that occur when conversing with persons with dementia (PWDs). Such communicative challenges were described as disorientation, short-term memory impairment and difficulties keeping track of everyday things.

³ Francoise Petersen, Semcon, (Personal communication, Gothenburg: 20th December, 2016)

⁴ Francoise Petersen, Semcon, (Personal communication, Gothenburg: 25th January, 2017)

5.2.1 The problem domain

According to Petersen, the PWD is not the only person affected. Since PWDs require care and special attention, either at a special care center or in their own home, the condition involves other people affiliated with the PWD. The conversation with Petersen resulted in a map of affected parties. This map was dubbed the *problem domain trinity* (Figure 6 below) and consists of three major parties:

- 1) PWD (Persons With Dementia)
- 2) Caregiver (e.g nursing homes and care centers)
- 3) Relative (to the PWD)

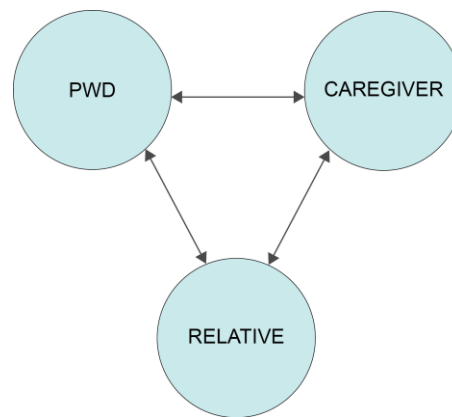


Figure 6. Problem domain trinity consisting of PWDs, caregivers and relatives

According to Petersen, the relationships between the above parties are challenging. A PWD can be limited in his or her abilities, thus making interaction with the other two parties demanding. Since common dementia symptoms are significant memory loss, language problems and general confusion, the affliction makes it hard for the PWD to communicate their emotions, preferences, habits etc.. These symptoms tend to worsen over time and may vary from day to day. Caregivers may have to rely on second hand interpretations from relatives, thus making it challenging to provide the best care possible.

As such, the design focus was directed towards an *ICT-solution that would aid communication between PWDs and caregivers for better personalized care.*

5.2.2 Re-focus

Following the aforementioned meeting it was realized that a more comprehensive design focus was required. It was realized that focusing entirely on GUIs was not the right approach. A broader investigation was called for, one that starts by researching the problem domain at large. This realization called for fundamental rethinking. An existing product did not exist, but rather an unexplored problem domain which called for further investigation. The project was broadened, encompassing the whole design process rather than focusing entirely on GUI design. As the design would most likely involve personalization of some kind, a UCD approach was decided upon. In UCD, a central tenet is to place the end user in the center of the design (Williams, 2009).

Consequently, there was a need to further explore and identify what component of the domain trinity to put an emphasized focus on as well as understand connections between PWDs, caregivers and relatives.

5.2.3 Literature study

More information was needed about dementia and its symptoms, as well as design recommendations for PWDs. A literature study was carried out, where domain related publications were obtained from the following databases:

- *Google Scholar*
- *Chalmers Library*
- *Gothenburg University Library*
- *Scopus*
- *IEEE*
- *pubMed*

Examples of the mostly used search words:

- *Dementia + ICT*
- *Dementia + Distributed cognition*
- *Dementia + Artefacts*
- *Dementia + Universal design*
- *Dementia + Symptoms*
- *Assistive technologies for dementia*
- *Designing for dementia*

Results from the literature study can be summarized as theoretical frameworks concerning:

- General design guidelines for ICT
- Definition of dementia and its symptoms
- Involving persons with dementia in user research
- Designing interfaces for people with dementia

This literature study resulted in the theoretical framework presented in the theory chapter (see 2. Theory and background).

5.3 Further domain exploration

Further exploration was needed to gain a deeper understanding of the problem domain. As Orpwood et al. (2004) recommend, the design process should start by consulting care professionals about needs and common problems. It was reasoned that employees at *retirement homes* who hold comprehensive knowledge about overall procedures and workflows would be able to provide insights regarding the problem domain as a whole.

5.3.1 Choice of methods

At an early stage, little understanding had been acquired in regards to work procedures and common problems in the actual environment. As such, overall exploration was needed. Unstructured interviews were therefore selected as the data gathering method.

Unstructured interviews are suitable when exploring an uncharted domain as they focus on the broader picture rather than smaller topics (Rogers et al., 2011). Semi-structured interviews were not considered suitable for this reason, as knowledge about the domain was somewhat insufficient at this point. Rather, the unstructured interviews served as a foundation for formulating more specific questions for semi structured interviews later on.

5.3.2 Interviews with retirement home managers

The Swedish elderly care sector is divided into municipal and private healthcare providers. About 80 percent consists of municipal care providers, the remaining 20 percent are private providers (Socialstyrelsen, 2012). Although no major qualitative differences have been found between the two sectors (Socialstyrelsen, 2012), it was reasoned that by visiting retirement homes from both *municipal* and *private* sectors, a more diverse depiction of the problem domain could be obtained. Also, persons in manager positions were picked, as they are more likely to hold insights about overall organizational routines.

Two retirement home managers, specialized in dementia care, were interviewed:

Christina Wångblad, manager, Lundby retirement home, municipal care
Malin Ekstam, manager, Agaten retirement home, private care

The interviews lasted about 1,5 hours. The problem domain trinity model (Figure 6.) was used as a mediating tool. No pre-written script was used, but rather open questions and instructions like:

“Describe the workflow at the retirement home.”
“What are the most common problems today [within the problem domain trinity model]?”
“What would you suggest in terms of ICT-based solutions?”

Notes from the interviews were then compared in order to find common denominators.

It was found that both retirement homes identified the *admittance procedure* as a troublesome process in regards to the problem domain trinity. The admittance procedure was described as follows by the two interviewees^{5 6}:

A few weeks after a PWD moves into a retirement home, a *life story* is compiled (See Appendix II). The life story contains information about the PWD, such as childhood, interests and hobbies. The story is drafted together with the PWD and their personal contact at the retirement home, then used as a template for personalized care. It also serves as support and inspiration during conversations between PWDs and caregivers.

Sweden in general, and Gothenburg in particular, suffers from shortage of available vacancies at retirement homes. PWDs are often unable to move into a retirement home before more severe symptoms begin to surface, often developing middle to late stage dementia before admittance. This makes it hard for the PWD to provide personal information for the life story.

Common dementia symptoms are lack of motivation and short-term memory impairments. This makes it difficult for PWDs to account for likes, dislikes and habits relevant to them, particularly from recent years to present time. Both interviewees agree that as much personal information as possible should be collected long before the PWD is admitted. Preferably, this information should be compiled by the PWDs themselves before severe symptoms begin to surface.

When asked about whether a study was feasible to conduct at retirement homes, Wångblad discouraged the proposition. PWDs admitted to retirement homes usually suffer from late stage dementia, which makes them unsuitable as participants in a study of this kind. It would also require an extensive ethics review procedure by the Swedish Central Ethical Review Board (see 3. Ethical considerations).

5.3.3 Findings

A *life story* for personalized care, consisting of personal information about the PWD, is compiled a few weeks after admittance to a retirement home. The plan is drafted together with the PWD. Many PWDs have started to develop more severe dementia symptoms before being admitted, thus making a personalized care plan hard to draft.

User group and need

It would be preferable if PWDs could compile a personal profile on their own accord, before being admitted, as this would make drafting personalized care easier and more accurate. Hence, the following need was identified from caregiver interviews: a *life story tool* that allows PWDs to compile a personal profile before severe symptoms begin to surface.

⁵ Cristina Wångblad, manager/supervisor, Lundby municipal elderly care City of Gothenburg (Personal communication, Gothenburg: 14th February 2017).

⁶ Malin Ekstam, group manager, Agaten retirement home, Vardaga AB, (Personal communication, Gothenburg: 15th February 2017).

Such a tool should be introduced to the PWD as early as possible since it becomes increasingly more difficult to learn new things as the disease progresses. Therefore, the target user group was defined as people with *early stage dementia*.

Interviewing PWDs at retirement homes is not feasible

Because PWDs who are admitted to retirement homes have progressed too far in their disease, they are not suitable as interviewees, according to Christina Wångblad, manager at Lundby⁷. Furthermore, since the life story tool is intended to be used by PWDs with early stage dementia, interviewing PWDs at retirement homes would focus on the wrong target group. Also, in regards to the moral standpoint (See 3.2. Moral standpoint) it was deemed ethically objectionable to involve PWDs admitted to retirement homes.

5.4 Finding participants

More research was needed to obtain more specific data on user needs. In UCD, the user is placed at the center of the design and during the research part of a UCD process it is vital to gain an understanding of who the users are as well as their needs (Williams, 2009). A major part of this study consisted of accessing potential users as well as gaining an understanding of these users. Preparation was made in order to map out possible interview candidates. Several decisions and rationales were made during this preparation:

Relatives to PWDs

At first, attempts were made to establish contact with relatives to PWDs through various support groups in the Gothenburg municipality. However, it proved difficult to find support groups interested in participating. Support groups usually operate more as interest groups for relatives with very few regular meetings. Furthermore, most support groups involve relatives to PWDs with late stage dementia; individuals incapable of participating in a study⁸. The *relative* part of the problem domain trinity was therefore left unresearched.

Rationale for using day centers

As establishing contact with relatives to PWDs was deemed impractical due to the project time frame and interviews at retirement homes were not feasible, an alternative was required. It was therefore decided to do further research at *day centers*.

A day center is a form of non-residential meeting place designed to relieve caregivers and relatives of their duties while ensuring that the PWDs receive proper supervision and social interaction in a safe environment.

⁷ Cristina Wångblad, manager/supervisor, municipal elderly care City of Gothenburg (Personal communication, Gothenburg: 14th February 2017).

⁸ Birgitta Garnemark, The Swedish Dementia Association, (Personal communication, Gothenburg: 15th February 2017)

These centers normally operate during business hours on weekdays and are staffed by nurses and care professionals (Socialstyrelsen, 2014b). By performing interviews at day centers it was possible to quickly establish contact with persons with early to middle stage dementia.

During early attempts to reach out to day centers, it was common for day center personnel to express concerns and suspicions about the study. It was realized that this reaction was likely due to a somewhat vague project description. During succeeding attempts to reach day centers, the purpose and the moral standpoint of the study were clarified in greater detail, resulting in considerably more positive response.

5.5 Interviews at day centers

Five day centers in the Gothenburg municipality were visited where both PWDs and personnel were interviewed. As common dementia symptoms are anxiety and spatial confusion (Prince & Jackson, 2009), it was also reasoned that day centers would provide a safe environment when interviewing PWDs.

5.5.1 Choice of methods

Insights about the problem domain had been acquired from interviews with retirement home managers in previous steps. At this point in a UCD approach several methods like interviews, a day in the life and shadowing are available. However, intrusive methods like shadowing were considered problematic as it could cause stress and anxiety, a common problem when involving PWDs in research (Orpwood et al., 2004).

Other less intrusive methods common in UCD practice are formal interviews that may contain a mix of close-ended and open-ended questions (Williams, 2009). Semi-structured interviews were chosen as this method may be carried out as a conversation (Rogers et al., 2011) and was considered less stressful. Also, this method is suitable for exploring, allows for probing and is suitable when seeking more specific information (Howitt, 2010). Since the need for a life story tool had been identified in previous steps, these findings served as a basis for the semi-structured interviews.

The interviews were conducted in two parts separately, with different outcomes in mind:

Interviews with day center personnel

Orpwood et al. (2004) recommend getting ideas for products from caregivers. Hence, these interviews focused more on desired functions with the intended product in mind.

Interviews with PWDs

Early telephone conversations with day center personnel revealed that most of their PWDs had very little experience with technology. These interviews were therefore less technology oriented and more personality based. By focusing on personal interests, technology acceptance, preferred information visualization etc., this information could be used to capture user needs and goals when constructing personas during later stages in the design process.

5.5.2 Interviews with day center personnel

Personnel interviews were conducted using an interview template as guide (see Appendix III). Interviews focused on present procedures, shortcomings and desired improvements as experienced by day center personnel. During the interviews, probing was used to explore topics at depth. Answers were written down and later compared and summarized.

Overall, 5 day center workers were interviewed. All interviewees were trained nurses specialized in dementia care. The interviews lasted about 30 minutes each.

Using the aforementioned life story tool as a theme, the interviews aimed to capture:

- Shortcomings with current life story templates and desired improvements
- How ICT has been used (and received) at the day center
- How documentation (if any) of daily activities at the day center occur today

Notes were then compared from all five interviews. Similar and recurrent comments were then picked out and compiled.

Excerpts from interviews with day center personnel:

On life stories

“Present life story formats are too formal and boring.” - Nurse 2

“Life stories tend to focus too much on the past.” - Nurse 3

On photos

“Being able to capture events in-the-moment would make the life story richer.” - Nurse 5

“Using pictures during conversations are usually greatly appreciated by our PWDs.”-Nurse 2

On technology

“Tablets are great because then you can take pictures.” - Nurse 5

Findings

Interviews with day center personnel generated valuable insights about daily work routines and desired improvements:

- Photographs are highly appreciated by both PWDs and day center personnel. Pictures make conversations with the PWDs engaging and sometimes act as reminiscence support.
- Most day centers prefer tablets as they are portable and equipped with a camera, thus allowing for taking pictures.
- Existing life story templates are too standardized. They are designed as questionnaires and perceived as boring and un motivating to finish for the PWDs, as well as uninspiring to read for the caregiver.

- Existing life story templates focus too much on past history. Most PWDs remember remote memories such as events from their childhood, but not recent events due to short-term memory impairment. Life stories should therefore focus more on present time events and who the PWD is today.
- Complementing present day events, life stories should be able to capture present day likes and dislikes.
- PWDs generally accept technology and recognize its benefits. However, they are not technology savvy enough to fully understand technology specific expressions and terms.
- Diary writing is encouraged as this provides insights about the PWDs current life as well as intellectual stimulation for the PWDs themselves.

These findings were used as considerations for functional requirements during later stages of the project.

5.5.3 Interviews with people with dementia

The interviews with people with dementia were carried out at five different day centers. Based on their ability and willingness to participate, interviewees were suggested by day center personnel.

Eight persons with early to middle stage dementia were interviewed. The age span was from 71 to 88 years old. Aside from interviewers and interviewees, one nurse from the day center was present during the entirety of the interview to ensure a safe environment, as recommended by Orpwood et al. (2004). The nurse also acted as a facilitator when misunderstandings occurred or when clarifications were needed.

The interviews were carried out with two interviewers. One interviewer carried the main responsibility of maintaining a fluent conversation, the other took notes and assisted with complementary questions when needed. These roles shifted between interviews.

Before each session, interviewees were informed about their role in the study as well as their rights. Each interviewee signed an approval form (Appendix I) before the interview started. All interviews were recorded (as approved by the interviewee) and later transcribed.

Considering the age group and the communicative difficulties commonly associated with dementia, interviews were less technology oriented and more personality based. Regarding technical jargon, rephrasing was deemed necessary. Terms like “graphical user interface” were reworded into “what you see on the computer screen” etc.

The desired outcome from these interviews was as much valuable data as possible that could be used to construct personas. Consequently, the interview questions focused on personal interests, attitude towards technology, information visualization etcetera. It was reasoned that this information would be used to capture user goals and behavioral patterns.

Below are excerpts from the interviews:

On keeping diaries

“I write down things on paper sheets, but sometimes forget where I placed it” - Interviewee 4

“Going back and reading about things in the past makes me happy” - Interviewee 5

“I have written diaries in the past, but now I find it to tiring” - Interviewee 6

“I would keep a diary, but only if it’s not too time consuming” - Interviewee 8

On pictures

“I love looking at old pictures. And it’s fun showing them to my grandchildren”-Interviewee 3

“When my family visits me we always look at old photographs” -Interviewee 6

“My eyesight is so bad now... but looking at pictures is easier” -Interviewee 1

On technology acceptance

“They invent new things all the time. Modern gadgets are helpful, I guess. But they can be a bit too much” - Interviewee 2

“I have an old typewriter at home that I used to write shorter texts with.” - Interviewee 4

“I use one of these [holding up a smartphone] to call my husband. I like it, but sometimes it is hard to find things.” - Interviewee 5

“We live in a fantastic [information] age.” - Interviewee 8

“I only use it [computer] to read the news. It [computer] should do one thing.” -Interviewee 2

“I guess it [ICT] is a good thing. But I’m not using it. Not interested” - Interviewee 3

On text and reading

“I don’t read much. A few pages, then I get sleepy” - Interviewee 2

“I only read the newspaper... sometimes. I like it with my morning coffee” - Interviewee 3

“I read a lot. I like reading novels and memoirs.” - Interviewee 5

“Sometimes I read the newspaper. But watching TV is easier.” - Interviewee 6

Findings

Regarding product requirements, interviews with PWDs provided valuable information mainly about information visualization and attitudes towards technology. After the interviews were analyzed and recurring remarks were grouped together, the most recurring points were summarized as:

- Most interviewees use or have used a diary
- Most interviewees make use of a calendar to organize everyday activities
- Pictures are greatly appreciated
- ICT-experience is generally low, but technology acceptance is generally high
- Straight-forward design is favored - too many options is confusing

- Some of the PWDs enjoyed using smartphones for calling and sending occasional text messages but found the amount of possible actions overwhelming.
- Reading too much text is generally perceived as tiring. This is not to say that the interviewees avoid text altogether, however, large amounts of texts can quickly become exhausting.

These findings were then treated as important values to consider during interfaces design later on.

Additionally, the interviews provided valuable information about everyday life of the PWDs. This information was later used as basis when constructing personas.

5.6 Research summary

As the research phase of this project shows, there were several stakeholders with different viewpoints and needs. While caregivers seemed to express more functional needs related to their work routines, PWDs were generally more concerned with information display and ease of use. Hence, the design calls for a balance act between needs expressed by several stakeholders.

The research phase can be summarized as:

Interview with caregivers (retirement home managers) revealed that a life story tool could aid in drafting a better life story plan for personalized care at retirement homes.

Interviews with day center personnel described life stories as being too formal and uninspiring for both PWDs and personnel. Existing life story plans also often depict the early and middle stages of an individual's life, failing to capture preferences, habits, interests and needs that are relevant to them in present day. Furthermore, it was discovered that day centers often work together with PWDs using tablets and pictures as mediating tools for face-to-face communication.

Interviews with PWDs indicated that there was a high technology acceptance in spite of low technology experience. A majority of the interviewees used some form of calendar or diary and appreciated technology that helps them remain self-reliant. Artifacts that require less cognitive work to use were appreciated. In some cases, images were preferred over text as a consequence of declining eyesight, in other images were preferred due to fatigue caused by reading texts.

It was realized that PWDs were the most challenging stakeholder to interview. As discussed by Orpwood et al. (2004) there's a high risk that PWDs get stressed, anxious or uncomfortable in novel situations with researchers. This was observed during this study, as some interviewees became noticeably stressed by the interview situation. Dementia symptoms were in some cases obvious and would obstruct interviewees in their capacity to answer accurately. Some interviewees regularly forgot the questions, some did not remember the topic after merely a few minutes. One interviewee kept asking who the interviewers were, despite repeated introductions. Also, using proper phrasing proved important. Self-denial was observed in some cases, particularly when the word "dementia" was used.

Some interviewees expressed annoyance, reluctance or confusion about the word, which called for rephrasing such as “memory difficulties”. It was also challenging to maintain a natural flow during interviews as confusion and fatigue in many cases resulted in answers unrelated to the topic.

5.7 Personas

Based on transcriptions from interviews with PWDs, personas were created as mediating tools for a first version prototype as well as for future evaluations.

5.7.1 Choice of method

Between the research phase and the design phase in UCD, there is a need to bring findings about users into the design phase. Personas are helpful in this regard as they will make sure findings from the research phase are kept throughout the design and evaluation phase (Williams, 2009).

In this project, personas were considered particularly appropriate in regards to ethical considerations as personas alleviate the designer from accidentally sharing any person sensitive information about the participants. Also, as Orpwood et al. (2004) recommend, the well being of the PWD must be prioritized. As some participants showed signs of anxiety and stress during previous interviews, it was reasoned that using personas would substitute a potentially stressful evaluation session with PWDs.

5.7.2 Creating personas

The persona creation process followed Goodwin’s (2009) nine steps for persona creation:

Step 1: Divide participants by role

Role in this regard refers to professional roles when constructing personas for a corporate setting. In a company, employees hold many different roles such as accountant, janitor, receptionist etc. Goodwin (2009) points out that if there is doubt whether a role distinction makes sense, it is safest not to separate interviewees by role. For this project, the PWDs did not occupy “professional” roles in relation to the product. Therefore, this step was skipped.

Step 2: Identify behavioral and demographic variables for each role

Variables are aspects of behavior and demographics that seem to differ across interviewees. Frequency of tasks, mental conception and goals are examples of variables (Goodwin, 2009).

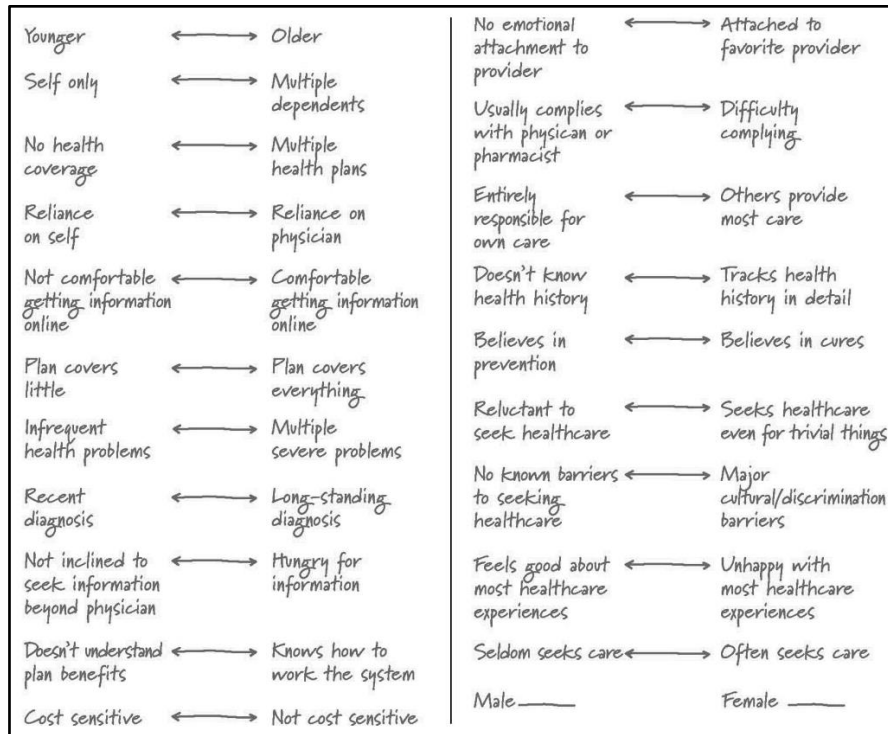


Figure 7. Examples of persona variables; continuous and multiple choice, as exemplified by Goodwin (2009, p.248)

According to Goodwin (2009), variables do not need to be opposites, but rather different means of doing something. One such example from figure 7 above are the two variables “Not inclined to seek information beyond physician” versus “Hungry for information”. As such, variables used in the creation of personas in this project were not necessarily mutually exclusive.

Variables in this project were generated from the transcribed material from interviews with PWD. The aim was finding variables describing the interviewees in the context of calendar usage, diary usage, technology usage and behaviors that may be of interest prior to the prototyping phase. The transcribed material was worked through in several cycles in order to best capture recurring themes from the interviews (Figure 8).

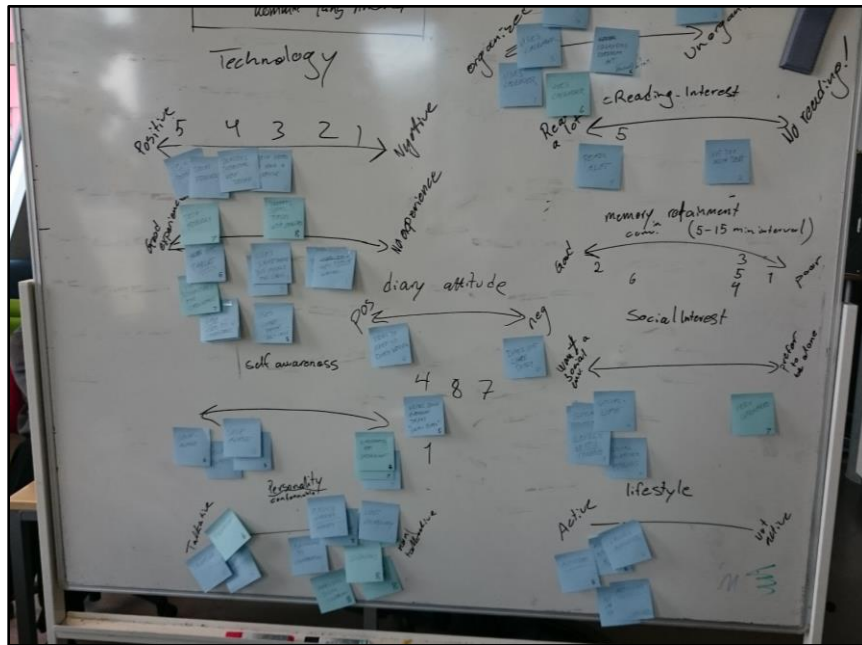


Figure 8. Early stage identification of variables.

Recurring themes and remarks were coded and drawn onto a whiteboard. Example: “I use this smart phone to call and send texts, it’s pretty good” was coded as “Comfortable using ICT”, “I have written diaries in the past, but now I find it to tiring” was coded as “Never keeps diary” (Table 3). This process resulted in the following final variables:

<i>Documents day-to-day activities</i>	vs.	<i>Does not document day-to-day activities</i>
<i>Often keeps diary</i>	vs.	<i>Never keeps diary</i>
<i>Shows interest in keeping diary</i>	vs.	<i>Not interested in keeping diary</i>
<i>Uses calendar to organize</i>	vs.	<i>Relies on spouse for support</i>
<i>Positive towards new technologies</i>	vs.	<i>Neutral towards new technologies</i>
<i>Comfortable using ICT</i>	vs.	<i>Reluctant to use ICT</i>
<i>Often uses computer/smartphone/tablet</i>	vs.	<i>Rarely uses computer/smartphone/tablet</i>
<i>Used to reading text</i>	vs.	<i>Prefers image based information</i>
<i>Social life outside of day center</i>	vs.	<i>Social life mainly through day center</i>
<i>High activity lifestyle</i>	vs.	<i>Low activity lifestyle</i>

Table 3. Summary of persona variables

Step 3: Map interviewees to variables

Interviewees were numbered from 1-8. Axis lines were drawn between the variables (Figure 9). Interviewees were then mapped to the variables from previous step. In step 2, the variables were identified, in this step participants were plotted onto the variables where they were considered to belong. This made it possible to identify possible patterns in the data.

The purpose of this was to place each interviewee relative to the others in order to generate groups of users as basis for the persona. As Goodwin (2009) points out, placement need not be precise. What is important is, for example, that participant 2 is at one end and participant 4 is towards the middle.

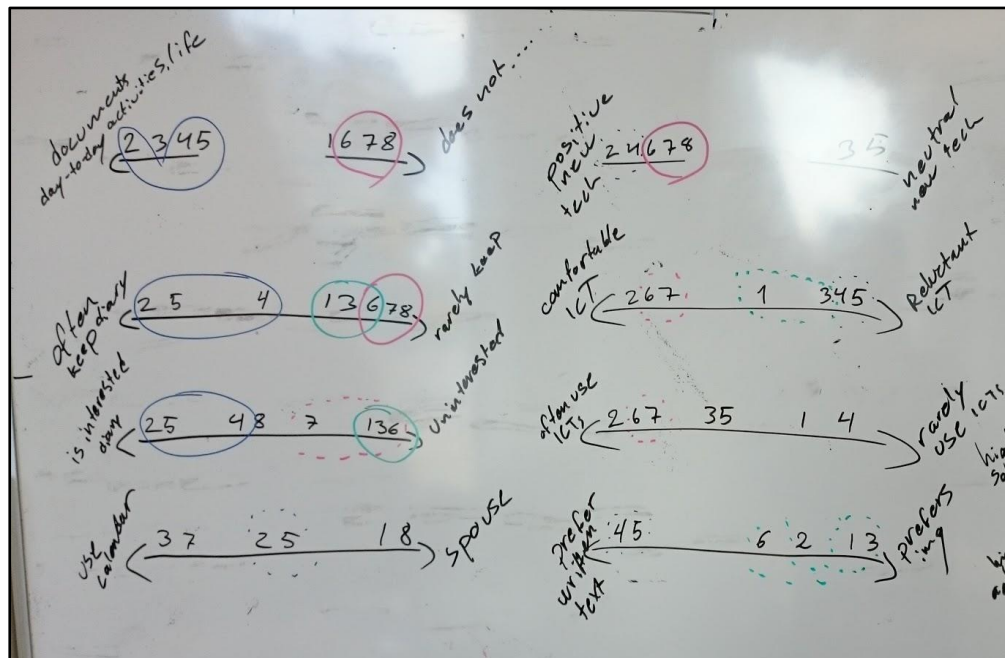


Figure 9. Interviewees mapped to variables, early stage identification of potential patterns.

Step 4: Identify and explain potential patterns

Two stronger patterns could be identified, there were also secondary patterns such as participant four often occurring together with the main pattern of participant two and five (Figure 10). The two patterns identified were used to create personas, secondary patterns that often occurred together with primary patterns were used to add details for respective persona.

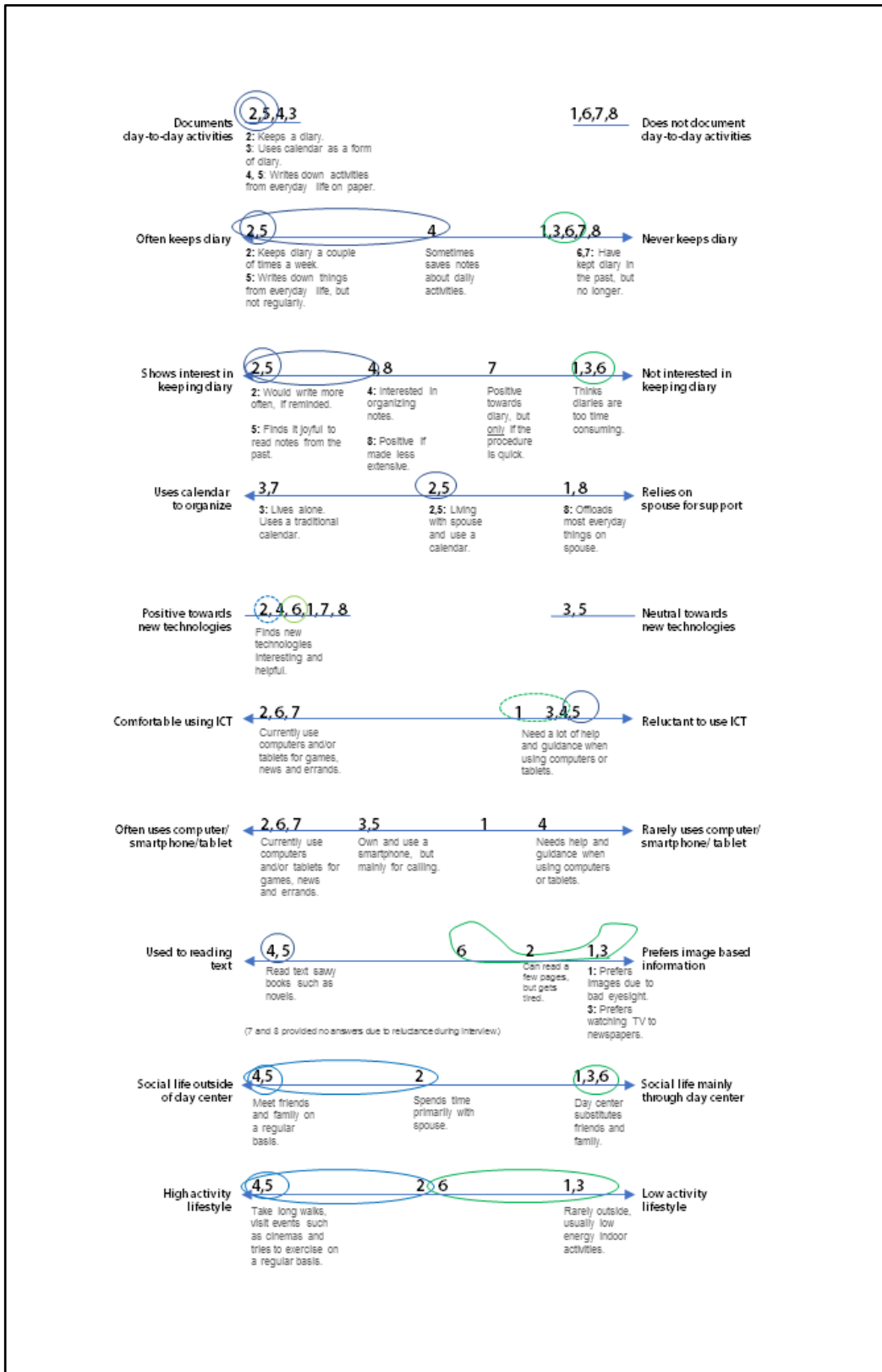


Figure 10. Identified patterns

Step 5: Define goals

Transcripts were revisited in order to ascertain that participants placement on the variable axis was reasonable. Persona goals were defined based on who the interviewees of the identified patterns were as technology users and what seems to creates well being for them.

Step 6: Clarify distinction and add detail

The interview data was then revisited and characteristics were added to the personas to give depth and detail. This fleshed out information served as basis for the persona biography (eg. behavior, frustrations and environmental factors). Circumstances of having an active lifestyle or not, how technology may be used and what living situations may look like are examples of added detail. Some of this additional information may to a certain degree be based on meta observations during the interview, second degree information etc. This is supported by Goodwin (2009) who states that while personas represent key patterns in research, the personas are primarily used to promote empathy for the users. Also, a detailed description can promote discussions about design decisions. Personas are not exact statistical representations of the user population (Goodwin, 2009).

Step 7: Fill in persona types as needed

If there are observable patterns other than those used to create primary personas, this is the time when step 4-6 are repeated to create other personas as supplement (Goodwin, 2009). Apart from the two primary patterns (see Figure 10), no other patterns were considered strong enough to stand on their own. Therefore, no other persona types were generated.

Step 8: Group and prioritize personas

If the resulting personas need different solutions, it may be necessary to prioritize them. This is particularly important if a large number of personas have been created (Goodwin, 2009). Since two equally strong patterns had been identified, there was no reason for this prioritizing. Both personas that were created were seen as equally important. Adding insights and details served more as a nuanced way of looking at the design.

Step 9: Develop narrative and other communication tools

Personas are communication tools and benefit from relatable narratives, particularly in discussion with stakeholders (Cooper et al., 2014; Goodwin, 2009). Hence, the personas were elaborated with details about their lives, such as being a widower or having two children. This elaboration may not heavily impact the design choices, but makes the personas more relatable. As well as elaborating on details, appropriate profile photos that capture the personality of the persona were also selected.

5.7.3 Results

The resulting personas were Astrid and Conrad, presented below:


ASTRID HANSSON, 71	
	
Astrid wants to: Be a mobile and active person Capture and remember activities and happenings of importance to her Be organized Wants to feel confident and in control Wants to focus on one thing at a time	
<p>Seventy-one-year-old Astrid is retired since six years and has previously worked as a teacher. She lives with her husband. Together they have two children and four grandchildren. Astrid has regular contact with her children and values their company greatly. She frequently takes long walks and reads a lot of books, preferably fiction. She regularly goes to musicals and theatres with her husband. Living an active life is important for Astrid and remembering these activities is just as important.</p> <p>Astrid got her dementia diagnosis about a year ago. She is beginning to forget simple, everyday things. Some days household activities like cleaning can be very hard to organize. Some days she cannot remember whether she likes coffee or tea. She is aware of her symptoms, and usually jokes about it as minor annoyances. Concerned by this, Astrid's husband has encouraged her to write down things and habits of importance to her. Astrid is open and casual during conversations with other people.</p> <p>Astrid is positive towards technology. If she ever gets lost or confused during one of her walks, she takes comfort in knowing she can use her smartphone to call her husband or one of her children. The phone contains a lot of functions which she finds it a bit daunting. Astrid uses her phone primarily for making calls. To Astrid, a phone is a phone.</p> <p>Technical gadgets in general are a bit off-putting and Astrid is reluctant to use a computer or a tablet without proper introduction. She is familiar with programs such as Microsoft Word, but believes it offers too many options. There are simply too many things on the screen. Astrid prefers simple applications designated for one specific thing. Like with her phone.</p> <p>Astrid keeps a diary in which she makes entries once or twice per week, but only when there is something worth mentioning. She is used to writing, but wishes she could be a bit more structured with diary entries. While it is important for Astrid that possible future caretakers know of her habits, the process of writing these things down is boring and the note papers end up scattered on the coffee table in the living room. For planned activities, Astrid uses a traditional calendar. Sometimes she trusts her husband to remember things for her.</p>	

Figure 11. The "Astrid" persona

CONRAD ALGOTSSON, 80



Conrad wants to:

- Be more social
- Remember recent events
- Document happenings in an effortless manner
- Feel that his actions have purpose
- Feel comfortable and at ease

Conrad has worked for the same company his whole life until he retired at age sixty-five. His wife passed away a few years back and he has been living a quiet life on his own ever since. He has no regular contact with his children. His social life is mostly limited to his day center activities. He does not indulge in outdoor activities or demanding exercises, although he does make sure to leave his home for occasional errands. When he is not at the day center he mostly watches TV. Staying up to date with what is going on in the world is important for Conrad, but he doesn't like newspapers. Reading large amounts of text makes him tired.

Conrad feels very uneasy about his memory impairments. He doesn't like the term "dementia" and finds it hard to accept his condition. Demanding instructions and intricate conversations makes him stressed and anxious. During conversations, he is reluctant to talk about his symptoms and often denies his memory impairment. However, he does want to share with other people how he feels about his loneliness. He appreciates being at the day center as it provides much needed company.

Conrad is neutral towards technology and has little experience with computers and tablets. He realizes the potential of technology, but is not very interested in using it unless it serves a purpose. As far as habits go, Conrad is firm. He is not keen on change unless thoroughly convinced.

Conrad used to keep a diary, but does no longer. Nowadays he finds it too time consuming and not particularly fun, especially not after his wife's passing. Since many of his friends have passed as well, keeping a diary can become a dreary task. Conrad writes down events for every month using a traditional calendar. Occasionally he glances at past notes to get an overview of his routines, but rarely uses the calendar as a diary.

Since his wife died, it has been lonely and hard to structure day-to-day life. Because of this, social stimuli through the day center has become very important for Conrad. He is even prepared to move to a retirement home as it offers social contact during longer periods of time.

Figure 12. The "Conrad" persona

Personas “Astrid” and “Conrad” would come to be used as design inspiration as well as mediating tools during cognitive walkthroughs with domain experts. However, there are factors that should be taken into consideration. Using information from contextual interviews is a recommended approach when constructing personas (Cooper et al., 2014). In this study, the personas represent a cross section of information from interviews with people with dementia. As observed during interviews, dementia symptoms can obstruct the interviewee’s ability to answer correctly. Consequently, the validity of the personas may have been affected.

5.8 Product idea

Now that needs had been recognized from interviews with caregivers and PWDs, a conception of a concrete design was beginning to take shape. As both *diaries* and *pictures* are appreciated as mediating tools at day centers, it was decided these components were to play a vital role in the design.

At first, the concept leaned in favor of a text based journal that would allow users to make entries placed on a timeline. Pictures could then be attached to the entries. The timeline would range from early life events to present time, thus providing something similar to a life story. However, this idea was considered too text heavy and tedious to use for PWDs. Also, it ignored the desire expressed by caregivers to focus less on early life events and more on present time. Furthermore, interviews indicated that a desired function is the ability for PWDs to report on their general well being and what makes them happy. Describing emotions and feelings through text was considered too difficult for a PWD user. Adding factors such as declining eyesight makes text heavy solutions even more demanding. Therefore, this design was discarded.

Instead, the approach would focus on day-to-day documentation of everyday activities using photographs. Also, emotions would be expressed using graphical representations rather than text. Since PWDs are familiar with calendars and diaries, the tool would incorporate these elements (eg. dates and the option to write text), but instead letting photographs act as the prominent mediator.

Consequently, it was decided to design a *photograph-based diary tool* that focuses on present time, allows for optional text entries and utilizes iconography as a means to express likes and dislikes.

5.9 Paper sketches

Paper sketches were drawn to find an appropriate interface design. As Rogers et al. (2011) point out, this type of low fidelity prototype is useful during early stages of interface design as it allows for quick and simple ideation. Designs that were deemed weak in relation to the aforementioned factors were discontinued.

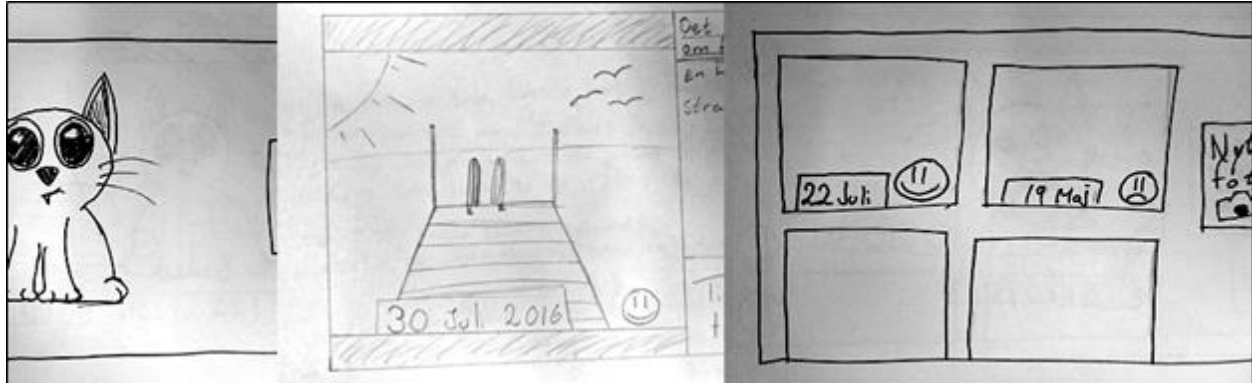


Figure 13. Early paper sketches.

When the design was deemed sufficient, a digital version was made (see Digital prototype below).

5.10 Digital prototype

An interactive digital prototype was made using Axure RP Pro (student license). This prototype may be considered as a hybrid between low fidelity and high fidelity (Rogers et al., 2011) as it behaves close to a finished product, but does not offer full functionality. Due to time constraints, this compromise was deemed the most feasible.

This first version of the prototype was created with functionality in mind, rather than aesthetics. Polished versions of an interface is generally recommended for later stages in the design process (Cooper et al., 2014). Therefore, this early stage prototype focused more on the overall layout and less on look-and-feel. The design was based on findings from interviews with day center personnel (caregivers) and PWDs. Interface design followed recommendations by Pang & Kwong (2015).

The prototype made use of six views:

Home view

This view presents an overview of photographs the user has taken. Each photograph is labeled with an automatically generated date of when it was shot. Smiley faces describe how the user felt when taking the photograph (see Emotion view). To activate the camera, the user presses Nytt foto (New photo) which brings up a new view for this purpose (see Camera view).

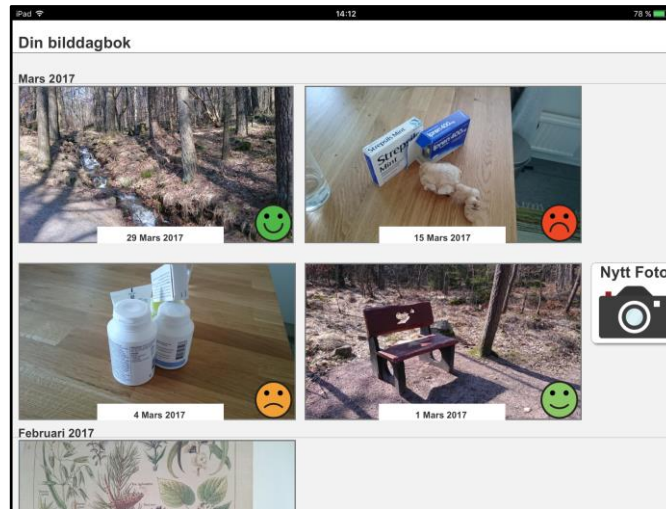


Figure 14. Home view

Read old entry view

This view appears when the user presses one of the pictures in Home view. It shows what the user has written about the picture, as well as the emotion attached to it (see Emotion view). To return to Home view, the user presses Tillbaka till album (Return to album).



Figure 15. Read old entry view

Camera view

The user presses Ta bild (Take picture) to take the photograph. (The prototype did not actually activate the tablet camera but instead a still frame was used to simulate this function.)

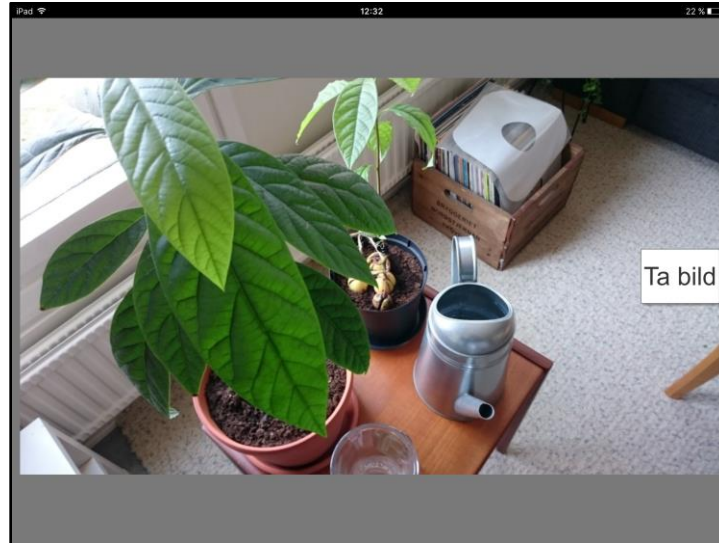


Figure 16. Camera view

Emotion view

The ability to express happy or sad feeling is a feature that was suggested by caregivers. In this view, the user presses one of the smiley faces that best describes the feeling associated with the motif. It was reasoned that by using iconography instead of text based labels, this could be accomplished in a more playful manner. Also, it would reduce the amount of text in the interface.

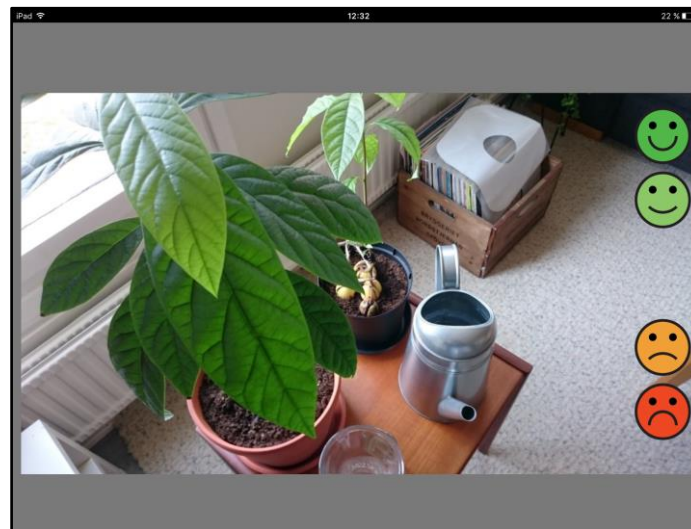


Figure 17. Emotion view

Write view

This view displays the picture taken in previous steps. The selected smiley symbol from Emotion view is attached to the picture. The user presses the text field if he or she wishes to write something about the picture. To save and return to Home view, the user presses Läggtill foto (Add picture).

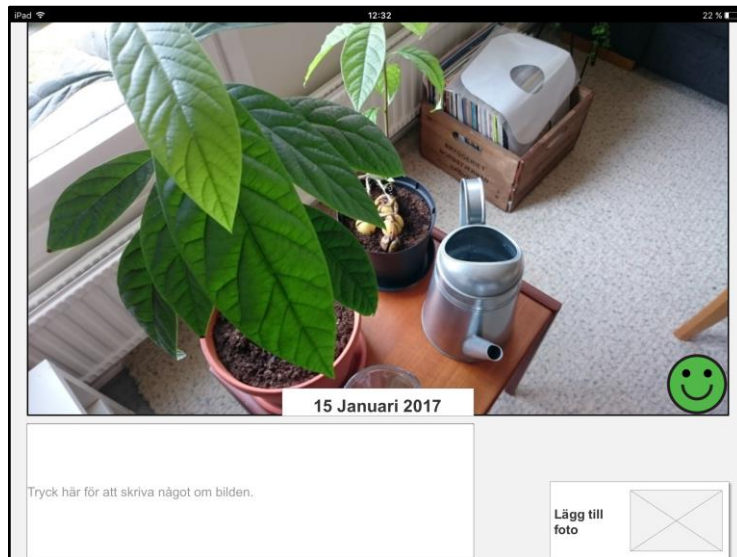


Figure 18. Write view

Keyboard view

The built in keyboard appears, allowing the user to type. When done typing, the user presses Läggtill foto (Add photo) in order to return to Home view.

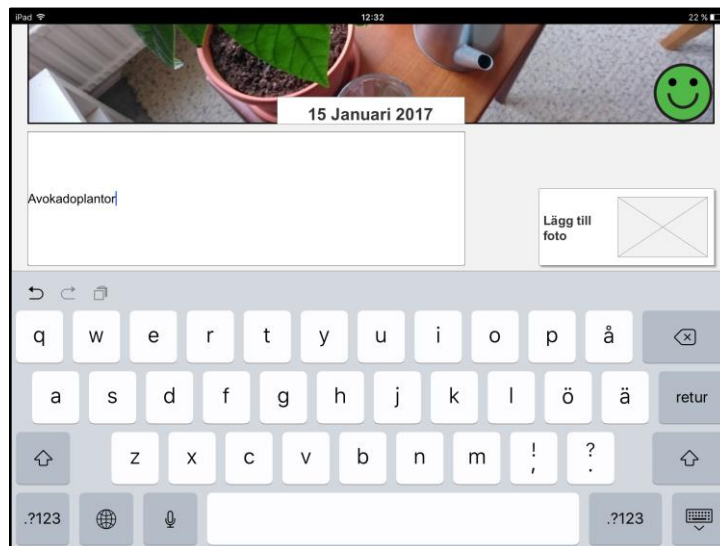


Figure 19. Keyboard view

Design rationale in relation to caregivers:

The tool is tablet based and allows for picture taking. Also, it is designed as a picture diary, as both diaries and photographs are encouraged by caregivers. Further, the design does not focus on remote life events such as upbringing and childhood, but rather on present time. By using *smiley idioms*, the tool provides information about the PWDs emotion connected to each picture.

Design rationale in relation to PWDs:

The tool revolves around photographs, as pictures are greatly appreciated. The tool is labeled Picture diary (Bilddagbok) in the header as most PWDs are familiar with diaries. The number of options is limited as most PWDs find large amounts of actions overwhelming. Also, it allows for making diary entries in Write view, but this function is not mandatory as some PWDs find diary keeping too demanding. Overall, the tool is straightforward as it only allows for viewing old pictures, taking new pictures and writing diary entries.

Design rationale in relation to design theory:

This version of the prototype considers the following design recommendations by Pang and Kwong (2015):

Reduce complexity

The number of items per view are limited to between 2 and 5. What is defined as an “item” is somewhat ambiguous and is not well defined by Pang and Kwong. Obviously Home view contains more than 5 items as it displays a grid of varying quantities of pictures. Therefore, it was reasoned that system related items such as buttons and instructions should be limited to less than 5. Also, dates attached to the pictures are automatically generated to relieve the user. Furthermore, no multi touch gestures are required to use the tool, as recommended by Pang and Kwong.

Tasks should be clearly structured

Pang and Kwong recommend using one page for one task. This recommendation was found challenging to follow subserviently. For example, Home view is for both selecting pictures as well as for activating the camera function. Instead, the design tries to limit the number of tasks as far as possible for each view.

Information consistency

Views are consistent in regards to color palette and object placement.

Feedback should be rapid and straightforward

As the prototype does not contain advanced functionality such as image editing or settings, feedback such as dialog boxes or confirmation questions was deemed unnecessary. It was reasoned that this would

clutter the interface and confuse the user, thus increasing complexity rather than reducing it. It was argued that because the tablet changes views when the user proceeds to the next step, this could be considered feedback in itself.

Support the user

Pang and Kwong recommend providing on screen help. This recommendation was not considered as it most likely would require more iterations. Given available time frame this was deemed impractical. Also, it was reasoned that since the tool is straightforward in itself, on screen help could potentially clutter the interface.

Interface optimization

The graphical appearance is simple and less cluttered. Easy to read fonts have been used and objects such as buttons are large. Pang and Kwong also recommend that the focus of attention should be placed on the center of the page, as is the case with images and text fields.

Also, Ware's (2012) principles for using *gestalt laws* (Koffka, 1935) were considered. Buttons were grouped together and consistently placed on the right, applying the *proximity* principle.

5.10.1 First iteration

The first iteration included four cognitive walkthroughs. First, a pilot evaluation was carried out by the design team in order to correct obvious oversights. After minor adjustments were made, another three cognitive walkthroughs were carried out together with domain experts.

5.10.1.1 Choice of methods

It can be cumbersome for PWDs to test a prototype before early pitfalls and design flaws are remedied. As observed by Orpwood et al. (2004), stress and anxiety are common when involving PWDs in research and can in many cases lead to dropouts from evaluation programmes. These tendencies were indeed observed during interviews with PWDs earlier in this project. Consequently, due to a somewhat constrained time frame as well as to ethical considerations, cognitive walkthroughs with experts were considered appropriate and affordable.

5.10.1.2 Pilot evaluation

Before doing evaluations with domain experts, a pilot evaluation was carried out by the design team. The reason for this was to get familiarized with the method so that proper guidance could be provided for the domain experts later on. Also, a pilot walkthrough would potentially discover shortcomings with the design.

For each task, the design team asked the following questions, as advocated by Rogers et al. (2011):

Q1: Will the user know what to do to achieve the task?

Q2: Will the user see how to do it?

Q3: Will the user understand from feedback whether the action was correct or not?

The design team then assumed the role of the personas, as recommended by Blandford et al. (2011). The cognitive walkthrough was carried out using pen and paper, printouts of the personas and a tablet for testing (Figure 20).

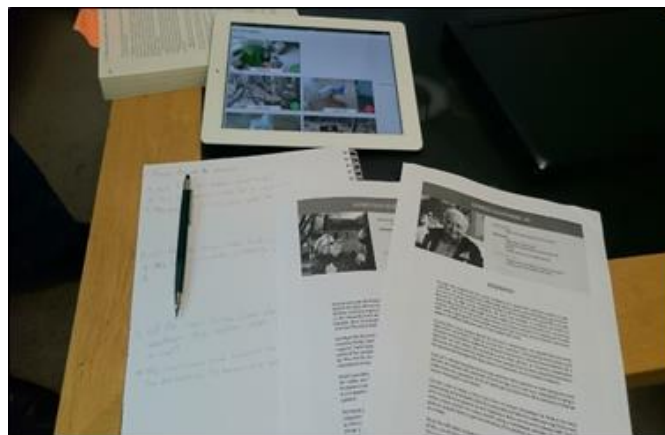


Figure 20. Evaluation setting for the pilot walkthrough with the design team

The pilot walkthrough focused on four tasks:

- Open an entry and read about it
- Launch the camera
- Annotate perceived emotion associated with a photo
- Write a comment about a photo

In some cases a question can be answered with both *yes* and *no*, referring to different aspects of the same issue. When this occurred, *no* was the justification for adjustments. This principle was followed during cognitive walkthroughs with experts later on. Below is a summary of the cognitive walkthrough with the design team:

Task: Open an entry and read about it View: Home view / Read old entry		
	Astrid persona	Conrad persona
Q1: Will the user know what to do to achieve the task?	Yes: Astrid has a basic understanding of computers and phones from using Microsoft Word and smartphones.	No: there is nothing on screen that tells Conrad to press a photo to interact with it.
Q2: Will the user see how to do it?	Yes: having basic experience with smartphones, Astrid is familiar with interactive GUI objects like icons and images.	No: there are no instructions for how to interact with things on screen.
Q3: Will the user understand from feedback whether the action was correct or not?	Yes: the screen will shift to the photo's detail view (Read old entry view).	Yes: as the screen will shift to the photo's detail view (Read old entry view). No: he may forget that it's his picture. A more clear label is needed.
Task: Launch the camera View: Home view		
	Astrid persona	Conrad persona
Q1: Will the user know what to do to achieve the task?	Yes: she knows to look for a camera button or function.	No: since Conrad is unfamiliar with tablets and technology he needs a more direct approach.
Q2: Will the user see how to do it?	Yes: the camera button is visible and stays positioned on the right side of the screen when scrolling through the album.	No: the camera button is poorly labeled Yes: the camera icon is clear
Q3: Will the user understand from feedback whether the action was correct or not?	Yes: the screen (Camera view) will behave as a traditional camera viewfinder.	

Task: Take a picture View: Camera view		
	Astrid persona	Conrad persona
Q1: Will the user know what to do to achieve the task?	Yes: there is only one button to press.	Yes: there is only one button to press.
Q2: Will the user see how to do it?	Yes	Yes
Q3: Will the user understand from feedback whether the action was correct or not?	Yes	Yes
Task: Annotate perceived emotion associated with a photo View: Emotion view		
	Astrid persona	Conrad persona
Q1: Will the user know what to do to achieve the task?	No: an instruction or label is missing to give context to the smiley faces.	No: for the same reason.
Q2: Will the user see how to do it?	Yes: Astrid can see the smiley faces and associate them with the task.	No: Conrad needs more explicit instruction regarding the smiley buttons.
Q3: Will the user understand from feedback whether the action was correct or not?	Yes: the next screen (Write view) is updated with the current smiley face.	No: some form of labeling or indication of what the previous action meant is needed.
Task: Write something about a photo View: Write view / Keyboard view		
	Astrid persona	Conrad persona
Q1: Will the user know what to do to achieve the task?	Yes: there is a clear instruction in the text field for what to do.	
Q2: Will the user see how to do it?	Yes: Astrid has used a keyboard before and recognizes how to use it.	Yes: Conrad recognizes the keyboard as he has used typewriters in the past.
Q3: Will the user understand from feedback whether the action was correct or not?	Yes, since the text field is updated in real time. Keyboard provides feedback both audibly and visually (iOS built in keyboard).	

Table 4. Pilot walkthrough with the design team

Adjustments:

Based on findings from the pilot evaluation, minor adjustments were made. Essentially, it was found that explanatory instructions were needed in Home view and Emotion view.



View	Changes
Home view	 <p>Explanation added to the header: "Tryck på valfri bild för att läsa mer." (<i>Press an image to read more.</i>)</p> <p>Camera button relabeled for clarity: "Ta en ny bild" (<i>Take new picture</i>)</p>
Emotion view	 <p>Explanatory text added: "Hur får bilden dig att må? Tryck på en av ansiktena" (<i>How does the picture make you feel? Press one of the faces.</i>)</p>

Table 5. Adjustments

The above changes were incorporated into the design before cognitive walkthroughs with domain experts were carried out.

5.10.1.3 Expert Evaluation

Three evaluations were carried out as cognitive walkthroughs together with three domain experts respectively. Throughout the walkthrough a think aloud protocol was followed. The domain experts were nurses with extensive experience in interacting with PWDs. For each walkthrough, the domain expert was roleplaying as the two personas “Astrid” and “Conrad”.

For each expert, a typical evaluation session proceeded as follows:

The expert was informed about the purpose of the study. The cognitive walkthrough method was then explained. When the domain expert understood the process, the two personas “Astrid” and “Conrad” were introduced. The domain expert read both persona biographies and was instructed to roleplay as the personas during the walkthrough. Each expert then signed a form of consent, allowing the session to be recorded.

The walkthrough was then carried out, using the same structure as the previous pilot evaluation.

The walkthrough focused on four tasks:

- Open an entry and read about it
- Launch the camera
- Annotate perceived emotion associated with a photo
- Write a comment about a photo

For each task, the design team asked the following questions, as advocated by Rogers et al. (2011):

Q1: Will the user know what to do to achieve the task?

Q2: Will the user see how to do it?

Q3: Will the user understand from feedback whether the action was correct or not?

Each expert carried out the walkthrough twice, one for each persona. First the expert would roleplay as “Astrid”, then as “Conrad”. (For a detailed compilation of the cognitive walkthrough with experts, see Appendix IV.)

One member of the design team acted as facilitator, the other member as observer. The observer would, when needed, encourage elaboration of interesting aspects that surfaced during the session. Before the evaluation started, the participating domain experts were briefed on what a think aloud protocol is and encouraged to out loud explain what they were thinking.

The setup was the same for all three walkthroughs. The evaluations took place in a closed off room, the domain expert was seated in between the designers so that both designers could observe what transpired. During the walkthrough, the facilitator took notes for each step of the walkthrough. The session was recorded on a smartphone and later transcribed. The prototype was evaluated on a tablet with a 6,7 inch screen.

It should be noted that the second walkthrough was somewhat rushed due to time constraints. When telephone contact was established with the second expert, an unfortunate error in communication was made by the design team. It was realized that the description of the walkthrough had not been adequate enough. Therefore, the second expert did not fully realize the time required for the evaluation. As a consequence of this, there was not sufficient time to thoroughly read through the personas during the second walkthrough. Instead, a short summary of each persona was given by the design team. This may have affected the results somewhat for the second expert evaluation (Expert 2).

In addition to the cognitive walkthrough, experts were asked to evaluate the personas based on their own experiences with PWDs.

5.10.1.4 Findings

The personas were found useful in providing context for the domain experts in relation to the design. In interviews following the evaluation sessions domain experts attested to the relatability of the personas.

“Yeah, I recognize a lot of these patterns” - Expert 3 on the reliability of the personas

Overall, Astrid was perceived as quite capable of using the prototype without any major issues. Conrad, on the other hand, was interpreted as more problematic. Conrad was also interpreted as being in a later stage of the disease than Astrid. Despite difficulties that may arise from being inexperienced with technology, the prototype was perceived as a valuable tool for someone like Conrad as long as he gets help on how to use it.

“Once again, I’m leaning toward Astrid being able to do it.” - Expert 1

“I’m just thinking... imagine if Conrad got to sit down with someone who would help him with this! What a nice photo diary he could have.” - Expert 2

The ability to take photographs was recognized as a useful function since writing can be problematic. Moreover, experts highlighted the potential of using the tool as a memory aid:

“People in early stages of dementia want to be able to handle their everyday life as well as possible. Most people want to retain their self sufficiency as much as possible. If they are able to handle this tool, it may help with this.” - Expert 2

“Taking pictures is great because then you’ll remember that ‘right! I went out for a walk today’” - Expert 1

Domain experts testified that the smiley faces could offer caregivers some much needed indication of how PWDs feel about things in their lives. However, when assessing emotional relation to a photo, the smiley faces were hypothesized to be hard to understand as well as hard to differentiate.

“Of course, there’s a value for caregivers to have the faces there.” - Expert 3

“Smiley faces are not self explanatory to this generation, it might be too hard to interpret smiley faces as representations of emotions.” - Expert 3

“I’m hesitant to whether PWDs would be able to tell the difference between all four faces, maybe two or three more distinct faces would be easier to tell apart.” - Expert 1

“In a later stage, it could be helpful when drafting what we call a life story, to document what one likes and what makes one feel good.” - Expert 2

Furthermore, it was speculated that smiley faces in Home view could prove problematic. It was reasoned that a sad smiley attached to a picture of medicine cases could be interpreted as a warning. Knowing in the moment the picture was taken that the sad smiley means “it makes me sad when I am sick”, the PWD could interpret the same smiley as “do not take this medicine” a few moments later.

“It could possibly color the PWDs to think how they should feel, rather than remember how they did feel.” - Expert 3

“Red could mean danger, rather than dislike.” - Expert 3

“An angry face can be perceived as a warning, rather than a mood.” - Expert 2

In summary, experts expressed concerns about the following shortcomings:

- Write view and Keyboard view may be too complicated as it is not obvious what to do.
- The header “Din bilddagbok” (*Your picture diary*) may cause confusion as the user may not understand who the word “Your” is referring to.
- In Camera view “Ta bild” (*Take picture*) may not be self explanatory enough.
- Overall, text labels are a bit scanty and do not provide instructions clearly enough.
- In Emotion view, too many smiley faces are presented. This may cause stress and confusion, as the number of options can be overwhelming. Also, the meaning of each face is somewhat ambiguous.
- Smileys may cause problems in Home view as they may be interpreted as warnings rather than graphical representations of emotions.

For a detailed compilation of the cognitive walkthrough with experts, see Appendix IV.

5.11.1 Second iteration

This version of the prototype was adjusted based on feedback from experts. Also, in this iteration, look and feel was more emphasized. It is recommended that polished graphical design is given more priority during later stages in a design process (Cooper et al., 2014).

Adjustments

Based on feedback from expert evaluations, the following adjustments were made:

Choice view and New write view

The original Write view (figure 18) was considered too complicated, as it offered both the option to write a diary entry and to go back to Home view. Also, if the user chose to make an entry, the following Keyboard view (figure 19) omitted a large portion of the photograph. Instead, a linear approach was used with the added *Choice view* (figure 21). In this view, the tool asks whether the user wishes to make a diary entry or go back to Home view. If the user presses “Yes”, the *New write view* (figure 22) appears. This view merges the old Write view and Keyboard view, thus presenting a layout where all components are fully visible at the same time.



Figure 21. Choice view

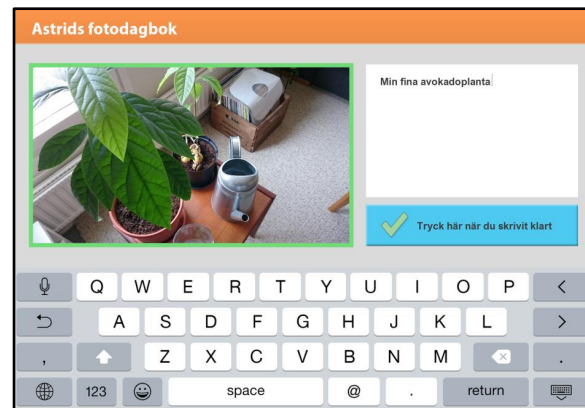


Figure 22. New write view clearly displaying both keyboard and photograph.

New personalized header

As experts expressed the need for a personalized header to avoid confusion, this new design was utilized. Instead of a generic header, the user's name is now displayed (figure 23).

Astrids fotodagbok

Figure 23. New header displaying the name of the user

More didactic text instructions and easy to understand iconography

Some experts expressed concern regarding text instructions and labels in previous version. They were found to be short and non descriptive. For this reason, text labels were elaborated and iconography was introduced for clarification.

It is recommended by Pang and Kwong (2015) to make the interface as simple and straightforward as possible. This applies to written text as well. It was therefore challenging to find the right balance between elaborate instructions and a less cluttered interface. Much thought had to be put into formulation short sentences with as much descriptive information as possible.



Table 6. Examples of elaborated text instructions as well as added iconography

The number of smiley faces reduced and explanatory labels added

According to experts, the first version of the Emotion view (figure 17) presented too many smiley faces. This could potentially create confusion both considering the number of options, but also due to the somewhat ambiguous meaning of smileys as graphical representations of emotions. Therefore, the number of smileys were reduced and explaining labels were added. In addition, a *Neutral* smiley was introduced, to accommodate situations when users may experience difficulties assigning emotions to a photograph (figure 24).

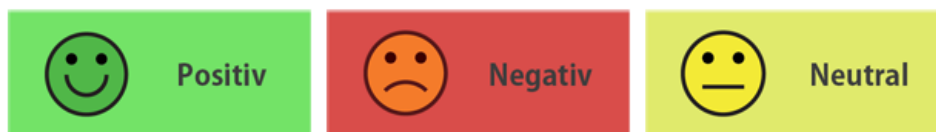


Figure 24. The new design of smiley faces with added labels.

Smiley faces replaced with colored frames in Home view

An important observation that surfaced during expert evaluations is that iconography might be misinterpreted in unforeseen ways. The previous Home view used smiley faces attached to each photograph thumbnail to show how what emotion users experienced when taking the picture (figure 25). However, a person with dementia may interpret such idioms as warnings. A sad smiley attached to a picture of medicine boxes can be interpreted as “do not take this medicine”.

To minimize this risk, smiley faces were replaced with colored frames (figure 26.) If the user expresses sadness when the picture is taken, using one of the above smileys (figure 24), a frame with the corresponding color will enclose the picture instead of showing the smiley face icon.



Figure 25. Old visualization of emotions in Home view.



Figure 26. Sad smiley face replaced with a red frame

New design

With the above adjustments incorporated, the prototype was revised into the following design:

Home view

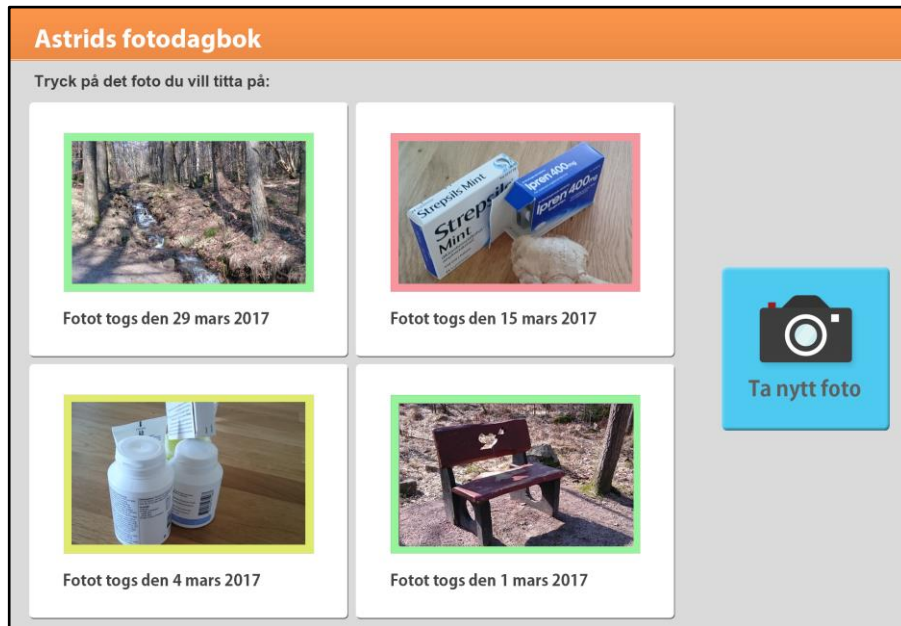


Figure 27. Redesigned Home view with color frames enclosing the picture thumbnails.

Read old entry view

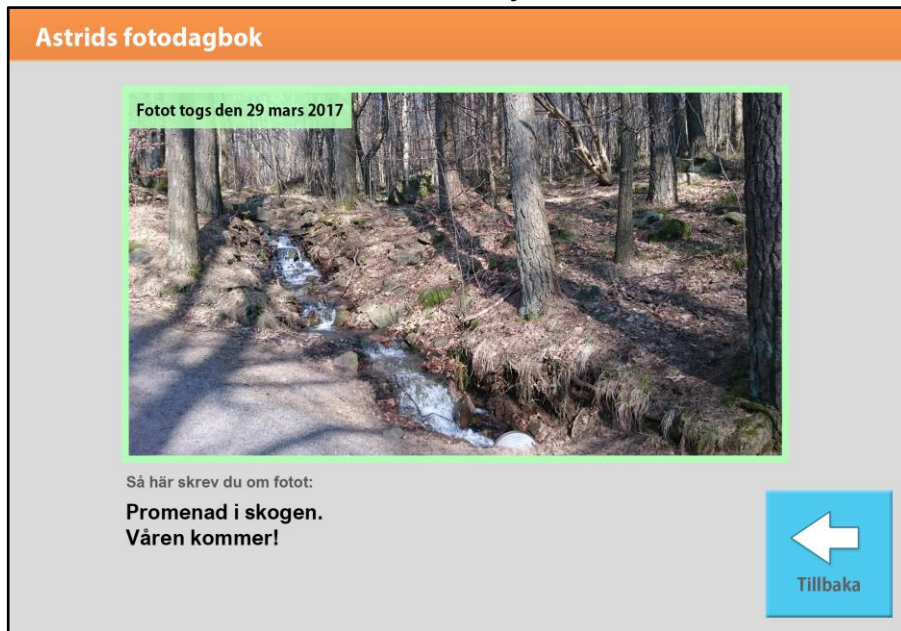


Figure 28. Redesigned Read old entry view utilizing the colored frame design.

Camera view

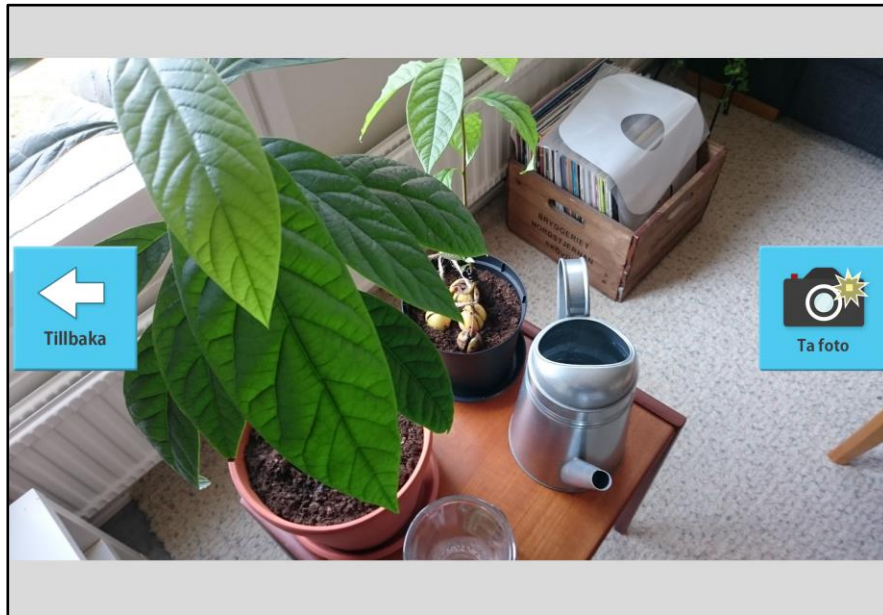


Figure 29. Redesigned Camera view with new iconography.

Emotion view

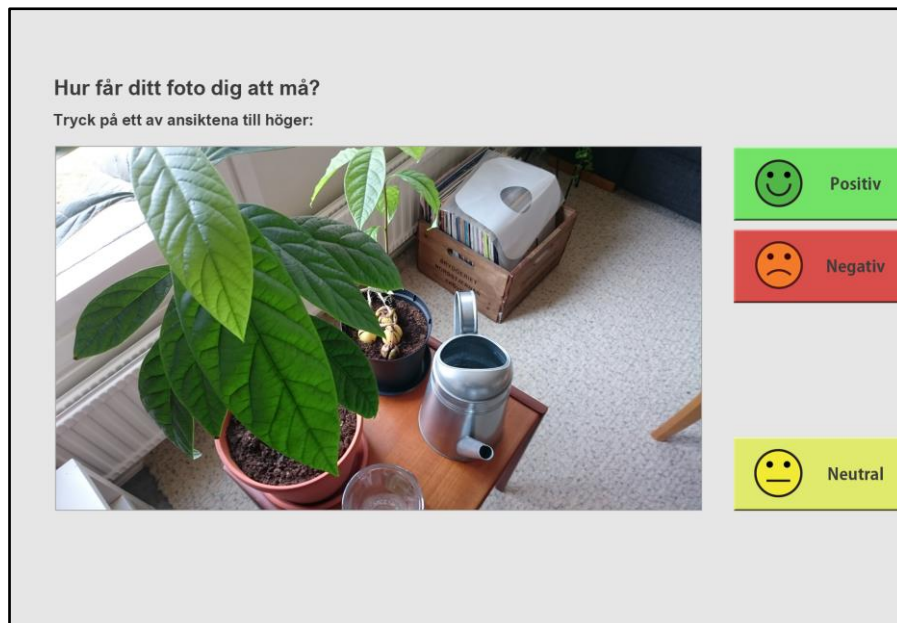


Figure 30. Redesigned Emotion view with reduced number of smiley faces, explanatory labels and an added Neutral smiley.

Choice view



Figure 31. Choice view asking users whether they wish to write a diary entry.

New write view

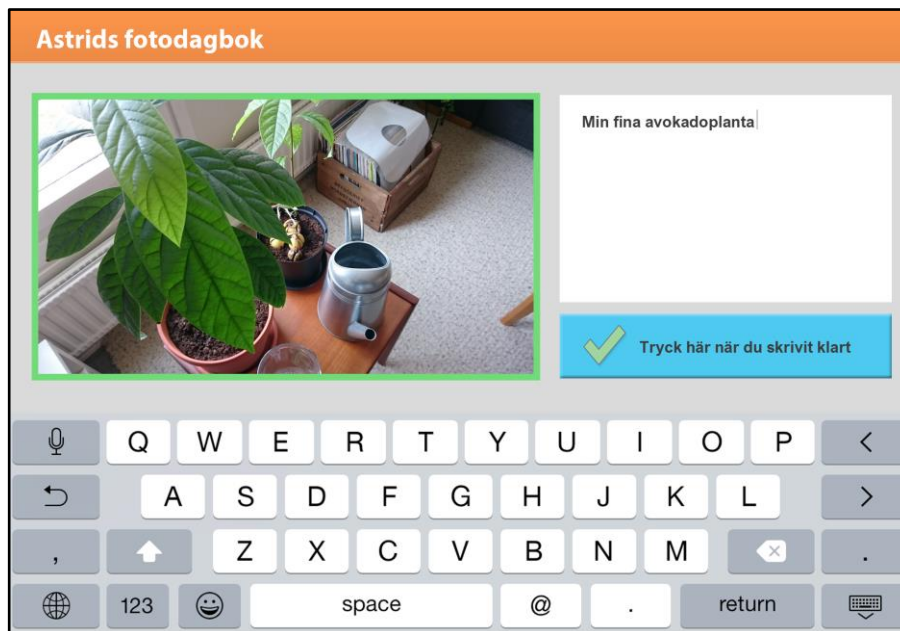


Figure 32. New write view displaying all interface components at the same time.

As a consequence of previous evaluations and the more polished graphical design, this version of the prototype better accommodated for design recommendations by Pang and Kwong (2015):

Reduce complexity

It is recommended by Pang and Kwong to reduce the number of options per page as much as possible. By reducing the number of smiley faces in *Choice view*, the prototype offered less options and consequently presented a less complicated interface.

Tasks should be clearly structured

Pang and Kwong argue that one page should represent one task. This guideline was better accommodated by introducing *Choice view* as it reduces the somewhat complicated *Write view* (Figure 18.) from the earlier prototype.

Information consistency

As Pang and Kwong recommend, colors should be used to emphasize meanings of a button or a region. As look and feel was more emphasized in this version, colors were given greater prominence. Orange was picked as the header color, blue for system related functions such as “Take picture” buttons etc.

Support the user

Pang and Kwong advocate on screen help to support the user. By adding more explanatory labels to the interface, better user support was offered. Also, refined iconography was used to clarify functionality.

Interface optimization

The interface should be optimized by utilizing a simple graphical design and by using fonts that are easy to read, according to Pang and Kwong. This prototype uses only easy to read sans serif fonts to accommodate for readability. Overall, the graphical design uses a plain design with simple geometrical shapes and few interface objects in each view. Moreover, with the more prominent use of colors, Ware’s (2012) recommendations for grouping objects using *gestalt laws* (Koffka, 1935) were better accommodated. In *Home view* (Figure 27.), *similarity* was better applied as the thumbnails were given a white backdrop, contrasting the light gray background. Also, functionality buttons such as “Take picture” and “Back” were assigned the same blue color consistently to signal affiliation.

After the new design was deemed sufficient, an interactive prototype was made using Axure Pro (student licence) for a second expert evaluation.

5.11.1.1 Expert evaluation

As in the previous iteration, this evaluation made use of cognitive walkthrough as evaluation method. The walkthrough focused on four tasks:

- Go back to start page from *Read old entry view*
- Submit emotional response in *Emotion view*
- Write something about a photo in *New write view* via *Choice view*
- Save a photo in *New write view*

For each task, the following questions were asked, as recommended by Rogers et al. (2011):

- Q1: Will the user know what to do to achieve the task?
- Q2: Will the user see how to do it?
- Q3: Will the user understand from feedback whether the action was correct or not?

The walkthrough was carried out with domain expert 3 from previous iteration. This expert was deemed most appropriate for a final evaluation due to extensive experience from all stages of dementia as well as from working in both care centers and home care.

This walkthrough differed somewhat from previous iteration. In this session, the expert was encouraged to make use of own experiences instead of personas as in previous walkthroughs. It was reasoned that this approach might generate new insights by not being limited to personas.

The walkthrough was then followed by a short conversation about color, spatial layout, phrasing and use of icons.

5.11.1.2 Findings

The major issue identified during the cognitive walkthrough concerned phrasing. When *Read old entry view* was evaluated, it was pointed out that the word “Back” may be hard to understand. A more elaborate label should be used. However, verbs like “Go” should be avoided as they may be interpreted literally. For a person with dementia, “Go” may be interpreted as an imperative to take a walk. “Back to start page” was suggested instead.

“‘Back to start page’ would be better, but avoid using the word ‘go’. That could make a confused individual wonder if they are supposed to walk somewhere.” Expert 3

Results from the cognitive walkthrough is presented in Table 7 below.

Task: Go back to startpage View: Read old entry view	
Q1: Will the user know what to do to achieve the task?	No, using only 'Back' as label can be hard to understand.
Q2: Will the user see how to do it?	Yes, and the button is inviting to press.
Q3: Will the user understand from feedback whether the action was correct or not?	Yes
Task: Submit emotional response View: Emotion view	
Q1: Will the user know what to do to achieve the task?	Yes, I think so.
Q2: Will the user see how to do it?	Yes, I think so, as long as they are used to pressing things on a screen
Q3: Will the user understand from feedback whether the action was correct or not?	No. You can't tell that something has happened with the photo...
Task: Write a comment View: Choice view / New write view	
Q1: Will the user know what to do to achieve the task?	Yes, it is evident
Q2: Will the user see how to do it?	Yes, since the keyboard shows up. Most people have experience with typewriters, keyboards or smartphones.
Q3: Will the user understand from feedback whether the action was correct or not?	Yes
Task: Save and exit View: New write view	
Q1: Will the user know what to do to achieve the task?	Yes
Q2: Will the user see how to do it?	Yes
Q3: Will the user understand from feedback whether the action was correct or not?	Yes

Table 7. Results from cognitive walkthrough with expert 3

In addition to the cognitive walkthrough, a conversation was carried out where the prototype was discussed overall. In terms of look and feel, the prototype was appreciated. Particularly the placement of buttons were well received. According to Expert 3, individuals with dementia tend to perceive elements that *pop out* from the background easier than objects that blend in with the background. The camera launch button was considered well placed as it floats vertically centered on the right hand side of the screen. This placement makes it stand out, strengthening the impression that it represents a separate action, according to Expert 3.

“It feels like the camera button is well placed, it’s like it’s beside the photos instead of after. I can either look at the photos or take a picture, it’s not something following interactions with the photos.” Expert 3

Furthermore, expert 3 advises against moving the button further down on the screen. A possible outcome of placing the camera button at the bottom right corner of the screen might be that persons with dementia interpret the button as a last step in a chain of interactions, rather than as an encouragement for further exploration of the interface.

The added *Choice view* was considered an improvement that made the prototype easier to understand. Having the keyboard instantly turning up in *New write view* without the user having to press the text field was also deemed necessary in order to clearly demonstrate what is expected of the user.

The smiley faces were further discussed. The change from smiley faces to colored frames around photos was greatly appreciated and thought to be a good idea.

“That’s clever! Because the colors are for meant for me as caregiver and then I can better choose what to talk about.” - Expert 3

Problems arise however when there are still smiley faces in *Emotion view*. A simple change can be made here: take away the smiley faces all together. The point of the smiley faces were for caregivers to be able to better understand likes and dislikes as well as provide material for conversation between caregiver and caretaker. The colored frames with text do this job just as well as the smiley faces if the caregivers have been briefed on the (potential) meaning of the colors.

Size of objects were also discussed, a rule of thumb being as long as the button is not smaller than a finger there’s no need to worry that the button is too small to press.

“As long as the buttons aren’t too small. You’ll have to consider that people become a bit butter fingered as they get older. So it’s good if all buttons are at least the size of the end of your index finger.” - Expert 3

This walkthrough was the last to be carried out during this project. It can be argued that the most precarious aspect of the design is still the risk of users misinterpreting textual formulations and graphical idioms literally. Particularly the smiley faces in *Emotion view* and the use of imperative labels like “Go back” can cause confusion. Overall, the prototype was well received, demonstrating the usefulness of expert evaluations for this project, as Orpwood et al. (2004) advocate. Moreover, as an outcome of having consulted experts, the interface design is now even more aligned with recommendations by Pang and Kwong (2015). This suggests that using aforementioned guidelines was beneficial for this project.

6. RESULTS

The research question for this study was:

What factors should be considered when designing an ICT-based tool for persons with dementia?

6.1 Factors designing for people with dementia

Based on challenges and findings during the design process, a list of factors to be considered when designing for people with dementia has been compiled.

6.1.1 Access to participants

The following factors concern challenges that may arise when establishing contact with stakeholders during early stages of the research phase.

Retirement homes may not be a suitable platform if designing for early stage dementia

It was found from early interviews with caregivers that residents at retirement homes, in most cases, suffer from middle to late stage dementia. At this stage, the PWD will most likely not be able to participate in a study. Retirement homes were therefore considered not suitable for interviews with people with dementia. Day center were approached instead, as these meeting places cater to people with early to middle stage dementia.

Guideline: If the design requires interviewing people with early to middle stage dementia, consider visiting alternatives to retirement homes, such as day centers.

Establishing contact with relatives requires extensive coordination and time

It was reasoned that relatives to PWDs could offer valuable insights about family life and everyday issues that arise in a non-care environment. However, plenty of time is required to find relatives that show interest and have sufficient time to participate. Support groups for relatives were considered an option. However, it was found that support groups arrange relatively few meetings. Also, telephone contact with these groups proved difficult as group members in most cases are volunteers. Extensive time expenditure would have to be assigned to contacting relatives individually, even if these individuals were members of a support group. Due to time constraints, the 'relative' stakeholder was not approached in this project. Relatives were therefore considered the most challenging stakeholders to involve in regard to coordination, planning and time.

Guideline: If interviewing relatives is vital to the project, acquiring participants may prove time consuming. Support groups may provide a starting point for further exploration, but make sure there is enough time assigned for this endeavor.

Establishing contact with PWDs through day centers may require a pitch

At first, when early attempts were made to establish contact with PWDs through day centers, the study was scantily described as just “interviews”. Consequently, it was common for caregivers to express concerns and suspicion. However, day centers that were given a short description of the project, such as purpose, extent, ethical considerations etc., were generally willing to participate.

Guideline: Make sure the purpose of the project is explained when booking PWDs for interviews, specifically if contact is established through caregivers. A brief pitch may be required.

6.1.2 Need identification

This factor was identified during early need identification.

Balancing needs and requirements of different stakeholders

In a UCD project it is important to filter out needs and requirements from different stakeholders, most important is that the users are put at the center of design (Williams, 2009). When designing for PWDs, this can be particularly hard since they are often unable to account for specific needs and desires. This study made use of caregivers in order to gain a better understanding of PWDs needs and requirements, as recommended by Orpwood et al. (2004).

Guideline: Although PWDs are at the center of design, consult domain experts and caregivers for inspiration and guidance when identifying user needs and behaviors.

6.1.3 Communication barriers

From difficulties met during interviews with PWDs, a number of challenges have been identified.

Dementia symptoms can obstruct interviewees capacity to answer accurately

Several symptoms associated with dementia and Alzheimer’s disease can make it hard for PWDs to truthfully answer interview question. Symptoms may manifest as suspiciousness, becoming increasingly withdrawn and mood changes (Alzheimer's Association, 2016b). This has been supported by findings in this study where day center personnel after interviews corrected details in participating PWDs answers. In this example one participant admitted to using a GPS tracker in a certain manner while day center personnel later corrected how and why the individual was fitted with a GPS tracker in their jacket.

Guideline: Make use of caregivers and other professionals during and after interviews for complementary information and verification of interview materials.

Self-denial can make it hard to assess user needs and behaviors

Self-denial is for many a part of having dementia. Talking to PWDs about dementia and symptoms thereof can therefore be quite difficult. Attempting to talk about their needs as persons with dementia can often be met with confusion, self-denial and irritation. When asked about what challenges they met as a consequence of their disease an interview participant was confused by the question and did not understand what was meant by the question.

Guideline: Avoid labeling terms that may induce shame or self-denial (e.g. words like “dementia” should be rephrased into “memory difficulties”). Accommodate for self-denial.

Insufficient experience with technology may lead to confusion

As technology experience was generally low among PWDs participating in this study, this presented a challenge both in terms of phrasing and how to ask questions when talking about technology. Researchers may be tempted to use technical language such as “user interface”, “drop down menu” etc. When these terms were accidentally used, it seemed to cause confusion.

Guideline: Simplify language and find mediating terms (e.g “interface” can be reworded into “what you see on the computer screen”).

Interview flow can be challenging to maintain

PWDs sometimes gave answers in a manner unrelated to the questions, and would become confused when attempts were made at remedying the misunderstanding. This makes probing difficult as the interview topic then quickly starts revolving around something completely different than what was intended. When interviews get derailed in this manner it may be hard to maintain an interview protocol and flow in the conversation.

Guideline: Clarify misunderstandings sooner rather than later, be precise and pedagogical in the line of questioning.

Longer interviews may result in fatigue

Time is a factor when interviewing PWDs as they run a higher risk of becoming anxious or growing tired from lengthy interviews. During some interviews this manifested as tix such as shaking hands and confusion (one interviewee asked repeatedly where the design team was from). Effects such as fatigue or nervousness may linger after interviews. Day center personnel reported one such case following an interview, where the participant was described as being agitated and roused.

Guideline: During interviews it is important to be observant for signs of discomfort. Close down the interview should such signs appear. Interviews should not last longer than necessary.

6.1.4 Domain expert predisposition

These factors were identified during expert evaluation.

Cognitive walkthroughs are not self-explanatory

In any usability test it is important to remember to provide participants with information about what they are expected to do. During cognitive walkthroughs this is especially important since the participants are expected to roleplay as the end user, not to provide their own personal opinions.

Guideline: Make sure participant's roles are understood prior to a cognitive walkthrough and that expected output is sufficiently explained

Domain experts are not designers

While domain experts offer insights into what PWDs may be able to handle in a GUI they are not designers. For example suggestions of incorporating non-essential functions such as a music player because it would be neat is not necessarily a good idea when designing a tool supposed to do one single thing for PWDs.

Guideline: Be sure to weigh domain experts evaluative results against other factors such as existing design guidelines and other domain expert opinions.

Past experiences can affect domain expert opinions

Some of the domain experts mainly had knowledge about PWDs in the middle to later stages of dementia. It was evident during evaluation that these experts had a hard time evaluating the prototype without thinking of difficulties that would occur during later stages of dementia. Domain experts 1 and 2 for example used to interact with PWDs who were in the later stages of dementia and often referred to them as not being able to do something in the application. In these situations it was helpful to steer the evaluation with the help of the personas (e.g. "Imagine Astrid doing this, would she know what to do in the situation?").

Guideline: Use mediating tools such as personas help create a common ground to support discussions about usability. Using personas help navigate conversation toward the concerned user group instead of other close related groups.

6.1.5 Validity of research data

These factors regard the validity of data gathered from interviews with PWDs.

Validity of data should be taken into account when constructing personas depicting PWDs

Personas are fictional characters representing real users. The purpose of personas is to create archetypical users describing attitudes and needs towards a specific product. Furthermore, personas are based on user research data (Rogers et al., 2011), preferably from interviews (Cooper et al., 2014). During interviews in this project it became evident that PWDs are users that require special considerations as dementia symptoms affects how the interviewees respond to questions. Data validity may be affected. Therefore, depending on the severity of the disease, it can be difficult to create reliable personas.

Guideline: Knowing what dementia symptoms the interviewee displays can help in rephrasing questions or what exemplifications to use. Consult caregivers about validity of answers.

6.1.6 Interface design clarity

This section accounts for factors in regards to interface design as identified from cognitive walkthroughs with experts.

Interface text can be interpreted literally by persons with dementia

Confusion is a common symptom for dementia, particularly during middle and late stages (Alzheimer's Association, 2016b; Prince & Jackson, 2009). Hence, interface text, such as object labels and instructions, require thorough consideration. It was pointed out during expert evaluations that labels such as “Go back” may be interpreted literally. Instead of being perceived as an interface feature, the label might be interpreted as an incitement for how to behave in the physical world (e.g. “go back to the kitchen”). A more elaborate label like “back to photo album” might be more appropriate.

Guideline: Use written instructions and labels with caution as they may be interpreted literally. Avoid ambiguous phrasing and be precise.

Icons may be misinterpreted

The prototype in this project made use of smiley faces as idioms for emotions and feelings associated with photographs. One domain expert cautioned that smiley faces could be misinterpreted if taken out of context. For example, *Emotion view* (figure 30) uses smiley faces as a means to express emotions in relation to a recently taken photograph.

In the *Home view* overview, the same smiley is then attached to the photograph's thumbnail. However, PWDs might not remember having connotated photos with an emotion in the past.

According to domain experts it is possible that they would experience a frowning smiley as a warning against what the photo represents (e.g. a warning not to take their medicine or a warning not to go on walks at a certain location).

Guideline: Use caution when designing icons (such as smiley faces), although used as a means of remembering something in the past it can be understood as a warning in the present. Consider using explanatory text labels.

Finding the right balance between explanatory instructions and less text is challenging

As discussed in previous paragraphs, explanatory text is sometimes needed to avoid confusion. However, it was found during interviews with PWDs that less cluttered interfaces are preferred. Finding the right balance between written instructions and the risk of cluttering the interface was challenging. Cognitive walkthroughs with domain experts provided helpful guidance in this regard.

Guideline: Assume that misunderstandings will occur and provide as elaborated instructions as possible thereafter. Evaluate this aspect of the design with domain experts.

Interface design require special consideration

As the design of the prototype progressed and evaluations were held, feedback regarding the interface design suggested that the guidelines for interface design provided by Pang and Kwong (2015) were well suited when doing interface design for people with dementia.

Guideline: When designing a graphical user interface, apply existing interface guidelines for people with dementia.

Summary of factors

1. Access to participants
<ul style="list-style-type: none"> A. <i>Retirement homes may not be a suitable platform if designing for early stage dementia</i> B. <i>Establishing contact with relatives requires extensive coordination and time</i>
2. Need identification
<ul style="list-style-type: none"> A. <i>Balancing needs and requirements of different stakeholders</i>
3. Communication barriers
<ul style="list-style-type: none"> A. <i>Dementia symptoms can obstruct interviewees capacity to answer accurately</i> B. <i>Self-denial can make it hard to assess user needs and behaviors</i> C. <i>Insufficient experience with technology may lead to confusion</i> D. <i>Interview flow can be challenging to maintain</i> E. <i>Longer interviews may result in fatigue</i>
4. Domain expert predisposition
<ul style="list-style-type: none"> A. <i>Cognitive walkthroughs are not self-explanatory</i> B. <i>Domain experts are not designers</i> C. <i>Past experiences can affect domain expert opinions</i>
5. Validity of research data
<ul style="list-style-type: none"> A. <i>Validity of data should be taken into account when constructing personas depicting PWDs</i>
6. Interface design clarity
<ul style="list-style-type: none"> A. <i>Interface text can be interpreted literally by persons with dementia</i> B. <i>Icons may be misinterpreted</i> C. <i>Finding the right balance between explanatory instructions and less text is challenging</i> D. <i>Interface design require special consideration</i>

Table 8. Summary of factors

6.2 Digital prototype

Apart from a set of factors, a digital prototype was developed (table 9). The prototype was conformed to design recommendations by Pang and Kwong (2015), a theoretical framework that proved valid in this study. The prototype abides the following guidelines from Pang and Kwong: *reduce complexity, tasks should be clearly structured, information consistency, support the user and interface optimization.* The prototype was more aligned with the above guidelines after expert evaluations, further validating the findings from the previous study by Pang and Kwong (2015). However, more evaluation is encouraged for further validation of the prototype as well as usability testing with PWDs.

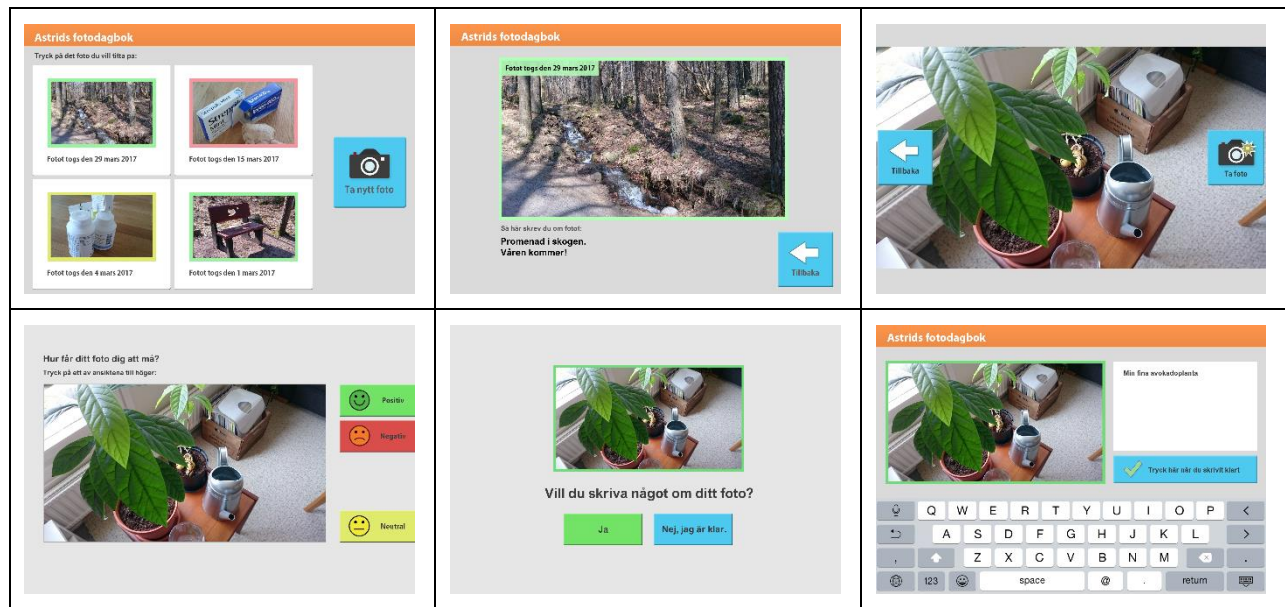


Table 9. The digital prototype

The prototype was positively received by Semcon, the project initiator. Albeit rudimentary in its current form, the prototype will provide a starting point for further development by the company.

7. DISCUSSION

The discussion chapter is divided into a discussion of the design process and a discussion of the results of this study. In the discussion of the design process choice of methods, interpretations of findings and alternate approaches will be discussed. The result discussion will bring up factors and guidelines found in this study and their applicability in other design projects.

7.1 Process discussion

A user centered design (UCD) approach was applied during the course of this project. UCD was chosen because it puts the user at the center of the design focus. This means engaging the end users in different ways through the whole design process. Although the UCD approach in this study helped creating an understanding of persons with dementia, it required certain considerations. As the design was intended to be used by persons with dementia when fully implemented, PWDs were considered the end users. However, focusing entirely on end users in this case might not be the right approach. Interviews with PWDs provided information in regards to interface design, such as information display and interface complexity. Interviews with caregivers, on the other hand, provided starting points for the design, as well as functional requirements. It was through caregivers that requirements like camera functions, and preference towards tablets were obtained. In this regard, a UCD process when designing for PWDs needs to involve multiple sources of information to support UCD design choices.

Contact with the user group through interviews at day centers was good. The PWDs participating in the study volunteered to do so and were generally accommodating with few exceptions. A large part of the learnings in this study has been the practical experience of interviewing PWDs. In the first few interviews there was an uncertainty performance-wise that gradually let go as the design team got more familiarized with the PWDs. In the beginning of the project, it was thought that the participating PWDs in interviews would be more lucid. The contact persons at the different day centers were informed of the sought after interview participants. However, it cannot be disregarded that some participating PWDs were further gone in their dementia than anticipated. It may be beneficial (and indeed even required) to communicate with caregivers, relatives and PWDs in order to elicit user needs when designing for PWDs. As relatives were not accessible in the study, caregivers point of view got a lot of focus. Had relatives been involved in the study, the resulting design would probably look different. This is not to say that the core design is wrong, but certain features and functions would possibly look different if relatives had provided information of the daily activities of their still living at home relatives with dementia. As it was problematic from an ethical point of view to access this information directly, and as PWDs cannot readily confide it in detail, it could not be accessed.

Personas were used in the project as user models during the design phase and also as mediating tools for usability testing during the evaluation phase. A big part of the motivation to use personas was to keep the user's interests close to the design throughout the design process. During the design phase the personas were helpful as inspiration but required a larger time consumption to create than anticipated, mainly because of factors connected to interviews. Interface design guidelines for PWDs were used to create the interface, due to the interviewed PWDs having very little opinions about design. The personas helped this stage by providing estimations of functional variance in the tool as well as a concrete way of talking about

user's capacities. Looking at it this way, personas were a success, since it can be hard talking about design choices without risking self-referential design and elastic users (Cooper et al., 2014). In evaluation, the personas came alive likely thanks to domain experts previous knowledge about PWDs of different stages and could be better used by the domain experts as a reference for PWDs who could or could not perform certain tasks. It was suspected that the personas were more alive to the domain experts than to the design team because of the domain experts knowledge in the field. In this way, personas can be useful tools to help both designers and evaluators reach a common understanding of challenges and opportunities of a design.

Not being able to do usability evaluations with the intended user group at the early stages of design can be costly as well as harmful towards the design. The proposed design in this study is small, however, for larger designs this could become a problem.

Persons with dementia may not be suitable for user testing because of the nature of the disease. It may be necessary to perform usability tests with caregivers rather than with PWDs themselves. This approach could be good in order to assess acceptance of the tool developed as well as give a just approximation of the tool's usability. A possible drawback of this approach is that domain experts are not designers. Domain experts and day center personnel were throughout the study enthusiastic about the design idea and gave predominantly positive feedback. However, as experts lacked knowledge about design, some technical issues may have been overlooked. For example, how well the design will behave in an actual outdoor setting was not addressed.

The tool could also help individuals with cognitive functional variations that have a hard time expressing feelings about things, such as children not able to communicate their likes or dislikes of activities or foods.

7.2 Result discussion

The result of the study was a collection of guidelines for factors to consider when designing for PWDs as well as a prototype of how a photo diary tool could take form when designed for PWDs. Throughout the design process a large focus has been on the development of the prototype, through the various stages of development the final guidelines could be elicited. These guidelines are thought to be of help to designers new to the field. Circumstantial factors such as access or not to PWDs or relatives play a large role when it comes to how to structure a design process such as the one in this study. Other factors such as PWDs experience of computers and smartphones also affected the results in this study but may look different in other cases.

The prototype developed is thought to be used on a tablet. The choice stood between a computer based solution or a tablet solution. Since tablets offer an all-in-one solution (interface and camera) without involving external tools it was thought to be the better choice. A risk using a tablet is that it may be misplaced, as opposed to a stationary computer for example. The final version of the prototype stand untested by PWDs making it difficult to say whether it would receive positive response or not.

However, as shown in the related CIRCA project (Alm et al., 2007), pictures and photographs as conversational support are greatly appreciated by PWDs. There is considerable support for that in this study as well, mainly from interviews with day center personnel and caregivers. Multimedia can therefore offer several benefits as conversational support and as aid for reminiscence.

In terms of the applicability of theoretical frameworks, this study demonstrated the benefits of using existing guidelines. After adjustments had been made after the first expert evaluation, feedback was predominantly positive during the concluding cognitive walkthrough. This indicates that using experts as proxy users were beneficial when designing for PWDs, as advocated by Orpwood et al. (2004). Furthermore, the interface design was consequently more aligned with recommendations by Pang and Kwong (2015).

Pierce and Jackson (2009) conclude that dementia is a cognitive impairment that makes affected individuals dependent on external support and cognitive offloading. As with Clark and Chalmers' (1998) example of Otto using his notepad to extend his mind into the world so can the tool developed in this study help individuals extend their minds and recall memories better. The colored frames used in the prototype to denote what the experience was like can potentially help PWDs remember some qualities of the memory as well. For caregivers and relatives the colored frames offer an easily read hint of what to talk about and what to possibly avoid. The tool could work as an extension of the PWDs mind and aid them in communicating with others as well as help others communicate with them based on the photographs in the tool. As cognition is shared between individuals (Clark & Chalmers, 1998), for example between close relatives, these sources can also help make the most out of the tool. During evaluation participating domain experts remarked what a great tool it could be, even for PWDs not able to use it on their own as relatives with extensive knowledge of the PWD could help fill the photo diary with content. Since relatives know of PWDs likes and dislikes this could even be recommended when PWDs cannot themselves readily account for them.

The results of this study, can to some degree be generalized. The concept and prototype developed in this study may also be applicable on individuals with other cognitive impairments with similar or related symptoms. In cases where users are individuals who have a hard time expressing emotion or remembering day to day activities, unrelated to dementia, the prototype can arguably assist or provide inspiration. One such user group may be autistic children unable to express their emotions. More research is desired in this regard.

7.3 Future work

Future work within the problem domain explored would mean creating a fully implemented product for user testing. An implementation of approximately the size of the prototype should be cheap since the prototype is very minimal in its design. After having a functional product, acceptance and continued use will have to be studied in longitudinal studies, researching how and if PWDs find the tool rewarding for their own use, not only if the tool is good from a caregiver perspective. In such a study, caregivers familiar to the PWDs could act as evaluators in order to interpret user responses and avoid unnecessary discomfort for the participating PWDs.

Future iterations of the design could entail making it readable by caregivers or relatives connected to it. Allowing caregivers and relatives to view the PWDs photo albums does not necessarily have to mean more functionality in the tool used by the PWDs.

The social aspect of the prototype can be developed further so that the concept offers the possibility to share photographs with other users. The current prototype shows similarities with other picture based platforms such as Facebook and Instagram. Further development in this direction may be possible. However, the minimalistic, modern design of these existing platforms would likely be a confusing experience for a PWD. The interface would most likely have to be contained and clarified in accordance with existing design guidelines for PWDs. Also, ethical considerations would have to be considered. Information sharing services like Facebook may compromise personal information, a risk that may be particularly serious for people with dementia due to nature of the disease.

During the course of this study it was found that caregivers desire hints on what topics to discuss with PWDs and what topics to avoid. For this purpose, it makes sense to have a range of positive, neutral and negative attitude towards memories and topics. However, for PWDs own sake it may be a bad idea to keep the bad memories, or at the very least offer an option to filter these out in the start view. Having too many functions is against previous guidelines and recommendations (Pang & Kwong, 2015), filtering could be one such problematic function since elements and photos could be experienced as disappearing if the PWD filtering it away is not aware of 1) that there is such a thing as filtering or 2) that they have pressed it. Due to these factors, it may be relatives or caregivers performing such filtering. One could also consider the tool to automatically filter content to create clusters as in *Talking Mat* (Murphy et al. 2010), a previous work discussed earlier in this report. The filtering can be an especially valuable aspect the further the dementia progresses, in the early stages, there's still a desire to remain self sufficient to which dates play a large role. In the later stages, dates play a much smaller role and it can then be more valuable to filter on other factors.

A wizard mode was discussed on drawing board level for the prototype. Such a mode would show a first time user the purpose and workings of the design so they get an immediate understanding of it, without depending on someone else showing it to them.

Today, many elderly are still lacking the technological experience needed in order to comfortably wander between digital mediums. This means that any digital design introduced come with quite some learning before it can be used. An interesting question is how ICT-technology will be received by digital natives with dementia in the future.

8. CONCLUSION

This study has examined the problem area of designing for persons with dementia not yet living at a retirement home or other form of care facility. The research phase explored the problem domain through interviews with caregivers, persons with dementia and day center personnel. The research phase was concluded with the creation of personas intended to be used in the design and evaluation phase. During the design phase, existing guidelines were used to create a digital prototype. Cognitive walkthroughs of the prototype with domain experts confirmed existing design guidelines aptness when designing for people with dementia. After the design process was concluded, a series of factors and guidelines for designing for persons with dementia were created.

As Orpwood et al. (2004) argue, persons with dementia is a group that require special considerations when designing for. This conclusion is applicable to this project as well. This study followed a user centered design approach with three major stages: research, design and evaluation. A common denominator for these stages is that even though persons with dementia is the intended target group, it is not always advisable to involve them directly in the design process, as user centered design typically advocates. Rather, using caregivers as proxies proved more successful.

The research question for this study was:

What factors should be considered when designing an ICT-based tool for persons with dementia?

In total 16 factors were identified (6. Results), summarized as six category groups; *access to participants, need identification, communication barriers, domain expert predisposition, validity of research data and interface design clarity.*

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Appendix I – FORM OF CONSENT (In Swedish)

CHALMERS TEKNISKA HÖGSKOLA
INSTITUTIONEN FÖR TILLÄMPAD IT

Medgivande till användande av inspelning

Jag ger mitt samtycke till att den ljudinspelning jag medverkade i den _____ kan användas i följande syften (stryk över de alternativ du inte håller med om):

- Som data till uppsatser och andra vetenskapliga arbeten.
- Inspelning, transkription och anteckningar kan presenteras för studenter och handledare vid Chalmers Tekniska Högskola.
- Transkriberade utdrag ur inspelningen kan publiceras i vetenskapliga texter.

Jag har även fått information om följande påståenden:

- Jag har tagit del av information kring studien och är medveten om hur den kommer att gå till och den tid den tar i anspråk.
- Jag har fått tillfälle att ställa frågor angående studien innan den påbörjas.
- Jag deltar i denna studie frivilligt och har blivit informerad om syftet för mitt deltagande.
- Jag är medveten om att jag har rätt att när som helst under studien avbryta deltagandet utan att behöva förklara varför.

Ort:

Datum:

Namnsteckning:



Giltigt inom organisation:
Vardaga

Kapitel:
1 Från ett hem till ett annat

Avsnitt:

Dokumentansvarig:
Ansvarig kvalitetsutvecklare

Dokumenttyp:
Blankett

Version: R2

Dokumentnamn:
1.10 a Försättsblad till levnadsberättelse

Godkänt av:
Ansvarig affärsområdeschef

Godkänt datum:
2014-11-25

Levnadsberättelse – syfte och information till dig som kommer fylla i din eller din närståendes levnadsberättelse

I Vardagas äldreomsorg använder vi ett formulär som kallas Levnadsberättelse. Den person som flyttar till ett boende och eller närstående ombeds fylla i formuläret i samband med inflyttningen.

Levnadsberättelsen är en viktig del i arbetet för oss inom vård och omsorg. Den är extra betydelsefull för personer som har svårt att minnas sitt liv eller som inte kan göra sig förstådda. Levnadsberättelsen blir en viktig del i vår strävan att utforma vården individuellt med utgångspunkt från tidigare vanor och värderingar.

Genom levnadsberättelsen kan vi som medarbetare få lära känna personen som bor hos oss genom att vi får ta del av hans eller hennes liv. Vi får ökad kunskap om bland annat familjesituation, intressen, sorger och glädjeämnen under livet, vilket ger oss möjlighet att möta den som bor hos oss på ett personligt sätt och finna ut meningsfulla sysselsättningar.

Du skriver bara i det du själv vill och du måste inte fylla i allt på en gång utan kan fylla på mer efterhand.

Behöver du hjälp för att skriva eller vill ha mer information om Levnadsberättelsen hjälper din kontaktman gärna till.

Levnadsberättelsen behandlas med sekretess, medarbetare lyder under lagen om tystnadsplikt.

Tack för din hjälp.

Levnadsberättelse



Innehållsförteckning levnadsberättelse

Personuppgifter	3
Barndomstid	3
Ungdomstid	7
Vuxenliv	8
Familj, kärlek och vänskap	9
Pensionsålder.....	11
Personligt	11
Intressen.....	13
Vanor och önskemål.....	14

Levnadsberättelse

Personuppgifter

Namn	Personnummer
Civilstånd <input type="checkbox"/> Är gift <input type="checkbox"/> Har varit gift <input type="checkbox"/> Sambo	
Eventuellt tidigare efternamn	
Smeknamn	
Vill nu bli tilltalad	
Språk, dialekt	
Födelseort/land	
God man	
Kontaktperson	

Barndomstid

Mammas namn, eventuellt smeknamn
Hur var mamma

Mammas yrke

Vad gjorde ni tillsammans

Vad tyckte hon om

Berätta om hur personen minns sin mamma, relation etc.

Mamma dog år på grund av

Levnadsöden hos mamma som känns viktiga att minnas

Pappas namn, eventuellt smeknamn

Hur var pappa

Pappas yrke

Vad gjorde ni tillsammans

Vad tyckte han om

Berätta om hur personen minns sin pappa, relation etc.

Pappa dog år på grund av

Levnadsöden hos pappa som känns viktiga att minnas

Syskonens namn/ev. smeknamn	Födda ev. bortgång	Namn på syskonens make/maka

Plats i syskonskaran
Speciell kontakt med syskonen
Barndomshem och bostadsorter
Adress, landet/staden, hur det såg ut
Bra/mindre bra med barndomshemmet
Hur länge bodde personen där
Kan barndomshemmet besökas
Händelser från barndomen som ofta återkommer
Arbetsuppgifter i barndomshemmet, tyckte mindre om, tyckte mer om
Andra viktiga personer i uppväxten
Intressen som barn; lek, böcker, sport, musik

Ungdomstid

Skolan/skolor namn och orter och utbildningar
Namn på lärare som personen särskilt minns
Favoritämnen
Fritidsintressen i ungdomen
Konfirmation <input type="checkbox"/> Ja <input type="checkbox"/> Nej
Om ja, År
Ort
Kyrka
Präst

Vuxenliv

Körkort <input type="checkbox"/> Ja <input type="checkbox"/> Nej
Om ja, År
Vart
Bilmärke
Militärtjänst <input type="checkbox"/> Ja <input type="checkbox"/> Nej
Om ja, Vilket regemente
Vilken grad
Vilken försvarsgren
Arbetsplatser
Det första jobbet
Yrkesroller

Hur länge arbetade personen på varje plats

Hem i personens vuxna liv

Flyttat mycket/sällan

Sommarhus, var

Andra platser som har varit betydelsefulla

Familj, kärlek och vänskap

Är/har varit gift med

Hur träffades ni

Vilken kyrka/ort

Andra detaljer som känns viktiga

Änka/änkeman, år

Ev. bortgång på grund av		
Ev. skilsmässa, år		
Barns namn och ev. partner	Var de bor och arbetar med	Barnbarns namn
Särskilda händelser förknippade med barnen		
Särskilda händelser förknippade med barnbarnen		
Hur firas högtider, namnsdag/födelsedag/bröllopsdag etc.		

Pensionsålder

Blev pensionär år
Intressen som pensionär
Livsföring som pensionär
Morgonpigg/kvällstrött
Matvanor, favoritgodis, frukt etc.
Eventuella sjukdomar

Personligt

Händelser/upplevelser personen ofta återvänder till eller pratar om
Utmärkande personlighetsdrag, ex. sällskapsmänniska, velat vara själv

Är/var rädd för t.ex. åska, mörker, vara ensam, simma, tandläkare etc.

Glädjeämnen i livet

Några svåra sorger/motgångar i livet som personen vill dela med sig av

Hur har personen gjort för att hantera motgångar/stress

Livsåskådning

Höger/vänster hänt

Syn/hörsel problem

Personliga tillhörigheter som är värdefulla och viktiga

Föremål från barndom/vuxenlivet som finns i lägenheten

Intressen

Aktiv i någon förening. Namn och uppgift

Naturintresserad, växter och djur

Musiksmak, sjunger eller spelar själv

Favorit böcker/författare/facklitteratur

Dagstidning/veckotidning

Tv/radioprogram

Artister/skådespelare som uppskattas mycket

Annat viktigt ex. språk, politik, konst, kungligheter

Resor, finns fotografier

Språkkunskaper

Husdjur, namn vad de betytt

Sport, vad, vilken roll

Vanor och önskemål

Klädesvanor/plagg/kvalitet

Favoritfärg

Smink/smycken

Färga håret

Parfym

Rakning dam/herre

Mat/dryck

Favoriträtter/tycker mindre om

Kryddor

Sovvanor

Dusch-/bad-vanor

Något att tänka på vid personlig hygien, dusch, bad

Rök-/snus-/alkohol-vanor

Kroppslig smärta

Utevistelse

Uppgifter i hemmet

Hur har vardag och helg sett ut

Övrigt

Uppgifter till levnadsberättelsen lämade av:

Datum	Namn	Relation

Namn och datum för kompletteringar av levnadsberättelsen:

Datum	Namn	Relation

Samtycker till informationen vid behov lämnas till annan vårdgivare t ex inom kommunen.
Namn:

Appendix III. Interview guide day center personnel (In Swedish)

Om PWDs på dagcentrumet

Vilka är de gemensamma demenssymptomen?

Vilka behov är viktigt för dem att uttrycka?

Om teknik

Hur är den allmänna datorvanan hos era PWDs?

Arbetar ni något med datorer ihop med PWDs?

I sådana fall till vad och hur?

Vad föredrar ni? Tablet / stationär dator / mobil? Varför?

Hur anser ni att en bra programvara för PWDs bör vara utformad?

Levnadsberättelsen (life story)

Arbetar ni med levnadsberättelser? I sådana fall, hur?

Vilka brister finns hos den levnadsberättelse som görs idag?

Vad skulle kunna förbättras?

Arbetar ni något med dagböcker idag? Hur?

Appendix IV

COGNITIVE WALKTHROUGH WITH EXPERTS

Task: Open an entry and read about it View: Home view / Read old entry			
	Expert 1	Expert 2	Expert 3
Q1: Will the users know what to do to achieve the task?	Astrid will remember that the pictures are hers and she understand what to do. Conrad: No.	Yes, Astrid will know what to do based on experience. No, Conrad will have a hard time to do it if he's afraid of trying.	Yes, provided that the responsiveness of the tablet works.
Q2: Will the users see how to do it?	Yes, Astrid recognizes this type of interaction based on previous experience. No, Conrad will have a hard time understanding the idea of pressing on the screen.	Yes, Astrid will know how to it based on experience. No, Conrad will not know how to do it if he's afraid to experiment.	Yes
Q3: Will the users understand from feedback whether the action was correct or not?	Yes, Astrid can understand it based on previous knowledge No, Conrad is further gone in his dementia and not used to this type of tool.	Yes	Yes, when pressing something a reaction is expected.
Task: Go back to Home view View: Read old entry			
	Expert 1	Expert 2	Expert 3
Q1:	Yes, the text is clear. No, the button needs an explaining/attention icon.	Yes, both because the text is clear. No, Conrad needs some guidance to find the text as well as understanding 'album'	Yes, <i>tillbaka</i> is very clear No, need better labeling, 'album' is miss guiding
Q2:	Yes	Yes, Astrid know to press the button No, Conrad might be hesitant to press the button if he's not sure what it does	Yes
Q3:	Yes, it is clear that one is back in the starting view.	No, it's not guaranteed that Conrad will interpret 'your diary' as his diary. There need to be a more clear text. Yes, Astrid will understand that she is looking at her own diary	
Task: Launch the camera View: Home view			
	Expert 1	Expert 2	Expert 3
Q1:	Yes, because the camera and text tell the user that something can be done there	No, Conrad would have a hard time doing it, he has different references to what a camera means. Yes, Astrid will know what to do here.	Yes, both will understand what to do, it's a very clear icon and text
Q2:	Yes, the camera icon and the text tell the user that it can be interacted with	Yes, Conrad knows what to do and how to do it No, Conrad is afraid to try and needs to be convinced or get help to do it	Yes, both understand how
Q3:	Yes, they both understand that the camera started because of the moving image	Yes, Astrid will understand from experience as well as family support	Yes, it's like an ordinary camera with a seeker so it's a familiar look

Appendix IV

COGNITIVE WALKTHROUGH WITH EXPERTS

		Yes, Conrad understands, he's in an earlier stage and will still be able to understand what is happening with the picture	
Task: Take a picture View: Camera view			
	Expert 1	Expert 2	Expert 3
Q1:	Yes	No, there need to be a clearer text	Yes, <i>Ta bild</i> it's clear
Q2:	Yes, because it says take picture, which is clear. No, it needs an icon to further strengthen that it can do something.	Yes, the interaction is the same as everywhere else	Yes, they will see the button
Q3:	Yes, you can tell that the image froze when you clicked the button, that is easy to understand.		Yes, as the picture freeze they will understand
Task: Annotate perceived emotion associated with a photo View: Emotion view			
	Expert 1	Expert 2	Expert 3
Q1:	Yes, they would understand the instruction at the top of the page.	Yes, the text is clear enough to make them think in the right direction	No, Conrad will not know what to choose, it is too hard to interpret these figures in connection to distinct emotions Yes, Astrid will understand what to do since she's open with her disease and general well being
Q2:	Yes, they would have understood how based on the text. No, there should not be as many choices to press, there should be just two or three clearly distinct choices	Yes, the faces and symbols are clear	Yes, both understand that they should press a face
Q3:	Yes, based on the character you pressed it is evident that this is the same image	No, Conrad won't understand the transition from smiley faces to this step Yes, Astrid will get it	Yes
Task: Write something about a photo View: Write view / Keyboard view			
	Expert 1	Expert 2	Expert 3
Q1:	No Astrid, needs clearer indication to write here No, Conrad would not understand this, maybe if instructed but not otherwise	Yes, Astrid would definitely know what to do since she has texted before No, Conrad would be sceptical as to why he would write something	Yes, both will understand that they can write a comment
Q2:	No, there need to be a more clear instruction that one is supposed to write here.	Yes Astrid, would have seen something like this before and know how to behave with it No, Conrad, page need more	Yes, if they are used to texting or have any keyboard or typewriter experience

Appendix IV

COGNITIVE WALKTHROUGH WITH EXPERTS

		clear structure and guidance of user	
Q3:	Yes, since the letters pop up when you press a button.		Yes, since the text shows up on screen as you type they will both understand it
Task: Save the photo and return to Home view View: Write view / Keyboard view			
	Expert 1	Expert 2	Expert 3
Q1:	Yes, they will understand this task, it's clear	Yes, Astrid No, for Conrad a more clear instruction is needed	No, in connection to previous task this is unclear. More suitable label is needed
Q2:	Yes, the text is easy to understand No, it needs iconography to draw attention to it	Yes, Astrid Conrad, No, it needs to be more clear that this is a button	Yes, since it's like the previous types of interaction No, the button need more suitable label as well as some form of icon
Q3:	Yes, since the image popped up in the start view it's clear that it's there now.		Yes, but where did the text go?