Using a digital life story book application to enhance communication between people suffering from Alzheimer's and their caregivers

Developing a prototype for a personalised digital life story book

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Creative Technology Bachelor thesis

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Abstract

People suffering from Alzheimer's disease suffer from a host of symptoms, from memory loss to aimless wandering. One extremely harmful symptom is the increase in linguistic and communicative difficulties. This makes it harder for individuals suffering from Alzheimer's and their caregivers to effectively and positively communicate, resulting in a communication divide between the two. The aim of this project is to bridge this divide using a digital life story book application. Out of several pharmacological and nonpharmacological treatment types, one of the most effective methods to bridge the communication divide seems to be reminiscence therapy through a life story book. In order to allow for the inclusion of more reminiscence tools such as music, videos and stimulating activities in such a life story book, a digital application is preferred. A multitude of design requirements should be taken into account when designing such an application. Based on design guidelines and reminiscence tools which were developed during this project, several sketches were developed for a prototype for a digital life story book application. With these sketches an iterative design process was followed. This process resulted in a final prototype that is expected to effectively bridge the communication divide between people suffering from early stage Alzheimer's and their caregivers, together with comprehensive design guidelines and an extensive code of ethics. Both the design guidelines and the code of ethics can be used by others working on similar projects related to digital life story books. The developed prototype is expected to be successful in achieving its goal due to the freedom it offers users to customise the application whenever they want.

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Contents

1 Introduction

In 2022, over 55 million people worldwide were suffering from dementia. On a global level, it is one of the biggest causes of death and a major cause of dependency and disability rates among the elderly [1]. Alzheimer's is the most common type of dementia [2]. An Alzheimer's diagnosis has a massive impact on both people living with the condition and their caregivers [2]. Among many other difficulties, communication between those suffering from Alzheimer's and their caregivers often becomes a challenge. People suffering from Alzheimer's commonly lack the skill to adapt their communicative behaviour to different situations, burdening caregivers with subsequent communication breakdowns [3]. To help both the individuals suffering from Alzheimer's and their caregivers, bridging this communication divide is necessary. Using information and communication technologies (ICT) for this is becoming increasingly popular [4]. Especially in the fields of reminiscence therapy and informative social interventions with linguistic experts, ICT can be applied. Various types of memory trigger applications have been developed for reminiscence therapy over the years, but the 'life story book' appears to be most effective [4]. The life story book typically includes pictures and text organised based on chronology or theme. Most commonly, life story book are analog. Analog life story books make the inclusion of several other strong memory triggers impossible. Where analog life story books might include photographs, stories, memorabilia, quotes, cards, news items, blank pages for the future, and written accounts [5], digital storybooks can also include auditory materials and video clips. This allows for the incorporation of more memory triggers into a person's life story book [4]. The aim of this thesis is to develop a digital life story book application for people suffering from early stage Alzheimer's to bridge the communication divide between them and their caregivers. To achieve this, an answer will be sought to the following question: how could one develop a personalised digital life story book application to effectively bridge the communication divide between people suffering from early stage Alzheimer's and their caregivers? In order to answer this question, several aspects should be considered. The first constitutes an assessment of how a digital life story book application is designed in order for people suffering from early stage Alzheimer's and their caregivers to feel comfortable with using the application on a daily basis. To ensure that users experience positive results when using the application, it is also important to identify which functionalities are most effective. To ensure that the application has a positive impact on not only users but on society as a whole, the ethics of developing such an application should also be pondered. Based on all of this information, a prototype for a digital life story book application has been developed.

2 Background

2.1 Alzheimer's Disease

Alzheimer's disease is a type of the brain disorder dementia [6]. It is the result of harmful proteins and subsequent cell destruction, which leads to permanent brain damage [7]. Alzheimer's develops in stages, each with its own set of complications. The disease first destroys neural connections related to memory, including the hippocampus (see section 2.2). As the disease progresses language, reasoning and social behaviour are affected. As a result of this decline in brain function, individuals lose their ability to function independently. Eventually, Alzheimer's is fatal. In Alzheimer's Disease International's 2022 World Alzheimer Report, they define the disease as 'a condition that groups symptoms of impaired memory, thinking, behaviour and emotional control problems resulting in a loss of autonomy' [2]. Alzheimer's disease (AD) is the most common type of dementia, being responsible for up to 80% of all cases. Rupal and Schneider [8] describe dementia as a manifestation of various biological process which cause damage and/or loss to neurons and neural processes. In the case of Alzheimer's, the biological process responsible for damaging the brain is the disruption of brain cells and nerves by proteins that hamper with the transmission of brain messages (see section 2.2); especially transmitters responsible for memory storage are affected [2]. There is currently no treatment for Alzheimer's, but there are treatments available [9].

2.2 Memory retrieval and Alzheimer's

Memory

In his paper *What Memory Is*, Klein describes memory as 'the manner in which content is presented to awareness during an act of retrieval' [10]. Such an act of retrieval is in common language often referred to as remembering. According to Daniel Schacter the process of remembering according to psychologists was similar to retrieving files from a computer until around the early 1990s, as he explains in his book *Searching For Memory* [11]. However, that idea has been shifting to a more subjective interpretation of this process. A contemporary definition of memory as offered by Klein goes as follows: 'memory can be taken as organically-based activity [...] in which information made available (via perception of the external world or introspection) results in an alteration of the neural machinery (i.e. encoding). These neural signatures are laid down (typically subject to considerable and ongoing modification[...]) in various cortical substrates [...]' [10]. These neural alterations are often referred to as *engrams*, the fleeting and/or permanent changes that happen within the brain as a result of storing, encoding and/or retrieving an experience [11]. These engrams are not limited to a single location, but are a part of neural structure networks in the brain. Schacter calls this a 'constellation of networks in the brain that involve different neural structures, each of which plays a highly speciali[s]ed role within the system' [11]. He describes memory as consisting of various distinct and separable processes and systems, which depend on these networks. When considering memory, it is important to consider that engrams are not static. Schacter and Bostancıklıoğlu both argue that when an engram is reactivated as a result of the memory retrieval process, it becomes vulnerable to changes [11], [12]. This suggests that, in addition to not being restricted to a single area of the brain, memory is subject to the context of the situation in which it is retrieved. It is the question whether this is also the case for a brain in which the engrams resulting from memory retrieval are likely to be weak or incomplete and what this means for the original memory.

Engrams and early stage Alzheimer's

In the previous section Memory, engrams were described as a manifestation of memory in the brain. These engrams depend on billions of neurons in the brain and their communication [6], [11]. However, Alzheimer's causes disruptions in this communication. Characteristics of this disruption are high levels of harmful proteins known as beta-amyloid ($A\beta$) proteins - sub-type $A\beta$ 42 is considered especially harmful. These $A\beta$ proteins clump together into plaques. These then settle between neurons, where they disrupt the function of those cells. $A\beta$ proteins themselves naturally occur in the brain as a product formed from the breakdown of larger proteins [6]. Another characteristic of the brain of someone suffering

from Alzheimer's is the accumulation of tau proteins inside neurons, called neurofibrillary tangles. When a neuron is healthy, tau proteins support the transport of nutrients and molecules throughout the cell. In the case of Alzheimer's these proteins cease to bind with the neural cell and instead clump together, disrupting the transport system of the cell [6]. As a result of these developments in or between individual neurons, the connections between neural networks can break down [6]. Destruction of engrams becomes inevitable and memories start to fade. However, different types of memory are affected differently by this destruction. The different types are declarative, nondeclarative and working memory. Declarative memory can be split into two further types, semantic and episodic memory [13].

- Semantic memory
  Concerns the remembering of facts, both short and long term
- Episodic memory
  Also called autobiographical memory, it relates to the recollection of specific moments in someone's life; both short and long term
- Nondeclarative memory
  Procedural memories such as emotional response memory or muscle memory, which are unconscious memories
- Working memory
  Concerns the process of temporarily storing information whilst allowing manipulation of that information

The types of memory affected in early stage Alzheimer's are working memory and long-term declarative memory. This is also reflected in areas of the brain that are affected at this stage, namely the parietal lobe, parts of the prefrontal lobe and the hippocampus which are all vulnerable to the brain damage caused by symptoms of Alzheimer's [14].

Effects of Alzheimer's on the hippocampus

In the Memory section, it is stated that the encoding, storing and retrieving of memories depend on a massive neural network within the brain. According to Opitz, the area of the brain responsible for connecting all parts of this network into a traceable engram is the hippocampus [15]. Rao et al. confirm the importance of the hippocampus in cognitive function. The hippocampus plays a role in generating episodic memory, signals outlining memory formation depend on it, it plays a role in long-term object recognition, and it produces signals that transport new memory traces into other areas of the brain where those traces are consolidated [16]. During early learning stages, new engram cells are generated with input from the hippocampus as well. Next to this, the hippocampus is also associated with spatial memory and navigation [17] The hippocampus is located in the inner (medial) region of the temporal lobe and has several subdivisions as well as connections to other parts of the brain [16], [17]. The hippocampus is extremely susceptible to the neural cell loss and gliosis (the chemical reaction to brain damage [18]) associated with Alzheimer's. This advances the rate at which the hippocampus shrinks [16]. This susceptibility of the hippocampus to Alzheimer's-related brain damage is why memory loss is one of the first symptoms of Alzheimer's [16], [19].

2.3 Definition of caregiver and caregiver's burden

The definition of caregiver given by the Oxford Dictionary is as follows: 'a person, typically either a professional or close relative, who looks after a disabled or elderly person, invalid, etc.' [20]. These persons may sometimes experience a phenomenon known as 'caregivers' burden', which is often used to express how an individual taking on the role of caregiver for someone else could impact them negatively. The term burden, rather than stress for example, has become prevalent in scientific literature due to the fact that it is more easily quantifiable [21].

2.4 Communication divide

The term 'communication divide' refers to the breakdown in communication and subsequent schism in the relationship between someone suffering from Alzheimer's and their caregivers as a result of the disease. Besides decreased memory as described in section 2.2, linguistic and communicative skills are also affected by Alzheimer's symptoms [19]. In early stages of the disease, this means that people suffering from Alzheimer's struggle with word retrieval and more subtle conversational skills such as descriptive abilities. A decline in reading, writing and the comprehension of both only appears as the disease progresses [19]. The aforementioned issues present a threat to the relationships between those suffering from Alzheimer's and their caregivers. Frustration and miscommunication resulting from the decline in communicative abilities may lead to feelings of isolation, which in turn can lead to social withdrawal and depressive symptoms [19]. Communicative difficulties also appear to be correlated to other behavioural problems in people suffering from Alzheimer's, contributing to caregiver's burden (see section 2.3).

2.5 Definition of memory triggers

In the field of psychology, a trigger is a stimulus that causes a memory to resurface [22]. This stimulus can include any experience, sensory or otherwise, such as an image, a sound, a smell, a feeling, an emotion, or even a season or time of day [22]. Memory triggers are commonly used in a trauma context, but in the field of Alzheimer's treatment and reminiscence therapy they are referred to in a more positive light [23].

2.6 Reminiscence therapy and life story books

Where reminiscing used to be seen as a sign of senility, in the 1960s psychiatrist Robert Butler first proposed the idea that putting ones life in perspective by reminiscing could be therapeutic [24]–[26]. Woods et al. define reminiscence therapy as 'the discussion of past activities, events and experiences, with another person or group of people. This is often assisted by aids such as videos, pictures, archives and life story books [25]. In addition to the aforementioned photographs, pictures and videos, researchers also list music, art, activities, smell, and food to this list [27], [28]. This triggering of memories allows individuals suffering from Alzheimer's to socialise with their environment according to Quail et al. [28], to rediscover and express their individual personalities according to Gowans et al. and O'Leary & Barry [24], [27], as well as increasing their feelings of self-worth and confidence according to Yamaguchi et al. and O'Leary & Barry [24], [29]. Both those suffering from Alzheimer's and caregivers experienced a multitude of benefits as a result of reminiscence therapy. Gowans et al. found that the people suffering from Alzheimer's brought up new memories to caregivers, who also experienced less pressure to communicate [27]. Woods & Subramaniam, O'Leary & Barry, Quail et al. and Yamaguchi et al. added to this that depression rates were lower and quality of life and happiness levels had increased [4], [24], [28], [29]. Woods & Subramaniam also found that those suffering from Alzheimer's as well as their caregivers indicated a warmer relationship [4]. O'Leary & Barry focused on group reminiscence therapy, which allowed individuals suffering from Alzheimer's to develop friendships and social intimacy and to increase the amount of interpersonal communication they participated in [24]. One specific tool for reminiscence therapy is a life story book. According to Woods & Subramaniam, life story books are the most effective method of reminiscence therapy [4]. Dementia UK define a life story as 'a 'fact file' about the person with dementia, such as their background, interests, and who and what is important to them' [30]. On their website, Alzheimer's West Australia offers guidelines on how to create a life story book. They suggest using a physical photo album, scrapbook or digital photo album service to make an life story book [31]. Both Dementia UK and Alzheimer's WA recommend life story books as a tool for caregivers to improve communication and thus build closer relationships with the people they are caring for [30], [31]. These physical life story books, however, have big limitations in terms of what kinds of materials can be included. Several powerful memory triggers such as music are not compatible with an analog printed format. A digital life story book is a favourable solution for this, with people suffering from Alzheimer's preferring it over a physical life story book according [4]. Gowans et al. add to this that digital systems lead to more relaxed atmospheres and increased communication initiatives, as well as easier choices for those suffering from Alzheimer's in terms of directions of the communication with caregivers [27]. Reminiscence therapy is one of the more

popular non-pharmacological interventions in Alzheimer's care, and its intended outcomes are autobiographical memory and level of communication [25]. The use of life story books in general is further supported by the information in section 2.2. Memory consists of pathways in the brain, all converging in the hippocampus. In early stages, Alzheimer's starts destroying these pathways at this cerebral junction leading to memory loss. Triggering memories through an life story book can help people suffering from Alzheimer's to circumvent this breakdown of the hippocampus by offering external stimulation of memories. This facilitates increased contact between the person suffering from Alzheimer's and their social circle. However, as the disease progresses, so does the breakdown of the networks in which memory is stored - making this method of reminiscence less effective as time goes on.

2.7 Current treatments for Alzheimer's

Pharmacological treatment

Several treatments have been applied over the years to combat Alzheimer's symptoms. These can be divided into two categories, pharmacological treatments that use drugs to affect specific chemical processes in the body of a person suffering from Alzheimer's and nonpharmacological treatments that focus on social interventions such as therapies and workshops with individuals suffering from Alzheimer's and caregivers.

Kuca et al. name the four approved drugs for Alzheimer's treatment as acetylcholinerase inhibitors donezepil, rivastigmine, and galantamine and N-methyl-D-aspartate receptor antagonist memantine [32]. Scarpini et al. add to this that in addition to acetylcholinerase, rivastigmine also breaks down butyrulcholinerase which breaks down many different types of salt-based acids [7].

For donezepil, Kuca et al. found that improvements were seen in terms of language and general outcomes had also improved. With higher doses, better results were reported; it is suspected that this is due to impact on brain areas that are connected with language, memory and concentration [32]. Scarpini et al. note that positive impact on quality of life, however, could not be demonstrated [7].

Rivastigmine did not have a positive effect on every participant nor in earlier phases of Alzheimer's according to Kuca et al., but positive effects were more significant than with donezepil [32]. However, Scarpini et al. argue that rivastigmine also showed positive effects in early stage Alzheimer's after 26 weeks and suggest a small but significant increase in efficiency when compared to donezepil. Many side effects were noted in relation to the drug, but those appeared easily avoidable by maintaining a proper diet [7]. This is, however, an inconvenient condition for someone suffering from Alzheimer's who suffers from memory loss.

According to Kuca et al., galantamine did not seem effective in improving language impairments [32]. Scarpini et al. did find that cognitive benefits could be observed after 21-26 weeks and that deterioration was slowed, but no significant benefits over donezepil were found. Dosage levels also strongly impacted the effect, and a large number of side effects also make the drug less attractive than others [7].

Memantine, according to Kuca et al., has positive effects on communicative abilities in persons suffering from Alzheimer's, especially if they are already in a later stage [32]. Scarpini et al. observed the same after a 12-week period, but did not see any beneficial cognitive effects after a 24-36 week period. Combining the drug with donezepil did show these benefits, but no improvement in daily living situations could be ascertained [7]. Woodward also noted improvement in communication skills after participants had started taking memantine and noted higher effectiveness in a combined memantine and donezepil treatment than in donezepil monotreatment [19].

Nonpharmacological treatment

When it comes to nonpharmacological treatments, the possibilities seem endless. Gowans et al, Woods & Subramaniam, O'Leary & Barry, Quail et al. and Yamaguchi et al. discuss reminiscence therapy [4], [24], [27]–[29] and Beales et al., Kuca et al., Woods & Subramaniam, Quail et al. and Yamaguchi et al. consider communication training interventions for individuals suffering from Alzheimer's and caregivers with experts [4], [28], [29], [32]–[34]. More information on reminiscence therapy can be found in section 2.6.

The second main type of nonpharmacological treatment, social communication training interventions, also demonstrated many benefits. According to Beales et al., persons suffering from Alzheimer's and caregivers indicated an increased sense of hope after getting feedback on their communication strategies from a speech-language pathologist, as well as improved communication support, personalised communication strategies, increased motivation and a more valuable family support system [33]. The findings of Kuca et al. support this: they found that such social interventions had improved interaction of persons suffering from Alzheimer's, linguistic skill preservation, improved quality of life, and increased knowledge of caregivers as a result. They did note that even though caregiver's burden lowered in some cases, it increased in others due to caregivers taking on more responsibility during interactions [32]. Olthof-Nefkens et al. found that both those suffering from Alzheimer's and their caregivers had higher levels of patience after the social intervention, as well as caregivers indicating higher confidence levels and increased understanding. Both also indicated that they enjoyed their time together much more than before the interventions due to knowledge on how to keep interactions effective and positive. This also led to less communication breakdowns and misunderstandings [34].

Apart from these two main types of nonpharmacological treatment, educational sessions for caregivers and high-functioning individuals suffering from Alzheimer's were also considered massively successful in increasing understanding and decreasing stigmas surrounding Alzheimer's according to Kuca et al., Olthof-Nefkens et al., and Yamaguchi et al. [28], [32], [34]. Yamaguchi et al. also recommend practicing errorless learning, which does not focus on trial-and-error learning since people suffering from Alzheimer's suffering from memory loss typically do not recall previous errors [29].

Existing technical solutions

Various digital solutions already exist for life story books. However, the number of applications that has been developed beyond the scientific domain is surprisingly low. A search on the Apple app store in June of 2023 for the search term 'Alzheimer's' results in applications for reminders, stimulation activities and brain tests, but no applications aimed at reminiscence. 'Dementia' did not yield any more results either. The only application that could be found was found through the desktop version of the app store: Timeless I Care [35]. However, this application has seemingly not been updated since 2021 based on the activity of the Twitter account connected to the app [36]. When the researcher downloaded the app on a desktop computer, the application was not usable at all due to a pop-up asking for an update that could only be closed by forcefully quitting the program [37]. Therefore, there are no commercial digital life story books available on the app store at all.

Gowans et al. developed project CIRCA (Computer Interactive Reminiscence and Conversation Aid) in 2004, which employs several interactive media types such as audio fragments, videos, animations and virtual environments in order to prompt communication and stimulate long-term memory [27]. However, all of the content for this project came from a pre-existing database set by the developers of the project [27]. This hugely limits reminiscence on experiences that are specific to an individual's life. Also, rather than implementing the project on a ready-to-use device such as a laptop or tablet, they aimed to create an entirely new tool [27]. This leads to more depletion of natural resources than if an application were to be developed for pre-existing devices, which would thus increase its sustainability.

Woods and Subramaniam addressed both issues in their version of a digital life story book, the Life Story Movie. They allowed people suffering from Alzheimer's to direct their own movie with contents from their own life and voice-overs from people important to them. These movies were then burnt onto DVDs, which could be played on a television screen by inserting them into a DVD or Blu-ray player. Contents on the DVD included images, videos, and music [4]. However, a big issue with this is the fact that televisions and DVD/Blu-ray players are often controlled by remotes with small buttons. Since motor skills are also affected by Alzheimer's [38], this is not very user friendly. An additional issue is that DVDs are quickly becoming obsolete [39] and less and less households have DVD players - in the Netherlands, the number of households with a DVD player decreased by more than 4 million in a period of 6 years [40]. The Life Story Movie also does not allow for updates. Once the movie has been finished and burnt onto a disk, it cannot easily be changed unless someone in the user's direct environment has experience with video editing software and has the equipment that can handle processing long video files.

A third digital solution is the 'Book of You', a product from a Welsh company with the same name. It is an online

application that can be used on a laptop or tablet where users can look at images and videos and listen to audio together. Users can also add their own contents continuously. Privacy concerns are addressed by protecting the contents with a password [41], [42]. The book, however, does not allow for interactions beyond pressing 'play' on videos. Several design requirements as identified in section 4.1 have also not been taken into account, such as giving auditory feedback when completing an action or providing user cues. The password protection might also make it harder for people suffering from Alzheimer's to use the book without assistance from their caregiver, because they might not remember the password needed to access the contents.

Another digital solution that has been developed is the application myBook developed by Abu Hashim et al. myBook provides users with photographs, games and reminders for a user's daily routine. The application was developed for smartphones [43]. As was the case for Book of You, design requirements laid out in section 4.1 have not been taken into consideration in this application. When designing for people suffering from Alzheimer's, bigger screens are desired and smartphone screens are often quite small which means that fine motor skills are needed to control them. Additionally, the use of colours is not in line with common practice. The amount of reminiscence content is also limited, because only photographs are presented to the user.

Emobook, developed by Catala et al., does allow for personalisation and for the inclusion of video and music. It is also in line with most design requirements as described in section 4.1, making this a very viable potential solution [44]. However, there are still some things that could be improved. According to Statista, in the second quarter of 2022 Apple tablets held nearly 50% of the global market share [45]. The Emobook has been developed for Android devices, alienating a large amount of potential users. In addition to this, the risk of a user suffering from Alzheimer's accidentally adjusting or changing a reminiscence page is quite large. There are no safeguards in place to ensure conscious intent. Several symbols are also missing accompanying text, making the application less intuitive for users - elderly people who are not suffering from Alzheimer's may also want access to the application in their role of caregiver, and for them the use of a tablet application might also not come very easily.

In the prototype for the life story book application that will be developed for this project, an attempt is made to address all of these concerns.

3 Methodology

3.1 Ideation

In the ideation phase, relevant information is gathered and ideas are generated. A fine-tuned project idea and problem requirements should be the output [46].

Design requirements

The papers used for the design considerations of a digital life story book for people suffering from Alzheimer's were provided by Anis Hasliza Abu Hashim, the supervisor of this thesis. These papers are those written by Ancient & Good, Ghorbel et al, Lazar et al., Pang & Kwong, and Williams et al [47]–[51]. In addition to design considerations identified in these papers, an interview session was also held with a clinical psychologist expert to identify necessary functions of a digital life story book and to create a priority list for a minimal viable product. A transcript of this interview can be found in Appendix 11.7. The findings from both the papers and the interview were incorporated into design guidelines, which can be found in section 4.1. In section 3.1, the application of the guidelines to the prototype development is elaborated upon.

Reminiscence tools

In order to define memory triggers that should be incorporated in the life story book application, a search was conducted in Google Scholar using the search command *positive "memory triggers" alzheimer*. No papers were found that held a comprehensive overview of different triggers and their effectiveness. The papers that were used to identify memory triggers are written by Pöllännen & Hirsimäki, Barban et al., Cosley et al., Pringle & Somerville, and Subramaniam & Woods [52]–[56]. Some information on memory triggers was also found in the book *Searching for Memory* by Daniel Schacter [11]. In addition to memory trigger identification through literature, in an interview with a clinical psychologist expert they were asked which memory triggers they considered to be effective. The transcript of this interview can be found in Appendix 11.7. Based on the aforementioned papers and the expert interview, a final prioritised overview of memory triggers to be incorporated in the application was created.

Sketches

A number of digital sketches was made taking into account the design guidelines found in section 4.1, as well as the applicable reminiscence tools found in section 4.2. The sketches were made in Microsoft OneNote using an iPad and Apple pencil in OneNote's dark mode setting. The decision was made to develop the sketches and all subsequent prototypes in Dutch, because the expected prototype testing participants (see section 3.4) were native Dutch-speakers.

3.2 Specification

In the specification phase, the design space is explored and a short feedback loop takes place [46].

Use case scenarios

For this study, two personas and two use case scenarios were developed based on the results of the ideation phase. The personas were based on the target demographic for the digital life story book application, namely people suffering from early stage Alzheimer's and their caregivers. The use case scenarios were based on two aspects of the project aim, individual and collaborative use.

First prototype

The sketches from the ideation phase were then used to develop a first prototype in digital development tool Figma. Figma is a well-established digital prototyping application used for building products on a virtual canvas [57]. The first prototype can be found in section 5.2.

Expert interview

In order to validate the results from the ideation phase and briefly evaluate the first prototype, a semi-structured interview of 45 minutes was set up with a clinical psychologist expert and carried out over Microsoft Teams. The transcript of this interview can be found in Appendix 11.7. The outcomes of this interview were used to develop the second prototype in the realisation phase. The information sheet and consent form for this interview can be found in Appendices 11.3 and 11.4.

3.3 Realisation

During the realisation phase, the components and their integration are the focal point - so improving and elaborating on the results from the specification phase [46].

Based on the expert interview, this first prototype was later abandoned and replaced by a second prototype which was eventually developed into the final prototype (see section 7.2).

3.4 Evaluation

During the evaluation phase, functional testing plays a role. The most important thing is evaluating whether or not requirements identified in the ideation phase are met [46].

Application testing

Since the main aim of developing a digital life story book application for this thesis is the bridging of the communication divide between the caregiver and the person suffering from Alzheimer's, prototype testing sessions were designed to take place in dyads of someone suffering from Alzheimer's and their caregiver. As stated by Olthof-Nefkens et al., Quail et al., and Yamaguchi et al. [28], [29], [34], the recognition of the individual behind the person suffering from Alzheimer's is very important for treatment. Therefore, the decision was made to conduct user tests of the prototype with low fidelity paper prototypes. This way, dyads could add the functionalities they value the most as well as give suggestions for improvement of the interface design of the application. Besides this, beta-testing brings technical risks leading to errors. Since people suffering from Alzheimer's experience a lot of difficulty in recovering from errors, high fidelity prototyping is not preferred for the demographic [49]. In a 45-minute testing session, dyads were presented with a big sheet of paper with post-its of all interface functions and a separate set of post-its with treatment functionalities, as well as empty post-its to incorporate suggestions given by dyads before and during the time at which the prototype is presented to them. The original setup of the low fidelity prototype can be found in Appendix 11.9, in all Subfigures b of Figures 13 to 17. Participants could then add their own functionalities to an assigned space on the big sheet, but also move around or remove interface functions to make using the application easier. Before the prototype was presented, each dyad was asked questions about their needs for a digital life story book application. Then, during the testing of the prototype, they were asked more specific questions based on their previous answers and their interactions with the prototype. Anonymised and translated transcripts of the sessions can be found in Appendix 11.8. Three dyads agreed to participate in the user testing sessions. The names of these people were changed, their pseudonyms can be found in section 7.1. All sessions were carried out in the participants' homes in the period between the 9th and 19th of June 2023. The information sheet and consent form that participants received can be found in Appendices 11.5 and 11.6. It should be noted that the information brochure is in Dutch, because the participants in the testing sessions were native Dutch speakers.

Participant selection

The goal was to find three dyads consisting of one person suffering from early-stage Alzheimer's and their caregiver, since Moran writes that testing with five to ten participants is desired [58]. Since the testing sessions had to be carried out in The Netherlands due to travel limitations of the researcher, all participants were expected to be native speakers of the Dutch language. Three dyads constitute of six people but also do not amount to too much processing time for the testing sessions, so this amount was considered ideal. Several organisations working with people suffering from Alzheimer's were contacted if they knew people who would want to participate in the testing sessions. However, due to time constraints they could not give a timely response so the decision was made to plan testing sessions with proxy users. These proxy users were an elderly person over the age of sixty who did not specifically have an Alzheimer's diagnosis, together with a caregiver or family member. These people were found through the researcher's personal network.

Developing the final prototype

Based on the input from the three prototype testing sessions, the final changes were made to the second prototype as specified in section 6.1. The prototype was developed with a wizard of Oz method in mind, since not all required functionalities could be implemented using Figma. Using the product designed in Figma and Apple's screen recording software, a video of the prototype was made.

3.5 Ethical considerations

The consideration of ethics was also very important to this project. People suffering from Alzheimer's are a vulnerable user group, so developing a code of ethics to adhere to throughout the project was very important. This code of ethics was based on the World Health Organisation code of conduct [59] and additional values that were considered important to ensure the well-being of testing participants and potential users, as well as taking responsibility for any potential effects this project or the development of a digital life story book application might have on the world.

Then, using the code of ethics, several techniques were applied to assess the ethical aspect of environmental sustainability and privacy. The techniques used were both outlined by Fleddermann in his book Engineering Ethics: creating a line drawing and a flow chart [60]. In the line drawing technique, a line is drawn with a worst-case scenario on one side and a best-case scenario on the other. Then, the ethical dilemma that is faced by engineers is placed on this line together with additional information, similar examples or solutions. Based on where similar examples and the issue at hand fall on the line, a determination can be made whether or not a solution should be considered acceptable [60], [61]. Fleddermann suggests flow charting for resolving ethical issues. This is especially useful, he states, in cases where several events should be considered in sequence or where a decision has various consequences. This technique involves creating a flow chart depicting aspects to take into consideration when making an ethical decision [60], [61].

Ethical approval was given by the ethics committee of the faculty of EEMCS for the expert interview and user testing sessions as described in sections 5.3 and 7.1, with the respective application numbers being 230151 and 230210. The information sheets and consent forms in Appendices 11.3 to 11.6 were attached to these applications.

4 Ideation

4.1 Design requirements

A large number of design considerations should be taken into account when creating a digital life story book application. For the sake of readability, all considerations have been divided across six categories. The first category concerns the look of the interface, the second the functions of the application, the third privacy and security, the fourth the contents of the application, the fifth the use of audio, and the sixth the desired hardware features. Guidelines were made based on the considerations, the full list and references can be found in Appendix 11.1.

The guidelines used for creating the final prototype are as follows:

Lay-out of the interface

- The design of the application should be consistent across all pages, so colour use, iconography and font should not vary
- Text and buttons should be as large as possible
- All imagery is accompanied by a textual description
- Bright colours should not be used and the contrast between text and background should be as large as possible, by putting dark text on a light background; putting light text on a dark background is allowed for page headers and footers, but should be avoided otherwise
- The colour palette should include no more than four main colours and no more than two different shades per main colour

Functionality

- Options for explanation should be easily accessible, but should be kept on a separate page if it contains more than three words of text
- The settings menu should not be easily accessible
- Accessing an activity should not require more than three clicks
- Feedback should be given when a button is pressed, through colour changes and auditory feedback
- Allow for customisation of font, colours and content
- The application should not require control motions more complicated than a scrolling or tapping motion

Privacy and security

- Caregivers should be able to access the application with consent from the user and after signing a non-disclosure agreement

Contents

- Pages should contain as little text as possible, with the exception of pages adjustable by the user
- Users should be able to add images, videos and audio files
- The amount of content that can be added should be unlimited, or unlimited insofar as the storage of the tablet device allows

Use of audio

- Users should be able to decide how they would like audio to be presented to them

Hardware requirements

- The application should be developed for a tablet

4.2 Reminiscence tools

A wide range in reminiscence tools can be employed in a digital life story book application. The full list can be found in Appendix 11.2, where each memory trigger is also connected to different parts of the brain. Schacter argues that the storing of memories is more effective, and retrieval thus easier, when a memory is connected to knowledge an individual already has [11]. Therefore, when selecting experiences to reminisce on, it is important to consider what knowledge an individual suffering from Alzheimer's can access at which stage. Schacter also says that when deciding on what materials to present to an individual to assist their reminiscence process, the feeling the material invokes is more important than accuracy [11].

Schacter describes a mnemonic concept, the loci method, in his book. The loci method means that one creates a mental image of a place such as their own house and stores memories in specific locations within that place, so that in order to retrieve them they simply visit that place in their minds [11]. Translating this method to the digital domain might help improve the daily life of individuals suffering from Alzheimer's, since it could help them to remember objects more effectively. Barban et al. state that those suffering from Alzheimer's are more likely to remember remote memories than more recent episodic memories, so stimulating or triggering memories with material preserved from previous life phases is preferred over presenting new materials to an individual [53]. Cosley et al. also operate based on this idea. They focus on reminiscing through two main principles, namely using memory-laden materials people have already created within their own social systems and actively reminding people to reminisce on the content [54].

Since memory retrieval depends on the interaction between various areas of the brain [11], [12], it is important to consider which parts of the brain have been affected in each individual person who wants to use the life story book application. Even though, as Bostancıklıoğlu states, 'the interaction among different engram cells [...] makes the memory stronger and more retrievable' [12], it also becomes more susceptible to damage in other parts of the brain. At the same time, multiple engram pathways might be able to retrieve the same memory [12], so circumventing damage in one area of the brain becomes possible - but even so, it is still important to know how that circumvention can be accessed. There is a lack of research available on the topic of identifying specific engrams in humans, making the realisation of this knowledge close to impossible.

A diagram showing the locations of the different areas of the brain and their functions can be found in Figure 1. As becomes evident from the list of potential memory triggers, a functioning hippocampus is of huge importance to effective reminiscence therapy. Therefore, as the hippocampus sustains more and more damage as a result of Alzheimer's, reminiscence therapy through a digital life story book application becomes less effective.

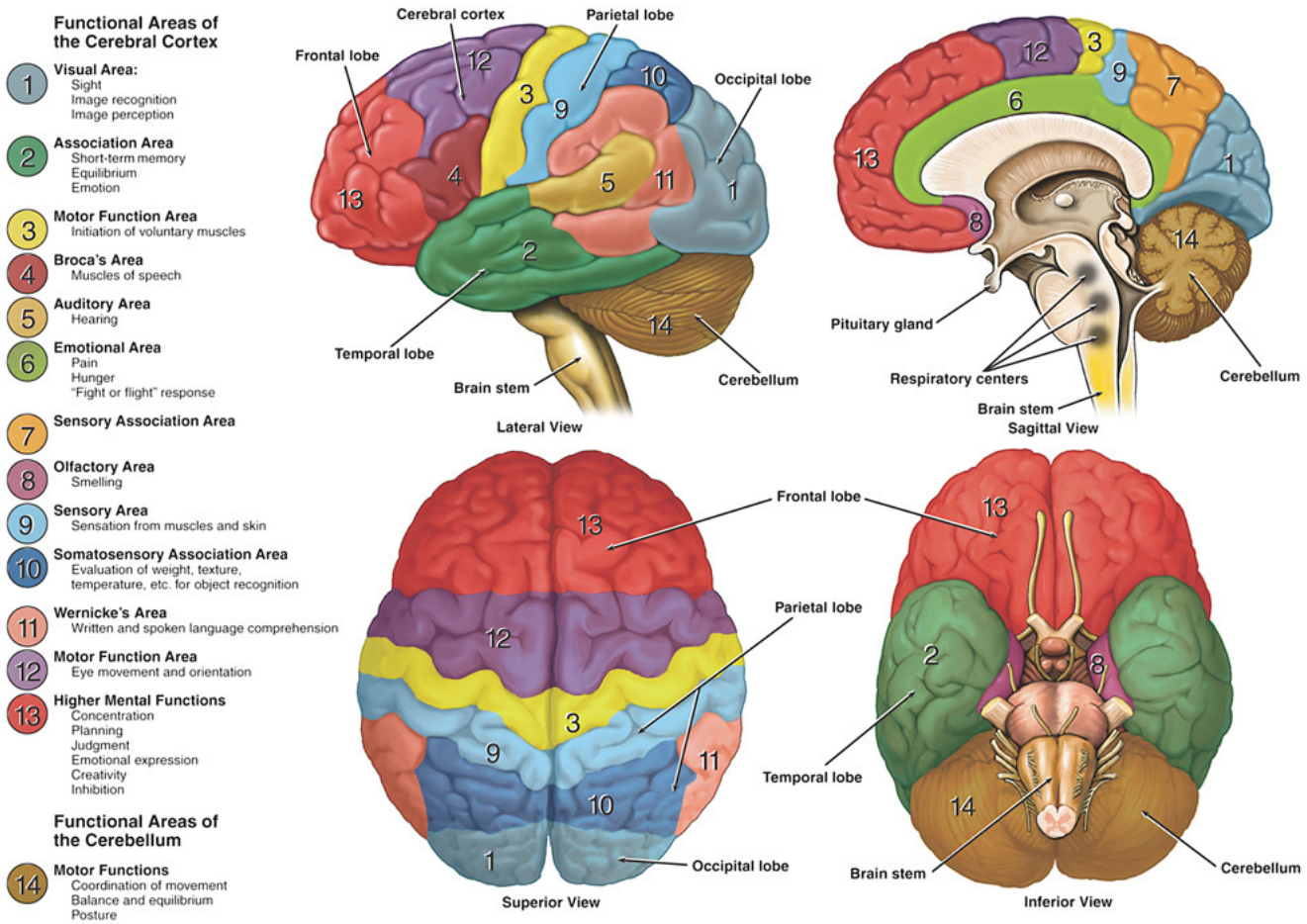


Figure 1: Diagrams of locations of the functional areas of the cerebral cortex in the human brain [62]

An initial selection of memory triggers was made based on whether they could work on a digital device or whether a digital device could offer tools to accommodate the trigger. The remaining list of triggers was then presented to a clinical psychologist expert, who indicated that all remaining functions were useful to add to a digital life story book application [63]. A complete transcript of this interview can be found in Appendix 11.7. Which triggers were removed from the priority list due to their incompatibility with the digital domain can also be found in Appendix 11.2.

The remaining functionalities are:

- Cultural phenomenons from an individual's past [54]
  Cultural phenomenons could be added to the application by adding pictures of newspaper articles, adding videos of news broadcasts, or adding content from other cultural phenomenons such as big concerts or the release of a big movie.
- Music that was relevant to a person's life [4], [27], [28], [54], [55]
  Audio files such as music can be added to the application.
- Other people relevant to a person's life [54]

Other people can be added to the application by adding pictures, videos and/or audio recordings from them. An accompanying piece of text could also be written for each person.

- Pictures and/or images containing content relevant to a person's life [4], [27], [54]–[56]
  Image files can be added to the application.
- Posing questions about an individual's life [28], [53]
  Within the prototype as it was developed (as seen in section 7.2, this functionality was not included in the application. However, users and caregivers can use the contents offered by the application as a starting point to ask these questions themselves.
- Practicing a relaxing, creative or sports activity an individual has practiced in the past [11], [28], [29]
  Within the prototype as it was developed (as seen in section 7.2, this functionality was not included in the application. However, users and caregivers can decide to practice such an activity based on a memory presented to them by the application.
- Videos containing content relevant to a person's life [27], [54]
  Video files can be added to the application.
- Words chosen by the individual suffering from Alzheimer's [4], [56]
  Individual words, short sentences or long stories can be added to the application.

In Appendix 11.2, stimulation activities are also mentioned. In favour of adhering to the guidelines of design requirements as outlined in section 4.1, these activities were not included in the prototype.

4.3 Sketches

Based on the guidelines in section 4.1, a number of sketches for the home screen were developed. The first set of sketches (see Figure 2) was developed with a focus on offering the user choices and on clarity. This is reflected in the large number of options available to the user on the home screen, and the fact that all icons are accompanied by text and a lot of space is left for big text. However, the large number of options offered to the user leads to an interface that is very crowded. It leaves no room for explanations and reduces how intuitive the application is. To combat these shortcomings a second set of sketches was developed (see Figure 3) that aimed at offering the user a more intuitive experience by using a format similar to paper books and by leaving space for explanations. However, this gave another problem: the space for text was very limited, not allowing for large text sizes. Most of them were calmer than the first set of sketches. Since the second set of sketches offered more advantages, one of the sketches from the second set was chosen as the homepage for the first prototype.

Figure 2: Sketches with a focus on offering choices and offering clarity

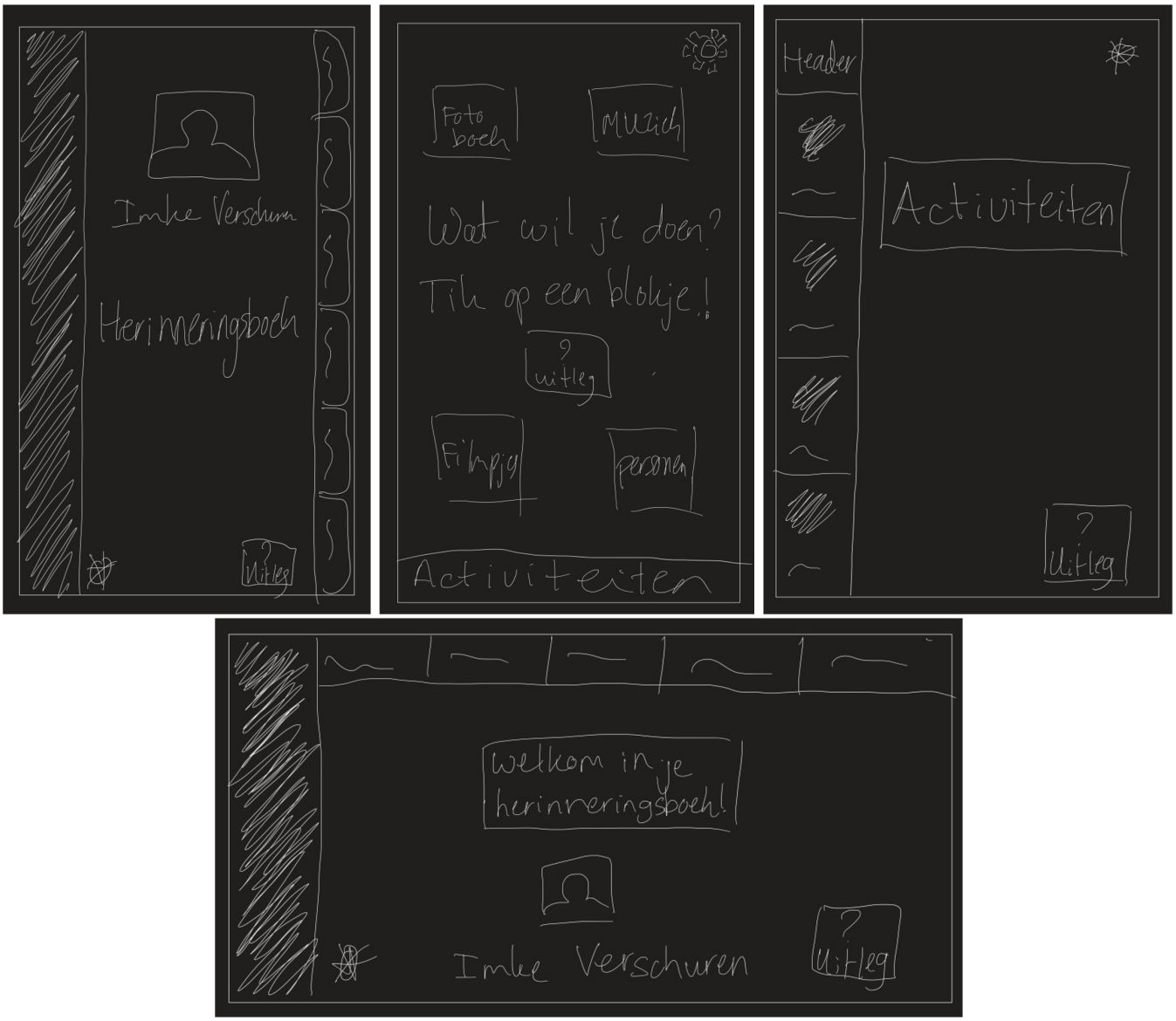


Figure 3: Sketches with a focus on offering intuition and explanations

5 Specification

5.1 Use case scenarios

Personas

Luke, 75 Luke was born in 1948. He grew up in the Dutch town of Landgraaf when mining still had a big part in the local economy. When he was 16 he graduated from high school and started work in a coalmine in Heerlen. When he had an accident at work he was sent to the hospital, where he met his wife whom he married in 1973. After his accident he moved to Malden and studied carpentry in Nijmegen, after which he became a carpenter which he did until he retired. In 1976 his daughter was born. Throughout his life he always enjoyed birdwatching, for which he often went on trips with his family. In March of 2022, he received a diagnosis for Alzheimer's disease.

Thalia, 48 Thalia was born in Malden in 1976. When she was 17 she moved to Nijmegen to study and became a primary school teacher in 1998. At work she met her husband and married him in 2000. They had a son in 2001. She visits her parents every other weekend with her family and once a year they all go on a camping trip, where she likes to watch birds with her father. After her father was diagnosed with Alzheimer's, she took up a lot of the caregiving duties.

Use case scenario 1 - Individual use

Luke is sitting on the couch while his wife is cleaning. He is bored, but his wife does not have time to entertain him. She suggests that he looks at his digital life story book to look at birdwatching trips and she gives him their shared tablet. He uses his fingerprint to unlock the tablet and opens the application, which is on the first page he sees when the tablet unlocks. He is excited to look at his old memories and quickly navigates to an overview of the contents in his digital life story book. He sees a memory of a birdwatching trip to Spain from 1995 and is curious, so he taps the screen to open the memory. He looks at the pictures and plays the sound of some of the birds they saw. As the memory resurfaces, he feels joy.

Use case scenario 2 - Collaborative use

Thalia and her son are visiting Luke. Thalia's son is telling a story about looking for a part-time job, and Luke feels eager to share his experiences. He begins to tell his grandson about his first job, but the memories are hazy and he is frustrated. Thalia remembers that her father's digital life story book application has a memory of his work in the coalmines and she asks Luke to open the tablet. Thalia quickly navigates to the overview of the contents, but cannot find the memory she wants quickly. She uses the search function to find the coalmine memory and hands the tablet to Luke. Luke sees some pictures from his time as a miner and begins to tell his story excitedly whilst showing the pictures to his grandson. He also plays a song they used to whistle when they were working. Luke's grandson and Luke talk excitedly about the mining industry of The Netherlands.

5.2 First prototype

The sketch in Figure 4 became the blueprint for the homepage of this prototype. The design for the other pages of the first prototype was then dictated by the basic elements of the homepage that had to be repeated on every page in order to avoid deep navigation menus. Only pages for the music interface, music settings and image settings were worked out. In Figure 5 the pages of this prototype can be found. The colour scheme was based on colours of old books, using colours of brown leather and off-white pages.

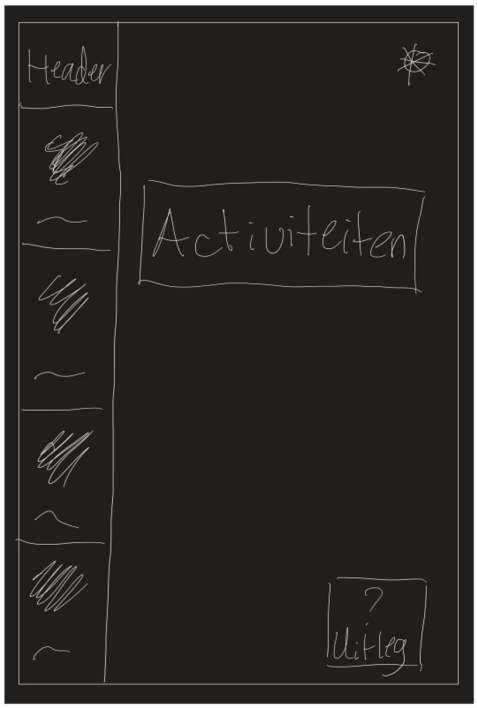
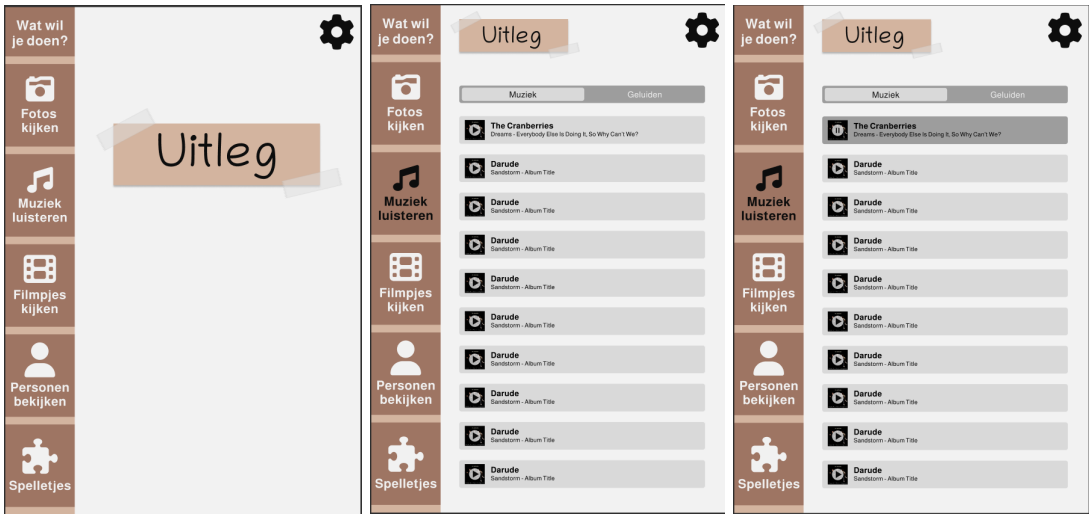
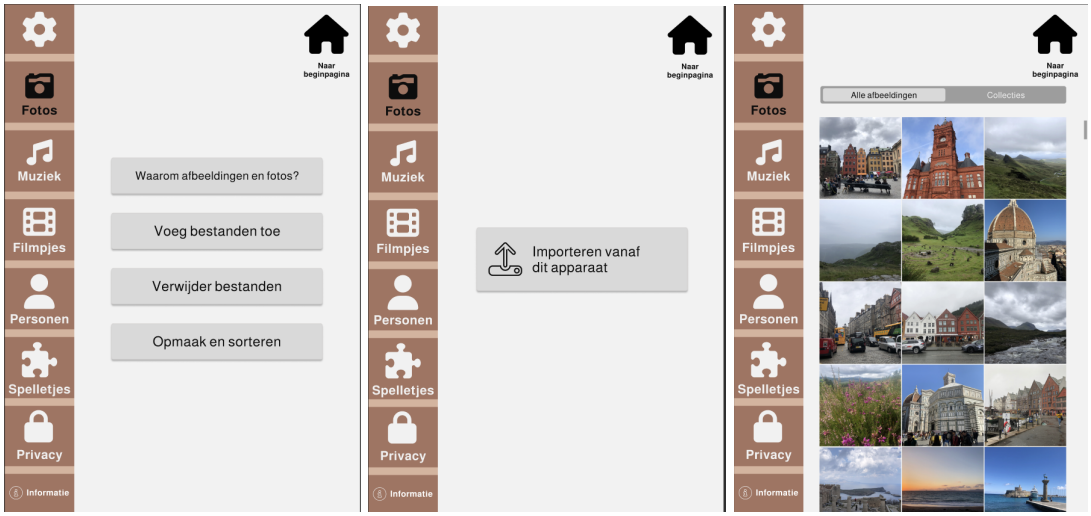


Figure 4: The sketch used as the basis for the homepage of the first prototype



(a) Homepage and music page, paused and playing



(b) Image settings start, upload and selection pages

(c) Music settings start and upload pages

Figure 5: First prototype

5.3 Interview with a clinical psychologist expert

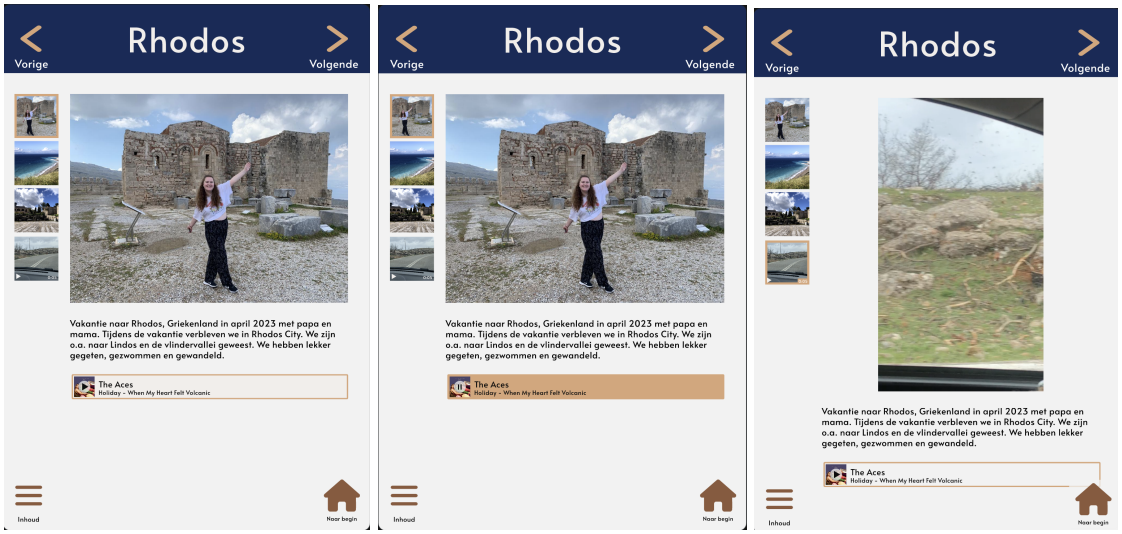
Based on the literature research and first prototype, an interview was held with a clinical psychologist expert to discover whether any design considerations or functionalities were missed or redundant and whether the set-up of the prototype was in line with the development of Alzheimer's in people suffering from it. The full interview can be found in Appendix 11.7. During the interview it became clear that the clinical psychologist expert advised an event-based application rather than a functionality-based one (functionality-based here means that the application is organised by separate reminiscence tools rather than separate events where different tools can be combined) [63]. Since the core idea of the application is to help people reminisce on events, the choice was made to develop a new prototype for an application that was organised more like a book where each memory was a separate chapter with a lot of different combined functionalities.

6 Realisation

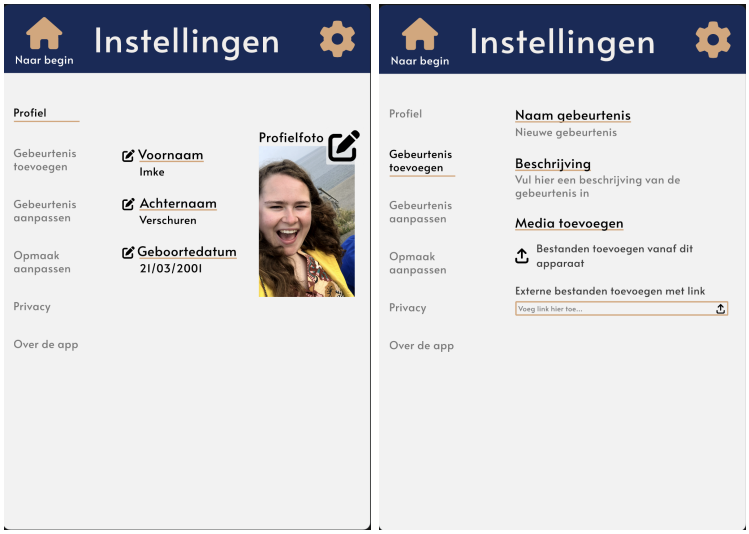
6.1 Development of the second prototype

For the second prototype, screenshots of the pages can be found in Figure 6. The colours for this prototype were also adjusted, the brown is still reminiscent of brown leather but the blue was added because it is a colour that is universally liked and is also associated with several positive traits such as trustworthiness, safety, calm and peacefulness [64]. In this prototype users are also able to structure the application in the way they want to, so it offers users much more of a choice which was very important according to the clinical psychologist expert [63]. Now, users can still decide to make the application functionality-based by creating events for every separate function if they want to but they can also organise the content based on events or even in the chronological order of their life. An additional advantage of this second version is that it adheres more to the design requirements as mentioned in section 4.1. There is space for larger buttons, less space is taken up by symbols and the amount of options is more intuitive because of the decreased amount of choices offered to the user.
In all stages the settings icon is not indicated with additional text. This was done on purpose, since the user should not be able to accidentally change the settings of the application in such a way that the application changes substantially and they are not able to remember why when they use the application at a later moment. This is also why the settings menu does not adhere to all design requirements set out in the framework, such as limiting the amount of text or the depth of the navigation hierarchy.

(a) Homepage and table of contents



(b) Example of an event page including pictures, video and music



(c) Settings pages for the user profile and adding a new event page

Figure 6: Second prototype

7 Evaluation

7.1 Prototype testing sessions

Demographics of participants in the prototype testing sessions

Dyad 1
Dyad 1 consists of a husband and wife, 'Mark' and 'Paula'. Mark is 84 years old (born in 1938) and Paula is 71 years old (born in 1952). Mark is currently undergoing memory assessment due to decreased memory to see whether or not he might receive a dementia diagnosis; Paula's memory has been affected by previous medical treatment but this does not hinder her in her daily life.

Dyad 2
Dyad 2 consists of a mother and daughter, 'Ginny' and 'Amanda'. Ginny is 79 years old (born in 1943) and Amanda is 56 years old (born in 1967). Neither indicated any issues with their memory prior to the testing session.

Dyad 3
Dyad 3 consists of a husband and wife, 'Chris' and 'Helen'. Chris is 75 years old (born in 1947) and Helen is 70 years old (born in 1953). Neither indicated any significant issues with their memory prior to the testing session, however, Chris indicated that he had suffered a cerebral infarction a number of years before.

Analysis of prototype testing sessions

Based on the testing session with dyad 1, the following changes should be made:

- An attempt should be made to increase the waiting time for the user cue to appear on the content page to sixty seconds. Figma only allows a delay of up to twenty seconds so this cannot implemented for this prototype.
- A search function should be added to the contents page
- An initial starting page with explanation and settings should be added
- The personal data from the profile and the corresponding settings should be added to the homepage
- The word 'settings' should be added to the settings symbol
- An 'add event' button should be added to the table of contents, and the settings wheel removed
- An extra user cue should be added to the play button on the event page
- A drop-down menu should be created for additional pictures on the event page
- The 'to start' button on the event page should be linked to the table of contents, and the table of contents button on the page removed
- The 'to start' button in the settings pages should be changed to a 'previous' button
- A security question should be added for the 'adjust event' page of the settings, which has been based on the system employed by the geriatric section of the TweeSteden hospital in Tilburg, where the same security question was asked to people wanting to leave

The interview from the user testing session with dyad 1 can be found in Appendix 11.8 and the images can be found in Appendix 11.9.

Based on the testing session with dyad 2, the following changes should either be made or have been verified:

- An 'add event' button should be added to the table of contents, and the settings wheel removed
- The symbol from the 'contents' button on the events page should be changed to a book
- The 'to start' button should be replaced with the 'contents' button on the events page, and the wording changed to 'table of contents'
- An extra user cue should be added to the play button on the event page
- A drop-down menu should be created for additional pictures on the event page
- A 'make invisible' option should be added to the 'adjust event' settings page

The interview from the user testing session with dyad 2 can be found in Appendix 11.8 and the images can be found in Appendix 11.9. Some suggestions from this session should not implemented because they contradicted the design guidelines as established in section 4.1.

Based on the testing session with dyad 3, the following changes should either be made or have been verified:

- The word 'settings' should be added to the settings symbol
- An extra user cue should be added to the play button on the event page
- A drop-down menu should be created for additional pictures on the event page
- An option should be provided for adding links to the event page that are not just media files

The interview from the user testing session with dyad 2 can be found in Appendix 11.8 and the images can be found in Appendix 11.9.

Both dyads 1 and 2 expected that the application could be useful and entertaining for a longer amount of time because the content can be personalised. This is further supported by Lazar et al. and Pang & Kwong, stating that users should be given the option to choose which functionalities and contents they would like to see [49], [50]. Dyad 3 expected the same for the application, but for a different reason. They expected that using the application would increase communication incentives between people suffering from Alzheimer's and their caregivers, thus making usage of the application more appealing.

Reaction to the prototype

All three dyads interacted with the low fidelity prototype in a surprising way. During the testing session, despite the prototype not including any pictures, all three dyads started reminiscing on events of their lives or their hobbies. Both Marc and Paula (dyad 1) and Chris and Helen (dyad 3) reminisced on their wedding while Ginny and Amanda (dyad 2) talked about art. Chris and Helen joked around a lot about their experiences together and Marc and Paula came up with example after example of events and things that they could add to the application.

7.2 Final prototype

This can be found by following this link, or scanning the QR code below:

Figure 7: QR code to access the video of the final prototype

Screenshots of the final prototype can be found in Figures 8 to 10.

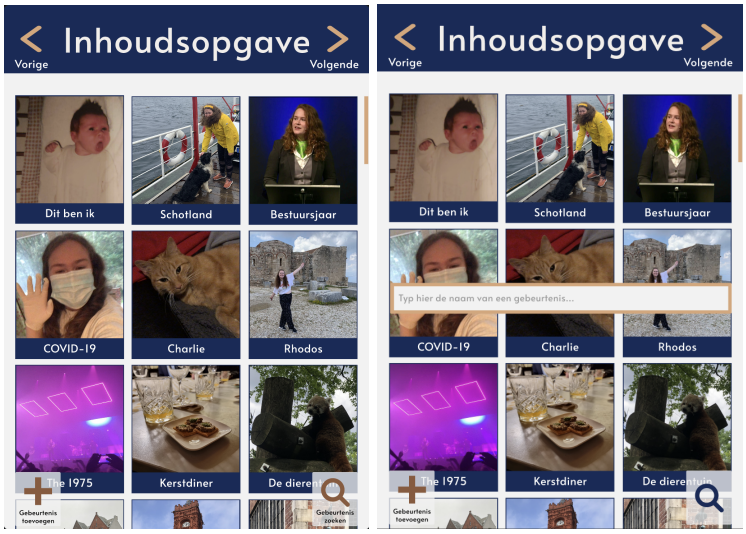
In Figure 8a, the two starting pages of the application are shown. The very first page is a page with a brief explanation of how the application works, which can also be read out loud. The full settings menu can also be accessed from here. The second page is the homepage showing personal information of the user suffering from early stage Alzheimer's showing their name, picture and date of birth. The edit button will go to the profile settings page.

In Figure 8b, the table of contents page is shown. In this screen users can select the event they want to see, add events or search for a specific event using the search button and subsequently appearing search bar.

In Figure 9 various event pages can be seen. Users can choose to expand the number of images they can choose from by clicking the arrow on the left. Users can play music, watch videos and look at images. They can navigate back to the table of contents by clicking the book icon.

In Figure 10 various settings pages can be seen. The choice to allow these pages not to adhere to several design guidelines was made consciously, since it should not be possible for users to delete or edit information without full intent and understanding. In Figure 10a the page for adding an event is shown. The settings page in Figure 10b shows the profile settings page, including the security question that needs to be answered before changes can be made. Lastly, Figure 10c shows how users can edit an existing event by toggling its visibility in the table of contents or by deleting an image.

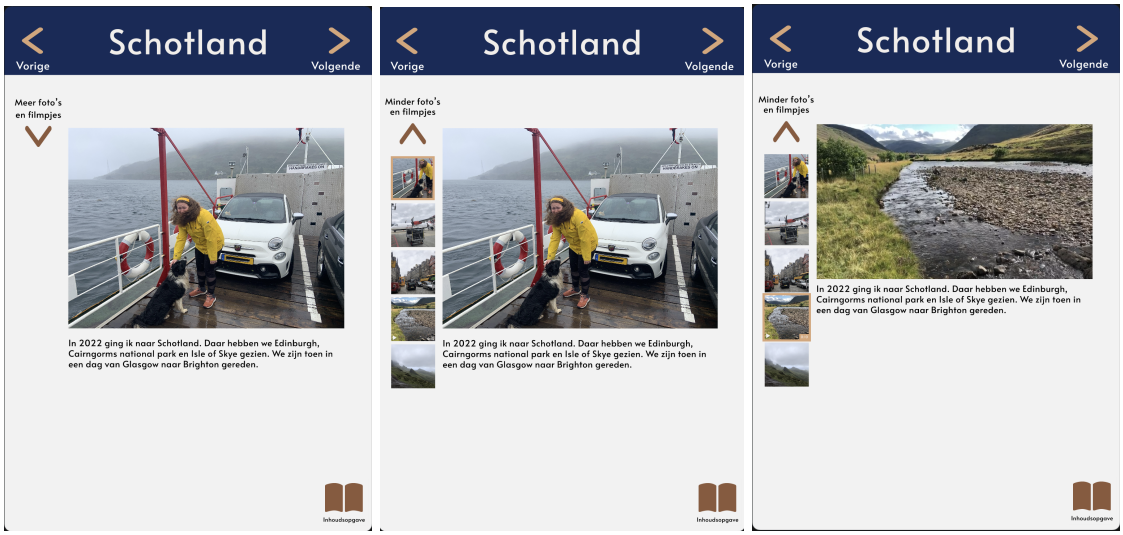
(a) The opening pages of the application



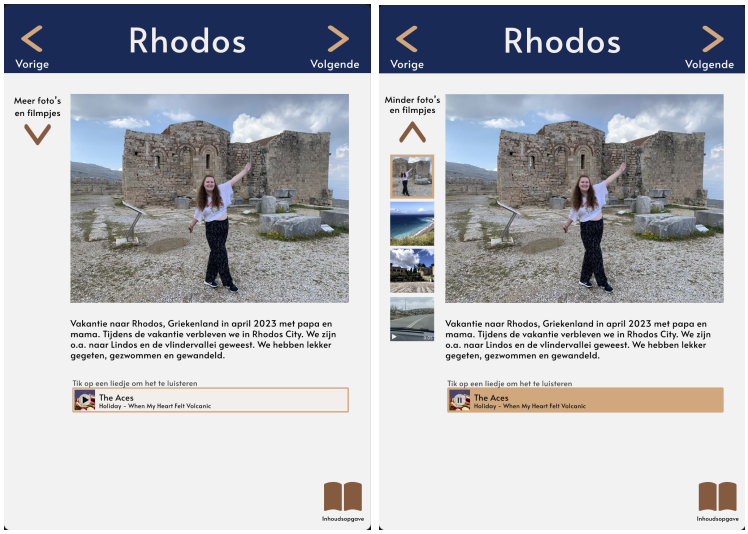
(b) Table of content page and the same page when searching for a specific event

Figure 8: The first pages a user accesses when they open the final prototype

(a) Event page 'this is me'

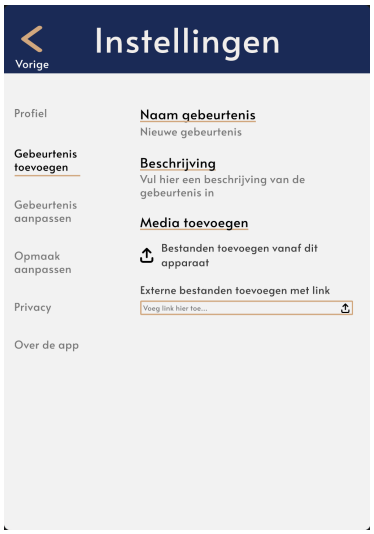


(b) Event page 'Scotland'



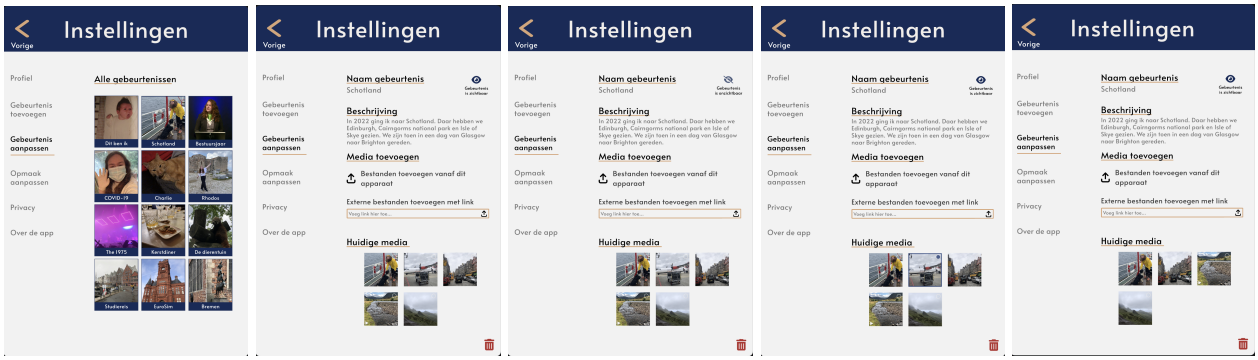
(c) Event page 'Rhodes'

Figure 9: The pages of three different events



(a) Settings page for adding an event

(b) Settings pages for the user's profile with the security question



(c) Settings pages for editing an event page, including toggling its visibility and deleting an image

Figure 10: The settings pages

8 Ethical considerations

The entirety of this project is carried out within the context of a code of ethics consisting of several moral principles. These moral principles are as follows:

- Accountability: Taking responsibility for your actions and decisions and accepting their consequences [59], [61].
- Flexibility: providing individuals with the autonomy to accommodate for their own needs without interference or restraints [61].
- Independence from the medical domain: Avoiding association with the medical domain [61].
- Integrity: Acting in accordance with ethical principles, assuming the best of people and acting with intellectual fairness and honesty [59], [61].
- Prioritising mental well-being: Mental well-being of directly involved persons always takes precedence [61].
- Respect: Respecting people's dignity, worth and privacy and being mindful of equality and diversity [59], [61].
- Sustainability: promoting positive economical, environmental and social impact that can be maintained in the long term as well as in the short term [61].

Accountability The life story book application aims to generate a positive effect on public health. However, risks of negative effects also exist. Accountability, and especially an open attitude towards feedback and willingness to improve based on this, are essential in mitigating these negative effects. As a developer who is not living with Alzheimer's and does not serve as a caregiver of anyone in that position, one can never fully grasp the experience of the potential users of the application. For the application to positively impact the experience of a devastating illness such as Alzheimer's, users must be able to hold developers accountable to improve upon the product [61].

Flexibility Everyone reminisces differently and has different preferences. Keeping in line with the moral principle of respect, the application should cater to those preferences. This is incorporated in multiple ways. Users are able to add their own contents to the application without interference from the developer, in order to strongly increase accessibility. They are also able to change the font and colour palette of the application, and the fact that the application is on a tablet means that it can easily be moved and used in locations outside of the user's home. The digital aspect of the application makes it possible for users to add more different types of content, making it more flexible in that way as well [61].

Independence from the medical domain This project is not carried out on behalf of a medical organisation or by anyone with medical experience, which is why it is an important principle of this project to remain separate from the medical domain. Any research conducted in the medical domain is subject to the Dutch 'Wet medisch-wetenschappelijk onderzoek met mensen' [65], adherence with which was not feasible within the context of the project. Therefore it should be kept in mind at all stages of the project that no definitive medical conclusions may be drawn from any of the conducted research, nor should any medical advice be given to or taken by participants of user testing sessions - be it pharmacological or non-pharmacological. That is why the effectiveness of the developed solution will not be evaluated during user testing sessions and why no definitive conclusions are drawn from literature research on (non)pharmacological treatments. A number of the additional research recommendations (see section 9) are about medical evaluation of the literature and prototype [61].

Integrity Integrity, and ethical conduct in particular, is relevant to this project due to the fact that, as stated by Fleddermann, design 'affect[s] public health and safety and can influence business practices and even politics' [60]. The design of a digital life story book application directly aims to affect public health in a positive way, but to ensure that 'positive' does not merely become a subjective term open to the interpretation of the developer, consideration of ethical theories and implications is vital [61].

Prioritising mental well-being Mental distress is a common result of Alzheimer's for both the people suffering from it and their caregivers [11], [19], [28], [29], [32]. One of the main goals of the life story book application is to alleviate this distress by eliminating the communication divide, which is one its contributing factors [19]. This principle should thus be kept in mind for the final result, but also in all steps leading up to it. Any decisions regarding design and user testing have been made with the mental well-being of those involved in the design process as a first priority [61].

Respect Respecting an individual is vital when developing an application to improve someone's well-being. Information regarding a person's life or medical condition is extremely sensitive and should be handled with care and confidentiality in order for a user to feel safe and benefit from the contents of an application, apart from privacy laws that should be adhered to such as the European GDPR legislation [66], [67]. This is why the digital application will be entirely offline unless chosen otherwise (when adding content from the internet), only available to those with physical access to the device on which the application is installed [61]. An ethical assessment using a flow chart was made for caregivers who would also like access to the life story book application, which can be found in Figure 11. An example of a non-disclosure agreement for the application can be found in Appendix 11.10.

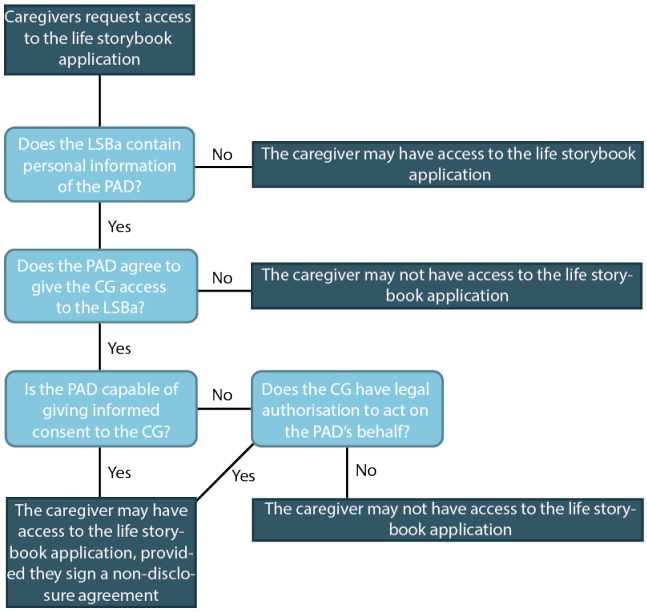


Figure 11: A flow chart providing a visual representation of the ethical decision-making process for allowing a caregiver to access someone's life story book application. Abbreviations: LSBa - life story book application; PAD - person living with Alzheimer's; CG - caregiver [61]

In addition to respecting privacy, dignity is also a very important part of this application. As Gowans et al. argue, caregivers can come to 'dehumanise' the person with Alzheimer's under their care as a result of memory loss and diminished

communication skill [27]. To improve the relationship between those individuals and their caregivers, preserving and respecting their dignity is important to create an equal playing field in using the application [61].

The language of all documents written within the context of this project, including this report, is aimed to be as inclusive and respectful as possible. Terms such as 'patients' are avoided, since they may diminish an individual's worth to only their shortcomings instead of considering the person behind the disease [61].

Sustainability Sustainability is usually measured in three different pillars: economic, environmental and social sustainability [68]. A product is sustainable when it promotes a positive impact on all three pillars. When a product cannot satisfy all three pillars (for example, an environmentally friendly manufacturing material might make the product too expensive to remain economically sustainable), the goal should be to fully satisfy the remaining pillar(s) and to limit the harm done to the other(s) as much as possible [61].

This application fully satisfies the social sustainability pillar, because it involves other people than just the primary user and can also be used by other generations once they reach an age where symptoms of Alzheimer's might start to express themselves. It is also easier to transport than a heavier analogue life story book, making it more accessible in different social contexts [61].

The economic sustainability of the application cannot be fully satisfied because design requirements do not allow for the inclusion of profit models such as in-app advertisements. Subscriptions or a purchasing fee could solve this problem. On the side of the user, purchasing a tablet device might also be a limiting factor for economic sustainability. By monetising the application, this problem might be solved: a scheme could be devised where part of the profits can be used to pay for tablets for people who cannot afford them [61].

An ethical assessment of the environmental sustainability was carried out in the shape of a line drawing (see Figure 12). Below the problem statement, paradigms, solutions and their corresponding number in Figure 12 can be found [61].

Problem statement (P): Most users will already have their own tablet or will use their caregiver's tablet for accessing the digital life story book application, but a small number of users will buy a new tablet specifically for this application. This will cause a slight increase in demand.

Negative paradigm: The application causes increased demand for tablets which negatively impacts the environment.

Positive paradigm: Tablets with the application installed have not contributed to environmental damage.

1. Developers donate part of a subscription/purchase fee of the application to environmental charities
2. Developers donate part of a subscription/purchase fee of the application to organisations promoting the circular economy and/or making manufacturing processes more sustainable
3. Developers only develop the application and hold the user accountable for any negative environmental impact
4. Developers work with a refurbishing company to restore old tablets and offer them with a purchasing license for the application
5. Tablet manufacturing companies actively work on decreasing environmental impact of their manufacturing process
6. The application does not cause an increase in demand for tablets
7. The application uses little battery life to lower the amount of electricity needed to recharge the tablet
8. Users can purchase full environmental compensation of their tablet through the application

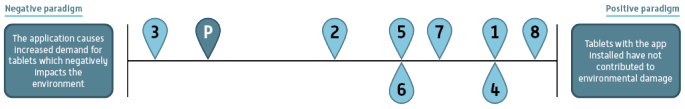


Figure 12: Line drawing depicting the ethical positioning of several activities that impact environmental sustainability of the digital life story book application [61]

9 Discussion and conclusions

An Alzheimer's diagnosis has a massive impact on not only the life of the person receiving it, but also the people around them. The continuous neural breakdown caused by the disease leads to a myriad of issues including memory loss and communicative issues and puts a strain on personal relationships, resulting in a communication divide. Using a digital life story book application to help people suffering from Alzheimer's and their caregivers improve their interpersonal communication can contribute to increased happiness in both the person suffering from the disease and the people around them. Digital life story books provide benefits over the currently prevalent analog life story book by offering more options for customisation over time and the inclusion of more memory-triggering materials. However, most of the existing digital solutions do not allow for modification by the user after the initial application has been delivered to them and/or do not adhere to design requirements for elderly people suffering from Alzheimer's. Developing a digital life story book application that allows users to modify it themselves and that is designed using an extensive set of design guidelines could play an important role in bridging the communication divide between people suffering from Alzheimer's and their caregivers.

9.1 Limitations

Time constraints

Due to the time frame of this project, 20 weeks, not all design aspects could be properly implemented in this prototype. Two reminiscence tools were not explicitly used: carrying out an activity or posing questions to the user. Stimulation activities have also not been added in this prototype. In the expert interview, the clinical psychologist expert also strongly recommended allowing for voice-overs and for the option of letting friends and family record those voice-overs. This could also not be added due to the time constraints. One big implementation also could not be carried out, namely allowing the user to change the font, text size and colour scheme of the application. This is an important aspect of customisation that should still be added.

Technical constraints

The prototyping program used, Figma, has certain limitations. Figma's prototype function does not allow for users to upload their own contents, so this was Wizard of Oz'ed for the final prototype. Another functionality Figma missed was the fact that the user cue suggesting where to click next could not be delayed for more than 20 seconds, even though user testing sessions made it clear that on some pages more time was needed.

Gaps in the literature

Some gaps in the literature were identified, especially when it came to memory. No research seemed to be available on the effectiveness of different memory triggers, which made it impossible to verify the reminiscence tools chosen for the prototype. Research is also missing on tracing and following the behaviour of engrams in people suffering from Alzheimer's. As engrams are destroyed by the breaking down of neural networks, the question becomes whether or not the engrams still exist. Schacter states that by activating other parts of the brain may still allow an individual to circumvent damage to an area of the brain where part of an engram is stored [11], but if an engram is destroyed or fades entirely as a result

of Alzheimer's, reminiscence therapy might become a re-learning of memories rather than remembering them. Currently researchers are able to identify and at times even manipulate specific engrams in rodents [12], [69], but not a lot of research on this topic is available for humans. This research is important for further defining reminiscence therapy and making it more effective for combating damage done to memory systems by Alzheimer's. It is also important for identifying which memory triggers might be more effective for which person.

Testing the application

One major limitation of the application testing was, that no respondents from the application's target group could be found. The conclusions that could be drawn from the application testing were also limited, because the researcher is not a medical professional and was thus unable to draw any medical conclusions on the application's effectiveness. This also requires longer monitoring than the time frame of this project allowed for, based on how many user testing sessions were needed for similar projects [4], [24], [27]–[29], [43], [44].

Ethical considerations

Based on the line drawing in Figure 12 it quickly becomes clear that in terms of environmental sustainability, the current situation is on the negative end of the spectrum and thus not acceptable. Economical sustainability should also be improved.

9.2 Future work

Time constraints

In a new version of this prototype, several functionalities should still be added. The application should ask the user questions, rather than leaving this solely to the caregiver. A facilitating function for carrying out activities such as gardening should also be made more explicit, by for example allowing a user to click a button saying 'I want to try this activity with my caregiver' and the caregiver getting a notification for this. Stimulation activities such as puzzles and memory games should also still be added to the application, as well as the option to change the font, colour scheme and text size of the application. Lastly, an option should be added to the 'add event' settings page for someone to record a voice-over that can read out the description of a specific event.

Technical constraints

A prototype should be developed using Swift, the programming language required for Apple developers [70]. In this prototype, it should be possible to upload files from the user's device. The time it takes for the user cue of the blinking hand to appear should also be increased to 60 seconds.

Gaps in the literature

Conducting more research on the topic of memory trigger effectiveness would be useful because it could lead to a complete restructuring of reminiscence therapy practices. More research should also be done on how Alzheimer's affects engrams in the human brain.

Testing the application

With proxy testing a lot of design issues could already be addressed, but additional user testing with people suffering from Alzheimer's who are still in an early stage of the disease's development should be carried out. The effectiveness of the application should also be validated by a medical professional who is able to draw definitive conclusions on the clinical

effectiveness of this digital life story book application and whether the application can actually improve communication between caregivers and people suffering from Alzheimer's.

Ethical considerations

An important future research direction for the final application would be to look at incorporating some of the suggestions on the positive side of the line drawing in Figure 12 into any business model that might be developed for this application in order to improve environmental sustainability. To tackle economical sustainability, schemes for making the application (and tablet devices in general) more economically sustainable should also be considered in any potential business plan in addition to the aforementioned environmental sustainability schemes proposed in section 8.

9.3 Conclusion

When designing a digital life story book application for people suffering from Alzheimer's, the focus should be on events that are supported by reminiscence tools. This thesis presents comprehensive guidelines for the design requirements of such a a digital life story book application. In addition to design guidelines, this thesis also offers an extensive code of ethics, to which everyone involved with the development of digital life story book applications should adhere. The options for personalisation that this prototype allows for give this digital life story book application a strong advantage over existing solutions. The positive reactions of all three dyads strongly suggest that using the developed life story book application induces positive emotions and encourages reminiscence and communication. Based on the proxy testing sessions it is therefore expected that this application could be an effective tool in bridging the communication divide between people suffering from Alzheimer's and their caregivers, but additional research is needed to verify this conclusion.

References

[1] W. H. Organisation, *Dementia*, English, Sep. 2022. [Online]. Available: https://www.who.int/news-room/fact-sheets/detail/dementia (visited on 14/02/2023).

[2] S. Gauthier, C. Webster, S. Servaes, J. A. Morais and P. Rosa-Neto, 'World Alzheimer Report 2022 – Life after diagnosis: Navigating treatment, care and support', English, Alzheimer's Disease International, London, England, Tech. Rep., Sep. 2022. [Online]. Available: https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf (visited on 14/02/2023).

[3] J. A. Small, G. Gutman, S. Makela and B. Hillhouse, 'Effectiveness of Communication Strategies Used by Caregivers of Persons With Alzheimer's Disease During Activities of Daily Living', en, *Journal of Speech, Language, and Hearing Research*, vol. 46, no. 2, pp. 353–367, Apr. 2003, ISSN: 1092-4388, 1558-9102. DOI: 10.1044/1092-4388(2003/028). [Online]. Available: http://pubs.asha.org/doi/10.1044/1092-4388%282003/028%29 (visited on 14/02/2023).

[4] B. Woods and P. Subramaniam, 'Digital life storybooks for people with dementia living in care homes: An evaluation', en, *Clinical Interventions in Aging*, vol. Volume 11, pp. 1263–1276, Sep. 2016, ISSN: 1178-1998. DOI: 10.2147/CIA.S111097. [Online]. Available: https://www.dovepress.com/digital-life-storybooks-for-people-with-dementia-living-in-care-homes--peer-reviewed-article-CIA (visited on 14/02/2023).

[5] T. R. Elfrink, S. U. Zuidema, M. Kunz and G. J. Westerhof, 'Life story books for people with dementia: A systematic review', en, *International Psychogeriatrics*, vol. 30, no. 12, pp. 1797–1811, Dec. 2018, ISSN: 1041-6102, 1741-203X. DOI: 10.1017/S1041610218000376. [Online]. Available: https://www.cambridge.org/core/product/identifier/S1041610218000376/type/journal_article (visited on 08/03/2023).

[6] N. I. on Aging, *What Happens to the Brain in Alzheimer's Disease?*, en, May 2017. [Online]. Available: https://www.nia.nih.gov/health/what-happens-brain-alzheimers-disease (visited on 27/03/2023).

[7] E. Scarpini, D. Galimberti and L. Ghezzi, 'Disease-modifying drugs in Alzheimer's disease', en, *Drug Design, Development and Therapy*, p. 1471, Jun. 2013, ISSN: 1177-8881. DOI: 10.2147/DDDT.S41431. [Online]. Available: http://www.dovepress.com/disease-modifying-drugs-in-alzheimer39s-disease-peer-reviewed-article-DDDT (visited on 27/02/2023).

[8] R. I. Mehta and J. A. Schneider, 'What is 'Alzheimer's disease'? The neuropathological heterogeneity of clinically defined Alzheimer's dementia', en, *Current Opinion in Neurology*, vol. 34, no. 2, pp. 237–245, Apr. 2021, ISSN: 1350-7540, 1473-6551. DOI: 10.1097/WCO.0000000000000912. [Online]. Available: https://journals.lww.com/10.1097/WCO.0000000000000912 (visited on 14/02/2023).

[9] *ADI - About Alzheimer's & Dementia*, en. [Online]. Available: https://www.alzint.org/about/ (visited on 01/06/2023).

[10] S. B. Klein, 'What memory is', en, *WIREs Cognitive Science*, vol. 6, no. 1, pp. 1–38, 2015, _eprint: https://onlinelibrary.wiley.com/doi/pdf/10.1002/wcs.1333, ISSN: 1939-5086. DOI: 10.1002/wcs.1333. [Online]. Available: https://onlinelibrary.wiley.com/doi/abs/10.1002/wcs.1333 (visited on 14/04/2023).

[11] D. L. Schacter, *Searching for memory: the brain, the mind, and the past*, eng, Nachdr. New York: BasicBooks, 1998, ISBN: 978-0-465-07552-2 978-0-465-02502-2.

[12] M. Bostancıklıoğlu, 'An update on memory formation and retrieval: An engram-centric approach', en, *Alzheimer's & Dementia*, vol. 16, no. 6, pp. 926–937, 2020, _eprint: https://onlinelibrary.wiley.com/doi/pdf/10.1002/alz.12071, ISSN: 1552-5279. DOI: 10.1002/alz.12071. [Online]. Available: https://onlinelibrary.wiley.com/doi/abs/10.1002/alz.12071 (visited on 27/03/2023).

[13] V. Hedges, *Introduction to Neuroscience*, English. Michigan State University, Dec. 2022, ISBN: 978-1-62610-122-7. [Online]. Available: https://open.umn.edu/opentextbooks/textbooks/1303 (visited on 14/04/2023).

[14] H. Jahn, 'Memory loss in Alzheimer's disease', en, *Dialogues in Clinical Neuroscience*, vol. 15, no. 4, pp. 445–454, Dec. 2013, ISSN: 1958-5969. DOI: 10.31887/DCNS.2013.15.4/hjahn. [Online]. Available: https://www.tandfonline.com/doi/full/10.31887/DCNS.2013.15.4/hjahn (visited on 14/04/2023).

[15] B. Opitz, 'Memory Function and the Hippocampus', en, in *Frontiers of Neurology and Neuroscience*, K. Szabo and M. Hennerici, Eds., vol. 34, S. Karger AG, 2014, pp. 51–59, ISBN: 978-3-318-02567-5 978-3-318-02568-2. DOI: 10.1159/000356422. [Online]. Available: https://www.karger.com/Article/FullText/356422 (visited on 14/04/2023).

[16] Y. L. Rao, B. Ganaraja, B. V. Murlimanju, T. Joy, A. Krishnamurthy and A. Agrawal, 'Hippocampus and its involvement in Alzheimer's disease: A review', en, *3 Biotech*, vol. 12, no. 2, p. 55, Feb. 2022, ISSN: 2190-5738. DOI: 10.1007/s13205-022-03123-4. [Online]. Available: https://doi.org/10.1007/s13205-022-03123-4 (visited on 14/04/2023).

[17] *Hippocampus — Definition, Location, Function, & Facts — Britannica*, en, Mar. 2023. [Online]. Available: https://www.britannica.com/science/hippocampus (visited on 14/04/2023).

[18] P. E. McKeever, *Gliosis - an overview — ScienceDirect Topics*, 2012. [Online]. Available: https://www.sciencedirect.com/topics/neuroscience/gliosis (visited on 14/04/2023).

[19] M. Woodward, 'Aspects of communication in Alzheimer's disease: Clinical features and treatment options', en, *International Psychogeriatrics*, vol. 25, no. 6, pp. 877–885, Jun. 2013, ISSN: 1041-6102, 1741-203X. DOI: 10.1017/S1041610213000318. [Online]. Available: https://www.cambridge.org/core/product/identifier/S1041610213000318/type/journal_article (visited on 27/02/2023).

[20] *Caregiver*, English, Oxford, United Kingdom, Jun. 2001. [Online]. Available: https://dictionary.cambridge.org/dictionary/english/caregiver.

[21] M. Bastawrous, 'Caregiver burden—A critical discussion', en, *International Journal of Nursing Studies*, vol. 50, no. 3, pp. 431–441, Mar. 2013, ISSN: 0020-7489. DOI: 10.1016/j.ijnurstu.2012.10.005. [Online]. Available: https://www.sciencedirect.com/science/article/pii/S0020748912003367 (visited on 15/03/2023).

[22] T. Pedersen, *Triggers: What They Are, How They Form, and What to Do*, en, May 2016. [Online]. Available: https://psychcentral.com/lib/what-is-a-trigger (visited on 24/04/2023).

[23] *Memory Care: 5 Ways to Trigger Positive Memories*, en-US, Apr. 2021. [Online]. Available: https://northbridgecommunities.com/blog-post/memory-care-5-ways-to-trigger-positive-memories/ (visited on 24/04/2023).

[24] E. O'Leary and N. Barry, 'Reminiscence therapy with older adults', en, *Journal of Social Work Practice*, vol. 12, no. 2, pp. 159–165, Nov. 1998, ISSN: 0265-0533, 1465-3885. DOI: 10.1080/02650539808415144. [Online]. Available: http://www.tandfonline.com/doi/abs/10.1080/02650539808415144 (visited on 27/02/2023).

[25] B. Woods, A. E. Spector, C. A. Jones, M. Orrell and S. P. Davies, 'Reminiscence therapy for dementia', en, *Cochrane Database of Systematic Reviews*, Cochrane Dementia and Cognitive Improvement Group, Ed., Apr. 2005, ISSN: 14651858. DOI: 10.1002/14651858.CD001120.pub2. [Online]. Available: https://doi.wiley.com/10.1002/14651858.CD001120.pub2 (visited on 17/04/2023).

[26] S. Klever, 'Reminiscence therapy: Finding meaning in memories', en, *Nursing*, vol. 43, no. 4, pp. 36–37, Apr. 2013, ISSN: 0360-4039. DOI: 10.1097/01.NURSE.0000427988.23941.51. [Online]. Available: https://journals.lww.com/00152193-201304000-00011 (visited on 17/04/2023).

[27] G. Gowans, J. Campbell, N. Alm, R. Dye, A. Astell and M. Ellis, 'Designing a Multimedia Conversation Aid for Reminiscence Therapy in Dementia Care Environments', English, Vienna, Austria, Apr. 2004. DOI: https://doi.org/10.1145/985921.985943. [Online]. Available: https://dl.acm.org/doi/10.1145/985921.985943 (visited on 27/02/2023).

[28] Z. Quail, M. M. Carter, A. Wei and X. Li, 'Management of cognitive decline in Alzheimer's disease using a non-pharmacological intervention program', *Medicine*, vol. 99, no. 21, e20128, May 2020, ISSN: 0025-7974. DOI: 10.1097/MD.0000000000020128. [Online]. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7249940/ (visited on 27/02/2023).

[29] H. Yamaguchi, Y. Maki and T. Yamagami, 'Overview of non-pharmacological intervention for dementia and principles of brain-activating rehabilitation: Brain-activating rehabilitation for dementia', en, *Psychogeriatrics*, vol. 10, no. 4, pp. 206–213, Dec. 2010, ISSN: 13463500. DOI: 10.1111/j.1479-8301.2010.00323.x. [Online]. Available: https://onlinelibrary.wiley.com/doi/10.1111/j.1479-8301.2010.00323.x (visited on 27/02/2023).

[30] *Creating a life story for a person with dementia*, en-GB, May 2023. [Online]. Available: https://www.dementiauk.org/get-support/living-with-dementia/creating-a-life-story/ (visited on 23/06/2023).

[31] *Creating a life story book*, en-US, 2017. [Online]. Available: https://www.alzheimerswa.org.au/helpsheets/creating-a-life-story-book/ (visited on 23/06/2023).

[32] K. Kuca, P. Maresova, B. Klimova, M. Valis and J. Hort, 'Alzheimer's disease and language impairments: Social intervention and medical treatment', en, *Clinical Interventions in Aging*, p. 1401, Aug. 2015, ISSN: 1178-1998. DOI: 10.2147/CIA.S89714. [Online]. Available: http://www.dovepress.com/alzheimerrsquos-disease-and-language-impairments-social-intervention-a-peer-reviewed-article-CIA (visited on 27/02/2023).

[33] A. Beales, K. Bates, J. Cartwright and A. Whitworth, 'Lost for words: Perspectives and experiences of people with primary progressive aphasia and Alzheimer's disease and their families of participation in a lexical retrieval intervention', en, *International Journal of Speech-Language Pathology*, vol. 21, no. 5, pp. 483–492, Sep. 2019, ISSN: 1754-9507, 1754-9515. DOI: 10.1080/17549507.2019.1625439. [Online]. Available: https://www.tandfonline.com/doi/full/10.1080/17549507.2019.1625439 (visited on 27/02/2023).

[34] M. W. L. J. Olthof-Nefkens, E. W. C. Derksen, F. Debets, B. J. M. de Swart, M. W. G. Nijhuis-van der Sanden and J. G. Kalf, 'Com-mens: A home-based logopaedic intervention program for communication problems between people with dementia and their caregivers — a single-group mixed-methods pilot study', en, *International Journal of Language & Communication Disorders*, pp. 1460–6984.12811, Nov. 2022, ISSN: 1368-2822, 1460-6984. DOI: 10.1111/1460-6984.12811. [Online]. Available: https://onlinelibrary.wiley.com/doi/10.1111/1460-6984.12811 (visited on 27/02/2023).

[35] *App store*, 2023. (visited on 23/06/2023).

[36] *Timeless (@timeless_ai) / Twitter*, en, May 2019. [Online]. Available: https://twitter.com/timeless_ai (visited on 23/06/2023).

[37] E. Yang, *Timeless*, en-US, Jul. 2019. [Online]. Available: https://www.timeless.care (visited on 23/06/2023).

[38] W.-C. Liou, L. Chan, C.-T. Hong *et al.*, 'Hand fine motor skill disability correlates with dementia severity', en, *Archives of Gerontology and Geriatrics*, vol. 90, p. 104 168, Sep. 2020, ISSN: 0167-4943. DOI: 10.1016/j.archger.2020.104168. [Online]. Available: https://www.sciencedirect.com/science/article/pii/S016749432030162X (visited on 12/05/2023).

[39] S. Whitten, *The death of the DVD: Why sales dropped more than 86% in 13 years*, en, Nov. 2019. [Online]. Available: https://www.cnbc.com/2019/11/08/the-death-of-the-dvd-why-sales-dropped-more-than-86percent-in-13-years.html (visited on 12/05/2023).

[40] J. Stoll, *Netherlands: Number of households with a DVD player 2010-2017*, en, Dec. 2022. [Online]. Available: https://www.statista.com/statistics/831595/number-of-households-with-a-dvd-player-in-the-netherlands/ (visited on 12/05/2023).

[41] *Book Of You, Reminiscence Therapy*, 2023. [Online]. Available: https://www.bookofyou.co.uk/what-it-is/ (visited on 12/05/2023).

[42] K. Productions, *Book Of You*, English, Feb. 2015. [Online]. Available: https://vimeo.com/120787781 (visited on 12/05/2023).

[43] A. H. Abu Hashim, A. N. Ismail, R. Mohd Rias and A. Mohamed, 'The development of an individualized digital memory book for Alzheimer's Disease patient: A case study', in *2015 International Symposium on Technology Management and Emerging Technologies (ISTMET)*, Aug. 2015, pp. 227–232. DOI: 10.1109/ISTMET.2015.7359034.

[44] A. Catala, D. S. Nazareth, P. Félix, K. P. Truong and G. J. Westerhof, 'Emobook: A Multimedia Life Story Book App for Reminiscence Intervention', en, in *22nd International Conference on Human-Computer Interaction with Mobile Devices and Services*, Oldenburg Germany: ACM, Oct. 2020, pp. 1–4, ISBN: 978-1-4503-8052-2. DOI: 10.1145/3406324.3410717. [Online]. Available: https://dl.acm.org/doi/10.1145/3406324.3410717 (visited on 23/06/2023).

[45] *Tablets market share by vendor worldwide 2023*, en, 2023. [Online]. Available: https://www.statista.com/statistics/276635/market-share-held-by-tablet-vendors/ (visited on 23/06/2023).

[46] A. Mader and W. Eggink, 'A DESIGN PROCESS FOR CREATIVE TECHNOLOGY', en, Apr. 2014.

[47] C. Ancient and A. Good, 'Issues with Designing Dementia-Friendly Interfaces', Jul. 2013.

[48] F. Ghorbel, E. Métais, N. Ellouze, F. Hamdi and F. Gargouri, 'Towards Accessibility Guidelines of Interaction and User Interface Design for Alzheimer's Disease Patients', English, 2017.

[49] A. Lazar, H. J. Thompson and G. Demiris, 'Design Recommendations for Recreational Systems Involving Older Adults Living With Dementia', *Southern Gerontological Society*, Journal of Applied Gerontology, vol. 37, no. 5, pp. 595–619, 2018.

[50] G. Pang and E. Kwong, 'Considerations and Design on Apps for Elderly with Mild-to-moderate Dementia', in *International Conference on Information Networking*, Siem Reap, Cambodia, 2015.

[51] D. Williams, M. Arif Ul Alam, S. Iqbal Ahamed and W. Chu, 'Consideriations in Designing Human-Computer Interfaces for Elderly People', Jan. 2013.

[52] S. H. Pöllänen and R. M. Hirsimäki, 'Crafts as Memory Triggers in Reminiscence: A Case Study of Older Women with Dementia', *Occupational Therapy In Health Care*, vol. 28, no. 4, pp. 410–430, Oct. 2014, Publisher: Taylor & Francis _eprint: https://doi.org/10.3109/07380577.2014.941052, ISSN: 0738-0577. DOI: 10.3109/07380577.2014.941052. [Online]. Available: https://doi.org/10.3109/07380577.2014.941052 (visited on 27/03/2023).

[53] F. Barban, R. Annicchiarico, S. Pantelopoulos *et al.*, 'Protecting cognition from aging and Alzheimer's disease: A computerized cognitive training combined with reminiscence therapy', en, *International Journal of Geriatric Psychiatry*, vol. 31, no. 4, pp. 340–348, 2016, _eprint: https://onlinelibrary.wiley.com/doi/pdf/10.1002/gps.4328, ISSN: 1099-1166. DOI: 10.1002/gps.4328. [Online]. Available: https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.4328 (visited on 27/03/2023).

[54] D. Cosley, K. Akey, B. Alson *et al.*, 'Using Technologies to Support Reminiscence', BCS Learning & Development, Sep. 2009. DOI: 10.14236/ewic/HCI2009.60. [Online]. Available: https://www.scienceopen.com/hosted-document?doi=10.14236/ewic/HCI2009.60 (visited on 27/03/2023).

[55] A. Pringle and S. Somerville, 'Computer-assisted reminiscence therapy: Developing practice: Alan Pringle and Sharlotte Somerville describe a pilot project that uses new technology to help unlock the memories of people with dementia', en, *Mental Health Practice*, vol. 17, no. 4, pp. 34–37, Dec. 2013, ISSN: 1465-8720, 2047-895X. DOI: 10.7748/mhp2013.12.17.4.34.e830. [Online]. Available: http://rcnpublishing.com/doi/abs/10.7748/mhp2013.12.17.4.34.e830 (visited on 27/03/2023).

[56] P. Subramaniam and B. Woods, 'Towards the therapeutic use of information and communication technology in reminiscence work for people with dementia: A systematic review', en, *International Journal of Computers in Healthcare*, Dec. 2010, Publisher: Inderscience Publishers. [Online]. Available: https://www.inderscienceonline.com/doi/10.1504/IJCIH.2010.037457 (visited on 27/03/2023).

[57] *Design Overview: A Collaborative Product Development Platform*, en, Jun. 2023. [Online]. Available: https://www.figma.com/design-overview/ (visited on 02/07/2023).

[58] K. Moran, *Usability Testing 101*, en, Jul. 2022. [Online]. Available: https://www.nngroup.com/articles/usability-testing-101/ (visited on 05/06/2023).

[59] W. H. Organisation, *Code of Ethics and professional conduct*, en, Apr. 2017. [Online]. Available: https://www.who.int/about/ethics/ethical-principles (visited on 28/03/2023).

[60] C. B. Fleddermann, *Engineering ethics* (ESource), 4th ed. Upper Saddle River: Prentice Hall, 2012, OCLC: ocn739646068, ISBN: 978-0-13-214521-3.

[61] I. Verschuren, *Creating a digital life story book for people suffering from Alzheimer's disease (Reflection Report: Graduation Project Spring Semester 2023)*, English, May 2023.

[62] K. Sukel, *Neuroanatomy: The Basics*, en-US, Aug. 2019. [Online]. Available: https://dana.org/article/neuroanatomy-the-basics/ (visited on 27/03/2023).

[63] I. Verschuren, *Interview with clinical psychologist specialising in the elderly and dementia regarding University of Twente graduation project 'A Personalised Digital Memory Book to Improve Quality of Life for People with Alzheimer's Disease'*, English, May 2023.

[64] D. Cyr, M. Head and H. Larios, 'Colour appeal in website design within and across cultures: A multi-method evaluation', en, *International Journal of Human-Computer Studies*, vol. 68, no. 1, pp. 1–21, Jan. 2010, ISSN: 1071-5819. DOI: 10.1016/j.ijhcs.2009.08.005. [Online]. Available: https://www.sciencedirect.com/science/article/pii/S1071581909001116 (visited on 05/06/2023).

[65] B. van Oranje-Nassau, *Wet medisch-wetenschappelijk onderzoek met mensen*, Dutch, Feb. 1998. [Online]. Available: https://wetten.overheid.nl/BWBR0009408/2020-01-01 (visited on 29/05/2023).

[66] I. Verschuren, *Reflection Outline: Graduation Project Spring Semester 2023 Creating a digital life story book for Alzheimer's patients*, English, Mar. 2023. [Online]. Available: https://acrobat.adobe.com/link/track?uri=urn:aaid:scds:US:b0e3498f-b2ae-370d-bcc7-8ccdc7d5e609 (visited on 29/05/2023).

[67] E. Union, *Official Journal L 119/2016*, English, Apr. 2016. [Online]. Available: https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=OJ:L:2016:119:FULL (visited on 16/01/2023).

[68] B. Purvis, Y. Mao and D. Robinson, 'Three pillars of sustainability: In search of conceptual origins', en, *Sustainability Science*, vol. 14, no. 3, pp. 681–695, May 2019, ISSN: 1862-4057. DOI: 10.1007/s11625-018-0627-5. [Online]. Available: https://doi.org/10.1007/s11625-018-0627-5 (visited on 29/05/2023).

[69] S. A. Josselyn, S. Köhler and P. W. Frankland, 'Finding the engram', en, *Nature Reviews Neuroscience*, vol. 16, no. 9, pp. 521–534, Sep. 2015, Number: 9 Publisher: Nature Publishing Group, ISSN: 1471-0048. DOI: 10.1038/nrn4000. [Online]. Available: https://www.nature.com/articles/nrn4000 (visited on 14/04/2023).

[70] A. Inc, *Swift - Apple Developer*, en, 2023. [Online]. Available: https://developer.apple.com/swift/ (visited on 23/06/2023).

[71] *Brain Anatomy and How the Brain Works*, en, Jul. 2021. [Online]. Available: https://www.hopkinsmedicine.org/health/conditions-and-diseases/anatomy-of-the-brain (visited on 27/03/2023).

11 Appendix

11.1 All design requirements

Lay-out of the interface

- Consistent design should be incorporated in each aspect of the interface [48]–[50]
- All images should be accompanied by text [48], [50]
- Use large buttons [48]–[50]
- Font size and use of colour should be important aspects of interface design [47], [48], [50]
  People suffering from Alzheimer's often experience increased problems with perceiving colours, shapes and movements due to damage to the part of the brain that translates visual information conveyed by the eyes (the occipital lobe). Therefore, several design considerations are important when it comes to font and colour use [47], [48], [50].
  1. *The larger the font the better when designing interfaces for this demographic - however, font sizes should not become so large that scrolling becomes a necessity [47], [49], [50]*
  2. *Ghorbel et al. recommend using sans-serif font types with spacing between 1.5 and 2 [48]*
  3. *Colour use should be limited, and the colour palette of the interface should consist of soft colours that do not combine green and red, or yellow and blue [48], [51]*
  4. *The background of the interface should not contain patterns or images or be dark or fully white [48]*
  5. *Text should clearly contrast from the background [48], [50]*
  6. *Text font and size and colour palettes should be adjustable by the user [48], [49]*

Functionality

- Clear explanations on the use of the application should be provided either through auditory or textual cues, or both [47]–[51]
- Avoid deep hierarchies in menu navigation [48], [49]
- Response time should not be limited [47]
  People living with dementia tend to have lower response speeds, which should be considered when time limits are implemented - or time limits should be avoided altogether [47]
- Feedback should be given after an action is taken by the user, and if the feedback is negative, instructions should be given on how to resolve the issue; negative feedback should be kept to a minimum [48]–[50]
  As Yamaguchi states, constant feedback is important when treating people suffering from Alzheimer's [29]. Combining visual and auditory feedback is preferred [50], [51]
- If games are implemented, the rules and controls should be intuitive and errors should be minimised [49], [50]
- Select games that do not remind people suffering from Alzheimer's of the challenges their diagnosis brings them
- Give users options in terms of which functionalities and content they would like to see [49], [50]
- The application should not be an alternative for people suffering from Alzheimer's to active engagement with their environment [49]

- The application should focus on managing activities in daily life and/or engaging individuals living with AD in digital activities [50]

Privacy and security

- Caregivers should be able to screen the contents of whomever they are providing care for [49]
- Only authorised individuals should be able to access data stored in the application [50]

Contents

- Important information on the interface that needs to be remembered by the user should be minimised [47]–[51]
  Interfaces that are intended for people suffering from Alzheimer's should account for decreasing short term memory capabilities [47], [49]
- Modern computer jargon or other complicated language should be avoided [47]–[49], [51]
  Most elderly people tend to be inexperienced with using computers and less knowledgeable on modern terms related to computers and other digital systems. For people suffering from Alzheimer's who already face struggles with diction, understanding computer jargon will be even harder [47]; understanding more difficult linguistic concepts such as double negations, abbreviations, complicated sentence structures are also difficult [48]
- Include multi-media contents [48], [49]
- The application should include a variety of content to avoid repetition for caregivers [49]

Use of audio

- Natural male voices are preferred for auditory messages [48]
- Make sure that pauses occur after every spoken sentence and that auditory feedback has a long duration [48]
- Both pitch and volume should be considered when designing audio [51]

Hardware requirements

- Precise movements should be avoided [47], [48], [50], [51]
  People suffering from Alzheimer's usually struggle with reduced motor skills. Actions that require fine motor movements such as manoeuvring scroll bars, typing on small screens or "pinch-zoom" functions are difficult actions for such users to properly conduct [47], [48]
- Use a touch screen [48]–[50]
- Allow the same outcome for different types of touches [49]
  People suffering from Alzheimer's might be physically impaired as a result of decreased motor skills, so allowing room for touches that reflect this impairment is important in creating an application [49]
- Use a mobile system [49], [50]
- Use a robust hardware platform [49]

11.2 All reminiscence tools

Memory triggers, alphabetical

- Cultural phenomenons from an individual's past [54]
  This trigger depends on image recognition and long-term memory. Image recognition takes place in the visual area of the brain in the occipital lobe, and memory processing largely takes place in the hippocampus [62], [71].

- Examination of arts and crafts projects that were made by an individual, or were of significance at some point in their life [52]
  This trigger also depends on image recognition and long-term memory. A functioning occipital lobe and hippocampus are necessary for this to be effective [62], [71].

- Living through a situation a person has experienced before [11]
  This trigger depends on image recognition, hearing, skin sensations, smell, and long-term memory. Apart from the occipital lobe and hippocampus the auditory area in the temporal lobe, sensory area in the parietal lobe,and olfactory area in the inner temporal lobe are important [62], [71].

- Mementos that were relevant to a person's life [52], [54], [56]
  This trigger depends on image and object recognition and long-term memory. A functioning occipital lobe and hippocampus are necessary for this to be effective, but the somatosensory association area in the parietal lobe also plays an important role [62], [71].

- Music that was relevant to a person's life [4], [27], [28], [54], [55]
  This trigger depends on hearing rather than image recognition, next to long-term memory. Therefore the hippocampus and auditory area in the temporal lobe of the brain are necessary for this trigger [62], [71].

- Other people relevant to a person's life [54]
  This trigger once again mostly depends on image recognition and long-term memory - effectiveness of this trigger depends on the hippocampus and occipital lobe. However, different people might become relevant at a later stage of a person's life; therefore also making short-term memory, which is stored in the association area in the temporal lobe, is also important [62], [71].

- Pictures and/or images containing content relevant to a person's life [4], [27], [54]–[56]
  This trigger once again mostly depends on image recognition, short and long-term memory - effectiveness of this trigger depends on the hippocampus, temporal lobe, and occipital lobe [62], [71].

- Posing questions about an individual's life [28], [53]
  The effectiveness of this trigger depends on short and long-term memory, but also on Wernicke's area which handles language comprehension. Wernicke's area is found in the parietal lobe, and the occipital lobe and hippocampus remain important [62], [71].

- Practicing a relaxing, creative or sports activity an individual has practiced in the past [11], [28], [29]
  This trigger depends on almost all areas of the brain. However, long-term memory is by far the most important as that can then trigger other relevant brain functions based on existing engram pathways; thus making the hippocampus the primary brain area of importance for this trigger to be effective [62], [71].

- (Re)creating a physical environment that held personal significance at a specific event or period in a person's life [11]
  Image perception, short and long-term memory and spatial awareness regulated by the parietal lobe are of importance for this trigger to be effective. So in addition to the parietal lobe, the occipital lobe and hippocampus are once again important [62], [71].

- The taste and/or smell of foods or drinks that an individual might associate with an important event or period from their life [11], [28]
  The hippocampus and olfactory area in the inner temporal lobe are important for processing triggers related to smell and taste in retrieving long-term memories [62], [71].

- Videos containing content relevant to a person's life [27], [54]
  Videos are a combination of images and audio, therefore making both the visual area in the occipital lobe and auditory area in the temporal lobe are important next to the hippocampus [62], [71].

- Words chosen by the individual suffering from Alzheimer's [4], [56]
  Wernicke's area and the visual area in the occipital lobe are important for words to be able to trigger a memory. Short and long-term memory are important for this as well, so the association area in the temporal lobe and hippocampus also play a role [62], [71].

Memory triggers, removed

An initial selection of memory triggers was made based on whether they could work on a digital device or whether a digital device could offer tools to accommodate the trigger. The remaining list of triggers was then presented to a clinical psychologist expert, who was asked to prioritise them. A complete transcript of this interview can be found in Appendix 11.7. Triggers that were removed from the priority list due to their incompatibility with the digital domain were:

- Examination of arts and crafts projects that were made by an individual, or were of significance at some point in their life [52]
  This requires the presence of physical art objects, which a digital medium cannot provide.

- Living through a situation a person has experienced before [11]
  A physical environment is required for this, as well as the presentation of stimuli such as smell and touch which a digital medium cannot accommodate.

- Mementos that were relevant to a person's life [52], [54], [56]
  As was the case for arts and crafts projects, this requires physical objects to be examined. While a digital medium can provide a digital representation, it cannot confront a user with physical mementos.

- (Re)creating a physical environment that held personal significance at a specific event or period in a person's life [11]
  Whilst creating a virtual environment for this purpose is possible and has indeed been used by Woods & Subramaniam [4], (re)creating a physical environment is not possible.

- The taste and/or smell of foods or drinks that an individual might associate with an important event or period from their life [11], [28]
  Platforms that are currently suitable for a digital life story book application such as tablets, phones, computers or televisions cannot present a user with smell or taste. This makes it impossible for this trigger to be incorporated in a digital life story book application.

Apart from reminiscence activities, mental stimulation is also considered a valuable aspect of reminiscence [53], [54]. Therefore, a list of stimulation activities is also included in this appendix.

Stimulation activities

- Remembering a list [11], [32], [53]
- Remembering locations of objects in the house [11], [53]
- Pairing images [53]
- Focusing on specified stimuli and avoiding distractions [28], [53]
- Explaining similarities through abstraction [53]
- Completing visual patterns that have a missing element [53]
- Making a puzzle [53]
- Identifying synonyms and/or antonyms [53]
- Maintaining a diary [32]
- Word retrieval exercises [19], [32], [33]
- The loci method [11]

11.3 Expert interview information sheet

Information sheet ‘A Personalised Digital Memory Book to Improve Quality of Life for People with Alzheimer’s Disease’

You will receive a copy of this information sheet.

Purpose of the study
This interview is a part of a Creative Technology bachelor graduation project at the University of Twente, titled ‘A Personalised Digital Memory Book to Improve Quality of Life for People with Alzheimer’s Disease’.

This project aims to address a challenge faced by people living with Alzheimer’s and their caregivers. This challenge concerns the issue that caregivers struggle to properly communicate with someone in their environment who is suffering from Alzheimer’s. Alzheimer’s causes many problems in those living with it, including but not limited to memory loss and linguistic impairments. This then leads to a decrease in ability to interact with others and to maintain relationships with them. Especially in early stages of progression, those who have been diagnosed realise what is happening to them. It is common for those living with Alzheimer’s to suffer from depression, anxiety and low self-esteem as a result of their awareness of their brain functions slowly starting to fail. The solution that will be used to combat the identified issues is a digital life story book application to support people living with Alzheimer’s with reminiscence therapy, which aims to stimulate discussion and recollection of the past through memory triggers.

Procedures for withdrawal from the study
You can decide to withdraw from the interview or the study at any moment, without having to give a reason for this. Upon this decision all data that has been collected from you will be removed. You can withdraw by contacting the researcher either before, during, or after the interview. Before or after the interview the researcher can be contacted via email, and during the interview you can simply mention it to the researcher.

Use of personal information
All data that could be used to identify you (including the consent form you will be asked to sign) will be stored in an offline and safe location. The recording will not be made public and will only be accessible to the researcher. It will be deleted no more than a month after this interview has been conducted. Any transcripts that will be made from the recording will be made anonymous.

Usage of data during the graduation project
The data from this research will be stored in the local storage of the researcher’s laptop, from where it will not be moved until it is deleted. Only the researcher has access to this.

Any data you provide (from which your identity cannot be traced back to you) may be used in the final thesis of this graduation project. This thesis may be published online, where it will be universally accessible.

If you want any more information or have any questions about the study, you can contact the researcher at this email address: i.verschuren@student.utwente.nl.

Contact information for questions about your rights as a research participant
If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher, please contact the Secretary of the Ethics Committee of the Faculty of Electrical Engineering, Mathematics and Computer Science at the University of Twente at ethics-comm-ewi@utwente.nl.

11.4 Expert interview consent form

Consent form 'A Personalised Digital Memory Book to Improve Quality of Life for People with Alzheimer's Disease'

You will receive a copy of this informed consent form.

Please tick the appropriate boxes	**Yes**	**No**
I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.		
I understand that taking part in the study involves answering questions on a call through Microsoft Teams in a session of approximately 30 minutes.		
I consent to the interview being recorded. The recording will be transcribed for the processing of the results and deleted after the results have been processed (no later than one month after the date of signing).		
I understand that personal information collected about me that can identify me, such as my name, will not be shared with anyone apart from the researcher.		
I understand that an anonymised transcript of my interview will end up in the published report, which will not be traceable.		
I understand that the information I provide will be used for deciding and prioritising which memory triggers to focus on in the prototype, as well as improving its interface design.		

Signatures

Name of participant _____ Signature _____ Date _____

I have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

Name of researcher _____ Signature _____ Date _____

Contact information research team

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the Secretary of the Ethics Committee Information & Computer Science: ethicscommittee-CIS@utwente.nl.

For content-related questions, you can contact the research team.

- *Imke Verschuren, bachelor student Creative Technology and main researcher i.verschuren@student.utwente.nl*
- *Anis Hasliza Abu Hashim, lecturer (Human Media Interaction) and supervisor a.h.abuhashim@utwente.nl*

11.5 Prototype testing information brochure

Digitaal herinneringsboek

Informatiebrochure gebruiksonderzoek

Inhoudsopgave

Waar gaat het onderzoek over?

Wat: Een digitaal herinneringsboek

Voor wie: Mensen die moeten leven met de gevolgen van de ziekte van Alzheimer

Door wie: Een afstuderend bachelorstudent van de studie Creative Technology aan de Universiteit Twente

Waarom is het nodig: Communicatie met familie, vrienden en verzorgers wordt moeilijker. Relaties tussen mensen kunnen hierdoor veranderen.

Het kan erg lastig zijn voor iemand die leeft met een Alzheimer-diagnose dat hun relatie met vrienden, familie en verzorgers verandert. Herinneringsboeken worden steeds vaker gebruikt om die relatie te verbeteren door communicatie makkelijker te maken.

Momenteel zijn dit soort boeken vaak van papier gemaakt, maar op papier kunnen niet alle herinneringen gedeeld worden. Filmpjes of muziek, allebei goede manieren om herinneringen op te halen, werken niet in een normaal boek.

Daarom willen we in dit onderzoek een digitale versie van zo'n herinneringsboek maken. Hierdoor kunnen we u hopelijk meer mogelijkheden aanbieden om terug te kijken op uw leven.

Waarom hebben we u nodig voor het onderzoek?

U weet zelf het beste wat u nodig heeft. Uw mening is daarom nodig. Graag nodigen wij u dan ook uit om samen met ons naar het digitale herinneringsboek te kijken en ons te vertellen wat u ervan vindt!

Wat vindt u van de bedachte oplossing? Op die vraag zoeken wij een antwoord. Uiteindelijk moet u het programma zelf gaan gebruiken en wij als onderzoekers weten natuurlijk minder goed wat u nodig heeft in een herinneringsboek. Daarom is het voor ons enorm belangrijk dat het digitale boek voor u duidelijk is.

Wij willen graag weten wat u van het digitale herinneringsboek vindt. Hierom zouden wij u graag uitnodigen om mee te helpen aan ons onderzoek. Wat we tijdens dit onderzoek precies gaan doen, kunt u lezen op de volgende pagina.

Wat gaat er gebeuren tijdens het onderzoek?

Wat: Vragen beantwoorden en meedenken over het ontwerp

Wie: Een persoon die symptomen vertoont van een vroeg stadium van Alzheimer en een familielid, vriend of zorgmedewerker waarmee zij een goede band hebben

Tijd: 30-45 minuten

Locatie: In overleg

Datum: In overleg

Tijdens het onderzoek gaat u met zijn tweeën en met de onderzoeker twee verschillende dingen doen. Er zullen u eerst wat vragen gesteld worden over uw geschiedenis met niet-medische behandelingen. Daarna gaan we kijken naar het ontwerp van het programma zelf.

U zult het ontwerp op papier te zien krijgen. Met behulp van plakkertjes krijgt u vervolgens zelf de mogelijkheid om het ontwerp zelf te veranderen. Ondertussen zal de onderzoeker een aantal vragen stellen over wat u van het ontwerp vindt.

De sessie zal worden opgenomen en er zullen fotos worden gemaakt van uw veranderingen aan het ontwerp.

Voor, tijdens of na het onderzoek kunt u altijd kiezen om toch niet meer mee te doen.

Het is uw verantwoordelijkheid om te bepalen wanneer u niet meer mee wilt doen aan het onderzoek. U wordt daarom verzocht om tijdens de sessie goed op elkaar te letten en indien nodig namens de ander het experiment te pauzeren of te beëindigen.

Wat gaat er gebeuren met uw informatie?

Audio: Anoniem transcript in eindverslag, wordt vernietigd

Fotos: Anonieme bijlage in eindverslag

Verschillende soorten persoonlijke informatie zullen verzameld worden tijdens de sessie. Voor uw antwoorden op de vragen zal een audio-opname gemaakt worden en voor uw veranderingen aan het ontwerp worden fotos gemaakt.

Audio-opname: Eerst wordt hier een transcript van gemaakt waar uw naam naar een nepnaam veranderd zal worden. Alle (delen van) antwoorden waaruit uw identiteit zou kunnen worden gehaald zullen niet in het transcript komen.

De opname zal alleen op de persoonlijke schijf van de computer van de onderzoeker opgeslagen worden, zodat deze nooit op het internet komt te staan.

Nadat het transcript is gemaakt zal de opname van de computer worden verwijderd, wat niet meer dan een maand na de sessie zal zijn.

Het transcript zelf zal als een bijlage in het eind-

verslag komen te staan.

Fotos: Alleen het papier wordt op de foto gezet, u zult zelf niet worden gefotografeerd.

Als u herkend zou kunnen worden door informatie die op het papier staat, zal die onleesbaar worden gemaakt.

De fotos zullen met een nepnaam als bijlage in het eindverslag worden gezet, uw naam wordt hier niet genoemd.

Voor de sessie begint zult u een formulier krijgen waarop u officieel akkoord moet geven om aan de sessie mee te doen en voor het verwerken van uw data. Dit formulier is ook te vinden op pagina 8.

De persoon die geen diagnose van Alzheimer heeft zal gevraagd worden beide formulieren te ondertekenen. Zorg dat u van tevoren onderling duidelijk heeft afgesproken dat u allebei akkoord gaat.

Als u toch niet meer mee wilt doen aan het onderzoek kunt u dit nog laten weten tot 1 juli 2023. Dan zullen alle gegevens die verzameld zijn tijdens het onderzoek verwijderd worden, dus ook het transcript en de fotos.

Na 1 juli 2023 zal het eindverslag gepubliceerd worden op het internet en kunnen de onderzoekers niet meer garanderen dat uw bijdragen volledig verwijderd kunnen worden.

Toestemmingsovereenkomst

Zie volgende pagina.

U krijgt deze overeenkomst nog een keer geprint voor de sessie begint, maar lees er toch van tevoren vast goed doorheen. Dan komt u bij de sessie niet voor verrassingen te staan. De verzorger zal gevraagd worden om voor jullie beide het formulier te ondertekenen. Ook zult u allebei nog een keer om mondeling akkoord gevraagd worden.

Toestemmingsovereenkomst 'A Personalised Digital Memory Book to Improve Quality of Life for People with Alzheimer's Disease'

U zult een kopie van deze overeenkomst voor geïnformeerde toestemming ontvangen.

Markeer aub het bijpassende vakje	**Ja**	**Nee**
Ik heb de informatie in de brochure 'Digitaal herinneringsboek' gelezen en begrepen, of het is aan mij voorgelezen. Ik ben in staat geweest om vragen over de studie te stellen en deze zijn naar mijn tevredenheid beantwoord.		
Ik accepteer dat ik vrijwillig deelneem aan deze studie en dat ik op elk moment kan weigeren om vragen te beantwoorden of nog deel te nemen aan de studie zonder hiervoor een reden te geven.		
Ik begrijp dat deelname aan de studie inhoudt dat ik vragen beantwoord en feedback geef op een laag-realistisch prototype in een offline sessie waar de onderzoeker ook aanwezig zal zijn.		
Ik accepteer dat dit interview opgenomen wordt. De opname zal worden getranscribeerd en hierna verwijderd, dit zal niet later dan een maand na ondertekenen van dit document gebeuren.		
Ik accepteer dat er fotos gemaakt zullen worden van mijn wijzigingen aan het prototype.		
Ik begrijp dat persoonlijke informatie waaruit mijn identiteit afgeleid zou kunnen worden, zoals mijn naam, met niemand behalve de onderzoeker gedeeld zal worden.		
Ik begrijp dat een geanonimiseerd transcript van mijn interview in het gepubliceerde verslag zal komen, welke niet naar mij getraceerd kan worden.		
Ik begrijp dat de fotos van mijn wijzigingen aan het prototype in het gepubliceerde verslag zullen komen. Deze kunnen niet naar mij getraceerd worden.		
Ik begrijp dat de informatie die ik verstrek gebruikt zal worden voor het bepalen welke geheugenactivators opgenomen zullen worden in het prototype, evenals het verbeteren van de interface van dit prototype.		

Contactgegevens

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Supervisor: Anis Hasliza Abu Hashim

Voor vragen of opmerkingen over dit onderzoek of het project in het algemeen kunt u terecht bij Imke Verschuren. Aan deze informatiebrochure kunnen geen rechten worden ontleend, het is slechts voor informatiedoeleinden bestemd.

11.6 Prototype testing consent form

Consent form ‘A Personalised Digital Memory Book to Improve Quality of Life for People with Alzheimer’s Disease’

You will receive a copy of this informed consent form.

Please tick the appropriate boxes	**Yes**	**No**
I have read and understood the study information provided in the information brochure with the name 'Digitaal herinneringsboek', or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.		
I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.		
I understand that taking part in the study involves answering questions and giving feedback on a low fidelity prototype during an in-persion session with the researcher.		
I consent to the interview being recorded. The recording will be transcribed for the processing of the results and deleted after the results have been processed (no later than one month after the date of signing).		
I consent to photographs being taken of my adjustments to the prototype.		
I understand that personal information collected about me that can identify me, such as my name, will not be shared with anyone apart from the researcher.		
I understand that an anonymised transcript of my interview will end up in the published report, which will not be traceable.		
I understand that the photographs of my adjustments to the prototype will end up in the published report. They will not be traceable.		
I understand that the information I provide will be used for deciding which memory triggers to focus on in the prototype, as well as improving its interface design.		

Signatures

Name of participant Signature Date

_____ _____ _____

I have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

Name of researcher Signature Date

_____ _____ _____

Contact information research team

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please

contact the Secretary of the Ethics Committee Information & Computer Science: ethicscommittee-CIS@utwente.nl.

For content-related questions, you can contact the research team.

- *Imke Verschuren, bachelor student Creative Technology and main researcher i.verschuren@student.utwente.nl*
- *Anis Hasliza Abu Hashim, lecturer (Human Media Interaction) and supervisor a.h.abuhashim@utwente.nl*

11.7 Interview with a clinical psychologist expert

For this graduation project, an interview was held with a clinical psychologist specialising in the elderly and dementia. A written version of this interview can be found in this section. It should be noted that this interview was not transcribed verbatim. Some paraphrasing liberties were taken to increase readability. This interview has been used as an additional source in this thesis and can be found as [63] in the reference list.

1. Could you explain how Alzheimer's affects the brain throughout various stages of the disease, and in which order parts of the brain are affected?
   I think it is well-documented that Alzheimer's disease is a very gradual decline of cognitive function. In the earliest stage it starts with forgetfulness, misplacing things... And gradually, the progress of cognitive decline really impacts the daily living activities of someone suffering from Alzheimer's. So when the progress gets worse, they need full-time care - someone to look after them 24 hours of the day to assist them with daily living activities. So with the decline of cognition and daily living, they become dependent on others. Memory, the hippocampus, is usually the first area of the brain to be affected. Registering information, short-term memory... We also call it working memory. When that part is disturbed, new information cannot be registered. You could ask them 'who visited you yesterday?' or 'what did you have for breakfast this morning?', and they would not be able to recall it due to the affected short-term memory. But especially during the mild and modest stage, if you ask them about remote memories (so for example where they went to school, who their friends were) they can tell you a lot of information about that. So really, when short-term memory is affected, we talk about the hippocampus. Each individual is very unique in how Alzheimer's further affects the brain. It is not only dependent on the disease, but it is a combination of a lot of factors. For example, when we take a person's own life history, they might have other medical conditions apart from Alzheimer's. Someone might have diabetes, hyper-pressure, some other cardiovascular illness... A lot of other factors determine how Alzheimer's disease manifests itself. It is different and unique for each individual. Usually at very severe stages people have lost their motor functions, but this varies per person.

2. What do you think the benefits of a life story book are in treatment of persons suffering from Alzheimer's?
   I personally believe that life story books are one of the best approaches for treating people suffering from Alzheimer's. I think the best treatment for people suffering from Alzheimer's is reminiscence work. That really means focusing on what they can do, rather than what they cannot. For this we usually focus on long-term memories, so life story book is a good way to engage people with Alzheimer's. It gives them a way to focus on their life story and it helps them to trigger a lot of conversations, so I really like life story books.

3. What functionalities would you expect in a digital life story book application?
   In a digital life story book one usually sees music, videos, some dialogues... We even sometimes record people telling their own stories. When given a choice between a hard copy life story book and a digital life story book, six out of six people chose the digital option. This is because the analog life story book is only visual, so it is limited to what you can see. Digital life story books can stimulate multiple senses to trigger good memories.

4. In terms of photographs, videos, music, et cetera, do you have any ideas on which might trigger the strongest memories or which might be most useful in triggering memories?
   Personalised photos generate a lot of memories. Pictures from school, outings, wedding photos... We need to be very careful, we need to have a very good understanding of someone's life history. We should work with family members, children and spouses to better understand a person's life. Sometimes family members will prefer it if certain photos are not included, because for example someone in it has passed away. So then we should not include it in someone's life story book, because it will trigger sad memories. In my experience, personal photographs are really most effective. Someone could have a hobby of drawing or painting; we might include that as something in their life story book, as that can also trigger a lot of thoughts or happiness.

5. What do you think people suffering from Alzheimer's are currently missing in nonpharmacological reminiscence treatment?

I think there is still a lot of work to be done in this field. We want to focus on good effects for people suffering from Alzheimer's. For example, when we would see an life story book one or two times we become used to it and it becomes repetitive. But for someone suffering from Alzheimer's, opening their book will be a surprise every time because it is something new for them. Every time they see it they get excited, because they do not remember what happened yesterday. So then they want to tell a lot of their stories again. But the problem is that we need to maintain this effect, and how do we do that? The caregiver will not open the life story book every day, someone may not be there every day to go through the life story book together with the person suffering from Alzheimer's. It would be great if we can find a way to sustain the positive effects of life story books. So really something that people can use themselves without depending on others.

6. At what level would you estimate the baseline knowledge of individuals suffering from Alzheimer's in mild phases?
   This is very important. We talk a lot about the reminiscence bump, which is an important aspect because we recall a lot of memories from that period. From ages 18 to 40 a lot of things happen like our first relationship, finding jobs, studying, buying your first car, your first house, things like that... I agree that those are important, but at the same time I think that the early parts of their life such as childhood are also important. So for example, memories from when someone was four or five years old. Those memories are very well-preserved in their long-term memory, so we should not limit ourselves to only reminiscing with materials from a certain time period of someone's life. When we bring back memories, we should do it in chronological order rather than jumping around. For example childhood, then the childhood school, then hobbies, then interests... We slowly want to trigger them in order to help their memories move forward to connect all of this. And the period is also very important, it must match. When a person is 70 or 80 years old today and we look back, the 40s or 50s would have been when they started going to school. But then they grow up. So what happened during this period is also very useful and important. It is not only about someone's personal experiences, cultural events are also very important - what movies were people watching, what music were they listening to, what big events were happening at the time... So even though a memory is not personal, it might be very significant. Including those things is also very important. You also have to consider the reminiscence bump; a lot of events happen in the 18-40 period of a person's life, like their first relationship, getting a job, going to college, buying a car, buying a house, having children... Including this period is very important.

7. I have identified the following functionalities based on literature, which do you think is most important or would you consider some of them redundant?

   - Cultural phenomenons
   - Music
   - Other people significant to an individual's life
   - Pictures/images
   - Questions about someone's life
   - Encouraging the practice of past activities such as hobbies
   - Videos
   - Words

   I think all of these are very important. In what way are you planning to offer auditory cues?

   I am not sure yet. My plan is to either have someone close to the user record narration, or to work with professional voice actors because some research has been done on certain types of voices being preferable. Would you have any suggestions?

The decision should really come from the user. Per different piece of content they might want someone else to narrate it, for example. Offering them choices is really the most important; so letting their daughter record a part, letting their wife record a voice-over for another section...

8. What should I keep in mind when designing a digital life story book application for people suffering from Alzheimer's?
   All decisions should come from the person suffering from Alzheimer's, so letting people know that they have choices is important. Having the person suffering from Alzheimer's be the director of their own life story book is a big thing in this. For example, someone can choose to have their daughter record a voice-over for the life story book and have their wife record a voice-over for a specific memory. We should be secondary in the process, having them decide on the contents of their own life story book which we then facilitate. It is also important to speak to the caregivers or family members, so which topics and/or photos should we avoid in order to not set off bad memories? And how are you planning on organising the application? By chronological order?

   Right now it is not based on a chronological timeline, but I have been considering whether I should change that.

9. Do you have any tips on working with people suffering from Alzheimer's for a user test of a prototype for a digital life story book application?
   Testing the prototype in small parts. You ask them to look at it, you change what they want to see changed and then you bring it back to them and test it again.

10. Is there anything else you think I should keep in mind when designing a digital life story book application for people suffering from Alzheimer's?
    Based on this interview, I feel confident that you are on the right track and that you will create something good. I hope that one day people can actually use this application.

11.8 Prototype testing session transcripts

During each user testing session an audio recording was made. These recordings were then transcribed in Dutch and a paraphrased English translation of all sessions has been provided below. After transcription, all recordings of the sessions were destroyed according to European GDPR guidelines [67].

Dyad 1 - Mark and Paula

Interviewer: Do you have any experience with or knowledge about reminiscence therapy or life story books?

Mark: I have no experience with either of those things myself.
Paula: I have seen it with other people, but I have no experience with it myself.

Interviewer: What kind(s) of things would you like to look back on when you are using a life story book?

Mark: At least pictures and text that help you recognise the situation at the time, so contextualising is important.
Paula: Music, books and photographs I think.

Interviewer: What do you think of the amount of options on the home page?

Paula: I think the number of options is good like this for older people, since we only learned to use computers at a later age. That makes it easier to forget again. I think the 'next' button goes to the table of contents and the 'explanation' to what you are supposed to do. I think the 'settings' button goes to settings, but I think it would be good to also add the word 'settings' there.
Mark: Yeah, this one goes to what is coming. The explanation is not about the picture, that is just a profile picture.

Interviewer: If you want to look at an event, how would you do that?

Mark: I would like to click explanation first.
[The interviewer explains the application]
Paula: I think it would be good to start the application with a separate page for the explanation, and to show the homepage after. And then you could add the personal information, so the name and date of birth, to the homepage as well.
[The interviewer shows how to access the event page]

Interviewer: Was the navigation to this page logical, or could it be improved?

Paula: Yes, I think so.

Interviewer: What do you think of the amount of options offered on this page?

Mark: The pictures are a little confusing. The fact that there are multiple pictures is difficult. But I really like the music, it could bring The Beatles back - *I'll Take Your Hand*!
Paula: Having a hidden menu for the pictures would really help with that confusion. But I am not sure if the play button for the music is clear; it would be good to give an explanation on how to play the music.

Interviewer: How would you get back to the first page from the event page?

[Mark immediately touches the home button]

Mark: I expected this button to go back to the table of contents. When you are looking at an event, you want to be able to go back to the overview to select another event to look at.
Paula: I think the 'previous' button would also work.

Interviewer: How would you add a new event to the application?

Mark: I think I would go to the table of contents, that makes the most sense to me.

Interviewer: Once you get to the page to add an event, is everything clear?

Mark: The difference between adding media and external files is confusing. But I think it is good that the button to delete events is not easily accessible.
Paula: I think that you would need help to figure this out, but with the two of us we can do it quite easily. We also know where to ask for help if we need it. But changing the header to the 'add media' functionality to something like 'add files from my device' would already clear things up.

Interviewer: For each page, which changes would you suggest?

Paula: I would add an additional page at the start with an explanation. In general, I would add 'previous' and 'next' buttons to each page when applicable.
Paula: On the homepage you can then remove the explanation button, but I would keep the settings button here. I would also add the profile settings and information.
Mark: It would make more sense to add new events in the table of contents page, so adding a '+' button there would be helpful. Then you can fill the contents at the start and add stuff later.
Paula: The navigation order should be super clear.
Interviewer: There is a hand that starts blinking when no action is taken for a long time. For the homepage and table of contents this is about 10-15 seconds, for event pages this would be a lot longer - if at all.
Paula: For the table of contents, 10 seconds is very short. That is a page people might look at for a long time.
Mark: When something starts blinking too quickly, it could cause stress.
Mark+Paula: The event page is clear with the changes mentioned earlier, so hiding the extra pictures in a side menu and adding an explanation to the music play button.
Mark+Paula: The 'add event' settings page is also clear if the change of header is implemented.

Interviewer: Were there any functionalities that you missed on the events page?

Mark+Paula: No.

Interviewer: Do you think people could use this application for a longer amount of time?

Mark: The application is meant for people who already suffer from a bit of memory loss, so they might want to look at the application more than at photo albums which people would probably only open once in a period of ten years. So I think this application can be useful until the user's death.
Paula: I also think it really brings the book to life because of the videos and music.

Interviewer: Do you think that this application could improve communication between people suffering from Alzheimer's and the people around them?

Mark: I have heard that people suffering from dementia can talk about something in an old photo album for an entire day.

Paula: And there are a lot more options. Instead of having to look through multiple photo albums to find a specific picture you can simply look it up in the application.

Interviewer: Would a search function be useful for this?

Paula: Yes, if there are a lot of events in the application an index overview would be nice for someone who wants to use the application to find a specific event. For someone suffering from Alzheimer's I think it is less relevant. Even when you are in a more advanced stage and you cannot actively remember the events anymore, looking at something you did in the past can still be nice.

Dyad 2 - Ginny and Amanda

Interviewer: Do you have any experience with or knowledge about Alzheimer's treatment?

Ginny: Yes, a little bit, with the mother of my sister in law. She was in a care home, but the care there was very uniform - they all received the same treatment. People were also trying to leave constantly or they were nagging each other. Old behaviours start to resurface, basically.
Amanda: I know that treatment can include singing songs to trigger memories and that sometimes speech experts work with people suffering from Alzheimer's.
Interviewer: Do you feel like something is missing from this treatment at the moment?

Ginny: I think that there should be more focus on what an individual needs. People have different backgrounds, so it is important to consider that in treatment plans.
Amanda: Going with the times. In care homes for older generations caregivers usually sing children's songs for example, but the new generation of people that is being diagnosed with Alzheimer's might be into very different things; they might prefer music like the Beatles. This generation lived in a completely different world than earlier generations, so treatment should reflect that.
Ginny: In my city, there is a care home focusing on people from Indonesia where they can do things together such as cooking. They share that cultural background, so it is nice for them to reminisce on that together.
Amanda: The same goes for people whose native language is not Dutch. My son's girlfriend used to work in a care home and she said that those people sometimes reverted to their native language and became unable to speak Dutch. They understood you, but could not talk back.
Ginny: Wishes, desires and interests are also important. It could be that I would prefer not to listen to The Beatles because it might give way to sentiments that could make me sad. I might want to listen to Arvo Part instead, for example, because it is a lot more peaceful.

Interviewer: What kinds of functionalities would you expect in a digital life story book?

Ginny: That is difficult to say. The most important thing is to trigger things that relate to your interests. I love art and history and like to stay involved so I would like to see things involving art, history and news.
Amanda: Yeah, if I were to hang an artwork by a certain painter in front of you...
Ginny: I would immediately start talking about it!
Amanda: I would use images, sounds, maybe smells... But that is difficult to do digitally.
Ginny: Not everything in the app needs to trigger emotions, sometimes triggering something as simple as 'oh, that's right, that's how it used to be' is just as nice.

Interviewer: What do you think of the amount of options on the homepage?

Amanda: More than enough.
Ginny: I agree, more would only be distracting.

Interviewer: What do you think each post-it does?

Ginny: That is quite easy. Settings are here, that one says explanation and the 'next' button is for when I am done looking at the homepage.
Amanda: I would expect the 'next' button somewhere else on the page, at the middle line or at the bottom.
Ginny: I do not really have a preference.

Interviewer: If you wanted to look at an event, how would you navigate to the right page?

Ginny+Amanda: By pressing 'next'.
Amanda: If you change the height of the 'previous' and 'next' buttons on the content page the risk of clicking the wrong thing increases. Mum, how would you continue?
Ginny: I would pick one or two events from this list by tapping them.

Interviewer: What do you think of the amount of options on the event page?

Amanda: There are quite a lot.
Ginny: I am quite confused by the little images next to the big one.
Ginny+Amanda: The music function is pretty clear, but it could be made more explicit - adding some more instructions and/or description would be nice.

Interviewer: What do you think each 'button' does?

Ginny: I did not know what to expect if I would press 'to start'.
Amanda: I expect it to go back to the homepage.
Ginny+Amanda: The 'contents' button is not clear to me.
Interviewer: Would changing it to 'table of contents' help?
Ginny: Yes, I think so.
Amanda: I think that it would also be beneficial to repeat the symbol on the button on the contents page itself. You could change the symbol as well to make it more clear. Swiping instead of clicking might also be nice to access next pages, because it is more similar to how you would use a book.
Ginny: I prefer to click, I am not a big fan of swiping.

Interviewer: How would you add a new event to the application?

Amanda: I would start by checking whether or not it really has not been included in the app yet. Mum, on the contents page, which button would you click now?
Ginny: Settings? Or...? I was just saying something, it was not very clear. Oh, I did it!
Interviewer: If you are surprised that you accessed the right page, the navigation should be clarified.
Amanda: I would expect a '+' here.

Interviewer: From a caregiver's perspective, do you think the settings page for adding an event is clear?

Ginny: Yes, it is very clear.

Amanda: Does 'about the app' also include a page with an explanation on how the application works? I think that would be good to add, then you do not have to go back to the homepage.

Interviewer: Do you have any suggestions for things you would like to change on each page?

Amanda: For the settings page, an explanation should be included in the 'about the app' section.

Interviewer: Is the settings page for the profile clear?

Ginny+Amanda: Yes.

Interviewer: On the event page you already gave some suggestions. You would find another symbol for the 'contents' button more logical as well as the text - table of contents, or something?

Ginny: Yes, or 'menu'.
Amanda: Or 'all events'.
Ginny: As for the symbol, I think a calendar would make sense.
Amanda: I agree.
Interviewer: I will make it into a heart for now, I will take a look at this.
Amanda: I think it could be beneficial to add buttons on the left and right of the big picture, to clarify that you can swap between the different pictures on one event page.

Interviewer: On the contents page you already said you expected a '+', is there anything else you would like to change apart from adding the symbol from the 'contents' button on the event page?

Ginny+Amanda: No, it is clear like this.

Interviewer: Is there anything you would like to change on the homepage?

Amanda: For me, showing the profile information is not of added value. I would put the name underneath the picture rather than on top of it.

Interviewer: Were you missing any functionalities on the event page?

Amanda: Voice recordings would be nice, then someone can sing a song or record a goodnight message.
Ginny: Doing this with a regular file is fine.

Interviewer: Do you think the application would be useful to someone suffering from Alzheimer's for a longer amount of time?

Ginny: I think so, you can access it continuously.
Amanda: And you can add and adjust things.
Ginny: Like one of those cute robots you can talk to when you get older. Integrating the app with such a robot would be really fun.
Amanda: Having an archive would also be useful, museums also do not display their full collection most of the time. It would be nice if events could be hidden but not deleted.

Interviewer: Do you think that this application could improve communication between people suffering from Alzheimer's and the people around them?

Ginny: I think so, as long as people use it actively. People should enjoy it and be able to interact with the application.
Interviewer: And how do you think it could improve communication?
Ginny: The self-reflection aspect I think.
Amanda: I also think there is added benefit for caregivers who are tired of hearing the same story over and over again.

Dyad 3 - Chris and Helen

Interviewer: Do you have any experience with or knowledge about Alzheimer's treatment?

Chris: Well, I have been in therapy for my infarction. There are also several people at the chaplaincy who definitely suffer from Alzheimer's.
Helen: We volunteer at a nursing home where we work with a lot of people who have been diagnosed with various types of dementia. And I volunteer at a communal living room, where I also meet people suffering from Alzheimer's. For the nursing home I took a course on how to interact with people suffering from Alzheimer'snd how to help them settle in. It was an evening course for volunteers there.
Interviewer: And through your volunteer work, did you ever really hear anything about their treatment?
Chris+Helen: No, not really.

Interviewer: What kinds of functionalities would you expect in a digital life story book?

Helen: Pictures from the past. Taken on vacations, for example. And videos.
Chris: Yes, videos. And historical events, buildings... Pictures, sport, music.

Interviewer: What do you think of the amount of options on the homepage?

Helen: The 'next' button is for the next page...
Chris: The 'explanation' button goes to the explanation...
Helen: And this one... Where does this go?
Interviewer: That goes to settings.
Helen: Oh, right, the settings symbol.
Chris: I think the amount of options on this page is fine.
Helen: It looks simple, so yes!

Interviewer: If you wanted to look at an event, how would you navigate to the right page?

Chris: Is there a 'next' button? I would think that we should press that one.
Chris+Helen: We would press an event block on the contents page to access it.
Helen: Or I would press 'next'.
Interviewer: That is also an option that would work.
Helen: And the 'to start' button would bring you back to the first page, right? When you think, 'I want to go back.'

Interviewer: What do you think of the amount of options on the event page?

Chris: That one is for music... It says 'artist', 'title', 'album name'... I don't really know what to expect there.
Helen: The 'to start' button goes to the first page again, right? I'm not sure what the little pictures on the right are.

Chris: I think the amount of options is fine. But I do wonder if you can get that many stories on one page.
Helen: It's one page, with one event, with one story.

Interviewer: What do you think each 'button' does?

Chris: With the tiny pictures I expect to see pictures of different aspects of one event. So for our wedding that would be the church, or city hall, or something.

Interviewer: So the functions on this page are clear to you?

Chris+Helen: Yes.

Interviewer: How would you add a new event to the application?

Helen: I would press 'contents'. Then I think we should go to settings.
Chris: Yeah, so do I. I'm not entirely sure what the 'external media' function is supposed to do.
Helen: You could add a link to something, so for example a travel agency where you booked a vacation. A promotional video from the cruise line or something like that.
Interviewer: The idea was actually more for including YouTube and Spotify links and such, but that could also definitely work. Is the rest of the screen clear?
Chris+Helen: Yes.

Interviewer: Do you have any suggestions for things you would like to change on the event page?

Chris+Helen: No, everything is clear.

Interviewer: Would you like to change anything about the settings page?

Chris+Helen: No, this page is clear too.

Interviewer: Would you like to change anything about the contents page? Helen, you mentioned the settings button, would it help to add the word 'settings' there?

Helen: Yes, definitely.
Chris+Helen: The settings page itself is clear.

Interviewer: Would you like to change anything about the home page, apart from adding 'settings' to the settings button?

Chris+Helen: No, everything is clear!
Interviewer: Wow, good to hear.

Interviewer: Were you still missing any functionalities on the event page?

Chris: No, I don't think so.
Helen: I agree, this is good.
Interviewer: It's good to see that everything is so clear to you both.
Helen: I used to work with computers a lot for my job, I think that helps a lot. I recognise all the symbols and stuff.

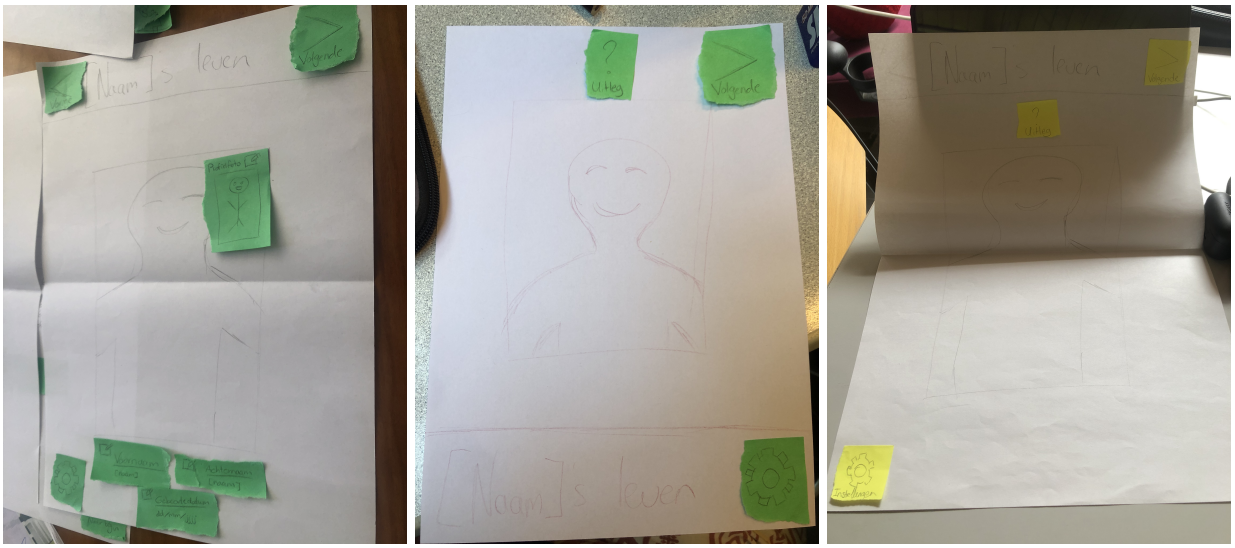
Interviewer: Do you think the application could be useful for a longer period of time?

Helen: I think, once you add a few events, you can definitely use it more.
Chris: It really depends on the type of event. We have an album with wedding photos, but we never really look at it. I think it helps a lot if it can be used to help people, to understand their context. So that if someone loves to cook, for example, that can be taken into account when caring for them and when trying to hold a conversation. I think it can help both people suffering from Alzheimer's and their caregivers to understand each other.

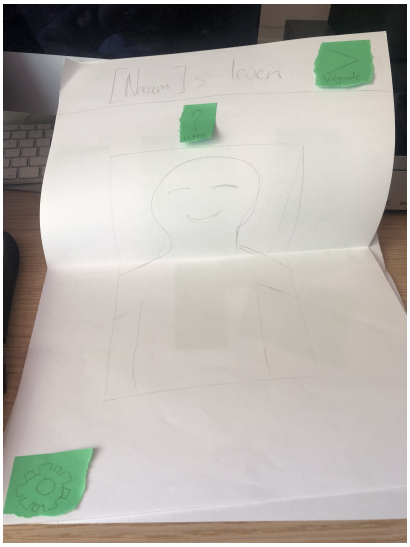
Interviewer: Do you think that the application could improve communication between those two parties?

Chris: I think so, as long as it is done responsibly. Privacy is very important. Certain information can be used to better understand a person and help them with problems, but this should stay within a limited circle of people.
Helen: I definitely think that it helps, once someone else helps the person suffering from Alzheimer's with starting up the application. I think that contact will become way more intense, and it provides a lot of prompts for questions. Such as, 'oh, what was that?', 'what was that like?', 'what kind of event?', 'what do you remember?'. It can definitely help start conversations.
Chris: Yes, definitely.

11.9 Prototype testing session final interfaces

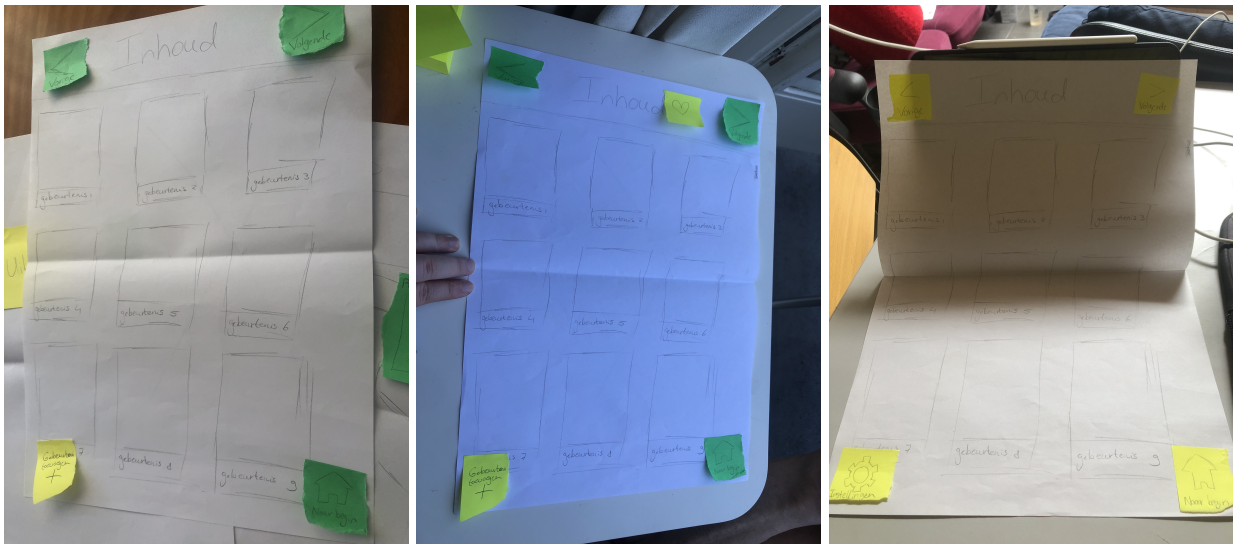


(a) Variations from the user testing sessions

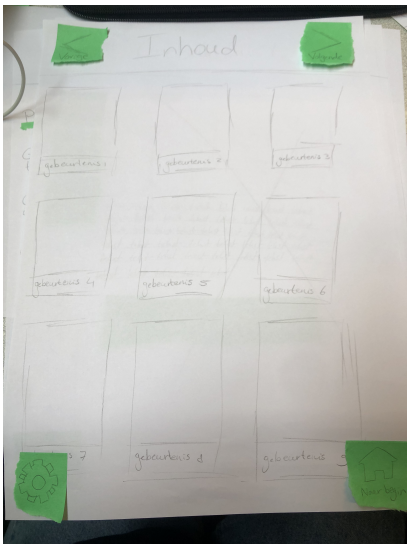


(b) Initial set-up

Figure 13: Homepage

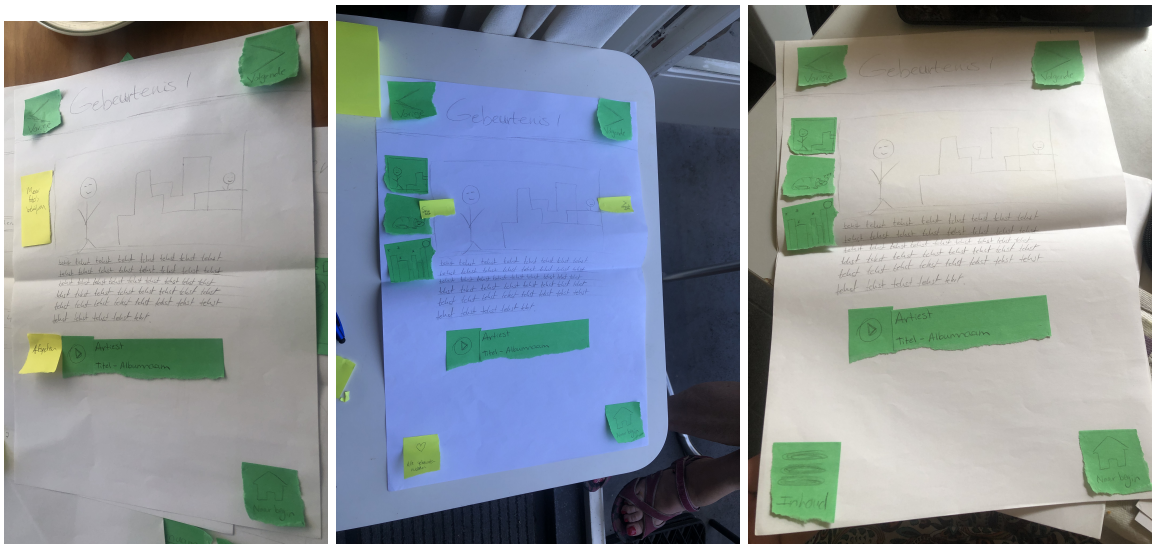


(a) Variations from the user testing sessions

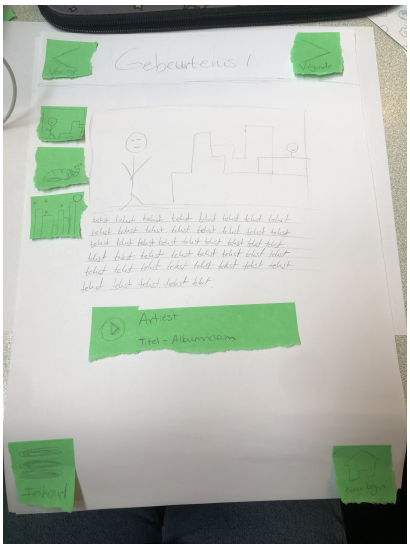


(b) Initial set-up

Figure 14: Table of contents

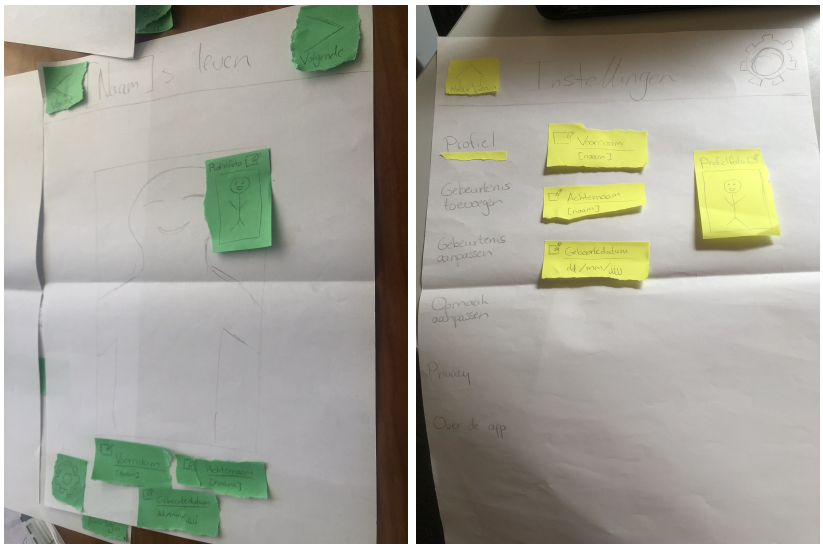


(a) Variations from the user testing sessions

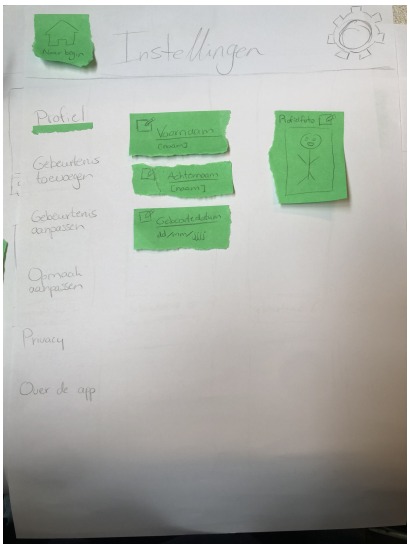


(b) Initial set-up

Figure 15: Event page

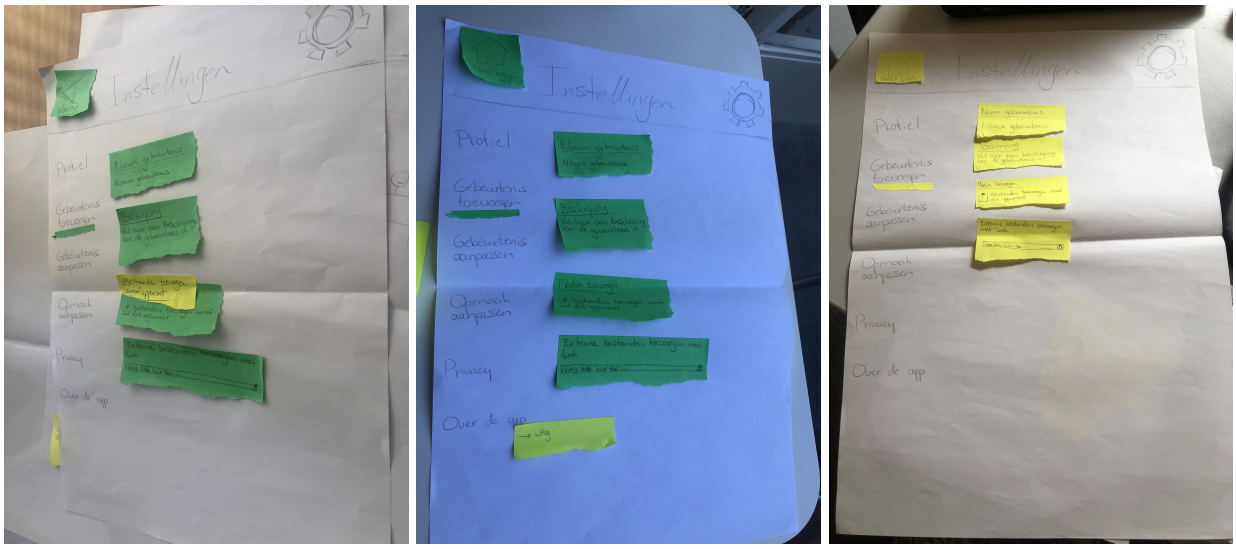


(a) Variations from the user testing sessions

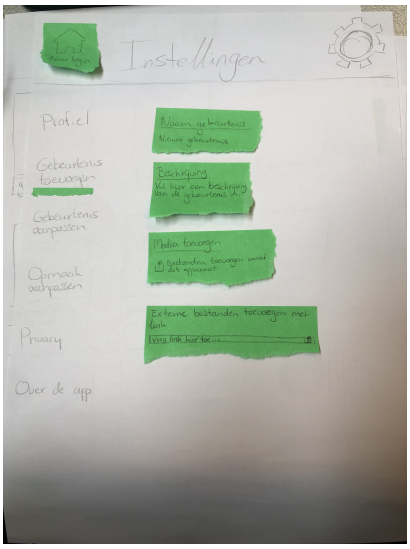


(b) Initial set-up

Figure 16: Settings: profile

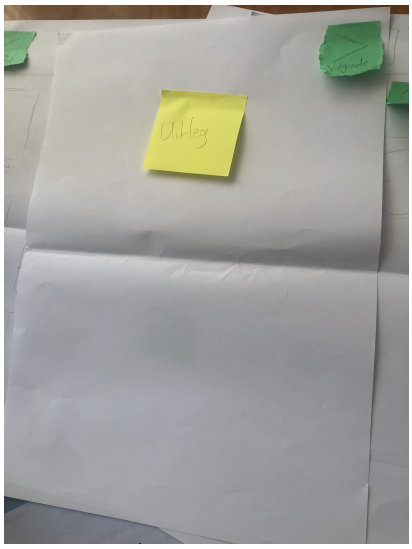


(a) Variations from the user testing sessions



(b) Initial set-up

Figure 17: Settings: add event



(a) Separate explanation page proposed by dyad 1

Figure 18: Other pages proposed by participants

11.10 Example of non-disclosure agreement for caregivers

Non-disclosure agreement, digital life story book application

For the activities I undertake regarding [user name]'s personal digital life story book application I hereby confirm that I will adhere to the literal contents as much as the intended meaning of the following rules and regulations.

1. I understand that with the activities I undertake when accessing [user name]'s personal digital life story book application I may receive access to their personal information. These include, but are not limited to: first and last name, date of birth, personal pictures, videos and audio files.
2. I acknowledge that use of this information is intended for reminiscence activities with me and [user name], and not for anyone's personal gain that is not in line with the outcomes of reminiscence work. I also acknowledge that that access to the application can enable me to perform various actions. I confirm that I will always use my access to the application to act according to the law.
3. I understand that information I get access to may be protected by the European GDPR (general data protection regulation). I confirm that I will treat this information in accordance with that regulation.
4. I confirm that I will never make public private information and/or knowledge that was gained via the information I got access to, without permission from [user name].

Compliance with these rules and regulations start the moment I gain access to any personal information, and continue also after termination of my access to the application.

Name and signature:

Date: