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**KEEPSAKEBOX: CAREGIVERS PLATFORM FOR SUPPORTING  
REMINISCENCE THERAPY**

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*To my family and friends.*



## Resumo

Com o aumento da população idosa por todo o mundo existem cada vez mais casos de demência, pois esta aparece mais neste grupo de pessoas. A demência é uma condição irreversível que é caracterizada pela perda de memória, problemas linguísticos, desorientação, mudanças de personalidade, dificuldades em atividades diárias, auto-negligência, sintomas psiquiátricos e comportamentos fora do normal. A terapia de reminiscência é um dos tratamentos não farmacológicos usado em pessoas com demência. Esta terapia ajuda pessoas a recordar experiências passadas e promove a comunicação entre as pessoas com demência e o resto do mundo, estimulando as suas memórias. A terapia de reminiscência convencional baseia-se em contar histórias e requer ativadores de memória, incluindo objetos domésticos e objetos relacionados com eventos passados. A pessoa que realiza este tipo de terapia deve ser treinada, e os objetos que funcionam como ativadores de memória devem ser preparados. Existem atualmente algumas soluções digitais para realizar a terapia de reminiscência e verificámos que a maior parte oferece a criação de sessões automáticas, o uso de diretrizes específicas para idosos e o uso de multimédia constituída por material personalizado relativamente à pessoa com demência como sendo características fundamentais deste tipo de aplicações. A privacidade também se mostrou ser um ponto fundamental, especialmente numa aplicação feita para pessoas mais idosas. Apesar de não serem tão considerados: o menor número de passos para realizar uma tarefa, as notificações, o design participativo e o fornecimento de ajuda e treino dos utilizadores também são importantes para o desenvolvimento de uma aplicação deste tipo. Para além disso, os cuidadores estão normalmente empregados a tempo inteiro e não conseguem estar sempre presentes para cuidar dos seus entes queridos. Tornando o processo de terapia mais rápido, os cuidadores poderão ter mais tempo para eles e seguir as pessoas com demência a seu cuidado.

Neste trabalho desenvolvemos uma plataforma digital para suportar a realização da terapia de reminiscência, de nome KeepsakeBox, e que teve em conta todos os aspetos referidos anteriormente. Para além disso, o nosso trabalho integra-se na solução para terapia de reminiscência de Alarcão et al. [1] como sendo a interface principal com que o cuidador, que é o utilizador principal da plataforma, vai interagir para realizar a terapia de reminiscência com as pessoas com demência. De momento a plataforma permite criar contas de cuidadores para que estes possam gerir a sua informação bem como as pessoas com demência de quem cuidam. É possível também editar a informação destas pessoas bem como adicionar conteúdo personalizado para cada uma delas, principalmente imagens que poderão ser depois utilizadas nas terapias e ajudar a alcançar um melhor estímulo. A partilha de cuidados de uma pessoa com demência entre vários cuidadores, bem como a sua informação também é suportado pela nossa plataforma, sendo um elemento essencial para o acompanhamento destas pessoas.

Para o desenvolvimento da plataforma começámos por efetuar um levantamento de requisitos. Este levantamento foi feito através de questionários online para cada um dos tipos de cuidador: formal e

informal. Com os dados obtidos destes questionários e considerando as diretrizes que identificámos para desenhar interfaces para idosos, sendo que estes são um dos nossos principais utilizadores, desenvolvemos um primeiro protótipo da plataforma. Nas entrevistas semi-estruturadas em videoconferência, ainda dentro deste levantamento de requisitos, esclarecemos algumas informações obtidas dos questionários. Os resultados obtidos deste levantamento de requisitos validaram a informação anteriormente recolhida pelo estudo realizado por Alarcão et al. [1] com cuidadores informais e acrescentaram novos requisitos funcionais relativamente aos cuidadores formais. Percebemos que os cuidadores formais precisam de uma ferramenta que lhes permita gerir todas as pessoas de quem cuidam, bem como a informação pessoal de cada uma delas. Para além disso, é importante poderem comunicar com outros cuidadores e partilhar os cuidados das pessoas de quem cuidam. Relativamente às sessões, percebemos que estes gostam de ter algum controlo na preparação da sessão, por isso deverão ser consideradas outras formas de preparação de uma sessão para além da automática. Os resultados das sessões, por sua vez, mostraram-se muito importantes para este tipo de cuidadores. Todos os requisitos funcionais identificados neste levantamento de requisitos irão ajudar os cuidadores a acompanhar as pessoas com demência, bem como a reduzir a sua carga de trabalho e stress. Desta forma melhora a qualidade de vida de ambos os cuidadores e das pessoas com demência, visto que esta plataforma irá ajudar a que estas pessoas tenham um melhor acompanhamento e a criar uma relação entre o cuidador e a pessoa com demência.

Para além disso, como um dos nossos objetivos era ter um desenho centrado no utilizador e envolvê-lo no desenvolvimento da plataforma, nestas entrevistas, os cuidadores formais e informais puderam remotamente experimentar o nosso protótipo da plataforma. Ao observar a interação dos cuidadores com o protótipo e também através dos seus comentários percebemos o que seria necessário mudar e acrescentar na plataforma de forma a alcançar as suas necessidades no que toca à realização da terapia de reminiscência e também a uma melhor usabilidade.

A plataforma está estruturada em três partes: *frontend*, *backend* e base de dados. Todas foram desenvolvidas neste trabalho, porém a base de dados e o *backend* foram adaptados e baseados no trabalho desenvolvido por Madalena et al. [34]. Adaptámos os conceitos da base de dados de forma a irem de encontro ao que os cuidadores precisam de gerir dentro da plataforma e realizar a terapia de reminiscência. Usámos o PostgreSQL [24] para incorporar a base de dados na nossa plataforma, e o *backend* foi feito utilizando o Spring Boot [29] em linguagem Java, e que consiste num serviço REST. Neste, mudámos alguns dos dados e *endpoints* a serem utilizados pelo *frontend* para enviar e receber pedidos. Para além disso adicionámos novos *endpoints* e serviços, tendo em conta as novas funcionalidades identificadas durante o levantamento de requisitos. O *frontend*, sendo a parte principal deste trabalho, foi desenvolvido em Angular [3] e teve em conta diretrizes identificadas para pessoas mais idosas no início do trabalho, relativamente à acessibilidade e ao desenho de aplicações web. Também mudámos algumas partes do desenho e implementámos algumas funcionalidades de acordo com a opinião dada pelos cuidadores ao nosso protótipo inicial.

Para finalizar o trabalho procedemos a uma avaliação remota da nossa plataforma contactando com vários cuidadores. Nesta fase só conseguimos recrutar cuidadores formais, que participaram remotamente em entrevistas individuais, onde puderam interagir com a plataforma e comentar o processo, ou em *focus groups*, onde foi feita uma apresentação da plataforma para vários cuidadores, e estes puderam comentar e dar opiniões sobre a mesma. No final destas sessões experimentais pedimos aos cuidado-



res para responderem a um questionário de avaliação relativamente à usabilidade (SUS) e outro sobre a utilidade (TAM). A opinião geral dos cuidadores relativamente à plataforma foi bastante positiva bem como em relação às ideias que irão ser implementadas de futuro. A pontuação do questionário SUS foi em média de 85, o que demonstra que a nossa plataforma está acima da média em termos de usabilidade. Para além disso o questionário TAM também teve um resultado bastante positivo e demonstra que no geral a maior parte dos cuidadores acharam a plataforma útil para ajudar a realizar a terapia de reminiscência.

Futuras versões da plataforma deverão começar por implementar as funcionalidades relativas à execução e aos resultados das sessões. Para além disso, todas as opiniões dadas na avaliação final pelos cuidadores, bem como todas as funcionalidades identificadas como sendo importantes de implementar deverão ser consideradas.

**Palavras-chave:** Cuidadores; Demência; Plataforma Digital; Terapia de Reminiscência; Levantamento de Requisitos



## Abstract

With the increase of older population all over the world, there are consequently more cases of dementia that mostly appear on this group of people. Dementia is an irreversible condition that is characterized by memory loss, language impairment, disorientation, changes in personality, difficulties with activities of daily living, self-neglect, psychiatric symptoms, and out-of character behaviour. Reminiscence therapy is one of the non-pharmacological treatments used for dementia. It helps people recall their past experiences and promotes communication between people with dementia and the rest of the world, by stimulating their memories. In this work we developed a digital platform, called KeepsakeBox, with the objective to support this type of therapy. The platform is to be used by caregivers to perform reminiscence therapy with people with dementia. It allows caregivers to create their accounts, manage their information and also manage the people with dementia they care for, and edit people with dementia personal data, such as uploading personal images, which can help achieve better stimulus when therapy is performed with them. Sharing the care of people with dementia is also possible. The platform was designed by considering guidelines for older people, as they are one of our main users, and a set of requirements collected through surveys and interviews. As we considered a user-centered design, the prototypes of our platform were evaluated remotely by formal and informal caregivers so we could understand if our platform was meeting their needs. Their feedback helped us improve the platform. After applying all changes identified we got our platform that was evaluated remotely by formal caregivers. The results from this final evaluation were very positive as caregivers liked the platform and the results from SUS showed an average score of 85 which shows that our platform is easy to use. The results from the TAM questionnaire in terms of usefulness also showed that caregivers would like to use this platform to help perform reminiscence therapy. Future versions should implement session related functionalities alongside the ones identified on this final evaluation.

**Keywords:** Caregivers; Dementia; Digital Platform; Reminiscence Therapy; Requirements Gathering



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# Chapter 1

## Introduction

In this chapter we present what motivated us to do this platform and what are its main objectives. We also briefly explain our developed solution. The contributions of our work are also detailed in this chapter. Finally, the document structure is described in the last section.

### 1.1 Motivation

With the increasing number of older population all over the world there are consequently more cases of dementia that mostly appear on this group of people. Dementia is an irreversible condition that is characterized by memory loss, language impairment, disorientation, changes in personality, difficulties with activities of daily living, self-neglect, psychiatric symptoms and out-of-character behaviour [1].

Reminiscence therapy is one of the non-pharmacological treatments used for dementia. This therapy helps people recall their past experiences, adds meaning to their lives and promotes communication between the person with dementia and the rest of the world, by stimulating their memories by normally using personal items and information which function as memory triggers [1, 19].

In the next chapter more details will be given about people with dementia and this therapy. For now it is important to understand that our work aims to improve this therapy from the caregivers perspective. This therapy usually takes a lot of time to be executed by a caregiver and automating the process can make it quicker and the collected results more useful for following the person with dementia's behaviour and the evolution of dementia disease. Informal caregivers often have full-time jobs and do not have that many time to prepare sessions and perform therapy with the persons they care for. On the other hand, formal caregivers perform therapy as their job and do not have the same problems as informal caregivers. However, they usually care for more people with dementia at a time and the process of preparing and performing the therapy sessions can be facilitated.

### 1.2 Objectives

Our main objective is to create a platform that can help both formal and informal caregivers to reduce their time and burden on managing, gathering and saving the materials needed to prepare and create a therapy session. This way, caregivers will be able to have all their data about the persons they care for at one place and it can be used to generate each person's therapy session. As the platform will use algorithms to create therapy sessions, this data can be used to help create those sessions as they are more

personalized and help caregivers to trigger more memories in people with dementia. It will also help caregivers to manage all the people with dementia they care for and will allow them to share the care of a person between them, so both know the same information and better track a person's disease progression. With this option different caregivers will be able to insert personal content about a person with dementia into the platform facilitating the gathering of those materials, principally for formal caregivers.

Informing informal caregivers about the benefits and in what consists reminiscence therapy is also very important as some of them do not know what reminiscence therapy is. We want to reach out to them by making this therapy more accessible and convenient to all caregivers as it can be a major benefit to help them care for people with dementia. We will help informal caregivers who do not have professional education in these areas to execute reminiscence therapy at home with their loved ones as a complement to formal monitoring. This will be a benefit to the well-being of the people with dementia and will help caregivers, specially the informal ones, so they feel better while caring for their loved ones.

We want to create an helpful tool for caregivers to perform reminiscence therapy and follow up the people with dementia they care for as well as their disease progression. We also want the caregivers to be able to communicate within our platform and discuss ideas about the persons at their care so they can have a better follow up. This will generate different points of view and caregivers can discuss a person's treatment by using our platform and also will enable the follow up to be more consistent and easier by different caregivers at the same time. By enabling multiple caregivers to care for a person at the same time we can help institutions who care for people with dementia reach out the most of them by facilitating the management of people with dementia and also the execution of therapy with a lot of different persons. This also applies to formal caregivers who care for several persons at the same time.

Personal information was also considered very important to reach our objective as it showed to be relevant and important to the person with dementia and is preferred by all caregivers. By using and consulting this personalized content, they will be able to achieve a better interaction when performing therapy session. By knowing a person's biographical data and images' details they will also be able to create an interaction with the people with dementia performing therapy about those topics, and this can help to achieve a better reminiscence. This will help caregivers perform therapy even when they do not know the person's life, which mostly happen on formal caregivers case.

Although we already had some user requirements that were defined from Alarcão et al. work which were more about people with dementia and informal caregivers follow up [1], we also needed to identify other user requirements more about the design of our platform and formal caregivers follow up, although informal ones were also involved. So another objective of our work is to execute a requirements gathering with caregivers who would use our platform so we can understand their needs and validate the design and functionalities of our platform. Approaching caregivers is also important as it will help us reach an user-centered design, so the platform can reach their needs, be easy to use and be useful to execute reminiscence therapy.

### **1.3 Developed Solution**

In this work we developed a platform for supporting reminiscence therapy based on the user requirements gathered by Alarcão et al. [1] and by our requirements gathering. We also adapted the work

developed by Vagos et al. [34] regarding the database and backend services needed to store and manage all the information needed for executing this therapy. Prototypes of this solution were shown when we were connecting with caregivers so we could clarify some aspects about our platform's design and understand if we were meeting their needs as a caregiver in terms of functionalities to perform this therapy. The platform described in this document allows caregivers to store and manage the data that will be used to execute personalized and generic reminiscence therapy in the future, and follow persons with dementia evolution over time. All caregivers, formal or informal, will be able to register in our platform and they will also be able to create registers for all the people with dementia they care for, which will have associated their sessions history, session results and personal information. This way they are able to manage all the persons they care for and will be also able to share that persons' care with other caregivers and message them.

It is also important to note that normally informal caregivers are the persons' companion or children. Knowing this, we have to assume that there may be older people interacting with our platform as their companions should be about the same age, which should be already an older age. So we designed our platform focusing on older people as they may not have the same ease of interaction with these platforms as younger ones, and these last ones can adapt more easily to a platform designed for older people. Imtiaz et al. also referred that usually the people that would use this type of applications are older adults and the design of an user interface should be user-friendly and consider all difficulties that older people/caregivers could have using these applications [14].

We conducted an online survey with 136 caregivers to gather information about caregivers needs and requirements. We uncovered aspects that shown to be important on the design of our platform. With that data and the previous ones obtained from Alarcão et al. surveys [1] and Vagos et al. work [34] we developed a first prototype of the platform. Some changes to the needed functionalities were implemented and new ones were added regarding the previous work, so caregivers could manage the information for reminiscence therapy and perform it in the future. A new design of the database given all the needed relations and all new forms of data treatment was made. As a result, the backend, which consists on a RESTful (Representational State Transfer API) web service, was restructured so the requests could access the new design of the database and fronted requests are supported.

The prototype developed was shown to caregivers in an interview so we could receive their feedback. We designed an interview script with some aspects we wanted to clarify from the surveys and a section where the caregivers would have a first interaction with the prototype by remote control, as we could not conduct face-to-face interviews due to the pandemic of COVID-19. The requirements gathering and the first interactions helped us calibrate some aspects within caregiver's needs in terms of design and functionalities. After implementing those changes we obtained the final version of the platform that was evaluated remotely with the caregivers in which they gave us their feedback about the solution, its usability and usefulness.

## 1.4 Contributions

The major contribution of this work relies on the study made with both formal and informal caregivers. With our requirements gathering we could identify the main differences between them while

taking care of people with dementia. Also, we could identify several aspects related to the use of new technologies and how they care for the people with dementia. With interviews we uncover some differences between the formal and informal caregivers in terms of emotions and how they do cognitive stimulation. All this information is useful for everyone who would conduct a project related to caregivers and reminiscence therapy.

Another contribution is the platform developed to support reminiscence therapy. With the platform developed, future works related to reminiscence therapy will be able to study and develop new functionalities based on the ones already structured for performing and managing reminiscence therapy. We established the principal entities to be managed on a platform related to reminiscence therapy from the caregivers' perspective as well as all the needed relationships and how to manage that data. Also, we show the importance to consider a design and guidelines oriented towards older people, as they will be the main users of applications regarding reminiscence therapy.

We also uncover the information that should be kept so different automatic algorithms for creating therapy sessions could work, for the caregivers to access each session history and view its results, and investigators could do their research on reminiscence therapy. From the requirements gathering we identified several features that could be added into therapy session together with images. Also, we got a first idea of how the therapy session should be conducted and what should appear on the screen while performing it, and what information is important to save after it. All this information and research made in this work will be a starting point for therapy session functionalities on future versions of this platform and helpful for everyone building a solution regarding reminiscence therapy.

In terms of helping people our work aims to contribute to the society as a tool to help both formal and informal caregivers perform reminiscence therapy and slow the development of dementia disease on people with dementia. We want people who do not have experience doing this type of therapies to be capable to, although, always with the help of someone who deals with this persons in a professional way. That is why we are trying to build a bridge between formal and informal caregivers by allowing them to share the care of a person with dementia between them and also allow them to exchange messages between them. Also, having a common register about the person within the platform will not require a variety of tools to execute this therapy, connect between them, taking notes and gather personalized materials. All these actions are simplified with our platform.

## 1.5 Document Structure

On Chapter 2 we present a background about dementia and reminiscence therapy along with some technological solutions developed for reminiscence therapy. We also present some user interface design guidelines for older people as it was very important on the development of our platform in terms of user accessibility, usability and usefulness. The web design guidelines for older people had a great impact on the design of our platform and we also enumerate some that were established on previous works. To finish we analyze and compare each technological solution for reminiscence therapy.

On Chapter 3 we present our requirements gathering. We first present our objectives for doing the requirements gathering followed by the procedures and methodology used. We explain and detail all the process along with its results, starting with the surveys and followed by the interviews. After all that, we



present our main findings after analyzing all the results obtained.

On Chapter 4 we present the concepts of our database. On this chapter we introduce the reader to the principal concepts of our platform which will be important for understanding the future chapters of our work.

On Chapter 5 we describe our system architecture and how our work is inserted in Alarcão et al. solution [1]. We describe all layers of our platform which are composed by the database (data tier), backend (business tier) and frontend (presentation tier). We describe the architecture of each of these layers, how they are related between them and what were the technologies used.

As our work main focus relies on the frontend, on Chapter 6 we describe all the important guidelines and requirements that were taken into account when building and designing our presentation tier and also show the most important use cases within our platform.

After explaining our platform's design, on Chapter 7 we describe the caregivers' interaction with a first prototype of the platform and what impact it had on platform's development. We also describe the evaluation made to the final version of the platform with caregivers and what were the results from that evaluation in terms of usability and usefulness.

Finally on Chapter 8 we present our final conclusions, a summary of our work and its contributions and limitations. We also present the future work that should be applied to future versions of the platform.



## Chapter 2

# Background and Related Work

In this chapter we give some background about our work. We briefly explain in what consists reminiscence therapy and how it could help people with dementia. We present some technologies that were developed in the area of reminiscence therapy but focusing on digital solutions. We also describe guidelines that should be taken into account when building user interfaces for older people. All these aspects are analyzed and compared in the final section of this chapter.

### 2.1 Dementia and Reminiscence Therapy

Dementia is an irreversible condition presenting not only cognitive dysfunction, depression, and behavioural and psychological symptoms but also dysfunction in activities of daily living [19]. Alzheimer disease is a form of dementia and it is a debilitating and slowly progressing neurodegenerative disease which often requires frequent supervision, monitoring, and support that presents unique challenges to caregivers, so as the other types of dementia [14, 10]. Pharmacological support in the form of antipsychotic drugs can be used. However, these are not always helpful and may have side effects such as sedation. To overcome this, other therapies are encouraged to treat people with dementia [14].

One of those therapies is reminiscence therapy which is an effective non-pharmacological treatment that promotes communication between people with dementia and the rest of the world, by stimulating their memories, while preventing their inevitable social isolation and declination of their well-being [1]. It helps people recall their past experiences, adds meaning to their lives, and can improve their cognitive function and quality of life allowing people with dementia to decrease or better manage their depression and other dementia symptoms [19]. Also, reminiscence therapy is a positive pastime for people with dementia [25].

Despite experiencing degeneration of short-term memory function, people with dementia can very often retain a facility for long term memory that will function strongly given appropriate stimulation [12]. Conventional reminiscence therapy, such as storytelling, requires memory triggers, including household items or objects related to past events. When performing this therapy the person leading the session must be trained, and items functioning as memory triggers must be prepared [19]. It can reduce boredom, stimulate conversation, and preserve personal identity by remembering past events and experiences with the aid of artefacts such as personal photos or objects [16].

Although this therapy can be done in a group, Moon et al. shows that an individual therapy approach is better because the life review process should be individualized [19]. This way, people may choose

to spend more time than anticipated focusing on specific life stages. Moreover, individualized therapy sessions are more effective in reducing depression in people with dementia, and are more effective than group sessions. They also adopt a model of familiarity because people with dementia when being in familiar environments feel more comfortable, both consciously and unconsciously.

Reminiscence therapy is an activity normally carried out in spaces conceived for this purpose but Kerssens et al. shows the opposite demonstrating that non-drug, psychosocial interventions can be delivered to seniors with dementia or assistive needs and their spouses at home using computer technology [16]. This helps address symptoms and needs common in dementia and late life. They also noted that caregivers referred that future studies in this area should try to focus more on wellness and ability as opposed to disease and dysfunction, as well as in both caregivers time and people with dementia's feelings.

In conclusion, reminiscence therapy has been shown to have a positive impact on mood and cognition in individuals with dementia. However, there are some barriers when performing this type of therapy sessions. Filoteo et al. referred that reminiscence therapy is typically provided in a formal therapy session; is only provided once a week; and is only provided within a limited time-frame, which greatly limits the consistent use of it [11]. Furthermore, this therapy often requires an individual to work one-on-one with a person, which can be very time consuming for the caregiver and is often not practical in most settings. This is why there are several technologies within this field developed to overcome these barriers with the objective to improve reminiscence therapy and perform it more often on people with dementia.

## 2.2 Technological solutions for Reminiscence Therapy

Caregivers and health care professionals are users that sometimes have difficulties in adopting new assistive technologies, because of their complexity and disorganized content which makes them lose interest on the technology [26]. Caregivers have extreme demands treating people with dementia. Thus research on information and communication technologies is important to help people with dementia to be more independent, so the caregivers can have more time for themselves and be more relaxed when treating people with dementia [10]. Technologies have the potential to improve the quality of life for both people with dementia and their caregivers. However, they should be included in the research and development to achieve the best possible solution for them and make it easier for caregivers to adopt this type of technologies.

Robillard et al. defined an ethical adoption model for the development of technology for dementia which is the deep integration of ethical principles into the design, development, deployment, and usage of technology [26]. This model considers usability, emotions, adoption of the technology, ethical considerations and education in the usage of a system as the five main pillars to help the adoption of assistive technologies by people with physical and mental limitations. They also refer that these people are very strict when it comes to privacy, education using the system and in support after learning it. This support is a way that shows they are not isolated from the society. It can also help with the use of technology which makes them feel less isolated and more confident.

Dishman's work refers several technologies that can be used in the context of helping people with dementia: virtual reality to measure visuospatial ability; music technologies which is applied in terms of

person's response; monitoring systems which can help the surveillance of a person, although they have a problem on mapping; multimedia technology to help with memory problems; interactive programs for complex signal detection and brain network identification; video systems like TVs which can help people with their everyday routine and with their surveillance, with the incorporation of a monitoring system; Magnetoencephalography(MEG)/Electroencephalogram(EEG)-based systems that measure brain activity noninvasively are also being developed for cognitive training; and digital television prompting systems [10]. Although, there are different solutions to deal with people with dementia our work will focus on providing a digital platform to support reminiscence therapy. So we will explain in what consists digital reminiscence therapy and show some solutions developed within that context.

Digital reminiscence therapy is an alternative to the conventional one which not only allows individual therapies but also can involve multiple users at the same time [19]. Digital products regarding this therapy have included personalized music platforms, virtual reality platforms to transport seniors to relive prior memories, and kiosk and desktop-based solutions for use in senior care facilities [11]. Moreover, it allows uploading personal materials and presenting individual triggers of personal memories [19]. Using information and communication technologies is a practical method to support reminiscence therapy delivery using multiple engaging media and users. It can use webcams, photos, interactions with computer graphics, and personalized videos. This digital content may include more or stronger visual and auditory stimuli for enhancing people with dementia engagement. Moreover, this therapy in the form of mobile applications is convenient because they do not require specialized space or equipment, and users can easily upload personal materials to stimulate their specific memories. Kerssens et al. demonstrate that the engagement of this digital therapy is higher than the normal one. All the benefits of personalization in reminiscence therapy are very important because people with dementia will have a better stimulus and the results will be more efficient when it comes to subject health [16]. That is why an application that could facilitate the upload of this personalized data to stimulate specific memories is needed and convenient in current times. However, in most of the existing technological solutions for reminiscence therapy the data used remains unchanged overtime [1]. In the cases where this does not happen, the provision of new content must be done by the caregivers and they do not take people with dementia's emotions into account.

We will now present some solutions regarding digital reminiscence therapy to see the different applications and the aspects and methodologies that each one of them considered so we can compare them with our expected solution further in this chapter.

The Companion is a touch screen computer that was developed by Kerssens et al. to deliver psychosocial interventions to people with dementia in their living environment [16]. It uses rich audiovisual programs (shows) that combine images, music, and messages from trusted individuals that are relevant and pleasant to the persons and thus engaging them meaningfully and positively. Reminiscence and simulated presence are provided through personal photos and videos by using the voices of loved ones to make announcements or recount personal stories. The Companion cues and primes for important activities and routines through explicit verbal and timed reminders followed by images that are congruent with the expected behaviour. Reminders are an important source of orientation to time, which is also provided by a clock, date, and day of the week displayed on the home screen that comes on when no show play. Preferred music accompanies each show unless requested otherwise. The Companion was developed in

the field working with people with dementia and their formal and informal caregivers with the goal of testing its usability, feasibility and adoption in a home and community-base setting. Post intervention measures indicated that the technology was easy to use, significantly facilitated meaningful and positive engagement, and simplified caregivers' daily lives. The majority of people with dementia in this study indicated they enjoyed the Companion shows, that they used it as a pastime which brought back good memories, helping them relax and enjoy life. Moreover, it did not make them feel monitored or watched, neither did they find it to be irritating. Caregivers were overwhelmingly positive in their assessment of the technology and felt it made their daily lives and helping their loved ones easier. However, this did not necessarily make caregivers more efficient or effective in their daily life, neither helped them to have more time for themselves.

Imtiaz et al. aim to create a calming and relaxing effect while helping resurface embedded event memory in people with dementia by tackling distressing behavioural and psychological symptoms by recreating events through the use of meaningful music, personalized images and textual descriptions [14]. They proposed a mobile multimedia solution, a technical version of the combined reminiscence, and music therapies to prevent the occurrence of behavioural and psychological symptoms of dementia. Their proposal creates an individualized multisensory mobile multimedia environment that is tied to a specific memory event. The caregiver can pick an important event in the life of the affected individual and use cues, such as pictures, videos, and music, associated with that event. The mobile application was built for the Android platform and was designed to be user-friendly so a caregiver can easily set up a patient and create the multimedia episodic happy memory event-based presentations for the people with dementia. They also built an algorithm describing the flow of the application which represents the quickest way to setup and start the technical version of the therapy with the least number of steps possible, which is important when building these type of applications for older people.

Filoteo et al. developed ReminX which allows the uploading of pictures and narration to create sideshow stories depicting important moments in the person with dementia's life [11]. This unique approach to reminiscence therapy allows users to record audio over photos as a way to share memories with family members who are suffering from a neurological or psychiatric condition. The platform transforms short audio notes and individual photos into rich documentary-like stories, by personalizing reminiscence therapy for the person with dementia into custom stories and optimizing content delivered to them, that are then archived in a private and secured database. These stories can then be viewed easily with a tablet whenever the person with dementia chooses and the interface is simple to operate. It allows them to reminisce about their past, but does not have the structured time requirement or one-on-one administration that is needed with formal therapies. It also allows multiple family members, even if they are separated by time and place, to collaborate on stories in just a few minutes a day, encouraging family engagement, providing benefit to the caregiver as well as the patient. It reduces caregivers' burden by making it easier for additional family members or friends to become involved in the care of a person remotely. It also reduces the guilt associated with not being directly involved in care, and at the same time provides a caregiver with satisfaction of being notified about positive emotional feedback from stories shared directly by that caregiver. The responsibility of the family application and the server together is to request story info via a custom artificial intelligence chatbot, which is a conversational goal-seeking tool that chats with family members and directs them to upload photos and tell audio stories. It can be also

considered as a helping system. The results of ReminX evaluation indicated that people with dementia reported significantly less anxiety, depression, and overall emotional distress after having viewed their story. Also, the accessibility, scalability, and ease of use of the software platform suggests that this technology holds great promise as a product for use in both the home and senior care settings.

Peesapati et al. discussed the design and use of Pensieve, a system that supports everyday reminiscence by emailing memory triggers to people that contain either social media content they previously created on third-party websites or text prompts about common life experiences [21]. Pensieve's design supports spontaneity while providing some control; leverages personal content without requiring perfect capture or precise access to memory; and allows people to easily create a "diary" that helps them write about the past at exactly the right time. It uses a variety of media, including photos, text, and music, to trigger memories. It draws triggers from people's activity in social media sites in an attempt to provide reminders with personal significance, while generic triggers encourage reminiscing across the entire lifespan. They found that people value spontaneous reminders to reminisce as well as the ability to write about their reminiscing. Shorter, more general triggers draw more responses, as do triggers containing people's own photos. They also find that people like using Pensieve and that it improves their mood; that reminding people to reminisce is important; and that both social media and generic prompts are useful triggers, although they lead people to write in different ways. Their findings also suggest that people responded more often but perhaps less thoughtfully to personalized picture prompts than to non-personalized text prompts. People tended to use the emailed memory triggers to reminisce spontaneously; if they were to write about their reminiscing, they were most likely to do so shortly after receiving a trigger and if they were regular writers. They also identified that even users who do not respond to triggers, still value the spontaneous reminder to reminisce, and it is important to pay special attention to the characteristics of triggers used to support reminiscence. They also noted the importance of focus the design work where it really mattered, what they did not do. Designers should also be aware of cultural differences and that people appropriate systems in unexpected ways and should build features that support this kind of appropriation. Although serendipity and random selection worked well enough, they think using context to intelligently choose triggers might be helpful and support personalized reminiscing. Also, social features would be good to include, but that they should not be forced on people.

Pringle et al. outlined a project called Computer Assisted Reminiscence Therapy (CART) that uses mobile tablet computer technology to structure reminiscence therapy sessions in care settings for people with dementia [25]. This mobile tablet stores a reminiscence file for an individual person. These files include visual material, such as photographs and films, as well as a playlist of songs and music that are significant to the person. Using touchscreen computer systems with zoom facilities for photographs and music playlists appeared to supply powerful triggers that help the reminiscence process. It also helps engagement between people with dementia and those supporting them. They found out that people with dementia, including those who are severely impaired, can often retain a facility for long-term memory that will function strongly given appropriate stimulation. The most significant observation they found was that the use of technology appeared to help expand conversation and increased the depth of memory through adding extra details. Although, most of the current generation of people with dementia may never have interacted with a computer before, they can benefit enormously from tablet-based computer-

assisted reminiscence. The process also offered staff and relatives an easy, inexpensive way of enhancing the time that they spend with people with dementia.

Cohene et al. designed an interactive multimedia application with personalized life stories for individuals with dementia [8]. They conducted a case study to discover and address the design challenges for that project. They also studied the effects of customized, personal life stories on the overall well being of the individual. Their objectives were to evaluate any resulting stimulation from this activity, evaluate the individual's mood and behaviours throughout the duration of the project, and to study the nature of the interaction of the dementia participant with the interactive media. They adapted their design methods to account for various communication and interaction barriers. They made use of secondary stakeholders and were sensitive to the cognitive and psychosocial needs of their participants, considering participatory design. The results showed that it is important to learn the most about the past years of the subject so life stories can reach their objective and the pretended stimulation, as they found that the participant could be meaningfully stimulated by activities involving personal life stories. The range of responses motivated them to design a system in which the participant could control the content that is presented. They also found that it is difficult to make generalizations when designing for a dynamic and degenerating disease. Also, a major challenge in presenting their prototype was to maintain the anonymity of their participant.

Gowans et al. developed Project CIRCA (Computer Interactive Reminiscence and Conversation Aid) which utilizes interactive multimedia to stimulate long-term memory to prompt verbal and non-verbal communication [12]. Their goal was to design a computer-based multimedia tool that could support reminiscence intervention by using contemporary technologies to provide an easy-start, intuitive, failure-free, uplifting and user-friendly alternative to traditional practice. One stated goal of CIRCA was to provide a facility to customize the system to allow users to input their own personal images. This brings some privacy issues and may bother both the person with dementia and their close relatives. To retain these problems they worked closely and collaborated with their end user group. Another challenge was to create a natural and convivial atmosphere when doing the necessary user tests with their user group. When it comes to design, they identified that CIRCA would need to be compact, easily transportable and easy to set-up. They also identified that: providing shortcuts for experienced users is unnecessary; on the other hand, preventing errors and fail-safe interaction however are crucial as well as guide people to specific locations. With this care they consider their end users' particular criteria for successful engagement. They used photos, videos and music as media, related with the recreation of memories, entertainment and local life. They also considered different user interface design guidelines normally used for older people like the contrast, the duration of events and the similarity to real world objects, in this case for playing music. The most significant outcomes they obtained evaluating their system was that: CIRCA prompted memories from a number of individuals that none of the caregivers had heard before; some people who normally react poorly to traditional reminiscence intervention were more involved and alert; people with dementia enjoyed physically interacting with the system themselves; CIRCA provided a more naturalistic conversation experience by removing pressure from the caregivers continually prompt; CIRCA empowered the person with dementia to participate on a more equitable basis, so they do not have to choose what to prompt which are something that these people do not enjoy.



## 2.3 User Interface Design Guidelines for Older People

Every time we are trying to solve a problem or design something new, we must check our biases at the door, forget our preconceptions and focus on the people using the product [2]. As our platform will be used by both younger and older people we should be careful when designing our platform considering that older people will have more difficulties. Also Urbano et al. showed that younger people can cope with challenges of a platform made for older people [33]. For that reason we studied some important guidelines for older people so our system is accessible and easy to use by this persons as they are our primary concern.

Urbano et al. identified some design implications namely: the use of skeuomorphic design for an overall faster and easier experience; younger adults can cope with challenges of flat design; for a compromise solution use skeuomorphic; and design skeuominimalist interfaces for younger adults and skeuomorphic for older adults [33]. The results of their work showed that skeuomorph design is more appropriated to older people while skeuominimalist is to younger people. Skeuomorph design is perceived as less trustworthy by younger adults while older adults perceived skeuomorph design significantly more interesting, beautiful and trustworthy. Skeuominimalist design showed inconclusive results in these terms. Although, normally people think that older people should be more engaged with a flat design which has simple images with no big diversity of textures and shapes, in this work they demonstrate that they are engaged a lot more by some aspects that could be more related to the real world, so the details are very important to them.

However, applications that are not useful are generally neglected by seniors [23]. They will only be motivated to use it regularly and respond to notifications if they see the benefits of using them. Nowadays, most user interfaces lack capability in guiding users to an adequate and efficient interaction [7]. Ideally the user interface should guide the user in accomplishing the tasks the application was designed for, by providing help and appropriate feedback about features, tasks, modalities and contexts of interaction. Older users who usually have one or multiple impairments require even more guidance from the user interface [7]. Thus, an adequate interaction is only possible when the system is capable of adapting its user interface components and modalities of interaction to these users' specific characteristics. Older people often suffer from visual impairments, which can make reading text on a computer monitor an arduous task [17]. Furthermore, on-screen animations can distract them and place too much strain on their cognitive capabilities. There are some physical and psychological changes that are responsible for the hesitation of older people while using the web which include a decline in working memory, increased motor noise and slower movements. However, research has shown cognitive adaptability in older people. Kurniawan et al. shows that one of the reasons often cited for the tendency of older people to shy away from the web is the lack of understanding from web developers that older people have different needs from their younger counterparts [17]. Also, their memory is not the same as of younger people and some older people have never used or been shown how to use the technology. Most of them have never had the opportunity to learn.

Considering the development of supportive multimodal user interfaces Coelho et al. referred several features to take into account [7]. However, some of these features can be applied to the majority of simple user interfaces that do not use artificial intelligence: the use of avatars so a persona is created with whom

the user can relate to and help them engage with the user interface and the use of quick tutorials so the user can learn how to use the application because normally these type of users do not have experience using these interfaces. Training is normally not considered and can help a lot to make these users adopt assistive technologies [26]. With training they will learn how to use the technology and will not have the burden of being incapable of using it. The avatars can be used to help in this training.

### 2.3.1 User Interface Accessibility for Older People

As people age, there are certain physiological and cognitive changes that are almost inevitable and need to be compensated for [23, 15]. Also, there are older people who aren't familiar or comfortable with technology so they need incentives to engage with these technologies and may have different usage patterns compared to younger people for user interfaces, so we need to beware of content or functionality that implicitly assumes someone is young or at a certain stage in life [4, 23]. User accessibility design for seniors is not as much about simplifying the work flow, but rather making the workflow clear and easy to follow [30]. There are a lot of works that describe different user patterns for older people. Thus, we made a compendium with all that is referred by this articles and that should be taken into account when designing interfaces for older people. We need to guaranty that in our platform the user can have a good experience when using it. The different aspects we show below are very important to reach that experience for them.

**Avoid animations** and consider keeping them only when they serve a functional purpose [32].

**Avoid time limited activities** but if such a solution has to be implemented, allocate more time to complete the task and display a notification when they are about to run out of time [32].

**Avoid splitting tasks** as they divide users' attention between multiple tasks or parts of the screen. Also avoid multiple screens if they require memory of previous actions [4, 23].

**Cognitive tolerance** is important for older people and for that reason product features should be introduced gradually over time to prevent cognitive overload. During longer tasks, give clear feedback on progress and reminders of goals [4, 23]. Provide reminders and alerts as cues for habitual actions [4, 23]. Also, older people may be more likely to use an application's help functions or tutorials when they run into problems. Therefore, designers should make sure these features are easy for users to find [23].

**Colour coding** should be supplemented with textual explanations so colour blindness is not an issue. In addition older users tend to prefer text, over symbols and colours, as a medium for information [32, 2].

**Communication** with a smaller and more important group of people is very important for older people. However, security and privacy controls should not be overemphasized when trusted people are involved [4]. To best serve older people, designers should make sure that privacy and security settings are easy to manage. They should also strive to be transparent in how information is used, and be forthcoming about any data breaches to ensure trust is maintained among older users [23]. Be sensitive to issues of isolation [4].

**Contrast** describes the difference of text colour to the background colour. It is recommended to keep contrast ratio of at least 4.5:1, although it would be best to stay over 7.0:1 [32, 2]. Also, avoid blue for important interface elements [4, 2, 23].

**Decision-making** is difficult for older people. However, they tend to emphasize prior knowledge and they give more weight to the opinions of experts. Another great help is to prioritize shortcuts to previous choices ahead of new alternatives [4]. It is also very important to minimize disruption while users are in the flow state (focused on finishing a task) [30].

**External links should be avoided** but if it is really needed to send someone out of the site or application indicate it clearly, and provide an explanation [32].

**Find analogies to processes in a physical world** helps a lot as older people relate a lot with elements of the real world [33]. Analogies can range from simple ones, like icons clearly referring to physical trash cans, or folders that can be manipulated with natural swipes on a screen [32]. This process induces familiarity which is very important for older users [30].

**High error tolerance** is very important when designing for older people, so consider increasing the tolerance, even at the cost of suggestions accuracy. Error tolerance is not applied to form fields, and search engines but miss clicks should be considered. An action should be easy to undo so previous information can be recovered [32]. When seniors encounter error handling, simplicity is even more important than usual. Focus on the error, explain it clearly, and make it as easy as possible to fix [15].

**Interaction** should be easy and all the feedback about the use of an application should be presented. Links should always be blue and underlined, always turning purple after a visit [32, 2]. Visual cues to clickable elements should be added, both in active and static states [32, 23]. Icons should be labelled with text whenever possible [2, 23]. When video or audio content is vital for interaction, it is important to include subtitles [4, 23]. Also, avoid incorporating gestures with quick movements, difficult positioning, or multiple gestures that require the use of both hands or more than two fingers, keeping it as simple as possible [23]. Fresher interactions and unique experiences continue to be designed for the younger generations which increases the gap between them and the older ones. To combat this problem we should keep consistent which reduces the learning curve and confusion, so older people only need to learn a few basic interactions [30]. Also, many sites and applications accept user inputs in only one form and seniors are frustrated by this narrow range of interaction [15]. The positioning of elements is also a very important point for interaction as they can influence the easiness of completing some tasks. For example, Gowans et al. concluded that the main controls of the interface should be presented on the bottom on touch screen devices because it reduces some of the effort in reaching the controls which could help people with different physical impairments [12].

**Interface size** should be the bigger as possible. Many older people use reading glasses or opt for much larger font sizes when given the option [23]. The distance between elements should be reduced when they are likely to be used in sequence, having at least 2mm apart. Interface elements to

be clicked with a mouse should be at least 11 millimetres diagonally with a minimum spacing of 44 pixels and not placed in corners to avoid accidental actions [4, 2]. Anything that is meant to be read or clicked should be scaled up. In general, wherever there is a recommended size or distance specified, designers should view that as the absolute bare minimum for any interface targeting older people [23]. Although the ultimate solution is to make it easy for users to increase or decrease font sizes and interface items at will [32, 4, 2, 23]. With the size adaptation of interface elements to meet user requirements some impairments of users can be attenuated when using the application [7]. However, it is very difficult to achieve this type of personalization in specific cases because there are several users and impairments to take into account so an artificial intelligence or quick start-up would be needed to implement this personalization. The best way to achieve a better usability to these type of users is to generalize all the problems of accessibility that could exist in the user interface and then build it to overcome the identified most relevant problems.

**Language** should be clear, objective, and educational without being condescending or patronizing [23]. Abbreviations are more difficult to process by our brain, hence much more for the older people to understand. Do not require extra cognitive effort from your users. Language is also very fluid in a sense that it changes all the time, so new words and meanings arise frequently and there may be words that are not recognised by older people [32, 2]. It is important to show exactly what is happening after an action is completed with feedback messages [2]. Older users who are not familiar with technology often already feel insecure while using it; a condescending message will only cause further insecurity and may turn them off to using the application altogether [23].

**Navigation and current location indicators** importance grows when designing for older generations, who may often feel lost in the web [32]. When designing for older people, it is important to make sure that navigation is not only simple to use, but that proper on-boarding exists to introduce users to functions they might not be familiar with. Keeping the RETURN function and the HOME NAVIGATION readily accessible serves as a sort of safe point on the interface [23]. While the younger generation has no problem finding the info they need, seniors feel lost. The logic may not be very clear for them, and they need more sequential patterns or a step by step guidance [30].

**Prototyping** can answer some questions, test hypotheses or help learning objectives to fulfil [2]. The prototyping that is chosen will also depend on the fidelity aimed for. Low fidelity is best for testing an idea. Medium works when you are focusing on layout and interaction design and high fidelity is needed when the most important things are visual design and micro-interactions. It is important to clearly explain that a prototype is not the same as the end product. Some things will not work as expected and older users tend to assume that every problem they face while using a prototype is their fault.

**Text** should not be justified so kerning and tracking are clear. Use line spacing of at least 1.5 [32]. Sans-serif font choices on screens are the most readable for older people [2, 23]. Font size choices on phones should be no smaller than 12 pt., 36 pt. on tablets and around 24 pt. on computer screens [2, 4, 23]. Also, always test a product using screen readers [4, 23].

**User testing** is very important to find an optimal solution for an application's target group. We should not rely on assumptions and always test the designs early and often [32, 2]. Older users may prefer to see the end result of a working prototype, and in this way the expected result of some aspects can be evaluated [2]. Also, the tests should be conducted avoiding small-screen devices [4].

### 2.3.2 Web Design Guidelines for Older People

Although we already have a lot of information on how to build an application for older people, we only have a general context of accessibility guidelines and not design ones. However, some of them are also applied to design. So we found a work with a lot of important guidelines which can be very helpful in the construction of our platform when it comes to the design and completes the information we already have. Kurniawan et al. identified a new set of web design guidelines for older people by analyzing several studies into more concrete guidelines, considering general impairments and including these people in the evaluation of their study [17]. Similar to Nielsen's heuristics for user interface design, Kurniawan's guidelines correspond to different heuristics that should be taken into account when designing an user interface for older people. These are more specific than Nielsen's heuristics [20, 17]. Although, we will consider Kurniawan's guidelines as the most relevant, Nielsen's heuristics should also be considered. Kurniawan et al. explained what should be taken into account for different types of users and impairments. They also ensured that the target user group addressed by the guidelines was consulted and that the guidelines were understood. We will now present a brief summary of these guidelines that can be consulted on their work [17]:

- H1. Target design:** consists in providing larger targets, clear confirmation of target capture, which sometime is not visible for older people, and the importance of not using double clicking for older people.
- H2. Use of graphics:** graphics should be relevant and not for decoration. Images should have alternative tags and icons should be simple and meaningful. Also, as already said, no animation should be presented.
- H3. Navigation:** clear navigation, as well, extra and bolder navigations cues should be provided. Also important is providing location of the current page and avoid pull down menus. Do not use a deep hierarchy and group information into meaningful categories.
- H4. Browser window features:** avoid scroll bars and provide only one open windows. Pop-up/animated advertisements or multiple overlapping windows should be avoided.
- H5. Content layout design:** language should be simple and clear. Avoid irrelevant information on the screen and important information should be highlighted. Information should be concentrated mainly in the centre and screen layout, navigation and terminology used should be simple, clear and consistent.
- H6. Links:** there should be differentiation between visited and unvisited links. Links should be clearly named and no link with the same name should go to a different page. Also, links should be in a bulleted list and not tightly clustered.

- H7. User cognitive design:** provide ample time to read information and reduce the demand on working memory by supporting recognition rather than recall and provide fewer choices to the user.
- H8. Use of colour and background:** colours should be used conservatively. Blue and green tones should be avoided. Background screens should not be pure white or change rapidly in brightness between screens. Also, a high contrast between the foreground and background should exist and content should not all be in colour alone (all colours other than black and white).
- H9. Text design:** avoid moving text. Text should be left justified and text lines should be short in length and have spacing between them. Main body of the text should be in sentence case and not all in capital letters. Also, text should have clear large headings and be in a San-serif type font.
- H10. Search engine:** should cater for spelling errors.
- H11. User feedback and support:** provide a site map. An online help tutorial should also be provided and support for user control and freedom. Error messages should be simple and easy to follow.

## 2.4 Analysis and Discussion

After describing in what consists reminiscence therapy and how it could help people with dementia, we described several technologies to perform it. We presented the current state of work about the type of technologies developed to help people with dementia. However, our work does not consist on all of that technologies. That is the reason why we describe more solutions in the context of digital reminiscence therapy which is where our platform is inserted. To analyze and compare all of those solutions with the work we developed we show in Table 2.1 all the principal characteristics that we considered important after concluding the background research, and what works take those into account. Before talking about the table we describe the meaning of each characteristic defined and why it is important to be considered on all works regarding reminiscence therapy.

**Automatic session creation** will free some time of caregivers' lives and reduce caregiver burden. Caregivers will not have to prepare the session as it is automatically generated so they can perform therapy more frequently. The algorithm to create a session can also be helpful to create different therapy sessions which would not happen when the caregivers prepare the session as usually they stuck with the same material for some time.

**Guidelines for the elderly** are very important to these applications as we explained earlier. They are normally used by both younger and older people. However, younger people can cope with challenges of a platform made for older people [33]. So it is very important to consider older people as the principal users of these type of applications and the design should be made considering that. For that reason a platform for digital reminiscence therapy should consider older people guidelines, taking into account all problems that can come with ageing and that may interfere with the use of an interface.

**Less steps as possible** is very important when building a simple and easy to use application. All users like an application to be easy to use. That is even more true when we are talking about older

people. So we should consider that a platform for digital reminiscence therapy should have the less steps as possible to complete all needed functionalities and they should be clear and not put the user in doubt. Users should feel comfortable and capable of concluding the different functions of an application in the shortest time possible, specially the older people.

**Multimedia usage** is very important to digital reminiscence therapy. For people to reminisce, caregivers normally use photos, videos and music to create an environment that the person likes and that helps remembering past experiences. So all platforms should consider these multimedia as an important part for an application regarding this therapy as without this multimedia there is no possible way to execute reminiscence therapy on digital way.

**Notifications or reminders** can help caregivers to manage the people with dementia. They can be very helpful when there are multiple caregivers caring for a particular person. Also they can be used from the perspective of a person with dementia to work more like a reminder that the therapy session will begin or help them with activities of daily living. Reminders can also be helpful to help caregivers manage the different therapy sessions schedules.

**Personalized content** about a person with dementia are usually preferred by caregivers for that person's reminiscence therapy. It is a better memory trigger than the generic content because it was part of that person's life. By being the best content to reminisce they should also be considered on all applications regarding this therapy as generic content alone will not generate the response we want from it.

**Privacy** is very important for all people nowadays, specially for older people. Older people are not so used to new technologies and they may be wary of various applications, especially those in which they have to insert personal content. For that reason these applications should assure the user that their information is secure and only those with permission can access it. This is a very complicated topic and should be treated very carefully with no disrespect to the privacy of our users.

**Providing help or training** is very important to all users for an application they do not know. Older people have difficulties to learn new technologies, so new applications are not that simple for them to learn. The best way to help them so they can use an application is by providing some training and explain all the application or have such help available on the application itself so they can consult it any time they need. Both forms of helping are very important for these applications, specially when older people are involved, as they do not have the facility as younger people to learn them.

**User-centered design** is very important when building an application for these users to execute some type of task or job. It is important to interact with the people who understand more about that topics so we can understand their needs and perspective. However, it is even more important when the application is going to be used by older people as we do not know how they would interact with an application and what would be more accessible for them. This will help with some design decisions and also help the application to achieve a better engagement and also a greater satisfaction from the people we are building the application for. In this case, we are talking about

the caregivers of people with dementia which will execute reminiscence therapy with the help of an application.

Work	Automatic session creation	Guidelines for the elderly	Less steps as possible	Multi-media usage	Notifications or reminders	Personalized content	Privacy	Providing help or training	User-centered design
CART [25]				x		x			
CIRCA [12]	x	x		x		x	x		x
Companion [16]		x		x	x	x			x
Happy Times [14]		x	x	x		x			
Interactive Multimedia [8]		x		x		x	x		x
Pensieve [21]	x			x	x	x	x		
ReminX [11]		x		x		x	x	x	
KeepsakeBox (Our work)	x	x	x	x	x	x	x	x	x

Table 2.1: Comparing works through characteristics identified as essential for digital reminiscence therapy.

Looking into the Table 2.1 we see that there are aspects who are normally more considered than others which are: the guidelines for the elderly, which can also correspond to studies on how an application could be easy to use by older people; multimedia usage, which is considered by all the works that execute digital reminiscence therapy; and finally personalized content which is very important to obtain the best stimulus from people with dementia when they are reminiscing.

When it comes to automatic session creation we can see that there are only two works who consider it. Gowans et al. have concluded that it reduces caregiver burden and helps people with dementia to better enjoy the therapy because they do not like to choose what to reminiscence [12]. Automatic session creation considering emotional factors is important as with the automatic association of contents the application selects the best options for the person, considering emotional factors, like described by Alarcão et al., by using algorithms that can identify what brings good reactions to the person [1]. As our platform is part of Alarcão et al. work we will consider automatic session creation, although it was not developed in this work. On the other hand, the content that is going to be by default and inserted by the caregiver, like photos and different aspects from patient lives, will be implemented in this work so we can achieve the personalized content that is considered on all works in this area.

All the works considered personalized content as a top priority to execute reminiscence therapy. People with dementia find to relate more with content which represents moments they lived in the past, and past memories. When this data is presented they present better stimulus and better results could be achieved from the therapy sessions. That is the reason why our work will also consider this personalized data that will be used as we explained earlier. However, this personalized content may cause privacy issues. Not all works considered this problem, although all of them considered personalized content. For this type of users is very important to take special caution when it comes to their privacy. Consents should be made between all parts involved even for the requirements gathering and tests. It is very important to considerate privacy as a top priority nowadays and even more for older people so we took special caution when it comes to privacy issues within our platform. We wanted to achieve the most secure database so all the data can be kept safe and only accessed by the caregivers of a person. We also provided consent explaining anonymity for requirements gathering and tests, as well for the usage



of data within our platform.

As we are implementing an interface for older people it is important to consider the different guidelines already identified for them as well as the ones identified in a requirements gathering. We can see from the table above that not all works considered those guidelines, although most of them did. On the other hand, we can see that only three of the works considered user-centered design. The other ones did not execute requirements gathering or tests with the users while implementing their solution. When implementing our interface we were cautious with the older people guidelines that were defined on the previous section of this chapter but we also had caregivers participate on the implementation of our platform by testing and commenting some prototypes and the platform itself. By doing this we could achieve the best possible solution regarding caregivers needs and perspective.

Other important characteristic that is only considered by Imtiaz et al. work Happy Times, is the application to have the less steps as possible [14]. By having less steps we want to provide our end user the quickest way to setup a session, import content and execute the therapy session, as well as consult its results from different people with dementia. When it comes to older people is very important to consider few steps to complete a task so our user can feel comfortable and capable of concluding the different functions of our platform in the shortest time possible so a better usability and accessibility is achieved.

Finally, there is an aspect that only Filoteo et al. considers on ReminX that is providing help and training [11]. In their solution family members of people with dementia are helped with an artificial intelligence chatbot when inserting personalized content for a person with dementia. The help and training topic is not considered in all the other applications we presented and is a very important topic for older people. Nowadays, older people do not have experience with most of the technologies. Thus, some help or training should be provided to these people so they can learn how to use an application and enjoy all its aspects and functionalities. We gave our best to implement different ways to help and train our end users even when we are not around to help them executing the functionalities of our platform so it could achieve a better engagement.

## 2.5 Summary

We started this chapter by explaining in what consists the dementia disease and reminiscence therapy. We explained how caregivers use this non-pharmacological therapy with people with dementia to help with their well-being and also with their memory. This therapy helps them remind moments of their lives and slows the progression of dementia disease. Normally personalized content are used on this therapy because they are better memory triggers as they represent parts of that person's lives.

After giving some background about the principal topics of our work we described some of the technological solutions that were already developed to help the people with dementia. There are many of technologies created to help those people. However, our work consists on a platform for reminiscence therapy so we only looked with more caution into solutions consisting in digital reminiscence therapy which were helpful to create a starting point for our work and also to understand the importance of considering older people design guidelines.

With that previous analysis we searched for several guidelines that should be considered when building an interface for older people. After compiling that information we described multiple accessibility

guidelines regarding older people. We also enumerated the web design guidelines for older people that were identified by Kurniawan et al. which considered general impairments and included these older people in the evaluation of that same guidelines.

After giving all the background about the principal topics of our platform and related work we made an analysis of all data and discussed it on the final section. On this section we identified and described the principal characteristics that an application for digital reminiscence therapy should have, regarding the previous sections of this chapter. We used that characteristics to compare all digital reminiscence therapy technologies described previously to see which ones respected that fundamental characteristics and then compared them with our expected platform which considers all of that important characteristics.

## Chapter 3

# Requirements Gathering

In this chapter we describe how we proceed with our requirements gathering. We explain what were the principal objectives for this gathering and describe the methodology used, which consisted on both online surveys and semi-structured interviews. The results from both methods were analyzed so we could identify the main findings from our research and compare them with the ones considered right from the start.

### 3.1 Objectives

Alarcão et al. conducted a study with informal caregivers for their work [1] where they identified the different scenarios in which people with dementia perform therapy as well as both requirements for the people with dementia and informal caregivers. The objective was to understand if that caregivers perform reminiscence therapy with people with dementia and what is the reason if not. Also, they wanted to understand in which conditions sessions are performed and what are the emotional reactions that emerge during these sessions, and how caregivers deal with these reactions. People with dementia activities on their daily living and what are caregivers' role and emotional state when caring for them were also important to understand. Finally, it was important to know the interest in technological functionalities using a Life Story Book which would help in the automatic adaption of the session's content considering also the emotional information generated during the sessions, as well as the automatic gathering of new multimedia stimuli personalized to each person with dementia, so the proposed solution by Alarcão et al. could be validated.

To conduct the study they performed a survey during 18 months, from July 2017 to December 2018. They made it available through Google Forms and was disseminated in Facebook groups and institutions related to dementia. The survey had 603 responses from 39 countries after closing it. The results were analyzed and with all data obtained they identified the functional requirements for the application, as well as the primary and secondary outcomes expected from their solution, which can be seen in Figure 3.1.

One of our objectives with this new requirements gathering was to validate the requirements obtained from that study and also define more specific ones related to our platform. We wanted to gather all the information related to both formal and informal caregivers' needs and how they care of people with dementia on their daily living. We also wanted to understand how they execute reminiscence therapy with these people and what functionalities they would need for the process to be more accessible and useful. We also wanted to validate if the guidelines considered in the previous Chapter 2 were appropriated for

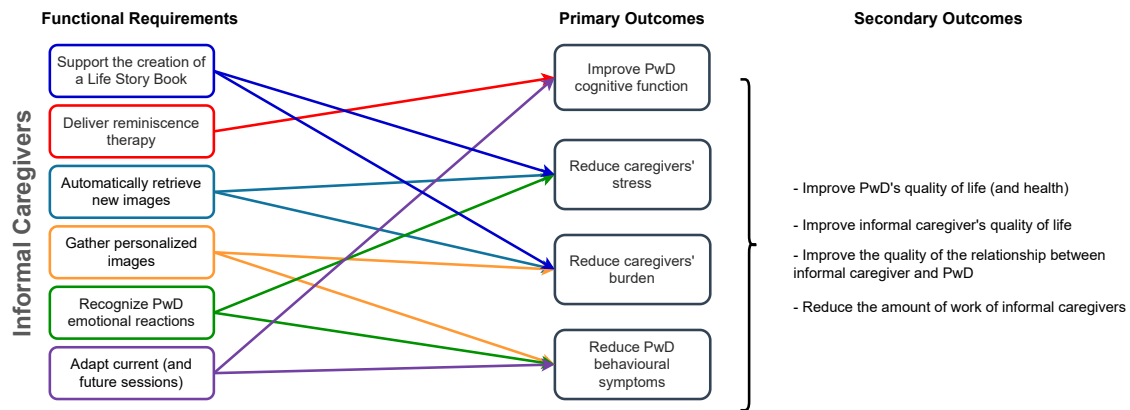


Figure 3.1: Functional requirements and expected primary and secondary outcomes for the informal caregivers identified by Alarcão et al. for their solution [1] (best seen in colour).

implementing our platform.

Regarding the informal caregivers we wanted to understand how their daily living is while caring for a loved one with dementia and if their loved ones are somehow related to them, and what is this connection. We wanted to know how much time they spend caring for the person and what are the activities they perform with them to help slow disease progression. Also, we wanted to understand how these caregivers feel as they spend too many hours caring for a loved one, which can be exhausting and stressful while living their lives [16]. From formal caregivers we wanted to identify other aspects such as how many people they care for simultaneously and if they do group sessions of reminiscence therapy. Also, we wanted to understand how much time they spend with each person when consulting them.

Regarding the reminiscence therapy, we wanted to understand how both informal and formal caregivers perform this type of therapy with people with dementia. We wanted to know how many times they spend in each session of therapy and how often they perform it. Another important point that we wanted to discuss was the emotions of the person with dementia during therapy. We wanted to know how they react to each type of material like images, music, objects, etc., and how caregivers deal with these emotions.

Regarding the materials used on therapies we wanted to know which ones caregivers use and if they are more personal or more generic. The objective was to confirm our intention of using images for now and to identify the possible materials that could be important to introduce in future versions of the platform. Still in the context of material we also wanted to know how caregivers obtain the materials for therapies, specially formal caregivers since they do not have direct access to personal materials. We also wanted to know what caregivers register during and after each therapy session, for use in future sessions, and what they consider before starting each therapy session. Understand how they follow the person in these sessions and outside them in a medical and clinical way was also one of our objectives.

Additionally, we wanted to clarify how some features that came from the first prototypes of the platform's frontend in the context of the present work should be implemented and validate the solution made on a previous master work for the backend and database [34]. One of our major doubts was the sessions history. We considered two possible ways: all sessions performed by the caregiver would be presented regardless of the person they performed the therapy with; all sessions of a person would be presented regardless of the caregiver that conducted the sessions. We wanted to know if both of this

histories are useful for the user and if not which one should we keep. The functionalities regarding sharing the care of a person with dementia were also one of our major doubts as we did not know how caregivers share the care of a person with dementia between them and how we should represent that idea within our platform. Notification, reminders and help for our platform were also important points that we wanted to discuss on this requirements gathering.

Privacy should also be considered when caregivers are using our platform. We know from previous works that privacy is an important issue, especially when other people are involved [4, 23]. That is why we wanted to address how comfortable people would be inserting personal content on our platform by knowing that only authorized people would be able to consult that data.

The last data we wanted to get out of this requirements gathering was the feedback about the first prototype of our platform. We wanted to show our first design of the platform to caregivers so they can give us their feedback and we could reach their needs and perspectives and also validate our ideas and guidelines. We wanted to know if what we designed was the best and helpful for caregivers to navigate within our platform and execute all needed functionalities.

## 3.2 Procedure

Before starting any surveys or interviews we submitted our study to the ethics committee of the Faculty of Sciences of the University of Lisbon regarding those two forms of requirements gathering. We described all the process of requirements gathering and the study got its formal approval from that ethics committee. Right after that we started the surveys.

Surveys were made available online through Google Forms and in an anonymous way, respecting the privacy of the people who answered it. The surveys were conducted making a distinction between formal and informal caregivers, so we could analyze the results and identify the differences from the different types of caregivers, and were designed in two languages, Portuguese and English. They were disseminated on Facebook groups related to reminiscence therapy and people with dementia. We published the Portuguese version on Portuguese groups and the English version otherwise. We also contacted several institutions that care for people with dementia by email, so they could spread our surveys within their institution. We repeated these methods of dissemination during several weeks until we achieved more than 50 participants, regardless of the language they spoke. With the surveys we also tried to gather participants for the interviews. We provided a link after the submission of the survey so that people could volunteering up for an interview. To that end, they needed to enter their name and email, and also their institution if they were a formal caregiver. The anonymity of the survey was kept, since we collected this personal information in another Google Forms independent from the survey one, so data could not be related.

While surveys were being answered we started developing some low-fidelity prototypes on paper which were converted on an high-fidelity prototype considering the requirements obtained from the study made by Alarcão et al. [1], and the backend and database solution developed on the previous master work [34] which was completely adapted to the new functionalities and requirements identified for the frontend of the platform. We established what could be the structure of the platform when it comes to all pages and component relations and also considered the older people guidelines that we referred earlier on Chapter 2

for designing frontend components. We wanted to show it on interviews so caregivers could give us their feedback about the solution that we were thinking and then validate our ideas and guidelines. With their comments we could also increment and modify this high-fidelity prototype corresponding to their needs and perspective.

After the online surveys data was analyzed we proceeded to interviews but first we made some changes to the high-fidelity prototype. With the results obtained from surveys we modified some aspects of the design and added some new functionalities which would be helpful for the caregivers to manage their data within our platform. With changes applied, we showed that version on interviews because it was more consistent with caregivers' needs and perspective.

Before starting the interviews we first contacted the caregivers who applied for them to clarify aspects from the survey and platform's design. We had two formal caregivers (one international) and five informal caregivers (three internationals) volunteering for the interviews. Due to the current pandemic of COVID-19 we did all interviews online by Zoom and only with Portuguese caregivers. Although we had interest for interviews from international caregivers it was not possible, yet. This was because our platform was being developed in Portuguese and although the interviews were to clarify some aspects relatively to caregivers life, the care of people with dementia and reminiscence therapy, we had also a section of this interview dedicated to a first interaction with our platform's high-fidelity prototype which could only be done by Portuguese people. We did not developed an English version before getting a final version of the platform because it was easier for us to connect with Portuguese people and we needed to know more about the correct terms to use before doing the translation. The interviews followed a semi-structured register considering the major doubts that resulted from the surveys. We created a familiar and natural environment so the people did not feel pressured, so they could give us a good report about the care of the people with dementia and what they need to do reminiscence therapy in a more accessible and convenient way. We started the interviews asking for their consent and always maintained anonymity while doing the analysis of results, as privacy is very important for them. As participatory design was not possible with remote interviews we decided to use Zoom as it has remote control. With remote control we gave access to a web page on one of our computers where the prototype was running so caregiver could give us their feedback. More details about this section of the interviews will be given on Chapter 7 of evaluation as this was a method to evaluate our platform and not part of requirements gathering.

In Figure 3.2 we can see all the implementations steps of our work. The requirements gathering final interviews correspond to the fifth step of that process. The first step consisted on the study made by Alarcão et al. [1] with informal caregivers which was not part of this work but important for the elaboration of the requirements gathering and the first prototype of the KeesakeBox platform (second step). The surveys corresponded to the third step and its results helped increment the first prototype of the platform to be more consistent with caregivers' needs and perspectives (fourth step). That version was used on the follow-up interviews where caregivers interacted with the prototype and gave us their feedback (fifth step). With all the results obtained from the requirements gatherings and prototype interactions we made the final version of the platform (step six). This version was the one used for step seven of evaluation and is the one explained on the next chapters of this work.

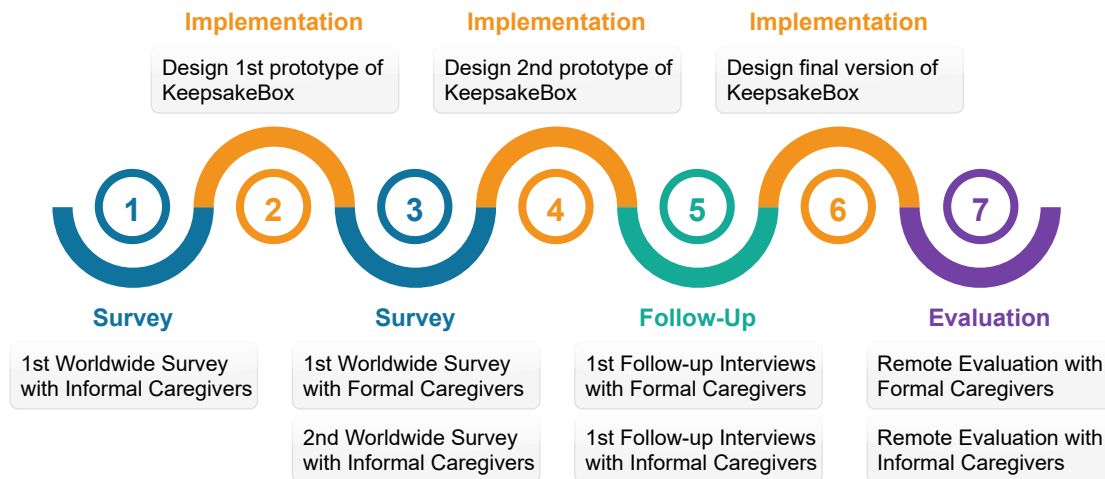


Figure 3.2: User-centered approach for the platform implementation (best seen in colour).

### 3.3 Surveys

In this section we describe and explain the structure of both formal and informal caregiver surveys, and how data was analyzed and results obtained.

#### 3.3.1 Structure

We tried to frame what the follow up is like for each of the caregivers so we developed two different versions of the survey. We separated the surveys so we could understand some differences from both caregiver types and also identify some aspects about each of them.

Regarding both caregivers we wanted to address the following differences: the number of persons with dementia each type of caregiver care; the usefulness of some management functions that can only be applied when caregiver care for multiple persons with dementia; which material each of the caregiver types uses to carry out the therapy; and how each of them analyses and interprets the results of each therapy session. We also wanted to get some information about caregivers such as their age, education, vision ability and problems that might make the platform difficult to use. As we referred before, this information would allow us to understand to what extent some of the design guidelines for older people would need to be implemented and if we are using the right approach. For example, if many users had vision problems we would have to be more careful about colour, contrast and the size of text.

Regarding only formal caregivers (health professionals and therapists) we wanted to collect information about: insertion of material by third parties; performance of reminiscence sessions; consultation of session results; notifications in the form of alerts and reminders; and the history of sessions performed with the people with dementia.

Regarding only informal caregivers (relatives and friends) we wanted to collect information about: the time available to carry out the therapy sessions; if they care for more than one person; insertion of personal material to carry out the therapy; how they carry out the sessions and consult their results; if the results have to be more perceptible to someone who is not connected to the health sector; and the sessions history for each person with dementia.

In Figure 3.3 we can see the flow that both versions of the survey can have. Both followed the same

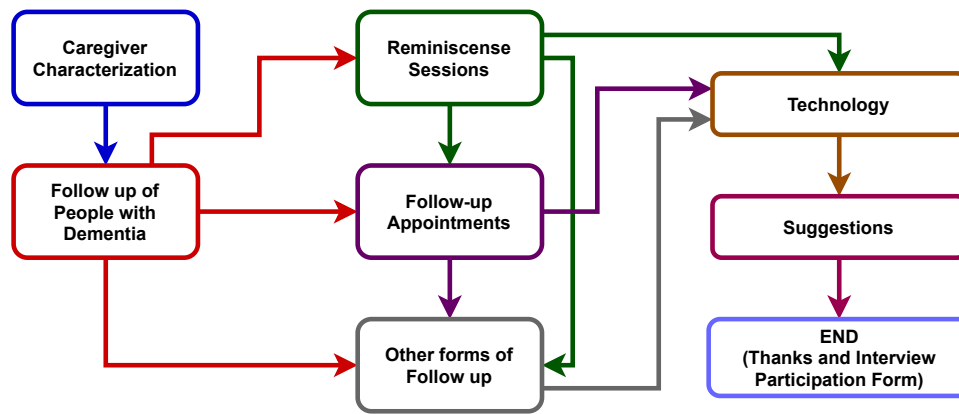


Figure 3.3: Survey flow between sections. Each block represents a section of the survey (best seen in colour).

flow as the sections were the same. There were different paths that the caregivers could take when they were answering to our survey as some sections could be skipped according to their answers. Also, there were differences on some of the questions presented for every section of each survey version and there were some questions that only appeared when the answer to a question above it corresponds to something that needed some validation. One example is when caregivers never update the material that are used on the therapies we wanted to know why they do not update the material more often.

Both survey versions start on CAREGIVER CHARACTERIZATION, which was the section where we ask for some data about the caregiver. The next section FOLLOW UP OF PEOPLE WITH DEMENTIA had questions about how caregivers care for the people with dementia and do the follow up. At this section, depending on the answer to the last question, caregivers would go to REMINISCENCE SESSIONS, FOLLOW UP CONSULTATIONS or OTHER FORMS OF FOLLOW UP. On REMINISCENCE SESSIONS section, if caregivers perform reminiscence therapy, we wanted to understand when and how caregivers perform this therapy with people with dementia. If caregivers carry out follow up consultations they would answer to the FOLLOW UP CONSULTATIONS section so we could understand what type of follow up they do on clinical terms. If caregivers do other forms of follow up they will answer OTHER FORMS OF FOLLOW UP section so we could understand the other alternatives to reminiscence therapy and if some could be applied to our platform. All the three last sections referred are optional so caregivers would only answer this sections if they answered yes to the first question of that section. This question has a description of what we meant to study in that section and asks if the caregiver really does what we mentioned. After all that sections the caregivers would enter TECHNOLOGY section where we tried to understand and validate the functionalities of our platform. After they answered this section they reach the end of the survey which has the SUGGESTIONS section that allowed for the participant to give us a suggestion for our platform. A section thanking for their participation and the link for the participation form of interviews would appear after submitting the survey.

### 3.3.2 Data Analysis

To analyze all the data obtained from the surveys we started counting the people who submitted the surveys (sample). In order to understand which caregivers showed more adherence and other important



statistical factors for data analysis we also used Google Analytics which we associated to the links of the surveys to calculate the user engagement and dropout rate. With that, we were able to see people who engaged with the survey but did not submit it. The dropout rate was calculated using the total sample value over the Google Analytics user\_engagement value, which is used to count users who have made any interaction with the survey. That way we discarded the ones who did not engaged with the study which would not help for the statistics because they did not knew what to expect from it.

After counting, we proceeded to data analysis through the cross-tabulation of all statistical data by creating two groups: formal caregivers (Portuguese and international) and informal caregivers (Portuguese and international). We decided to assess the data in this way because language was not a very important factor for the conclusions we wanted to reach. The objectives of this stage were to identify their characteristics, the differences between formal and informal caregivers and which are the most relevant functionalities for each of them.

In each of the groups we checked which data were inconclusive and which data were the most different between both caregiver types. This data were saved to be addressed in the following interviews. On the other hand, we identified which ones allowed us to draw a conclusion right away and were not very different between both caregiver types, thus they were not very important to be addressed in the interviews.

Regarding suggestions and short answers given by caregivers in some questions of the survey, we considered all those and filtered them. Those we thought that were more relevant and of possible implementation or consideration, we addressed and clarified in the interviews if they were really useful and important for the caregivers.

### 3.3.3 Results

We took 3 months, from March 2021 to May 2021, to gather at least the 50 participants we needed, regardless the type of caregiver. We believe that was somehow due to the current COVID-19 pandemic because people were not so available. Other thing that may have impacted was that some institutions need to approve a study before caregivers can answer to it. Our surveys did not have as many international formal caregivers as international informal so we believe that this could have been all because of institutions did not disseminate or let them respond. To have more data, we left the surveys open for about 1 more month and we got 136 responses submitted.

#### Dropout rate

Through Google Analytics we could observe that in the case of formal caregivers we had 124 people interested in the survey. However, only 34 submitted the survey and the dropout rate was of 73%. We assume that they may have forgotten to submit or lost interest further on the survey. Another important fact is that adherence was much higher among Portuguese caregivers than for international caregivers, where the dropout rate was 90%. That may be due to several factors, such as the ones we referred earlier or simply not being able or willing to answer.

In the case of informal caregivers, 361 people were involved in the surveys but only 102 people submitted the survey. Therefore, the dropout rate was of 72%. In the case of informal caregivers, the

dropout rate was higher in the case of Portuguese caregivers, which was 75% to 70% of the international ones.

The adherence of the international informal caregivers was much higher than formal ones, which helps us to reinforce the idea that there may be other factors that did not allowed formal ones to answer to the study. We also found that adherence was approximately identical between both caregiver types regardless the language, with the formal caregivers being 27% and the informal caregivers 28%.

### Caregiver characterisation

Looking at both formal and informal caregivers we observe that there is a high adherence by female caregivers. We also found that formal caregivers have less than 60 years old. On the other hand, the ages of informal caregivers are more distributed: 68% are up to 60 years old, 22% are between 61 and 70 years old and 10% are over 70 years old.

With regard to visual difficulties, 65% of the formal caregivers do not have any difficulties, while 15% have hyperopia/presbyopia, 18% myopia, 6% astigmatism and 1 caregiver has photophobia. In the case of informal caregivers there is a distribution by the various types of visual diseases because they are older people. Only 39% of the informal caregivers do not have any visual problems and hyperopia/presbyopia and myopia continue to be the most frequent problems, both with 29%. In addition, informal caregivers reported other diseases that were mostly rare syndromes.

Regarding education, we found that 85% of the formal caregivers have completed college education. From the remaining 12% have completed the third cycle and 3% have completed secondary education. In the case of informal caregivers, we found that three of them have only the first cycle. However, 40% have the third cycle, 28% have secondary education and 65% have at least higher education. Overall, approximately 70% of all the caregivers who responded to the surveys have a higher education degree.

About new technologies, 85% of the formal caregivers use the computer at least 5 days a week. On the other hand, only 50% of the informal caregivers use it at least 5 days and 21% of them do not use it at all, so we assume that they used other technology to answer the survey. We found that the computer is more accepted by the formal caregivers.

Regarding the use of tablet/iPad, the situation is the opposite, since 55% of the informal caregivers use it at least 5 days in contrast to 33% of the formal caregivers. In addition, 44% of the formal caregivers do not use it at all which is higher than the 23% of the informal who do not use it. This may be due to the fact that informal caregivers use this device because of its better accessibility, while formal caregivers use the computer more, probably because of their profession they are more used to them.

Finally, the mobile phone is used a lot by formal caregivers as 82% of them use it every day and only 6% do not use it. In the other hand, 29% of informal caregivers do not use it and its use is very distributed with only 25% using it daily. This can also be due to age, as older people do not use new technologies as much and probably do not have a mobile phone. In addition, mobiles have usually very small screens that many cannot even see, so they probably use the tablet/iPad as a substitute, which is why it has a higher rate of use among informal caregivers.

### **Follow up of people with dementia**

From the data obtained we have that 76% of formal caregivers care for more than 7 persons with dementia and 18% only care for one. In the other hand, 87% of informal caregivers only care for one person with dementia. These results were expected as informal caregivers usually care for their family members and formal caregivers have to care for more people with dementia, as it is their profession. In addition, approximately 64% of all caregivers care for someone with severe or serious dementia and almost all of them know the disease status of the person they care for.

As expected, 92% of the people that are informal caregivers care for family members. Only 8% care for a close friend or someone who does not belong to the family. The relationship that the caregiver has with the person with dementia, if they are family members, is spouse (39%) and son or daughter (25%). The latter value may not be correct because the survey was not very clean in this part and most participants probably selected the option relative instead of this one. So, of the 33% that chose relative, there may be some that are sons or daughters of the person with dementia. In addition, we also found that 57% of informal caregivers spend more than 8 hours per day caring for the person with dementia in their care. With this data, we can assume that these people require a lot of care.

### **Reminiscence sessions**

We found that 68% of formal caregivers and 44% of informal caregivers perform reminiscence therapy. From the formal caregivers who perform therapy, 39% perform it 3-4 times per month and 30% 5-10 times per month. The other ones do other forms of therapy with people with dementia or they do some type of reminiscence but do not know the meaning or about reminiscence therapy. On the other hand, 43% of informal caregivers who perform therapy, do it more than 10 times per month and 42% do it between 1-4 times per month. The emotional factor between the informal caregiver and the person they care for generates more concern and is a factor that influences the informal caregiver to do this therapy more often.

The duration of therapy is also different between the two types of caregivers. Of the formal caregivers, 65% spend between 30 minutes and 1 hour performing the therapy, unlike the informal caregivers, where 74% spend less than 30 minutes. This is probably due to the fact that the therapy done by formal caregivers is more technical and they try to take out as much information as possible while observing the person, whereas in the case of the informal caregivers they probably do recurrent sessions to try to slow down the disease progression and help the person reminiscence instead of doing a technical observation. For these reasons probably informal caregiver spend less time executing therapy than the formal ones.

Regarding the place where the sessions were conducted, 74% of the formal caregivers conduct therapy in an institution while the remaining caregivers conduct therapy at home, probably making home visits. On the other hand, 88% of informal caregivers carry out the therapy at home, while the remaining ones carry it out in an institution, probably a nursing home or a long-term care centre. There was also reference to a car trip to perform the therapy and there are also others who use video calls.

Both formal and informal caregivers use images and music in their therapies. Of the formal caregivers 91% use images and 87% use music. In the case of informal ones, 86% use images and 67% use music. Most likely, these two are interconnected to create an environment. This data mainly confirms

the perception that images are the most used material in a reminiscence therapy. Videos are also used by 57% of formal caregivers and 43% of informal ones. Regarding texts, they are used by 57% of formal caregivers, and by only 26% of the informal ones, making it the less used. Some of the caregivers also use objects, games, manual activities and visit places that are meaningful for the person with dementia. In addition to this, many mentioned the importance of talking with the person, or tell stories, as an important point to consider when conducting reminiscence therapy.

Approximately 92% of all caregivers that submitted the surveys prefer personal materials, being the most used by all caregivers. However, 83% of formal caregivers use generic materials as opposed to the informal ones where only 24% use them. This is probably because they have family albums and many images about and with the person with dementia and have no need to use other materials. However, this is not true for formal caregivers as it has to be the people close to a person with dementia to provide the personal materials which often may not happen.

Apart from images and music, 57% of formal and 52% of informal caregivers would like to be able to use videos in their therapies. Texts were also desired by 48% of formal caregivers but were not that relevant for informal ones (29%). In addition, there were many other suggestions such as animals, objects, games, memory boards, 3D glasses, visits to places significant for the person with dementia, food, exercises, scents and smells, and many more. Although they are all good suggestions, none of them fits our solution but they may be useful for other works on the same topic.

As for the materials that trigger more emotional reactions, both caregivers agreed that images and music caused more positive emotional reactions: 91% of the formal caregivers and 71% of informal caregivers. Videos were also mentioned but only 61% of formal and 31% of informal caregivers said that they triggered positive reactions. Texts were only selected by 26% of formal and 17% of informal caregivers so we assume they are not as relevant. Other things that trigger positive emotional reactions are cartoons, textiles, balls, musical instruments, smells, dance, movements, conversations, voices, poems, among others. The activities are not in the domain of our platform and may be carried out at a later stage. Conversation has been considered previously but the movement of the person with dementia was not and shows some relevance as it was mentioned by a formal caregiver that *"it is not a material but it is able to trigger emotional reactions and promotes reminiscence"*. Although we have not considered, it may be implemented in the future some type of movement activity to be carried out in the middle of therapy if it proves to be important.

Regarding the negative emotional reactions, 38% of all the caregivers answered that none of the materials cause this type of emotions. However, music was selected by 5% of the informal caregivers being the one who triggers less negative emotional reactions. On the other hand, 9% of formal caregivers consider that both videos and texts are the ones who trigger less negative reactions. The images were the most selected by both caregiver types, being considered the ones who trigger more negative reactions. They were selected by 48% of formal caregivers and 26% of informal. Being one of the most used and possibly most diversified materials, it is probably the one which most frequently generates these reactions. Other causes of negative emotional reactions were also mentioned, although they have nothing to do with therapy, such as going out on the street in some cases and technology being a source of frustration and anxiety. Despite all this the formal caregivers explained that it is difficult to know what causes these reactions as it *"depends on the state of dementia and individual experience"* and also *"depends on*

*the material content and individual sensibility”.*

As for the themes of the material used in the reminiscence therapy, almost all of the listed ones were selected with percentages above 60%. Pets, professions and places that people visited were some of these. Family members was the most selected with 87% of the formal caregivers and 93% of the informal caregivers considering it as one of the most important themes. Places where people lived was very relevant for formal caregivers with 96%, but less relevant for informal caregivers with 55%. Vehicles that people had was not a very relevant theme for the person with dementia compared to the others, being selected by only 33% of informal caregivers and 43% of formal ones. Some examples of themes mentioned that might be interesting to consider were: hobbies, food, TV shows, actors, important dates, movies, objects, sports, plants, parties and happy moments, city where they were born, childhood memories, memories with relatives, dancing and holidays, among many others. When given the possibility to create themes, the caregivers tend to make several ramifications on a theme, hence we confirmed our assumption of having a set of pre-defined themes to avoid an endless list.

To obtain the materials for therapy, 74% of the formal caregivers resort to relatives and 87% to the Internet. As for informal caregivers, 81% rely mainly on family members, while only 40% search on the Internet. From formal caregivers, 57% still resort to the person with dementia for this material unlike 21% of informal caregivers who are already family members and should already have that material. Friends are also sources of material for both, 43% of formal caregivers and 29% of informal ones, but are not as relevant as family members. In addition some of the caregivers create the material or use material from the workplace. Formal caregivers also resort to Alzheimer's and dementia groups or buy material to use.

Materials are updated over time, according to the data collected, Formal caregivers update these materials daily (17%), weekly (22%), every two weeks (17%) and monthly (26%). The data is widely distributed by these time intervals, but updating monthly stands out in relation to the others. The informal caregiver updates the materials daily (29%), weekly (17%) and monthly (26%). In this case, daily updates stand out more because informal caregivers have faster access to the person's materials and can update them more easily. The caregivers who answered that they do not update the materials at least within 6 months said that was mostly due to lack of time (50%) or lack of interest of the person with dementia (approximately 36%). Other explanations were given by caregivers saying that *“most of the time it is necessary to repeat activities”* and also that *“depending on the state of dementia there may be no interest to always be presenting new materials”*.

Regarding what caregivers saves about a therapy session, 48% of the formal caregivers mentioned the duration of the session. Besides this all the other information was considered important with more than 60% of the percentage, with some more prominent than others: emotional state of the person with dementia before the therapy session (65%); emotional state of the person with dementia after the therapy session (87%); material that helped recall past memories (83%); material that induced negative emotional reactions (70%); and material that induced positive emotional reactions (83%). The emotional state of the person with dementia after the therapy session and material that helped to recall past memories and induced positive emotional reactions were the ones that had a higher relevance. In the case of informal caregivers only two topics from those mentioned above had a percentage higher than 50%: material that helped recall past memories (55%) and material that induced positive emotional reactions (57%). This

is due to the fact that informal caregivers do not keep as many records as formal caregivers, so they only give relevance to the records who help them know what can be used in next sessions and bring positive emotions to the person with dementia. In addition, the caregivers mentioned other records that may be important, such as: the degree of engagement and interest in the session, dynamics with the caregiver or the group, periodic assessment of cognitive functions, responses during the session, among others.

Regarding what they would like to save about the therapy session, in the case of formal caregivers, only 4 of the records mentioned above stood out more: duration of the session (48%); emotional state of the person with dementia before the therapy session (52%); material that induced positive emotional reactions (43%); and material that induced negative emotional reactions (39%). The material that induced negative reactions is not much recorded but it is also necessary to understand what should not be used in next sessions. On the other hand, the material that induced positive reactions defines what should be used in the next sessions. In the case of the informal caregivers the data was very identical to what they already record, again due to the fact that they do not record much information as 17% also said they did not want to record anything else. However, those that stood out were material that helped recall past memories (36%) and material that induced positive emotional reactions (50%). Formal caregivers also suggested to record: the intensity of emotional reaction (positive and negative) to specific stimuli; permission to record for evaluation; how people with dementia were during the session; refusals; non-verbal language; behaviour; relationship with therapist; initiative in contact; and responses during the session relevant to future sessions.

### **Follow up appointments**

Although formal caregivers have professional training and there is usually the idea that they consult a person, the results show that this is not the case as they are divided: 53% have appointments and 47% do not. In the case of informal caregivers, this is already in line with what is expected as only 37% do follow up appointments and 63% do not. The formal caregivers perform these appointments mainly on a daily basis (28%), weekly (28%) and monthly (22%). In the case of informal caregivers this happens more on a daily basis (32%), although it also happens weekly (16%) and monthly (11%). There were also those who answered never, as they may not have immediately understood the concept of follow up appointments before answering this section: 17% formal and 34% informal. Of those who consult people over 6 months of difference between appointments, the reasons given by formal caregivers were: because of the costs and lack of time.

In these appointments the formal caregivers observe: emotional well-being of the person with dementia (93%); emotional reactions of the person with dementia (87%); and results from previous sessions (for comparison) (67%). The duration of sessions (13%) and the number of sessions per month/week (7%) are not as relevant for these caregivers as data is merely indicative. In the case of informal caregivers the data were very similar with different percentages but the most relevant to observe continued to be the same: emotional well-being of the person with dementia (64%); emotional reactions of the person with dementia (64%); and results from previous sessions (for comparison) (48%). Again the other two were not that relevant. One formal caregiver also suggested the assessment of cognitive functions in these appointments.

### Other forms of follow up

Other forms of follow up are also used by 59% of formal caregivers and 47% of informal caregivers. Some examples of other forms of follow up used are: individual or group cognitive stimulation; medication; outpatient consultations; video appointments; movement sessions; diary; daily support; conversation; joint sessions (person with dementia with family member); online and face-to-face therapeutic sessions; stimulation activities; psychotherapeutic support; speciality appointments (neurology, psychology, psychiatry, among others); games; observation of interaction with peers; physiotherapy; medical/clinical consultations; ABVD (Adriamycin-bleomycin-vinblastine-dacarbazine) therapy; gerontology techniques; visiting places relevant to the person; arterotherapy; visits from relatives/friends; medical examinations; primary care physician (PCP); telephone contacts; keeping a record of his mood and date and what they talked about; watching videos; keeping up with routine; duration of people's reactions both positive and negative; and psychomotricity.

Regarding technologies used for this follow ups, 65% of formal caregivers use technologies in contrast to 33% of informal caregivers. Caregivers mentioned some of those technologies: COGWEB [9]; computer; snozelen room; music; mobile phones; tablet/iPad; overhead projector; video; images; camera; internet; blue laser light; tv; radio; and audio books. Informal caregivers also referred many technologies to help with chronic diseases or pains like: oxygen machine; digital device to measure blood pressure; pneumatic mattress; and iPad with flash cards to help communicate with a person that has frontal lobe dementia / frontotemporal dementia (FLD).

### Technology

In this section we tried to validate some of the functionalities that were developed on the previous work by Vagos et al. [34] and also the new ones we found relevant considering the previous study made with the informal caregivers by Alarcão et al. [1] and the prototype being developed. Our objective was to understand what were the functionalities more relevant for each type of caregiver so we could identify the ones that should be implemented on our platform.

Regarding the person with dementia management functionalities, 66% of formal caregivers found it interesting to be able to notify other caregivers, unlike informal caregivers, in which the percentages were evenly distributed, with 36% being in a neutral position. The creation of reminders was also accepted by the formal caregivers, 67% of whom found this feature interesting, while the informal caregivers were again quite divided, with 31% being again on a neutral position. Being able to share the care of a person with dementia with other caregivers was very well accepted by formal caregivers with 79% finding this functionality interesting, and 41% found it quite interesting. In the case of informal caregivers, 38% were on a neutral position and the rest were evenly distributed. We believe that the fact that informal caregivers do not find these features anything special is due to the fact that most of them only care for one person and do not need to manage several people at the same time.

Regarding the reminiscence sessions we asked about session delivery and session history. The automatic adaptation of the session content based on the person with dementia's biographical information was found interesting by 82% of the formal caregivers, and 50% found it quite interesting. On the other hand, 45% of the informal caregivers did not find it interesting and 25% were on a neutral position. The

automatic adaptation of the session content based on the person with dementia's emotional reactions to the materials presented was found interesting by 88% of the formal caregivers, and 53% found it quite interesting. In the case of informal caregivers, again, we have rather distributed opinions that do not allowed us to draw a conclusion. Seeing the materials used in each therapy session was again very interesting for the formal caregivers, with 85% of them finding the functionality interesting and 44% finding it quite interesting. On the other hand, 42% of the informal caregivers found the functionality not interesting and 26% not very interesting, although opinion was again very divided. The caregiver session history was well accepted by formal caregivers with 76% finding the feature interesting, and 41% finding it quite interesting. In the case of informal caregivers we again had the values distributed and 31% were on a neutral position. The history of person with dementia's sessions where all their sessions, even if carried out by other caregivers, are presented was well accepted by the formal caregivers with 79% finding the functionality interesting and 44% finding it quite interesting. Informal caregivers were again widely distributed in their opinion. In this section, we believe that the results are due to the fact that many informal caregivers do not even perform reminiscence therapy and do not understand the purpose of the functions, unlike the formal caregivers who use it on a daily basis and found most of the functions at least interesting.

Regarding the material used in the therapy sessions, 85% of the formal caregivers found it interesting to be able to insert new material into the platform, and 44% found it quite interesting. In this case, 35% of the informal caregivers found this feature interesting and 30% were on a neutral position, so we can conclude that this feature was well accepted by all caregivers. Inserting new material topics beyond the ones mentioned above, on reminiscence sessions section, was considered interesting by 82% of the formal caregivers, with 47% finding it quite interesting. In this case, the informal caregivers again had rather scattered answers so that no conclusion can be drawn. The existence of a favourites section in each person with dementia's material was an idea that was very well accepted by the formal caregivers with 88% finding it interesting, and 50% finding it quite interesting. In this case, 36% of the informal caregivers found the feature interesting and 31% were on a neutral position. With these data, we can conclude that this feature was well accepted by all caregivers. Once again, some of the informal caregivers' doubts may be due to the fact that they do not manage much differentiated material and several people unlike formal caregivers who do it on a daily basis.

Regarding the help tools that could be available in our platform, for formal caregivers, the help within the platform proved to be the most feasible with 70% of the caregivers finding it interesting. In addition, the email/telephone was also well accepted, with 58% finding it interesting, but the instructions manual had a slightly higher percentage, also being well accepted with 65% finding it interesting. In the informal context the most viable idea was the email/telephone with 42% of the caregivers finding it interesting. Even so, the other ideas were not far behind, with the help within the platform being appreciated by 40% of the caregivers as being interesting and the instructions manual, even though it had fewer, was appreciated by 37% of the caregivers. In the case of the informal caregivers, the help within the platform had a percentage close to that of the email/telephone, although this last one was preferred by the informal caregivers. With these results the help within the platform is the most feasible solution for both caregivers. However, as informal caregivers prefer email/telephone at least an email address should be provided which they can use to ask questions they have about the platform.



To finish, we asked the caregivers how comfortable they felt introducing personal content within our platform. In the case of formal caregivers, although 21% were in doubt, 70% felt comfortable to do so. In the case of informal caregivers it is evenly distributed, but 55% feel free to introduce personal content into the platform. Although in the case of informal caregivers near half of them are still less comfortable with it, with the results obtained we can assume that there should be no major problems entering personal content into our platform.

### **Suggestions**

From all the suggestions we received we identified the most relevant and applicable. One of them was that relatives could have the possibility to upload material for reminiscence directly into the platform without having an account on it. Also, was explained that it is crucial that the visual/auditory material is easy for the person with dementia to perceive. Allow session planning and construction beyond the automatic tools that were considered for the platform can also be important, specially for formal caregivers. One caregiver also referred that the people with dementia loses interest with time and tends to settle on one idea leaving no options of activity which can be crucial when executing only reminiscence therapy.

## **3.4 Interviews**

After analyzing the results that came from the surveys we defined a set of topics to discuss on the interviews. In this section we describe those topics and also how we analyzed the data obtained from the interviews. We also present the results that came from this gathering.

### **3.4.1 Structure**

We started the interviews by giving the digital informed consent form, so caregivers could agree and participate in the study. The interviews followed a semi-structure format and started with a characterization of the caregivers like their age as it was important for the interaction section. Other important points were to understand if they do reminiscence therapy, how many people with dementia they care for and which are the new technologies they use, so we could identify which ones are easier for them. On the formal caregiver context we also wanted to know if they do reminiscence group sessions as it can be important to incorporate on our platform in future versions. For informal caregivers was important to understand if they know what is reminiscence therapy.

After characterization section we started our questions about reminiscence therapy, which was the most important topic we wanted to discuss on these interviews. We first tried to understand which materials caregivers use when performing therapy with people with dementia. From the surveys we had a lot of responses and we wanted to understand if our perception about using images is right. Besides that, we also wanted to know how caregivers acquire the material they use in therapies.

From the surveys we discovered that people preferred personal materials instead of generic and that was another thing we wanted to confirm. The emotional impact people with dementia have to these different types of material was also very important to understand. Other thing we wanted to know is how caregivers react when the person with dementia has an unpredicted or negative reaction.

Although on surveys was referred that updating materials depends on the person with dementia we wanted to understand if caregivers update materials and if not why. Is it because of the person with dementia or due to other factors. Also we would like to know their opinion about updating the materials as there were different opinions on the surveys.

Finally, we wanted to know how they conduct reminiscence therapy and if they register information about the emotional reactions that the person with dementia shows while performing it. If they do these type of registers, we also wanted to know where caregivers register these information.

After all these questions we introduced our platform high-fidelity prototype and its functionalities to caregivers and let them have a first interaction with it. We also made some questions about some functionalities that we were developing and trying to understand if they are really useful, and also about privacy concerns regarding caregivers' personal information. However, we only describe this part of the interviews on Chapter 7 where all the process of platform evaluation and its results are described.

### 3.4.2 Data Analysis

We used verbatim transcription while transcribing the audio as it was referred by Blake et al. they are partial accounts of a much richer interaction experience and are better for qualitative research [22]. All the conversations were transcribed exactly as they were listened through the audio, with all words and expressions. For this section we only considered what was spoken before the platform's remote tests.

After transcribing all the interviews, we used the software CATMA (Computer Assisted Text Markup and Analysis) [5] to coding. We identified what were the similar opinions between each of the caregivers as we only used one list of codes to all the interviews. With that codification we did an affinity map so we were able to analyze all the important aspects from the interviews and summarize the most important results obtained. The affinity map can be seen in Appendix G.

### 3.4.3 Results

While presenting what we concluded from interviews we will show some of caregivers' quotes which helped us to reach the following results. We did interviews with three Portuguese caregivers. We interviewed a 35 year old formal caregiver (C2) and two informal caregivers with the age of 53 (C3) and 60 (C1). All of them were female, which according to the survey data was very likely to happen since more than 90% of the caregivers were female.

We found that informal caregivers have some difficulties in using new technologies. An example of this was the fact that C3 did not have a mouse and had to use the touchpad, which proved to be complicated to use. However, they showed ease in using the mobile phone and the computer as long as it has a mouse. These two are also the most used by any of the formal and informal caregivers according to the surveys. We also realised that they prefer wider screens.

- C1: *"I do not have a tablet but I do have a good mobile phone which I use for what is possible. When I need something with a bigger screen I use the laptop."*

They easily accessed the Zoom interview through the link we sent them so it also helps us to realise that most of them will know what a link in our platform is. The formal caregiver, C2, already uses Skype

and Zoom on her daily living to do some appointments in addition to COGWEB [9] which is an application used by many formal caregivers to do cognitive training. None of these caregivers interviewed uses a tablet or iPad.

The informal caregivers care for only one person, who is their family member. In this case, C3 cares for her mother and C1 for her spouse. Both of them referred that it was their first major contact with a person with dementia.

- C1: *"It is the first one. I had contact with a relative of his but it was small."*
- C3: *"This was all very new for me, I was learning how to deal... I had never dealt with anyone before. I was discovering things little by little."*

In the other hand, the formal caregiver cares for several people with dementia at the same time. In this case, C2 cares for more than 8, and taking into account the surveys, this should be the case for most of the formal caregivers.

In these interviews some aspects regarding people with dementia were also mentioned. It was mentioned that people with dementia have less and less emotions over time.

- C1: *"I think emotionally there are fewer emotions. Let us say emotions are much more neutral. So, neither high or low. There is a kind of neutrality in emotions."*

Also, older people do not easily adopt new technologies. C1 also mentioned that not all of them try to isolate themselves and she believes that this is due to the right monitoring and not letting the person isolate himself/herself. Caregivers who care for these people should always try to pull the person up when they are feeling sad or lonely.

There are still some complicated reactions. C1 even mentioned that the spouse sometimes feels confused and has feelings of jealousy when she is caring for other person. Apart from the confusion that can occur, sometimes these people also fixate on certain issues and all interviewed caregivers believe that one should not challenge these ideas and try to bring up other subjects by diverting the conversation. It is important to interact through speech and explanation in these complicated cases.

Negative emotions are difficult to understand on the beginning of care. These negative emotions can arise when showing a picture to a person, but if you show that person the same picture again later, he/she has already forgotten about the reaction and the picture. However, at the moment it happens a different environment should be created for the person to forget what has just happened.

- C3: *"It is just that after a while you begin to understand (these emotions)"*
- C3: *"Sometimes, I deal with these reactions by saying "Look, the person did not die, the person will arrive tomorrow" because tomorrow she already forgets"*
- C3: *"When there is (...) a great deal of sadness (...) we create an environment... Differentiated. Because otherwise depression is very big too"*

Regarding the monitoring of the person with dementia, informal caregivers resort to dementia support centres and people with dementia undergo cognitive stimulation, physiotherapy, games and C3 even uses hipotherapy with the person she cares for. C1 also referred that promoting the accomplishment of as

many tasks as possible on a daily basis slows the process and encourages maintaining the autonomy of the person with dementia and that she follows all the person's suggestions to go out somewhere in order to maintain their well-being and autonomy. This helps to avoid the isolation of the person with dementia, which is very important for these people.

Formal caregivers show that they are more used to dealing with these people, being their profession, and are often able to help informal caregivers. Informal caregivers reported that sometimes they are uncertain about the care they are providing to the person and sometimes they have to resort to formal caregivers to understand if what they are doing is right and if everything is really okay with the person they are caring for. Taking into account that informal caregivers also spend much more time with the person they are caring for, they therefore show an increase in desperation and fatigue over time.

Regarding reminiscence therapy, only the informal caregiver C1 does not perform it and did not even know what it was. However, when it was explained to her, she considered that she does it intuitively by showing the person photos and talking about them, but not in a register of reminiscence therapy.

- C1: *"He was so emotional that when he got to one of the pyramids he started crying profusely (...) and occasionally I show him these photos and he always says he will go again, I mean, I do not do this every day but whenever I see him more fallen"*

The formal caregiver C2 reported that she does the therapy on average 2 to 3 times a week and that it usually takes 1 hour. On the other hand, the informal caregiver C3 reported that she only takes 30 minutes to perform therapy. Also C2 reported that they did reminiscence group sessions in the past between two and five people, as five being an exceptional case.

Both informal and formal caregivers show preference in personal material for the therapies. C3 also mentioned the importance of sharing personal material to reminiscence.

- C2: *"If I know there is a person who likes some in particular or that some make a particular impact on them, I particularise more"*
- C3: *"Many times informatics gives us that (opportunity). Many times through the telephone they send it (the photos). We have a family group, so they keep sending it to me."*

The formal caregiver usually prepares the sessions in advance and with her chosen material. When preparing the sessions the caregiver uses generic material under lack of personal material, as sometimes the person's relatives or friends do not provide her with such material. However, for the therapy to have an effect with more generic material, these materials have to be filtered according to the reactions of the person with dementia and the therapy.

- C2: *"Sometimes people bring their own photos. (...) Sometimes there are other people who never bring (...) And I end up, for example, bringing some photos of the old city or especially old objects that lead people to talk about them, about the tasks they used to do with them"*
- C2: *"In other words, I often start precisely by sometimes showing some more generic songs and then I also try to filter them"*

C2 also records the emotions of people with dementia, the therapy sessions and also the cognitive performance on a computer document she has for each person. In the other hand, informal caregiver C3 does not make any records and had never thought of doing so.

Regarding updating the materials used in therapy, the formal caregiver mentioned that this depends a lot on the experience and knowledge of the caregiver. Family members usually provide the new materials, but as already mentioned, sometimes they do not provide the materials and it becomes difficult for the formal caregiver to update them. In addition, this action should also depend on the person and the stage of the disease because in a state of major forgetfulness always changing the material can confuse the person, so they use older photos in these cases.

- C2: *"It all depends, once again, on the person and the stage they are in. In other words, people who, for example, have a greater degree of forgetfulness in relation to the present reality, sometimes bringing more up-to-date photos will confuse the person even more... In other words, it is really a job that has to be very personalised. "*
- C2: *"But in this sense, we are not always doing the same thing. As technicians ourselves, we also feel the need not to be always using the same thing. "*

Informal caregiver C3 also mentioned that she tries to do other different activities besides reminiscence therapy.

### 3.5 Main Findings

Due to COVID-19 pandemic we had difficulties executing the requirements gathering. There was an high dropout rate that were above 70% for both of caregiver types. We do not know if it was for lack of time or disinterest on the survey but we could assume that the pandemic could have something to do with that as most of the responses came later in the study when the pandemic was being finally controlled, at some point. Despite that, we got 136 responses submitted on our surveys which allowed us to validate the previous study from Alarcão et al. with informal caregivers [1] and most of the other requirements and functionalities that we defined as important to the implementation of our platform, as well as the identification of new ones.

We used surveys to gather the first data and complemented the results with interviews so we could clarify some aspects and understand what caregivers need to execute reminiscence therapy on our platform. That helped us understand how we could help them so reminiscence therapy is more accessible and convenient. At the end of the requirements gathering we were able to take lots of conclusions. In Figure 3.4 we enumerate the principal requirements and possible outcomes that we defined at the end of the requirements gathering after analyzing all the data obtained. We will now describe the major findings obtained from this requirements gathering and relate them with the identified requirements.

The first thing that jumps out from the results is the fact that more than 90% of the people who submitted the survey were female. Informal caregivers have greater ages than formal ones so as it was expected they have more visual problems. However, approximately 70% have an higher education degree.

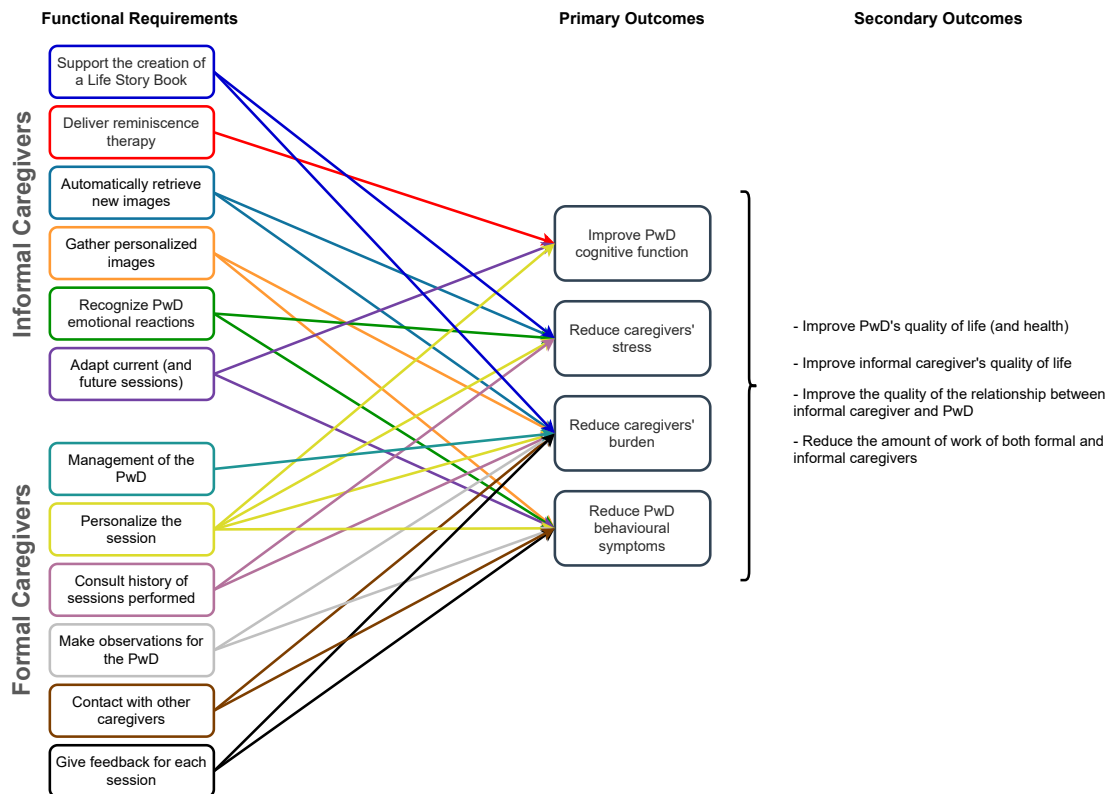


Figure 3.4: Requirements established after analyzing both surveys and interviews, and considering the previous study with informal caregivers from Alarcão et al. [1] (best seen in colour).

Regarding technologies the most used is the computer. Although mobile phone is also one of the most used by formal caregivers there are yet 29% informal who do not even use it. In the case of the tablet/iPad the situation is the opposite as informal caregivers use them more, probably in alternative to the computer as it could be more accessible for people with more age. However, we noticed on interviews that informal caregivers have some difficulties with these new technologies.

Regarding the follow up of people with dementia we identified that formal caregivers care for more persons than the informal ones, which normally only take care of one and he/she is normally their relative. Also, informal caregivers are the ones who spend more time a day with a person with dementia, probably because they live with them and this is one reason that makes them reach a state of desperation and fatigue over time. Thus, to help reduce formal caregivers' burden and stress the management of all the persons they care for should be facilitated. To help both caregivers what would help is to facilitate the process of preparing and performing this therapy. By using our platform different functionalities to perform reminiscence therapy the amount of work that both informal and formal caregivers would have preparing therapy sessions should be reduced, which is important to improve the quality of life for both caregivers. The person with dementia' cognitive functions will also be improved as they will have the possibility to make therapy with them more often.

When it comes to complicated reactions it was referred on the interviews that we should try to get to these persons by talking and explaining things to them. Also, was referred that it is important to not leave the person feel sad or lonely and help them maintain the most automaticity as possible, so they can feel better with them. By recognizing emotional reactions our platform will be able to understand what

should not be shown to these persons reducing people with dementia behavioural symptoms by adapting the session to what they like more so they could feel better after performing therapy, improving their quality of life.

The majority of caregivers perform reminiscence therapy with the person with dementia, although there are less informal caregivers who perform it. Our platform could be an help so informal caregivers start perform these therapies more often. This will help improve the relationship between them and people with dementia, as they have another activity to do with them, and improve people with dementia cognitive functions as they will work with their memory more often.

We also found that when informal caregivers perform therapy, they perform it more often. Probably because they care a lot for the person and want to help them. However, they take less time than a formal caregiver, which does a more technical therapy. As expected informal caregivers perform therapy at home while formal ones at institutions. Most of the caregivers showed preference for images and music. Videos were also considered but not as the last ones. Thus our perception of images being the most used is correct and should be the principal material to be used in our platform. Music is also very important and should be considered in future versions of this platform to create a better environment.

When registering the results of a session, formal caregivers showed more interest than the informal ones, probably because the last ones do not take registers so serious. However they showed to be important during and after therapy. The material that helped recall past memories and induced positive emotional reactions were referred by both caregivers as the more important ones to consider. The emotional state of the person with dementia after a therapy session was also very important to formal caregivers. Also, a formal caregiver referred on an interview that she had a file where she records the emotions of the person with dementia, the therapy sessions and the cognitive performance being somehow identical to a page for that person. Being able to make these registers on our platform will reduce the amount of applications that caregivers need to use, their burden and also show informal caregivers the importance to register feedback about a session. Also it will help caregivers to better follow up a person and reduce person with dementia behavioural symptoms.

All caregivers prefer personal materials when performing reminiscence therapies but formal caregivers are not always able to get these personal content, so they use generic ones. They need to resort to relatives of the person with dementia to get this personal materials, so they normally use the Internet to get generic ones. However, these generic materials should be filtered considering the information retrieved from the therapy sessions. On the other hand, informal caregivers have more access to the personal content so they do not use generic material as much. Our platform will also support the creation of a Life Story Book as people can introduce material with descriptions that helps understand what an image means to that person. This will also create a better interaction between the caregiver and the person with dementia, improving their relationship.

Our platform will allow to introduce personal material, so it will ease the accessibility to these materials by formal caregivers as they can share the care of a person with dementia with informal caregivers. As these ones normally have that personalized material, they can introduce it into the person's page reducing formal caregivers' burden and stress on finding materials to use. This will also help reduce people with dementia behavioural symptoms by using more personalized material with them. In the cases where there is no personal material our platform will be able to obtain generic material to be used on therapies

so caregivers will not have to search material very often.

When it comes to emotions the caregivers selected images and music as the ones who give more positive reactions and referred that conversation is also very important for that. For negative reactions music was selected as the one who gives less negative emotions and images as the one who gives more, probably because of being one of the most used and diverse materials. However, was referred that is difficult to determine what causes these reactions most as it depends on the state of dementia, the content of the material and individual sensitivity and experience of the caregiver. By using different algorithms, our platform will be able to identify the emotions from the person with dementia while executing therapy which will be helpful to identify the negative reactions, at least. This will help reduce people with dementia behavioural symptoms.

While asking the themes of material we identified that given the possibility to create them, the caregivers tended to make several ramifications around a specific theme, hence we confirmed our assumption of having a set of pre-defined themes so as not to have an endless list of them. We also find out that, although caregivers tend to update materials, they also referred that depending on the state of dementia there may be no interest to always be presenting new materials. That is why consulting a session history is considered important to help identify if new materials are good for a given person reducing the caregivers' stress and burden on understanding what should be used. If new materials are not helpful, caregivers are able to personalize a session with the content they want in this cases.

When it comes to follow up appointments as expected the informal caregivers do not perform it as much as formal caregivers, although it was divided as 53% of the formal caregivers perform these appointments. Formal caregivers perform these appointments daily, weekly or monthly as informal ones do it mostly on a daily basis. In these appointments what is most observed are the emotional well-being of the persons with dementia and their emotion reactions, as well as previous sessions for comparison. Being able to consult each session results will help caregivers to compare sessions. Also, the feedback register about a session will be helpful to understand the emotional state of a person with dementia alongside with images emotional reaction. General observations about a person with dementia will be also helpful to consider so caregivers can understand some general notes about the person, helping them prepare and perform reminiscence sessions and also follow up a person with dementia. Both this registers will help reduce caregivers' burden and help reduce the people with dementia behavioural symptoms. Other forms of follow up are also performed with resort to a majority of technologies. The follow ups most referred were physiotherapy, cognitive stimulation and also medical/clinical appointments.

Regarding technologies we could identify from the surveys what were the functionalities more relevant to consider from the ones we validated. Notify other caregivers and sharing the care of a person with dementia were functions specially approved by formal caregivers. The last one was also approved by most of informal caregivers. These ones will help reduce caregivers' burden and people with dementia behavioural symptoms as they can get personalized material more often and share ideas between them.

When it comes to how we will manage the session and its history, the informal caregivers did not help in this section, as responses were divided. However, formal caregivers showed interest on the adaption of session according to person with dementia's biographical information and emotional reactions to the materials presented. However, there are some formal caregivers who like to build the session. That is another reason why we should consider the manual creation of a session as there are some caregivers who



do not want to always use automatic session creation. Presenting the materials used for each session was also important to formal caregivers, as well as the session histories for both person with dementia and caregiver. Both of these registers are very helpful to understand what to use on the next therapy sessions. Informal caregivers could not respond well to this section because there are some that do not even know about the reminiscence therapy and do not perform it. All this session management, history and results will help reduce both caregivers' work as well as their stress and burden and help improve people with dementia cognitive functions.

Being able to insert new material and define the favourite ones has showed interest by all the caregivers. However, the insertion of new themes was only relevant to formal caregivers. So we defined a list of themes for the materials based on both surveys and interviews answers. This themes will be associated to an image when it is inserted in our platform so they can be interpreted by automatic algorithms and used on therapies. This will also help organize the material inserted and gathered by the caregivers reducing their burden.

Finally, regarding the help tools, all caregivers preferred help within the platform. However, we should consider the help by email address, specially for informal caregivers as they also liked that idea. When it comes to introducing personal content into the platform, the general opinion was that they are comfortable to do it so there should be no problems on entering that material.

### 3.6 Summary

We started this chapter by explaining our objectives with this requirements gathering. Beyond identifying the needs for caregivers to execute reminiscence therapy, their follow up with the person with dementia and validate the guidelines we defined to build our platform we also wanted to validate the data from the study with informal caregivers performed by Alarcão et al. [1]. On this study they identified the first requirements that were a base to our requirements gathering.

After that, we described our procedure when executing the requirements gathering. We started by getting a formal approval from the ethics committee so we could begin the study. After approval we made online surveys available through Google Forms and disseminated them by email and posting on Facebook groups related to dementia. After closing the surveys we did some interviews with Portuguese formal and informal caregivers that had volunteered. On these interviews we validated some aspects from the surveys and allowed caregivers to have a first interaction with our platform. Although this interaction was made on these interviews the feedback and results that came from these first interaction will be presented on Chapter 7.

After explaining the procedure, we started by explaining each methodology used. Starting by the surveys, we developed two version: one for informal and other for formal caregivers. Both these versions were made available in Portuguese and English. The surveys had 136 responses submitted and were open for 4 months. We explained the structure we used to build these surveys, the data analysis and the results obtained.

The interviews were made after analyzing surveys results. We first described the structure we would follow considering the most important topics that we wanted to clarify on the semi-structured interviews. We made interviews with one formal caregiver and two informal caregivers, all Portuguese. We used

verbatim transcription, coding and an affinity map to analyze the interviews we made. We detailed the results obtained with the help of caregivers' quotes during interviews.

Finally, we summarized all data obtained from the previous study with informal caregivers performed by Alarcão et al. [1] and also both surveys and interviews from this requirements gathering. With all this data we were able to identify the major findings of all this gatherings and also were able to define some principal requirements and possible outcomes that should be considered when building the platform. All major findings were related with this principal requirements so their importance could be explained.

## Chapter 4

# KeepsakeBox Database Concepts

In this chapter we describe all the entities and relationships of our database, as well as the concepts behind them. Establishing the database is a very important part of the platform as the next components will depend on the entities and relationships we defined on this phase. However it must be changeable as new elements can appear with future versions and it should be easy to implement them. Also, the caregivers' feedback about the functionalities of the platform can also imply some changes.

Vagos et al. [34] already made a first design of a database that could be used for this platform. Although all the principal entities were considered (caregivers, person with dementia, images, notifications and sessions), its attributes and relations were not well established according to what we intend to have in the platform and what was identified on the requirements gathering. Also, there were some entities that represented some input related to the life of the person with dementia (pets, vehicles, job, among others) that could be replaced by attributes like a description of an image associated to the person or an observation or note about the person. Thus, we made a new version of the database considering the mentioned aspects and all the functionalities needed that we identified from the requirements gathering.

Before explaining the database we need to make a primary note. Although, in this and future chapters we sometimes have the word patient associated to the person with dementia, we will avoid to use it in the text. We only learned that this word is not the best fit, when conducting the requirements gathering interviews. As we developed our platform components first, we used the word patient and we did not change it as the components that use this word will not be presented to the caregiver. Therefore, in the rest of the explanation we will use person with dementia instead. On our platform there will be other words associated to the person with dementia shown to caregivers so the word patient is completely avoided as we will see on the next chapters.

In the next sections we introduce every entity of our database and how they are related to each of the other entities in the system. On those sections we have different entity relationship diagrams to make it easier to understand the concepts of our database.

### 4.1 Caregiver

Caregivers are the main users of our platform. They will be responsible to create an account on the platform so they can manage all the content inside it. As we can see in Figure 4.1 each caregiver account will have an ID associated along with some information about the caregiver. EMAIL is part of that information and are unique so they will work as an unique key of caregivers. Also, caregivers will

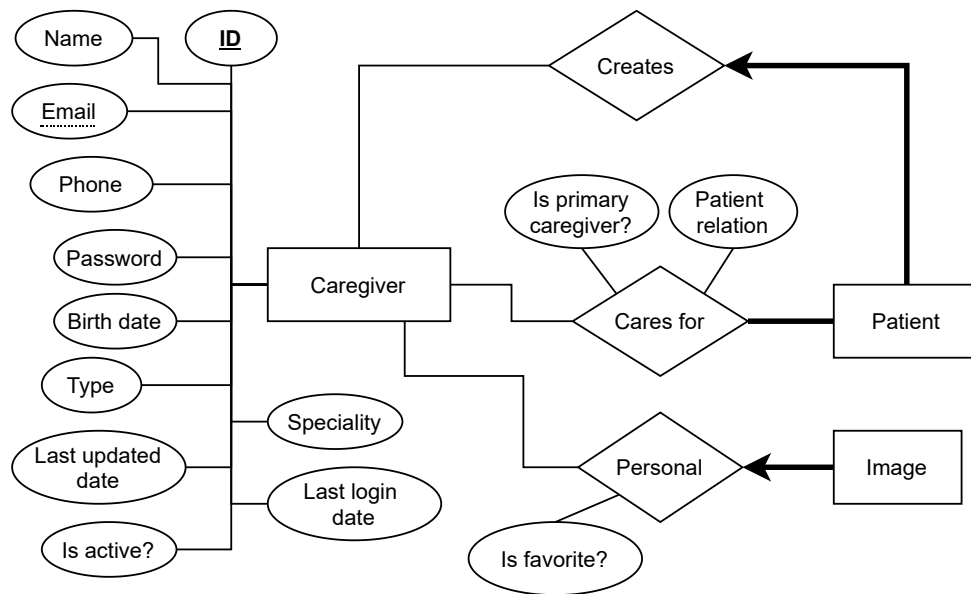


Figure 4.1: Caregiver entity relationship diagram.

have one of two types associated: formal or informal. With this information saved in the attribute TYPE we can apply some differences in terms of design and presentation of information for the different types of caregiver. If a caregiver is of the formal type he/she will also have to select a SPECIALITY which is their professional area when treating people with dementia. Besides this ones, there are some attributes that can be used to identify the caregivers that no longer use the platform, namely: IS ACTIVE? and LAST UPDATED DATE.

Caregivers care for persons with dementia (patients). Some of them care for more than one, specially formal caregivers, so we want them to be able to manage all the persons with dementia within our platform. They will be responsible to create the profile of a person with dementia within our platform becoming automatically associated to the person and as that person's primary caregiver. The primary caregiver is the one responsible to manage all the biographical information of the person with dementia and their associated caregivers and there can only be one for each person with dementia. He/she is the only one who can share the care of the person with other caregivers so both of them can view the same information about a person with dementia and perform therapy with him/her. To do that, the primary caregiver needs to insert the EMAIL of the caregiver, which is unique and easier to share between caregivers, that he/she wants to share the care with so a request is sent to that caregiver. If the other caregiver accepts the request he/she will become associated as one of the person with dementia's secondary caregivers. If the caregiver associated is an informal caregiver he/she will need to insert the relationship it has with the person so formal caregivers can know their relationship. Also, primary caregiver can transfer the primary care to other caregiver by sending a request to one of the associated caregivers of the person he/she is primary caregiver.

Caregivers can leave patients' care anytime. If that person is a primary caregiver it will have to transfer that primary care to other caregiver associated to that person, so he/she can not be the only one caring for that person before leaving. It will not be possible so the register is not deleted that easily as it could be needed in the future. A method of deletion for other reasons is not yet implement but should be

considered in future versions.

To finish, there is also another content associated to caregivers which is their personal images. Caregivers are able to insert personal images into our platform. These images will only be used on therapies that are conducted by the caregiver who has those personal images. Only if those images are considered public by the caregiver who owns them, can they be used on therapies conducted by other caregivers. Also the personal image relationship has an attribute IS FAVOURITE? which is selected by the caregiver and assigned to his/her more important images. These concepts and other related entities will be explained further in this chapter.

## 4.2 Person with Dementia (Patient)

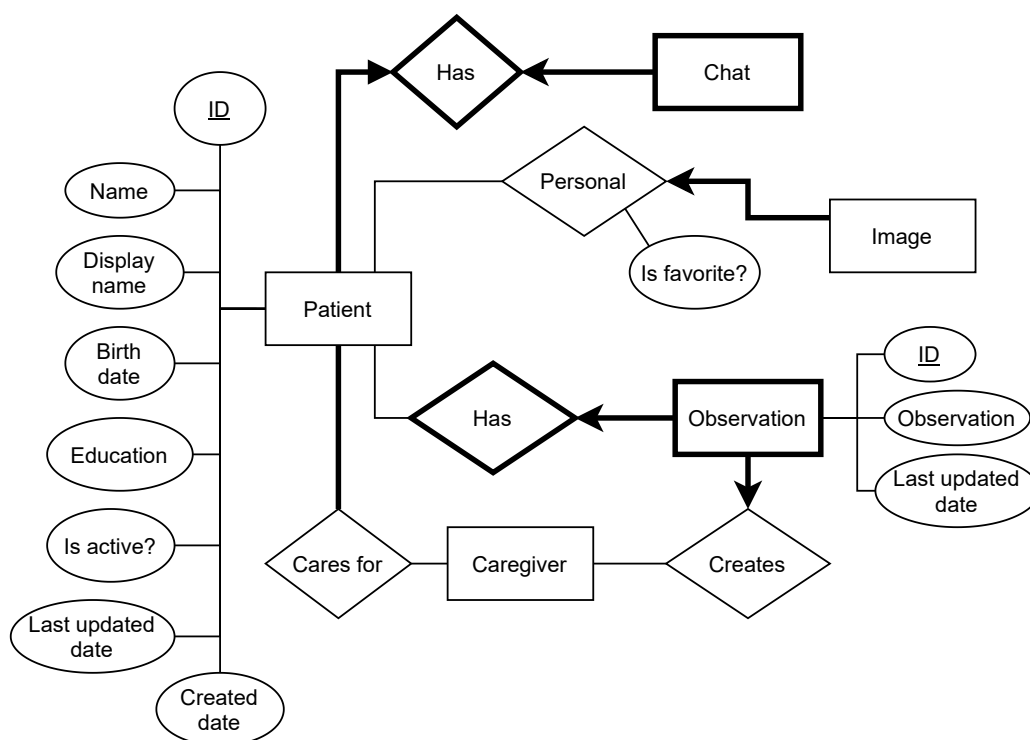


Figure 4.2: Person with Dementia (Patient) entity relationship diagram.

As we explained earlier with the help of figure Figure 4.1 the people with dementia are created by caregivers. After creation a person can have multiple caregivers associated, all participating in his/her care. Looking at Figure 4.2 we can see that a person with dementia has an ID, which is his/her unique identifier, and other identification attributes that are also important for the performance of therapy sessions. The NAME corresponds to that person's full name and the DISPLAY NAME is the name for presentation, which is optional so the first and/or last name will be presented if this one is empty. The attribute EDUCATION is very important to understand what should be used on therapy. As similar to caregiver, there are some attributes that can be used to identify the persons with dementia that are no longer followed with the platform, namely: IS ACTIVE? and LAST UPDATED DATE. A person with dementia also has a chat associated to him/her, where all of that person's associated caregivers can communicate. Each person with dementia has only one chat associated and that chat is only associated to that person.

As similar to the caregiver a person with dementia also has personal images associated to him/her so they can be used on his/her therapy. This images can have a favourite factor so caregivers can select the ones that are more important for the person, which is defined by the attribute IS FAVORITE? of the personal image relation. In addition to images, people with dementia also have observations which can be compared to what is inside the notebooks where caregivers register the general behaviour and emotional state of a person with dementia to help evaluate what to do in therapies and what is the state of disease. Observations are created by only one of the caregivers associated to that person, however caregivers can create multiple ones, and are made using only text which is saved on the attribute OBSERVATION. They only exist if the person with dementia exists, so they are a weak entity, and they have an ID and a LAST UPDATED DATE as they are editable.

### 4.3 Person with Dementia (Patient) Chat

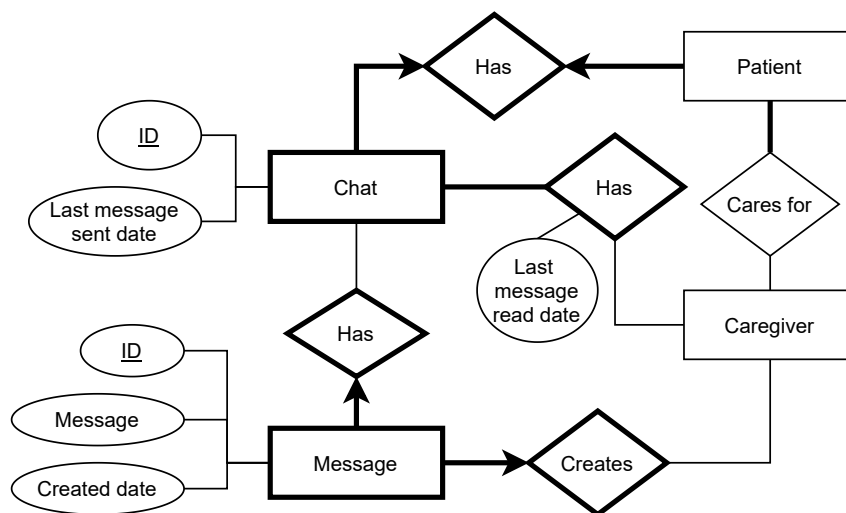


Figure 4.3: Person with Dementia (Patient) Chat entity relationship diagram.

We already referred from looking at Figure 4.2 that a person with dementia has only a chat associated to him/her and that chat only belongs to that person, so it is a weak entity as it only exists if the person with dementia exists. From Figure 4.3 we can see that person with dementia chat has an ID and a LAST MESSAGE SENT DATE which is the date of the last message sent on the chat and it is useful to understand if there are new messages on the chat for each caregiver associated with it. The caregivers that are associated to the person with dementia are all associated to the chat of that person. However, if a caregiver stops caring for a person they are also removed from that person's chat. To understand if a caregiver has new messages on that chat the platform will see if LAST MESSAGE SENT DATE attribute from the chat is greater than the LAST MESSAGE READ DATE attribute on the relation between the chat and the caregiver.

Considering that we are talking about a chat we should also save all of its messages. Messages are also a weak entity that only exist if the chat where they are associated continues to exist. A message can only be created by one caregiver and can only belong to one chat. Caregivers can create multiple messages for multiple chats, although they only can create one for each chat at a time and only on the

chats of the people with dementia they care for. This way, caregivers can send multiple messages on a chat and all the messages will be saved. Thus, all the messages sent on a chat are not lost after leaving it and the communication between caregivers is maintained. A message has an attribute called MESSAGE which will have the text that was created by one caregiver, which is associated to that message, and also a CREATED DATE which is important to calculate the LAST MESSAGE SENT DATE on a chat, as the one with a greater date associated to a chat will define this value. Also, it will define the LAST MESSAGE READ DATE of a caregiver as the value saved is the CREATED DATE of the last message that he/she saws on the chat.

## 4.4 Notification

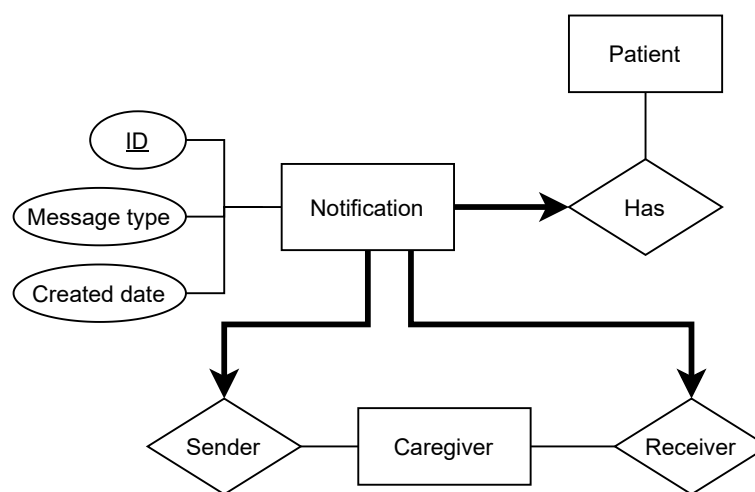


Figure 4.4: Notification entity relationship diagram.

As we can see in Figure 4.4 a notification should be associated to only two caregivers, a sender and a receiver. Also this notification should have a person with dementia associated to it, which is the one where the caregiver operation on that notification will occur. A person can be associated to multiple notifications and the caregiver can be associated to multiple requests as sender or receiver, but not both at the same time. A notification has a MESSAGE TYPE for the system to perform an operation in which the two caregivers and the person with dementia associated are the parameters. We defined different values for the MESSAGE TYPE that are associated to one operation of our system. Thus, the system can read that attribute and execute the operation associated to the value inside it. This way, different operations can be done with only one entity of our system by reading its attribute. The attribute CREATED DATE is only used for caregivers to see when the notification was sent.

A caregiver can send a notification with a share care request or primary care transfer to another caregiver involving a person with dementia. The other caregiver will receive the notification and has two options: the caregiver accepts it, the operation is executed and sends an accepted notification to the sender caregiver; or the caregiver declines it and sends a decline request to the sender caregiver. Other type of notification is sent when the primary caregiver (sender) removes a caregiver (receiver) from a person with dementia care, so that person knows he/she was removed.

## 4.5 Image

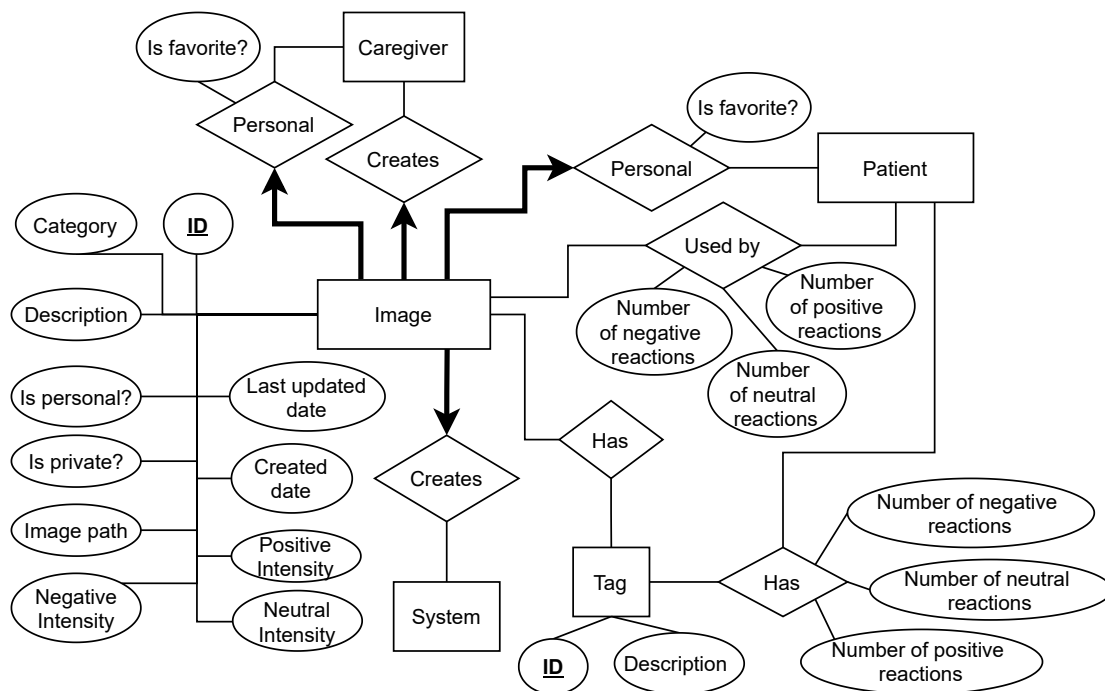


Figure 4.5: Image entity relationship diagram.

An image is very important to the context of our platform. It is with images that caregivers will perform therapy with the people with dementia and will be the ones used to analyze and draw conclusions about the evolution of the person's dementia disease. The caregiver is the one responsible to insert the images into our platform so they can be used on therapies. They can insert their own personal material on their profile page or insert the personal material of a person with dementia on the correspondent pages of the persons they care for. In future versions, the system will also insert images automatically into our platform. All the images retrieved by algorithms will be inserted by the system and considered as generic images, so they do not belong to a person.

As we can see in Figure 4.5 an image has an ID, a CATEGORY selected from a set of categories defined as the most relevant within caregivers and a DESCRIPTION, which can help explain what that image represents to a person. The last two attributes can be used in the future for the system to gather more generic images that are related to the personal images. The attribute IS PERSONAL? defines if an image belongs to someone registered on our platform or was retrieved by our system and it is a generic image. The IS PRIVATE? attribute defines if an image can be used on other persons' therapies within our platform. The caregiver is responsible to make that decision and they only can change this attribute on their personal images or the personal images of the persons they care for. This action is reversible. An image has also emotional polarities attributes that generically define what emotions they recall to the people they are shown when it comes to negative, neutral and positive emotions. The IMAGE PATH is used by our system to get images from the server where they are saved, which will be explained later on this document. The LAST UPDATED DATE and CREATED DATE will help define the most recent images and help in aspects of presentation.



As we have seen in Figure 4.1 and Figure 4.2, and described before, caregivers and people with dementia can have their own personal images inserted into our platform. However, as we can see in Figure 4.5, people with dementia can have other images associated in addition to the personal ones. This happens because when doing therapy the people with dementia are presented with images that were gathered by the system or from other caregivers or persons that allowed to share their images. All these images, including the personal ones, should have a register related to each person if they are presented to them, so we can record the number of negative, neutral and positive reactions related to that image which will help a future algorithm that creates a therapy session to understand what should be presented to that person.

Also, people with dementia can have tags associated to them. A tag consists on sets of images with a similar theme attached to them. When associating a tag to a person it also has the number of negative, neutral and positive reactions associated. This will help future algorithms to understand which tags are the best for that person's therapy and select more images regarding that theme. A tag has an ID so it is easier to edit its information and a DESCRIPTION that describes in what consist that set of images.

## 4.6 Session

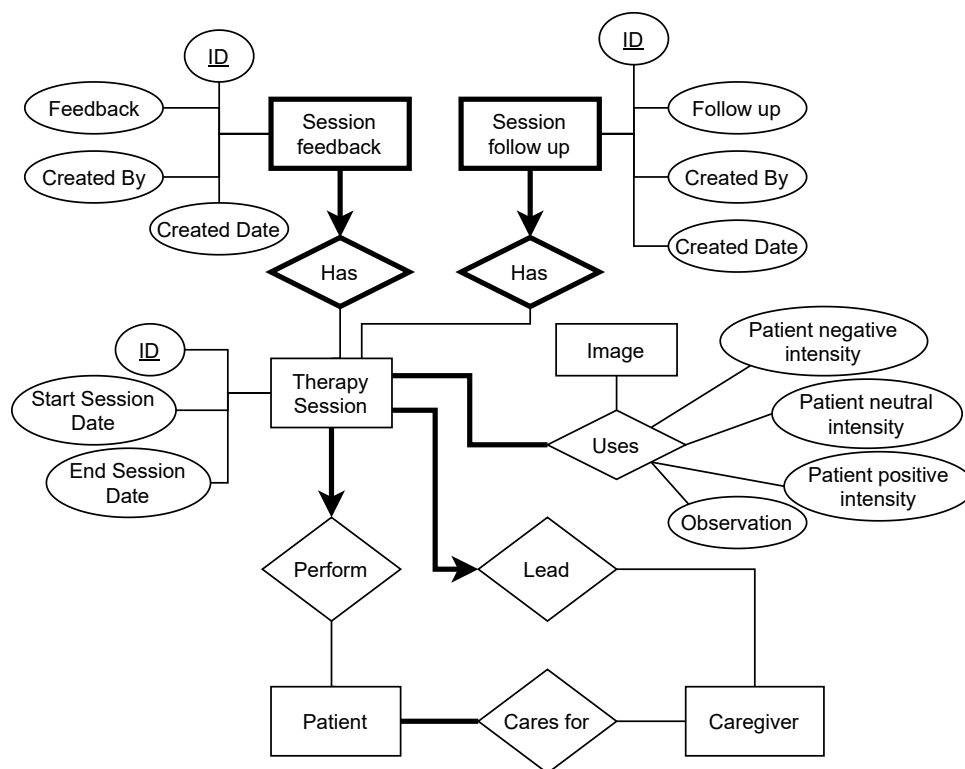


Figure 4.6: Session entity relationship diagram.

As we have referred our platform's main goal is to help caregivers perform reminiscence therapy with the persons with dementia they care for. Usually, this therapy consists on performing several sessions per month to help the persons recall past experiences and slow the progression of disease. In Figure 4.6 we can see that a therapy session has an ID, a START SESSION DATE and an END SESSION DATE. These last two help calculate the time interval in which the therapy was performed. The caregiver is responsible

to led the therapy session which is being performed by one of the persons with dementia associated to him/her, which he/she cares for.

As we could see in Figure 4.5 the images that are used by people with dementia on therapy sessions have a count to the number of negative, neutral and positive reactions shown by the person to each of the images that were presented to them. These counts are associated to the relation between a person and an image. However, when the therapy is performed we do not want to see only the number of reactions to that image but also the intensity of the reactions. So, as the number of reactions are already considered on the relation of the person with an image, when it comes to the relation between the session and an image we will consider the negative, neutral and positive intensity of the reaction shown by the person when the image appeared to them while performing the therapy session. This way, caregivers can analyze the intensity of a specific image when it was presented to the person at different points in time, as each session with a person can show different intensities for the same image. An observation can also be added in addition to those intensities as they can help caregivers describe better the reaction to an image, when it can not be described by intensities. An example is when a person starts remembering what happened on an image and each time that image is presented new aspects are remembered.

When it comes to what is register after the therapy session is concluded, we already talked about what is saved on the context of images presented. However, those are not the only aspects we considered important. As we can see in Figure 4.6 there are two weak entities related to therapy sessions. Both of them only exist if the session continues to exist and belong to a session only. One of them consists on the session feedback which is a register of what happened in the therapy session and should be considered important. It has a FEEDBACK which is the observation about that session and also a CREATED BY attribute as there can be multiple caregivers giving feedback about a session besides the one who led the therapy as all associated caregivers to a person can consult the results of a therapy session and register feedback. The CREATED DATE helps understand the distance to the END SESSION DATE in which the feedback was created. Very similar to this one we also have the session follow up which consists on what should be done in future sessions. This note will be registered on the FOLLOW UP attribute as the others are equal to the session feedback for the same reasons.

## 4.7 Summary

In this chapter we showed the main concepts within our platform's database that will help understand the relationships between them and what role each one represents. For that to be easily understand we used entity relationship diagrams as they are the most suited to show the relationships between each entities of our database and their attributes.

Caregivers are our main users and are the ones that will have an account on the platform and execute all its functions like creating persons with dementia, adding images and leading therapy sessions. When a caregiver creates a person with dementia he/she became his/her primary caregiver and is the only one who can manage their caregivers and edit person's biographical information. Also, when a person is created there is also a chat created and associated to that person. A person will only have one chat associated to him/her and that chat will only belong to that person. Thus, caregivers that care for a person can communicate between them with messages on that person's chat, as they are all associated to

it when they are associated to that person.

People with dementia have observations associated to them. These observations can be created by the caregiver and represent registers that should refer to the person with dementia's behaviour and emotional state throughout the times to help follow the progression of disease.

Caregivers are able to share their people with dementia's care with other caregivers so they can all participate on a person's care and access all person's information. By making a share request they create a notification to other caregiver involving a person so that caregiver can accept or decline it, notifying the sender caregiver about his decision. If a caregiver accepts a person's care he/she becomes person's secondary caregiver. However, primary caregivers can switch with a secondary caregiver of a person they both care for, making a request notification to a secondary caregiver and if he/she accepts it, he/she becomes person's primary caregiver. Other notification is sent when the primary caregiver decides to remove a caregiver from a person, notifying the caregiver removed.

The caregivers are also the ones responsible to insert personal images into our platform. They can insert personal images on their profile being only used on their people with dementia. Also they can insert personal images related to the people with dementia they care for on each of their respective pages. These ones will be only applied on the person's therapy which the personal images belong. Personal images from caregiver can be used in therapies of other persons not related to that caregiver and personal images of persons can be used in other persons' therapies if the caregivers select those images as public ones.

In the future there will be an automatic retrieval algorithm using the data within the platform about people with dementia, that will insert generic images into the system that can be used by all persons registered in our platform on their therapy sessions. The tags that describe a set of images will be also used by this algorithm to help find what better suits a person's likes as they also have person's reactions in their association with a person.

Finally, therapy sessions are led by a caregiver who cares for a person with dementia that is performing therapy. On these sessions, images are the material used to help recall past experiences. After the therapy sessions, the caregivers will be able to consult the reaction intensity of a person to each image presented on the therapy session and also can add a text observation to an image about something that happened when it was shown. The feedback and follow up are also good registers that should be considered after therapy so the caregiver can do a better follow up next time the therapy is performed.



## Chapter 5

# KeepsakeBox Platform

As we referred before, our platform is incorporated on the work of Alarcão et al. which proposes a novel digital person-centered personalized solution for reminiscence therapy [1]. Here, we explain how this work is incorporated in that solution and the overall system architecture of the platform developed, along with all the technologies used.

### 5.1 Reminiscence Therapy Solution

On their proposed solution Alarcão et al. take into account the use of dynamic data and automatic retrieval of it [1]. This is a major improvement comparing to the existing systems which are static and use the same data provided by the caregivers all over again. The burden to update the data is also overcome, since this solution is designed to do it automatically. The consideration of emotions during therapy sessions is another interesting point because it will identify how the person with dementia is feeling towards an image and can replace it if the person has a negative reaction. This can improve the results of therapy because the person with dementia is focused on photos that transmit good memories.

Alarcão et al. solution focus in the system easiness of use because it is expected to be mainly used by older people [1]. Our platform is the user interface for that solution, so caregivers can manage the people with dementia they care for, their information and also execute reminiscence therapy. It will also allow for caregivers to consult session history for each person and each session results so they are able to do a better follow up. Thus, while developing our work we considered all the points referred about easiness of use and older people guidelines so we could achieve a simple, useful and easy to use solution for all caregivers.

Figure 5.1 presents the architecture proposed by Alarcão et al. [1] for the entire solution. We explain briefly this architecture to understand all the components and identify the parts that were already developed in this work.

As we can see in Figure 5.1 there are two users considered for the application: the person with dementia and the caregiver. Although people with dementia are considered a user of the application the only interaction they will have with the application is when performing the session by viewing the images presented and reacting to them. The caregiver will be the only one to interact with the application platform, executing its functionalities and giving inputs.

When a session is being performed the person with dementia will react to each image and the PHYSIOLOGICAL-BASED EMOTION EXTRACTION will be responsible for identifying the emotional re-

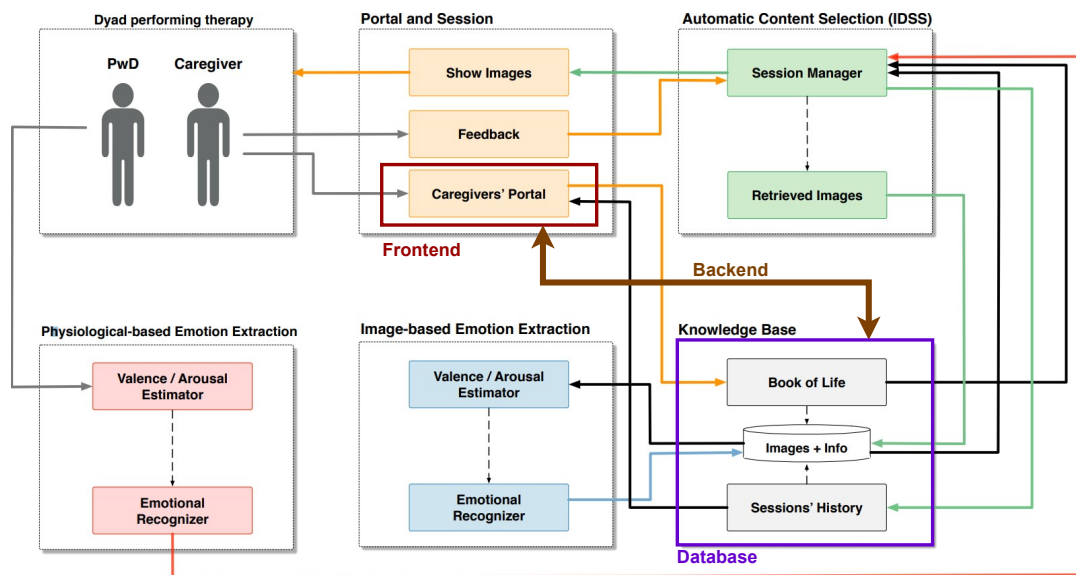


Figure 5.1: Alarcão et al. proposed solution architecture [1] (best seen in colour).

actions and save them, while the session is being performed. The images that are presented on the session are selected by the INFORMATION DECISION SUPPORT SYSTEM (IDSS). After a session is completed the reactions to each image presented will be saved on the KNOWLEDGE BASE along with the feedback given by the caregiver for that session. Also, all images will have an emotion value attached to them which is identified by the IMAGE-BASED EMOTION EXTRACTION.

Our platform will be the interface that will allow for the caregiver to manage all the data within the KNOWLEDGE BASE and execute all functionalities related to persons with dementia's data management and session performance. Also, in Figure 5.1 we can see the DATABASE, BACKEND and FRONTEND developed in this work, which were our major contribution to their work. KNOWLEDGE BASE consists on all information saved about caregivers, people with dementia and sessions as it represents the DATABASE that was already developed in this work, and its concepts were explained on the previous chapter. The BACKEND represents the connection between the FRONTEND and the DATABASE. It is represented with a two way arrow in Figure 5.1 because the platform's frontend makes requests and receives responses by interacting with it, as the BACKEND uses a RESTful service. It is also very important to all the other connections in that figure, because all of them need to pass through it so data about emotion extractions and image emotional values can be saved on the KNOWLEDGE BASE. Thus, IDSS can use that information to create and manage a therapy session. The FRONTEND represents our platform's interface and will be the tool which caregivers will interact with when using our platform.

In this work we only developed the platform related functionalities that interact directly with the KNOWLEDGE BASE. They were all related to: the management of people with dementia and their data; the caregivers' data management functions; and the share of people with dementia care. Session related functionalities were not considered in this work, although we gathered data to support those functionalities.

## 5.2 System Architecture

Figure 5.2 describes the architecture of the platform developed in our work as well as the relations between all the three tiers of the platform: the presentation tier which is the frontend; the business tier which is the backend; and the data tier which is the database/knowledge base.

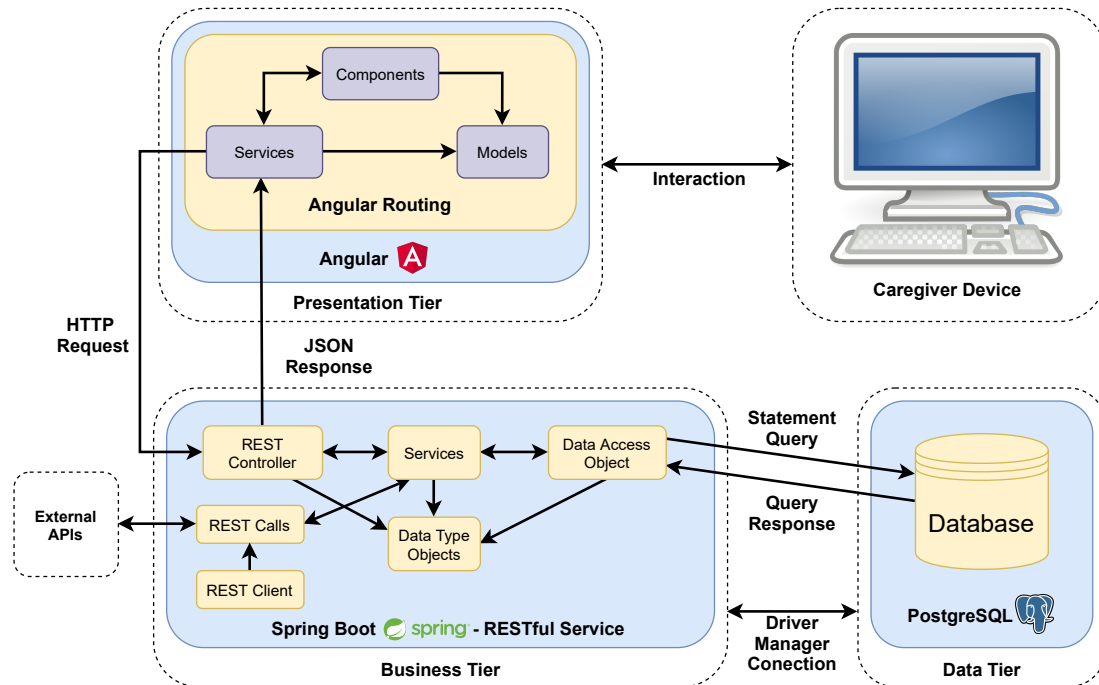


Figure 5.2: KeepsakeBox platform architecture (best seen in colour).

Caregivers will interact with the PRESENTATION TIER of our platform using their device, which allows all operations regarding entities and relations within our database. As the PRESENTATION TIER was built with Angular [3], we used Angular Routing to redirect caregivers to the needed components while interacting with the platform. Each component represents a page or section of a page. All models represent data types, like a caregiver, a person with dementia or an image, and are used by both components and services to manage inserted and retrieved data. Most of the services that we created are used to make HTTP (HyperText Transfer Protocol) requests to the BUSINESS TIER and others for defining useful functions that are used by different components.

The BUSINESS TIER was built using Spring Boot [29] and consists on a RESTful service. When HTTP requests from PRESENTATION TIER are received, the REST (Representational State Transfer) controller redirects them to the needed services so the requests can proceed and create a response that is sent back to the PRESENTATION TIER. For every service that needs to access the database there is a data access object. Requests are forwarded to the needed data access object that will create a statement query for the DATA TIER, which is the database. The DATA TIER was built and defined using PostgreSQL [24] and will return a response to that query. So, when a data access object gets a response from the DATA TIER, that response goes all the way back to service and REST controller, and this last one will send the response to the PRESENTATION TIER, so that data can be shown to the caregiver.

To create the connection between the BUSINESS TIER and the DATA TIER there are two other things we have to consider along with statements. The first one is the connection that should be established. For

that we used a JAVA Driver Manager to establish that connection. The other one is that for the BUSINESS TIER to interact with the DATA TIER it needs to have data type objects. Those ones represent all entities and relations of our database and all data needed for the requests from the PRESENTATION TIER, and are used by all services in BUSINESS TIER. They ease the responses from the REST controller to the PRESENTATION TIER as there are some data type objects of the BUSINESS TIER that are equal to the models on PRESENTATION TIER, so they can be easily read by the Angular service when a response is received.

There are also REST CALLS on the BUSINESS TIER. These ones are used to execute requests to other APIs (Application Programming Interfaces), like the one who gets the image polarity for each image, returning the image negative, neutral and positive intensity. A REST CLIENT is defined and used by REST CALLS to execute these external requests. Although we did not worked with external APIs yet, Vagos et al. as defined those two in their work [34] to make use of some APIs like Clarifai [6]. As this work was the base to build our BUSINESS TIER we defined the REST CLIENT and REST CALLS, so they can be used in future versions that have functionalities using external APIs.

### 5.3 Database

As we already mentioned for the data tier we used PostgreSQL database [24]. PostgreSQL is an open source and consists on an object-relational database which uses and extends SQL language. This database also has the capability to scale when loading enormous amounts of data at once in a good time. As we have lists with various persons with dementia, caregivers and images it is useful that the database can scale and gather these materials all at once without taking too long so the user do not experience enormous waiting times when using our platform. The database was built considering the concepts referred on Chapter 4 and its entity relationship diagram can be seen in Appendix H.

### 5.4 Backend

The backend was firstly developed by Vagos et al. [34]. We kept its structure, so it continues to be a RESTful service that has an app controller and uses services, data access objects and data type objects to complete the requests. However, its endpoints and all the components referred were completely renewed to match the new design of the platform. One of the things that remained unchanged was the session token logic as it is really useful to make session management within our platform, so only authorized users can execute functionalities within our platform's backend/business tier. The backend/business tier was implemented using Spring Boot [29] which allowed us to create a RESTful service using JAVA language. We used Maven as the project's building tool and compiler. Figure 5.3 presents the backend structure with more detail and describes the roles of each component so the requests can be executed and make their way to the frontend.

Looking into Figure 5.3 we can see that HTTP Requests are sent by the frontend/presentation tier, normally GET and POST. Those are received by the APP CONTROLLER which is the REST CONTROLLER of our platform. It will be responsible to forward the requests to services which will answer it by accessing the data needed and executing the needed functions. The APP CONTROLLER will also be responsible



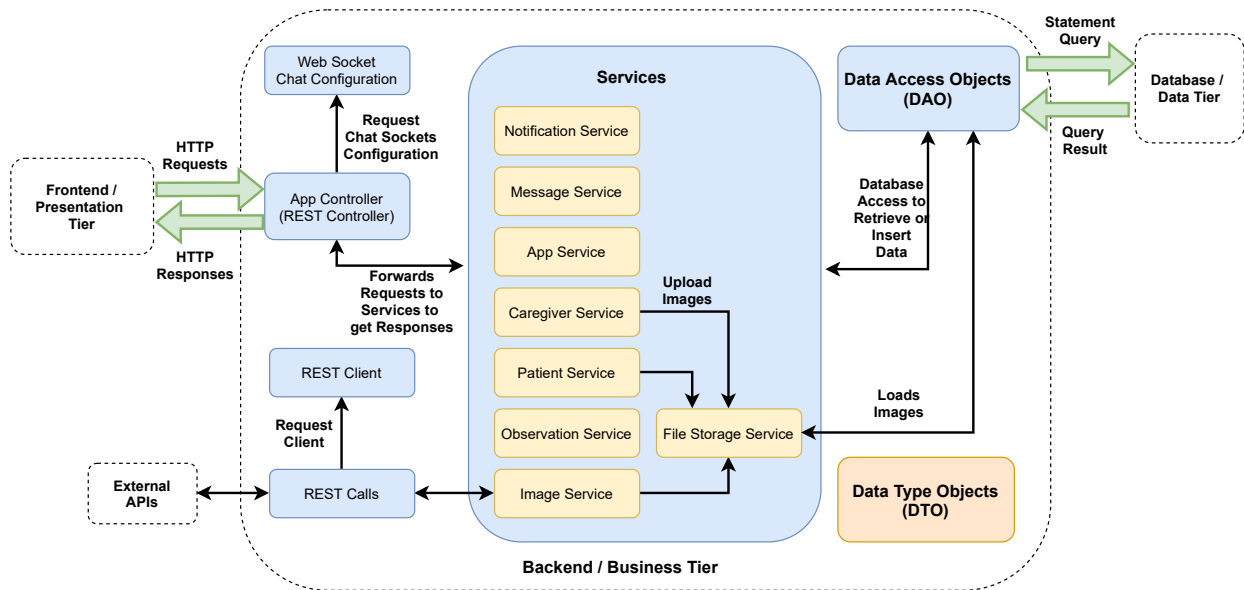


Figure 5.3: KeepsakeBox backend architecture (best seen in colour).

to make that answer reach the frontend. We describe now each of this services and their importance within our business logic.

The APP SERVICE is responsible for account creation, login and logout. Basically, is the one responsible for account management and supports the functionalities referred and others like password change and validation. When an account is created there are a lot of functionalities that a caregiver can execute when logging into our platform. When the login occurs there is a session token generated by the APP SERVICE which will be used throughout the session to address that caregiver, as that token is also associated to its ID and email. Only sessions with a valid token will be able to execute requests sent to the backend/business tier.

All information related to a caregiver after creating an account will be editable. Also they can add a new person with dementia into our platform, which will be associated automatically to them, becoming that person's primary caregiver. That person's care can be shared with other caregivers, so other caregivers are associated. When there are at least two caregivers associated to a person with dementia a caregiver can leave that person's care. Transferring the primary care to other caregiver is also possible. All this tasks are completed by our CAREGIVER SERVICE as well as the functions to search a caregiver by ID or email which are used for the login and other functionalities.

All actions regarding two caregivers and a person with dementia are handled by the NOTIFICATION SERVICE. This one will be responsible to notify the caregivers about actions executed by other caregivers regarding the persons with dementia at their care. All these actions need to be accepted by the receiver caregiver so they can be actually executed. The only one that does not need to be accepted by the receiver is when a primary caregiver removes a non primary caregiver from the care of a person with dementia.

Regarding the person with dementia there are also a lot of functions to be considered in addition to those mentioned above. When a person with dementia is created it should be accessible by our platform. So, the PATIENT SERVICE will be responsible to get a person with dementia by its ID as well as update person's biographical information. Another responsibility of this service is to get all caregivers associated

to a given person so the primary caregiver can do the management of all caregivers associated to that person.

The person with dementia also has other objects associated to it like the observations, which are annotations about that person, and the chat, where caregivers will be able to instant messaging. To address these ones we first have the OBSERVATION SERVICE which will be responsible to create, edit or delete an observation of a person with dementia. When it comes to the chat we have two components considered to make it work: WEB SOCKET CHAT CONFIGURATION and MESSAGE SERVICE. As the chat was built using web sockets we first need to make a web socket configuration to be used by our REST controller so it can differentiate all person with dementia's chats as the routes are defined by each person's chat ID.

When a caregiver accesses a chat it will appear all the information that is saved on our database. This operation is executed by the MESSAGE SERVICE as it retrieves all messages associated to a given chat along with the last message sent on it and the last message read by the caregiver who accessed it. After that, the caregiver's session will use STOMP (Simple Text Orientated Messaging Protocol) client to subscribe to a person's chat so it can receive and send messages instantaneously. All caregivers associated to a person with dementia can access that person's chat section, and they are all subscribed to the same chat which allows instant message trades between them. All messages sent and received while on this socket connection are saved on the database and the last message read is updated for all caregivers connected as well as the last message sent on the chat.

Images are of great importance in the context of our platform. There are images in either caregiver and person with dementia profiles. Also, they are used on reminiscence therapy sessions as triggers to the person with dementia's emotions. Lets begin to explain how profile images are managed. Although we saved our images on the database we only saved records and pointers for each image. Images are saved in a separate folder which is managed by FILE STORAGE SERVICE. This service is responsible to create all folders and save images in JPEG format. The main functionality of this service is to receive images converted into Base64 URLs (Uniform Resource Locators) and save them on the correspondent folder as a JPEG file, by reading and converting the given URL. The separate folder where images are saved is called uploads. On this folder the profile images are saved on the folders *caregiverProfileImgs* and *patientProfileImgs* for caregiver and person with dementia respectively. Each profile image is named after the ID of the caregiver or person with dementia followed by the *.jpeg* termination.

In addition to profile images, FILE STORAGE SERVICE also saves the therapy ones. The process of saving the image is the same although the folder creation is different. As caregiver and person with dementia can have images for therapy saved on their profiles we need to create two folders to save that images: *caregiver* and *patient*. Inside each folder there are more folders named after the IDs of the caregiver or the person with dementia, respectively. Inside those the images for therapy are saved named after the ID that was given by the database after the record to that image was created, followed by the *.jpeg* termination. We used JPEG as the extension for our images for being the smallest in terms of size and maintaining image definition. Although we referred before that there are generic images that are used by our platform we did not consider those, as we only dealt with personalized content in this work.

As FILE STORAGE SERVICE is responsible for creating the folders and save images received from the frontend of our platform we need to have a service that can manage all this data. IMAGE SERVICE is

the one responsible by that management. This service is responsible for getting all needed personalized images for the given caregiver or person with dementia. Also, this is the one responsible for adding those images into our database, update them and also delete the connection of that image with a person with dementia or caregiver, as we need to keep the image within our platform because it could have been used on other person's therapy sessions and the record should be maintained for session report. However, this image will no longer be available on that person's page and will be no longer be used on therapies. In the future, it should be possible to understand which images are being used or not to relieve some load from the server and database.

Although REST CALLS can only be used by IMAGE SERVICE at this point, in the future it could be used by other services. REST CALLS are responsible to resort for external APIs, like Clarifai [6] for image interpretation. For that to be possible there is a REST CLIENT who creates a client that will be used to make requests to the external APIs. At the moment we do not use this external APIs, however there is already a function to read image polarity when an image for therapy is inserted into our platform and should be completed in future versions using an external API.

We already described all the principal services of our platform but we did not explained how they access the data they need. The DATA ACCESS OBJECTS (DAOs) are used to execute the statements in our database. The DAOs will receive the results from that statements and interpret the data so the backend services can forward the response to the frontend. That is the principal function of all the DAOs built for our platform. The only exception to those accesses occurs when a DAO needs to load an image from the folders. They need to send the image loaded on the response so they use the IDs retrieved, and the image path in the case of therapy images, to forge the path to an image and use FILE STORAGE SERVICE to load it from the folders.

Finally, we have The DATA TYPE OBJECTS (DTOS) which are used by all the components of backend. When a HTTP request comes with data it normally brings a frontend's model associated. Those models are identical to backend's DTOS, so the APP CONTROLLER can interpret them and create a response more easily using them. With these DTOS it is easier to manage all entities of our platform as they represent database entries, that are retrieved from statements' results, and request data, that are used for a service to interpret the data and fulfil a request.

## 5.5 Frontend

Frontend was developed using Angular [3], HTML5 (HyperText Markup Language 5) to build the page structure, CSS (Cascading Style Sheets) for styling and TypeScript for functional behaviour. The latter adds additional syntax to JavaScript and allowed us to build different functionalities within our platform, and also the incorporation of HTTP requests to interact with the RESTful service of the backend. Figure 5.4 represents the structure defined when building our platform's frontend. The implementation of screens and functionalities will be described more carefully in the next chapter.

As we can see all components' access is managed by ANGULAR ROUTING which sets an URL for each component we defined. All components need a service to make requests to our backend, sending them to the proper URL (RESTful service endpoint) using HTTP requests and retrieving the correspondent answer. That is the function of most of the services on our frontend excluding the service regarding

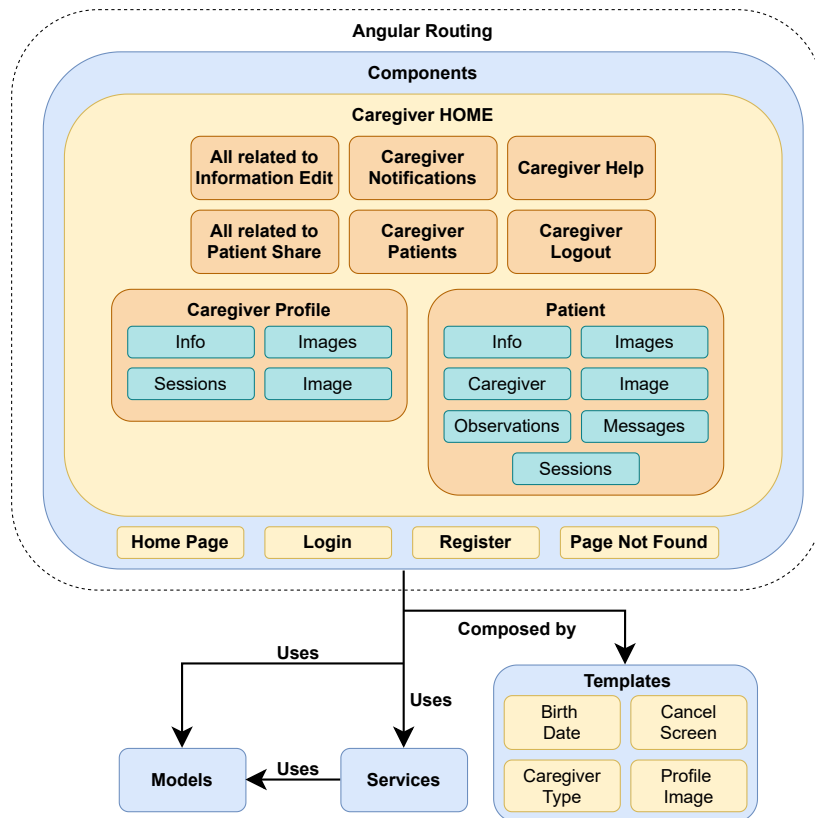


Figure 5.4: KeepsakeBox frontend architecture (best seen in colour).

general platform functions which are used by all components that need them and does not have HTTP requests. All the others use Angular HTTP Client to complete the HTTP requests.

Like we have seen on backend regarding DTOs we also have the Models here that are used by both components and services. These ones represent some of the entities and relations of our platform as well as some data needed for requests and frontend components. Externally to ANGULAR ROUTING we also have the TEMPLATES, which are separate components that can be used by all platform components to avoid repeating the same structure.

On the first layer of components we have the HOME PAGE which is the first contact of caregivers with our platform. From there, they can register an account going to REGISTER COMPONENT or, if already have an account, they can log into the platform by accessing the LOGIN COMPONENT. Both these last two components referred use one-side encryption on frontend's side, so the password goes encrypted to the backend. Also we have the PAGE NOT FOUND COMPONENT which appears when the URL accessed does not have any component associated to it. To finish this first layer we have the CAREGIVER HOME which is only accessible when a caregiver logs in. When a caregiver logs in, the authentication service of our platform saves the session token on cache and the caregiver service saves the correspondent caregiver data also on cache so they do not need to login every time they access the platform. This cache is cleared when caregiver logs out.

Inside CAREGIVER HOME we have all components related to a caregiver account. Caregivers can see all the persons with dementia they care for by accessing the CAREGIVER PATIENTS COMPONENT where they will also be able to add and associate new persons to them.

They also have a CAREGIVER NOTIFICATIONS COMPONENT where they will receive all notifications related to primary caregiver management and person with dementia care share. All the components related to sending notifications are located on this second tier of components as well. The data needed for the request, that is not on cache, is always sent using ANGULAR ROUTING current navigation extras. This attribute allows to add data to a navigation on ANGULAR ROUTING so we do not need to keep all data saved on cache and can do a better structure of components. This also happens to all components regarding add, edit or delete options about people with dementia, caregivers, images and people with dementia's observations.

CAREGIVER HELP COMPONENT will have all help and hints for the caregiver to understand our platform. It will be like its instruction manual. CAREGIVER LOGOUT will be responsible to clear cache related to the platform and also disables the session token that was active for that session. This way, the session is closed and caregivers will need to login again to access their data.

The CAREGIVER PROFILE COMPONENT has all the related information about the caregiver on cache. On the CAREGIVER INFO COMPONENT a caregiver can consult their profile information and change it, as well as change the password. They will also be able to consult the sessions they conducted with our platform on CAREGIVER SESSIONS COMPONENT. On the CAREGIVER IMAGES COMPONENT a caregiver can consult their images for therapy sessions as well as add new ones. These images are meant to be used on therapies with all the people with dementia the caregiver cares for. They also can choose an image to be consulted going into CAREGIVER IMAGE COMPONENT where they will see the information associated to the image selected and have the possibility to edit and delete that image.

To finish we have PATIENT COMPONENT where all information about a person with dementia can be consulted and actions executed. Like a caregiver, the person with dementia selected will also be saved on cache, so some actions can be executed easily and for the person with dementia page not to be empty.

On the PATIENT INFO COMPONENT it will be possible to consult and manage all of that person's caregivers as well as consult the information of each one by going into PATIENT CAREGIVER COMPONENT. Also, a primary caregiver can share person with dementia's care and edit person's information in PATIENT INFO COMPONENT. On the person with dementia page it is also possible to add, consult, edit or remove a person's observations by accessing PATIENT OBSERVATIONS COMPONENT.

On the PATIENT MESSAGES COMPONENT we can view the correspondent person with dementia chat. It is on this component that the chat subscription is made by the caregiver session using STOMP client. So, it is possible to receive and send instant messages on the chat by all caregivers associated to that person. The PATIENT SESSIONS COMPONENT will show all the sessions that were executed with that person with dementia.

Finally, the PATIENT IMAGES COMPONENT is where caregivers will be able to consult images for that person's therapy sessions as well as add new ones. They also can choose an image to be consulted going into PATIENT IMAGE COMPONENT where they will see the information associated to the image selected and have the possibility to edit and delete that image.

## 5.6 Summary

We started this chapter by explaining where our platform is incorporated into Alarcão et al. work [1]. Our platform represents the caregiver's portal of that work and we also developed the first components of the knowledge base/database and made its structure. All the direct interactions between the platform and database were also developed and are managed by the backend.

After that, we explained our platform's architecture, which is divided in three tiers: presentation tier/frontend; business tier/backend; and data tier/database. We explained all these tiers and their principal components so the interactions that occur on our platform could be understood.

We also explained each of the tiers referred starting by the database where we explained why we used the technology selected and show the structure implemented, as its entities and relations were already explained on the previous chapter. On the backend, we explained the technologies used to build our RESTful service and also its principal services so we could understand how they use Data Access Objects and Data Type Objects to complement the requests given by the App Controller, which receives them from HTTP request sent by the frontend. Some of its configurations were also explained.

Finally we described our frontend structure, while its implementation will be described in the next chapter. We explained how Angular Routing works and how components are structured in tiers. We also explained the functions of services and models. The templates were also explained as they ease some of the implementation.

## Chapter 6

# KeepsakeBox Frontend Implementation

In this chapter we describe the implementation of our platform's frontend. We start by detailing our design decisions for the user interface. After that, we present the principal use cases that can be executed with our platform, which will help explain some design decisions as well.

### 6.1 User Interface Design Decisions

Besides using the results from the requirements gathering, with both formal and informal caregivers, and Alarcão et al. first study [1] with informal caregivers, to identify the needed functionalities and requirements, we also did some validation about the user interface design guidelines presented on Chapter 2 regarding older people. Those guidelines were mostly focused on accessibility and web design.

To validate those guidelines we used surveys to make an anonymous characterisation of the caregivers so we could understand the need of the different guidelines identified. Also, on the interviews we let caregivers have an interaction with our platform's high-fidelity prototype which also helped us validate them.

As mostly older people answered to our surveys we confirmed our decision of making this platform more accessible for these group of people, principally from the side of informal caregivers. The results obtained from all the studies with caregivers helped us identify the subset of the guidelines previously referred that should be considered to build our platform's frontend, which we present below.

**Animations were avoided** as they are usually difficult to read for older users and can distract them from what they should be focusing when using the platform.

**Colour coding** was defined and we only used 5 principal colours: white, dark blue, grey blue, red and green. Our platform main features, as windows, borders, headers, navigators and card titles use dark blue background with white text. When there are information to see or insert, normally it reverses to white background with dark blue text. Our buttons use only 3 colours as background with white text: grey blue, red and green. Green button represents an action to be executed that will make a change on our platform. Red button represents a destructive action that mostly delete some data of the platform or that is being inserted. And finally, we have grey blue button which represents a neutral action that does not interfere with platform's data: no adding, editing or removing actions. All buttons and elements have text associated so colour blindness is not an issue.

**Contrast** was very important to consider for our platform as usually older people have visual difficulties.

We made the platform always with a contrast above 7:0:1. We used dark blue with white text colour for most of the elements of the interface as it has an high contrast of 18:71:1. Also, the reverse was one of the most used with the same contrast of 18:71:1. The green, red and grey blue buttons with white text have a contrast of 8:29:1, 7:88:1 and 10:26:1 respectively [35].

**Help and hints** are also considered for our platform's design. As most of the caregivers are older people they should have a page to consult if there is something they do not understand which is why we have a section like an instruction manual for them to consult. Also, there are hints when performing some functionalities of our platform. These hints will help them execute some functionalities so they do not have always to resort to the instruction manual.

**High error tolerance** is important because applications' users tend to make some errors of interaction, specially older people. So we tried to cater for all the errors that could occur while using our platform. Every cancel button while inserting information always asks for a confirmation if they really want to delete the data they inserted. Also, when inserting data if there is an error our platform highlights red on the field which has an error. Caregivers only can continue or complete a form when all required fields (which are marked) are filled so there could be no miss information in platform's data, and the request does not have errors. All functionalities also have a return button in case the caregivers miss click on the platform so they can always avoid errors.

**Icons were used** to make an analogy to elements of the physical world. These icons will help caregivers understand what is the meaning of each functionality as they represent elements of the real world which they are more familiar with. This process is very important, principally, for older users. However, these icons are always alongside with text to ease the perception of what they mean.

**Images have alternative text** as it can simplify the use of screen readers and help present information even if the image is not loaded. As some older people have visual difficulties it could be difficult to read the interface, even with bigger elements and text. That is the reason why some of them may use screen readers to help. Thus, consider alternative texts to images and all important elements to be readable by screen readers is very important.

**Interaction** was also very important in this platform as we need to give feedback to caregivers about the functions they are executing. So all clicking buttons or links have an hover style associated so they change when a cursor is above them. Also when information is loading there is always a spinner which simulates the page loading until the request is completed. Normally, submit buttons have also these spinners after they are clicked so the caregiver will have the feedback that information is being processed. After a request is completed without errors they will have a message saying that it is completed or they will be redirected to the new content they created, edited or added. In the cases where there is an error, the spinner will stop and a red warning will appear so caregivers know that something went wrong and by reading that message they will be able to understand the error.

**Interface elements are the biggest as possible** because some caregivers have visual difficulties. Having bigger elements and text will help them to use our platform without being worried of what they



can not see.

**Interface elements spacing** was also very important to consider so we could avoid some errors, like miss clicking. By having all buttons, principally, and elements separated the caregiver will differentiate them easily. As they are also bigger, the caregivers can click on the right one without doubts and understand each element borders and content.

**Links are used sometimes instead of buttons** in some accesses of the platform. Some of them are just a shortcut to some buttons and the ones who are not, are an invisible button which works as a link, so only text underlined is presented. We used these links as caregivers understand them and are very helpful in some cases where buttons are too large to add into the interface. So we do not replicate buttons and fill the interface with them, making it more clean. Also, links are always presented with blue colour and underlined. If the link is visited, it will indicate that it was used by turning purple.

**Multiple screens were avoided** as they could divide caregivers' attention between them and they would not focus on the functionality they are using.

**Navigation always have a current location indicator** so caregivers can understand where they are when using our platform. When navigating through caregiver's home there will be a navigator which will indicate which section they are using on the platform. When this navigator is not being used, card headers are also used to show in what step they are when completing a task or as a simple indicator of what page they are seeing. Also, some of these cards have navigation which will work as the principal navigator of that card and indicate which section they are seeing.

**No time limited activities** were implemented as they could make the caregiver uncomfortable. Caregivers will be more comfortable completing all the tasks at their time without being pressured. Thus, they will be more satisfied interacting with our platform.

**Presenting only relevant information for each functionality** is also very important as we do not want caregivers' attention to be divided into different elements of our platform. So, all our screens are simple and do not have unnecessary information for each page they are viewing.

**Scroll was avoided** because some caregivers, principally older people, do not like to use scroll and have difficulties using it. We used pagination and divided some tasks in steps so scroll did not need to be used. Although there are some scrolls in our platform, users can click in arrows instead of scrolling. The only place where scroll is really needed is on the help section as it is similar to an instruction manual, so we did not want to split information into different pages.

**Splitting tasks do not require memory from the previous steps** . If caregivers are completing a splitting task, after completing the first step they are not required to remember it to complete the next one. Also, they can always return to the previous steps if needed.

**Text formatting** is always left aligned. We also used Arial, Helvetica, Sans-serif on all the interface and the size of text is no smaller than 14 pt. We use 14 pt to smaller text elements and 16 pt for the

other elements of the platform. By having bigger text it will ease caregivers readability and they will have more satisfaction using our platform, without forcing their view.

## 6.2 Creating an Account on KeepsakeBox

When a caregiver first accesses our platform will see the first screen of Figure 6.1. That screen is the home page of the platform. It has a simple description of in what consists the platform and a slide show, which automatically changes, presenting some examples of the platform's screens after a caregiver logs into our platform. Here, the caregiver can choose his/her preferred language (Portuguese or English) and start using the application. There is also an email in case caregivers need to contact us and two buttons to LOGIN and CREATE ACCOUNT.

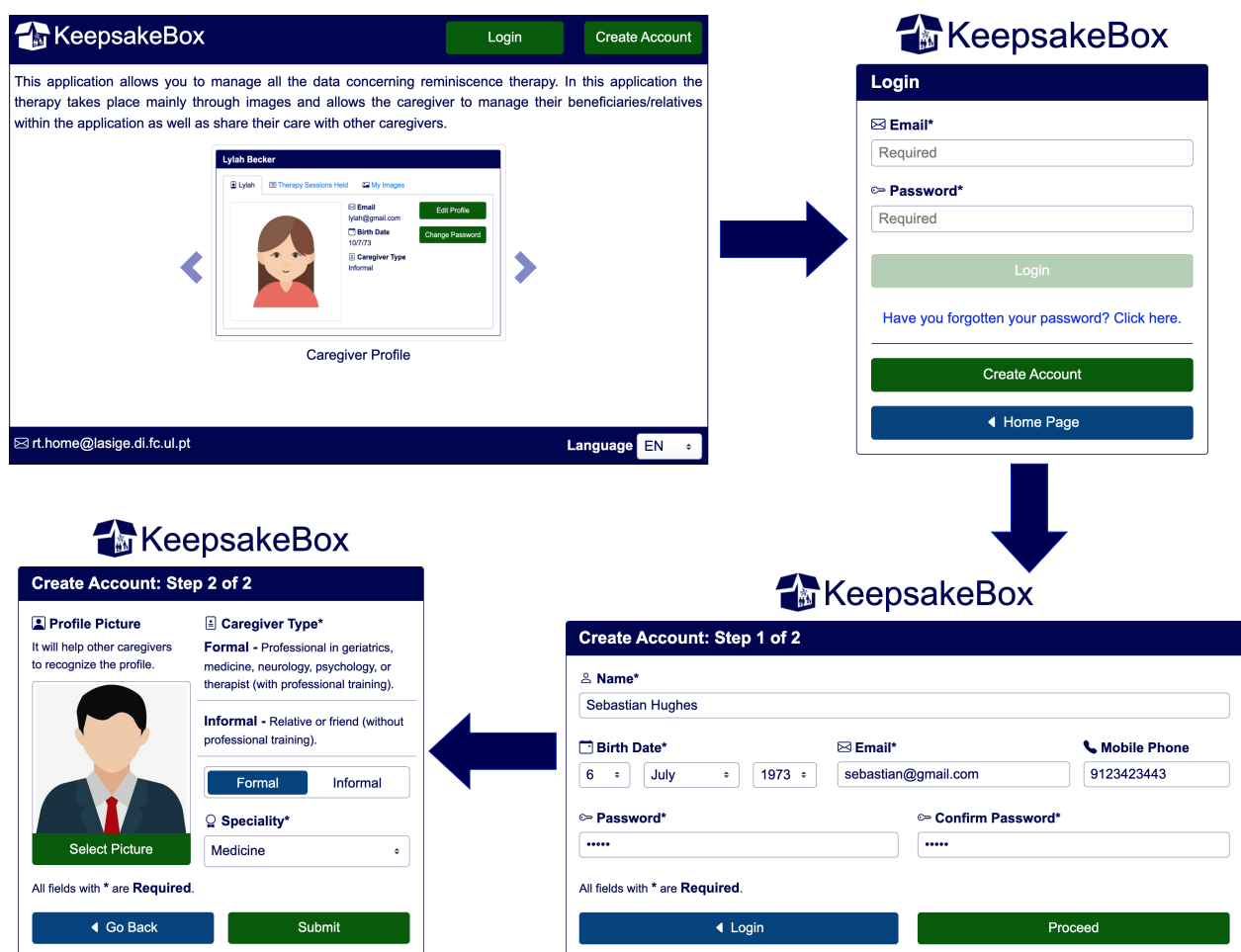


Figure 6.1: Creating an account on KeepsakeBox (best seen in colour).

When clicking on the button LOGIN the caregiver will see the platform's login page, which corresponds to the second image in Figure 6.1. The caregiver can login by entering his/her EMAIL and PASSWORD which will enable the LOGIN button and the caregiver can enter his/her account. Also, there is a link button that can be used to recover a password and the button CREATE ACCOUNT which will get caregivers to account creation form.

Let us now imagine that we have now a male formal caregiver named Sebastian who acceded for the

first time to the platform. The caregiver will click on `CREATE ACCOUNT` and will see the first step of the form for account creation which is the third image of Figure 6.1. The caregiver will need to fill all the fields that have the symbol \*, which points out the required fields. All the fields of this first step are related to personal information of the caregiver and also the definition of his password. After finishing this step the caregiver will click in `PROCEED` and will get to the last and fourth screen of Figure 6.1, which is the final step of the account creation form. In this section the caregiver will need to define his profile (formal or informal) and his `SPECIALITY`, as he selected formal caregiver. He can select one of the given options for `SPECIALITY`: geriatrics; medicine; neurology; psychology; and therapy. A profile image can also be added, although it is optional. After filling all the required fields he can `GO BACK` to the previous step or `SUBMIT` the data and create the account. After submitting the request, login is executed with the new data after account creation leading the caregiver to his caregiver home.

Looking again back to the third image of Figure 6.1 before continuing, we can see that we have a button to return to the login page. If the caregiver had clicked on that button the cancel screen presented in Figure 6.2 would appear so he could revert the action before continuing, so data is not deleted if he miss clicked or did not really want to cancel the account creation. The caregivers can click `NO` if they do not want to cancel register and `YES` otherwise. This last one is red as it describes the destructive option. These cancel windows are used along all the platform to revert actions. Although the information they present is different, the header is always the question and there is always a neutral option represented by grey blue, and a destructive one in red.



Figure 6.2: Cancel Account Creation (best seen in colour).

After logged in the caregiver will see his home page. This home page is the first screen of Figure 6.3. In this page the caregiver will see a list of the persons with dementia associated to him and at his care. As the account is new this list is empty. Also, as the caregiver Sebastian is a formal caregiver the term that appears to refer to the person with dementia is `BENEFICIARY`. The term patient and person with dementia is not well accepted by both caregiver types to refer to people with dementia so we had to find different terms to use on our platform. Caregivers suggested the term `BENEFICIARY` to be used with formal caregivers and the term `RELATIVE` to be used with informal ones to refer to persons with dementia, being the ones with the greatest consensus among caregivers. That is one of the principal differences between an informal and formal caregiver account besides some inputs.

Still in that home page we can see the principal navigator. The caregiver is now on the list of

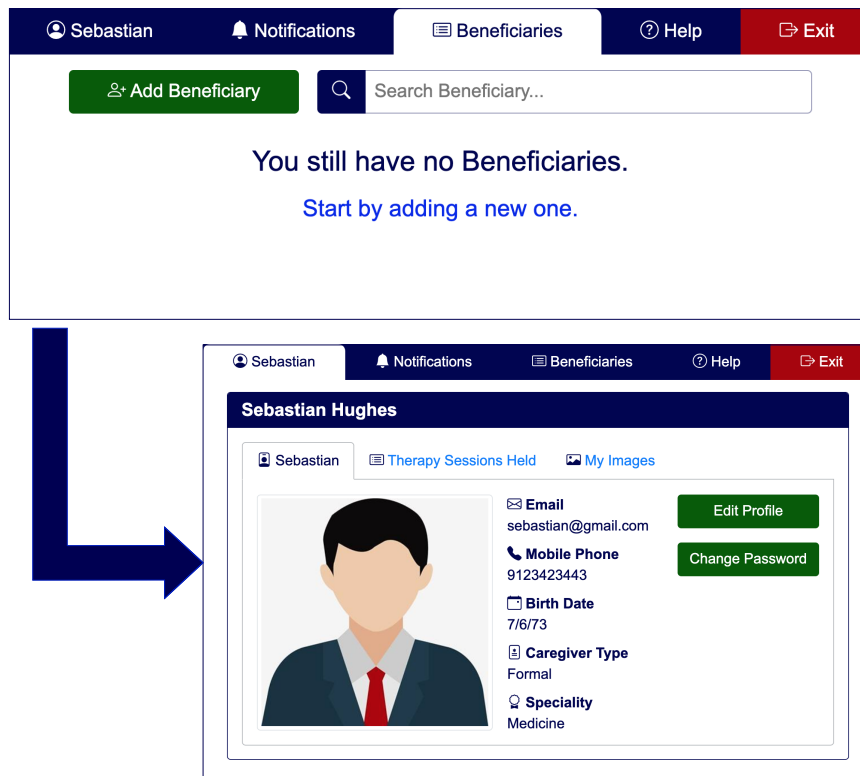


Figure 6.3: Caregiver Account (best seen in colour).

beneficiaries which is the tab selected. In that navigator we also have access to a logout button which is EXIT, the NOTIFICATIONS section and the caregiver's profile. In this case the tab is called SEBASTIAN because we found that it is easier for caregivers to identify their profile if it has their names. Thus, if the caregiver clicks on his name his profile page will appear, which is presented on the second screen of Figure 6.3.

Caregiver's profile page also has sections so it also has a navigator to navigate through them. The first section that appears is the one called SEBASTIAN as it is the one with his personal information. In this page, the caregiver can also edit his profile information and change his password. In the future, the caregiver can go to the section called THERAPY SESSIONS HELD to consult the results from different sessions that were made with the persons with dementia at his care. The caregiver also has other section called MY IMAGES where he can see the list of his personal images to be used in the therapies of the persons he cares for and add new ones. He also has the possibility to filter them by categories and consult and edit each image information. As this section is very similar to the IMAGES section of the person with dementia we will explain all the details inside that section later in this chapter when we associate a person with dementia's personal image to his/her profile, so it can be used in that person's therapy.

### 6.3 Creating a Person with Dementia

As we saw on the first screen of Figure 6.3 the caregiver has an empty list of beneficiaries as his account is a new one. However, he can add new ones by clicking on ADD BENEFICIARY that appears at the left side of the search bar where we can search for beneficiaries by their names. This search is

The image shows two screenshots from the KeepsakeBox application. The top screenshot is the 'Add Beneficiary' form, and the bottom screenshot is the resulting beneficiary profile for Loretta. A large blue arrow points from the 'Submit' button in the top form to the profile in the bottom screenshot.

**KeepsakeBox**

### Add Beneficiary

**Profile Picture**  
It will help other caregivers to recognize the profile.

**Name\***  
Loretta Herrera

**Name to Present**  
Loretta

**Birth Date\***  
10 September 1936

**Education:\***  
Primary School / Elementary School

Select Picture

All fields with \* are Required.

Beneficiaries Submit

---

Sebastian Notifications Beneficiaries Help Exit

### Loretta

Loretta Observations Messages Therapy Sessions Images

**Full Name**  
Loretta Herrera **Begin Therapy**

**Birth Date**  
9/10/36 **Edit Information**

**Education**  
Primary School / Elementary School **Share Care**

Caregivers	Relationship	Actions
	Primary Caregiver	<b>Leave Care</b>

◀ Prev 1 Next ▶

Figure 6.4: Creating a Person with Dementia (best seen in colour).

dynamic so the list will change while we are typing and only the ones that have an equal substring to what we are typing will appear. Also, has there are no beneficiaries yet, a message is shown to the caregiver saying it has no beneficiaries and a shortcut for adding new one is associated to that message, in a link button.

So as Sebastian is new to the platform he wants to add the persons with dementia at his care to it. By clicking on the button ADD BENEFICIARY he will start the process and the form to be filled with information about a person with dementia will appear so that the person can be added to the platform and associated to him. The form can be seen in the first screen of Figure 6.4. After filling all the required fields of that form the caregiver can click on SUBMIT to add, in this case, Loretta to the platform and associate that person to him. As the caregiver Sebastian was the one who created the profile of Loretta, he is associated as her primary caregiver.

The second screen of Figure 6.4 represents the profile page of the person with dementia and is created and showed after a person is added into the platform. That page is very similar to the caregiver's profile page as it also has sections and the navigator, however it has different sections and information. Being the primary caregiver, Sebastian can change the biographical information of Loretta and manage her caregivers in her information page, which is the one selected. In the future, therapy sessions can be performed by clicking on the button BEGIN THERAPY that is also on that page.

Besides the information page, a person with dementia has an OBSERVATIONS section where the caregivers can add the observations about the person and consult them. The MESSAGES section has the chat where the associated caregivers of a person can communicate and instant messaging between them. The THERAPY SESSIONS section will have the session history of the sessions made with that person and the section IMAGES will be explained later on this chapter but has that person's personal images and the caregivers can also add new ones on that section to be used on that person's therapies.

## 6.4 Sharing the Care of a Person with Dementia

Now that the formal caregiver Sebastian has a person with dementia associated to him, which is Loretta, he can now share the care of that person with other caregiver, as he is that person's primary caregiver. Sebastian normally does the follow up of Loretta with the help of her daughter Scarlett, which is an informal caregiver. Thus, to share the care of Loretta with her Sebastian will start the process by clicking on the button SHARE CARE which is on Loretta's information page as we can see on the second screen of Figure 6.4.

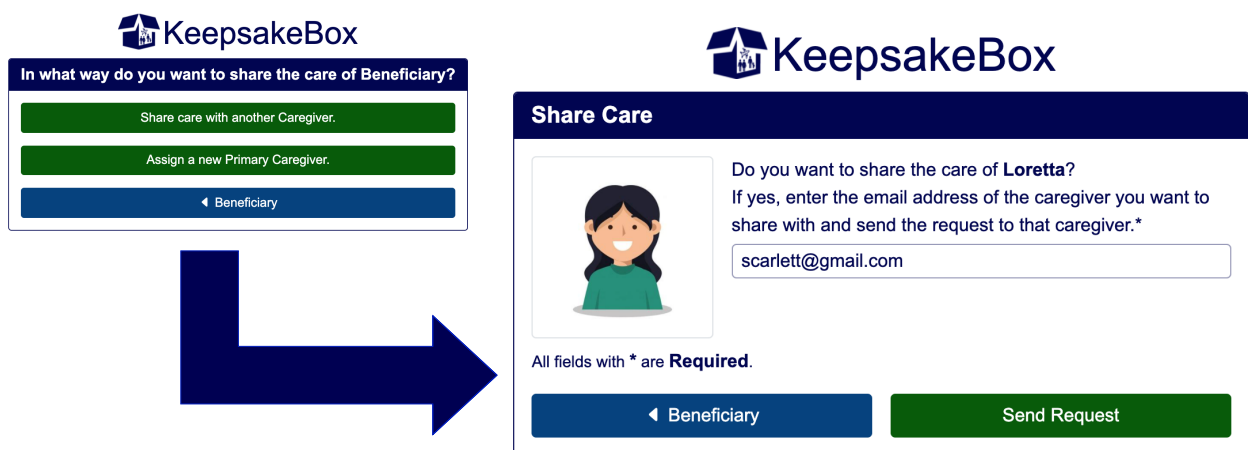


Figure 6.5: Sharing the care of a Person with Dementia with other caregiver (best seen in colour).

After clicking that button the first screen presented in Figure 6.5 will appear and the caregiver has two options: share the care with other caregiver or transfer primary caregiver. As Sebastian wants to share the care of the person he will select SHARE CARE WITH OTHER CAREGIVER. After that, he will see the second screen of Figure 6.5 where he will need to insert the email of the person that he wants to share the care with. In this case, he inserts Scarlett's email. After clicking on the button SEND REQUEST the process of care sharing is complete for Sebastian but Scarlett now needs to accept or decline that request. Also, this operation is only possible because Scarlett has already an account in the platform

associated to that email.

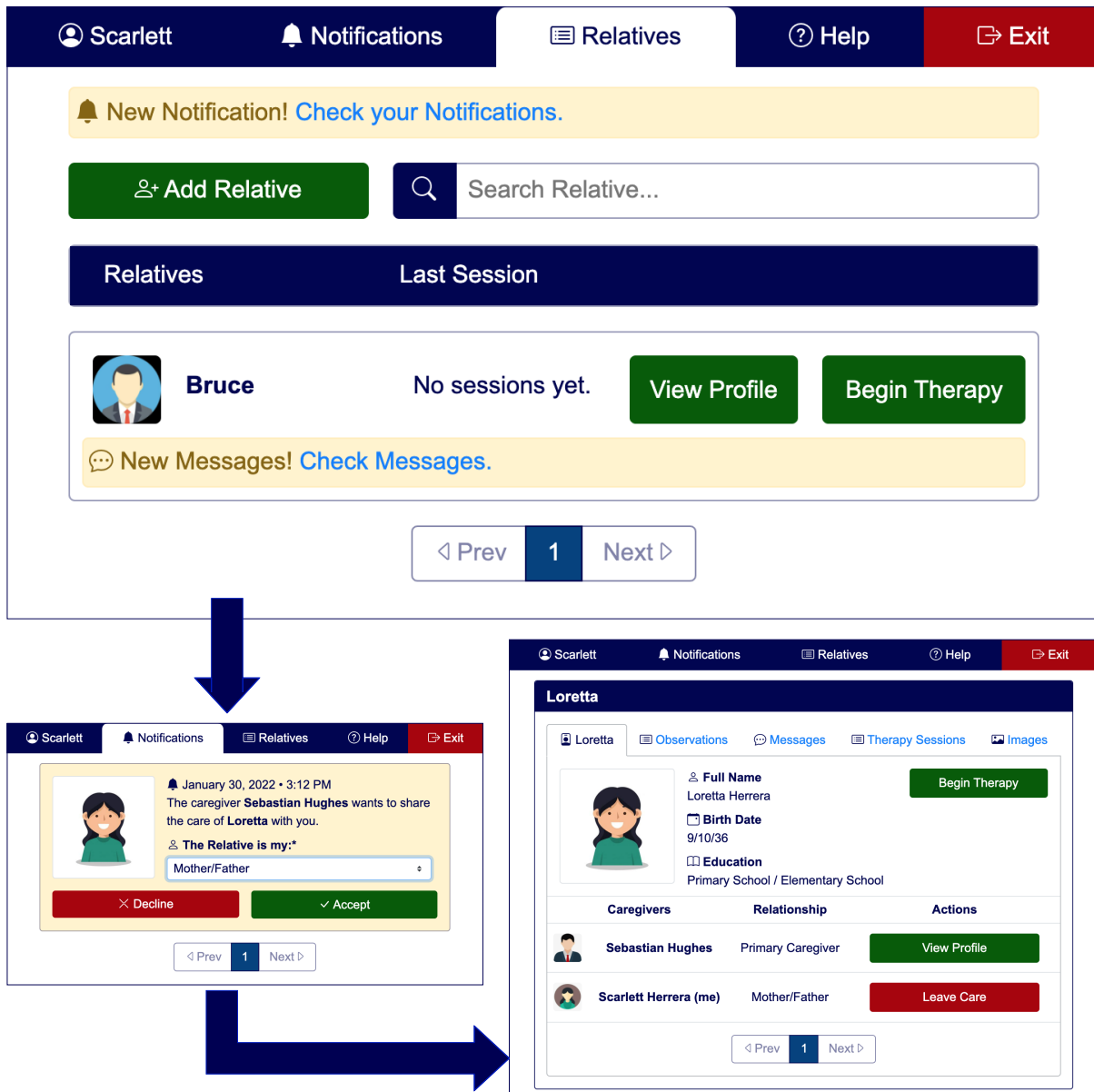


Figure 6.6: Accepting the care of a Person with Dementia (best seen in colour).

To show the rest of the process we will now change to Scarlett's account. Scarlett's account is shown in Figure 6.6. The first screen that Scarlett will see is her list of relatives (as she is an informal caregiver), which is the first screen of Figure 6.6. Scarlett has already a relative associated to her which is Bruce. Besides seeing that Bruce has yet no sessions performed with the platform we also can see a yellow warning associated to Bruce that says that he has new messages, sent by other caregivers on his chat, that Scarlett has not seen. A shortcut to that section is also on that yellow warning. Also, we can see other yellow warning on the top of that page saying that there are new notifications. This notification appears on this page as it is the first that the caregiver sees when logs into the platform and has a shortcut to the NOTIFICATIONS page. So, as Scarlett has new notifications she will go into NOTIFICATIONS page.

The second screen of Figure 6.6 presents what appears when Scarlett accesses the NOTIFICATIONS page. Has Sebastian has sent a request so Scarlett can participate in the care of her mother, a notification

will appear in this page as we can see in the figure. To accept the request, as Scarlett is an informal caregiver, she will need to select her relationship with Loretta and then click on the button ACCEPT.

After accepting the request, Scarlett will be redirected to Loretta's page as we can see in the third screen of Figure 6.6. Scarlett is now added as an informal caregiver of Loretta and as her daughter, as we can see on the list of caregivers. Scarlett can now add personal information to Loretta's page and execute therapy with her. Also, on the caregivers list she has the possibility to leave Loretta's care as she is not her primary caregiver and also view the other caregiver profiles. Also, the caregiver Sebastian is no more the only one who cares for Loretta so he can transfer the primary care of Loretta to Scarlett if for some reason he needs to leave Loretta's care.

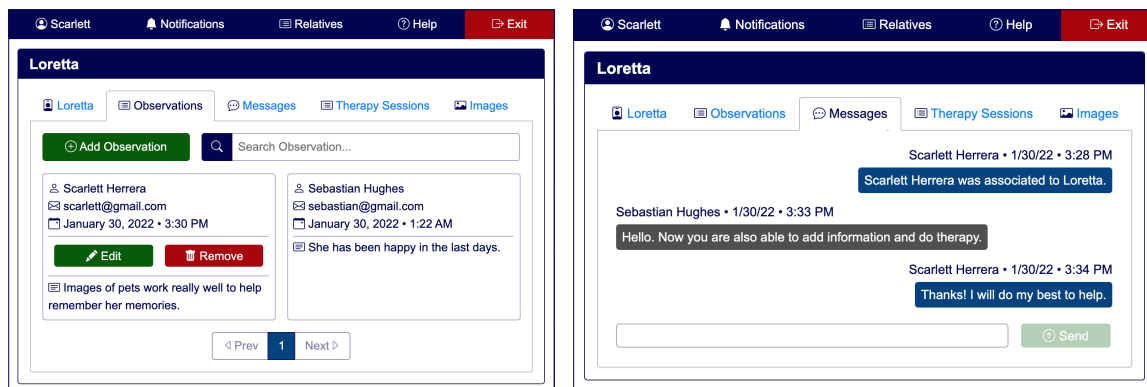


Figure 6.7: Observations (left) and Messages (right) sections (best seen in colour).

Also, now that Loretta has two caregivers we can see OBSERVATIONS and MESSAGES section with information entered by different caregivers. So in Figure 6.7 we can see on the left the OBSERVATIONS section with observations added by the two caregivers associated to Loretta. We also can see that only the one who inserted the observation can edit and remove it. As the account logged in is Scarlett's one the only editable observation is the one she entered. The caregivers can also search observations. It is also a dynamic search so the list will only show the observations that have the substring written by the caregiver. On the right of Figure 6.7 we can see Loretta's chat with already some messages traded between the two caregivers associated. As Scarlett is the caregiver logged in, the messages she sent appear on the right side.

## 6.5 Associating a Personal Image to a Person with Dementia

So, now that Scarlett has access to Loretta's page she can add observations, message the other caregivers associated to Loretta and, in the future, make therapy and consult the results of the sessions made with her (which will be implemented in future versions in THERAPY SESSIONS section). But besides that, Scarlett can now add personal images of Loretta into the platform. Being her daughter probably has more access to this material than the formal caregiver Sebastian and can help him access more material to use in Loretta's therapy sessions.

Returning again into the third screen of Figure 6.6, regarding Loretta's profile page, Scarlett will begin by clicking on the IMAGES section where she will see Loretta's personal images and also has the possibility to add new ones as we can see in Figure 6.8. We can see that Loretta already has an image



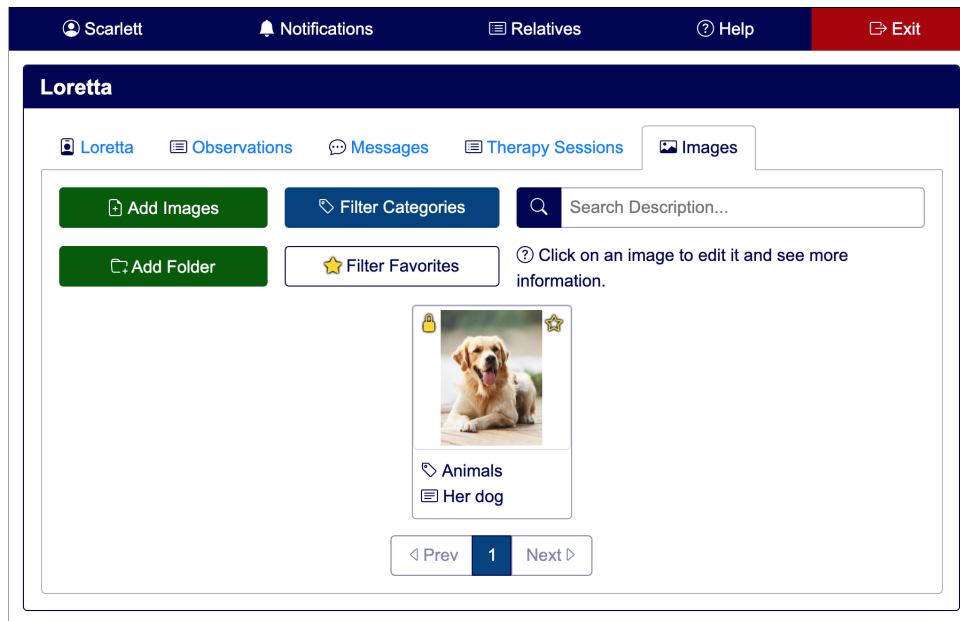


Figure 6.8: Loretta's Images section (best seen in colour).

associated to her that was added by Sebastian regarding her dog, which he already had from the previous sessions he made with Loretta and added into the platform. Besides that we can see that a caregiver can filter the images by categories and by favorites, as well as search for description, which is again a dynamic search. So, now that Scarlett is on the IMAGES section she wants to add a new image to be used on the therapies of her mother Loretta. To do that she can click on the button ADD IMAGES to add one or multiple images or click on the button ADD FOLDER to add an entire folder into the platform which will be responsible to filter only the images inside it. However, in this case she will click on the button ADD IMAGES as she only has one image to add.

By clicking on that button Scarlett will have to select one image using her operation system folder system to be entered into the platform. After that the first screen of Figure 6.9 will appear where she will need to select at least one category that defines the image selected. She also can discard the image before adding it into the platform in this screen by clicking on the button DISCARD IMAGE. After selecting at least one, she can click on the button PROCEED and she will see the second step of adding an image which is the second screen of Figure 6.9. In this step she will be asked to add a DESCRIPTION and select if the image is more relevant to the person, by changing it to FAVORITE. She will also needs to define if an image is PUBLIC and can be used by other persons with dementia in their therapy sessions. If not selected, the default value is PRIVATE so the image is not shared with other persons with dementia. As we already referred this process is reversible as well as the favorite selection. After filling the description and selecting all the options for the image she can click on the button SUBMIT and the image will be added into Loretta's images.

As we can see in the left screen of Figure 6.10 the image that Scarlett added is already on Loretta's images. In that screen we also can see the menu that appears after clicking in the button FILTER CATEGORIES of Figure 6.8. Each time the caregiver selects one of the categories, the platform will filter the image list showing only the images that have at least one of the categories selected.

All the images of a person can also be consulted. By clicking above one image from the list, the

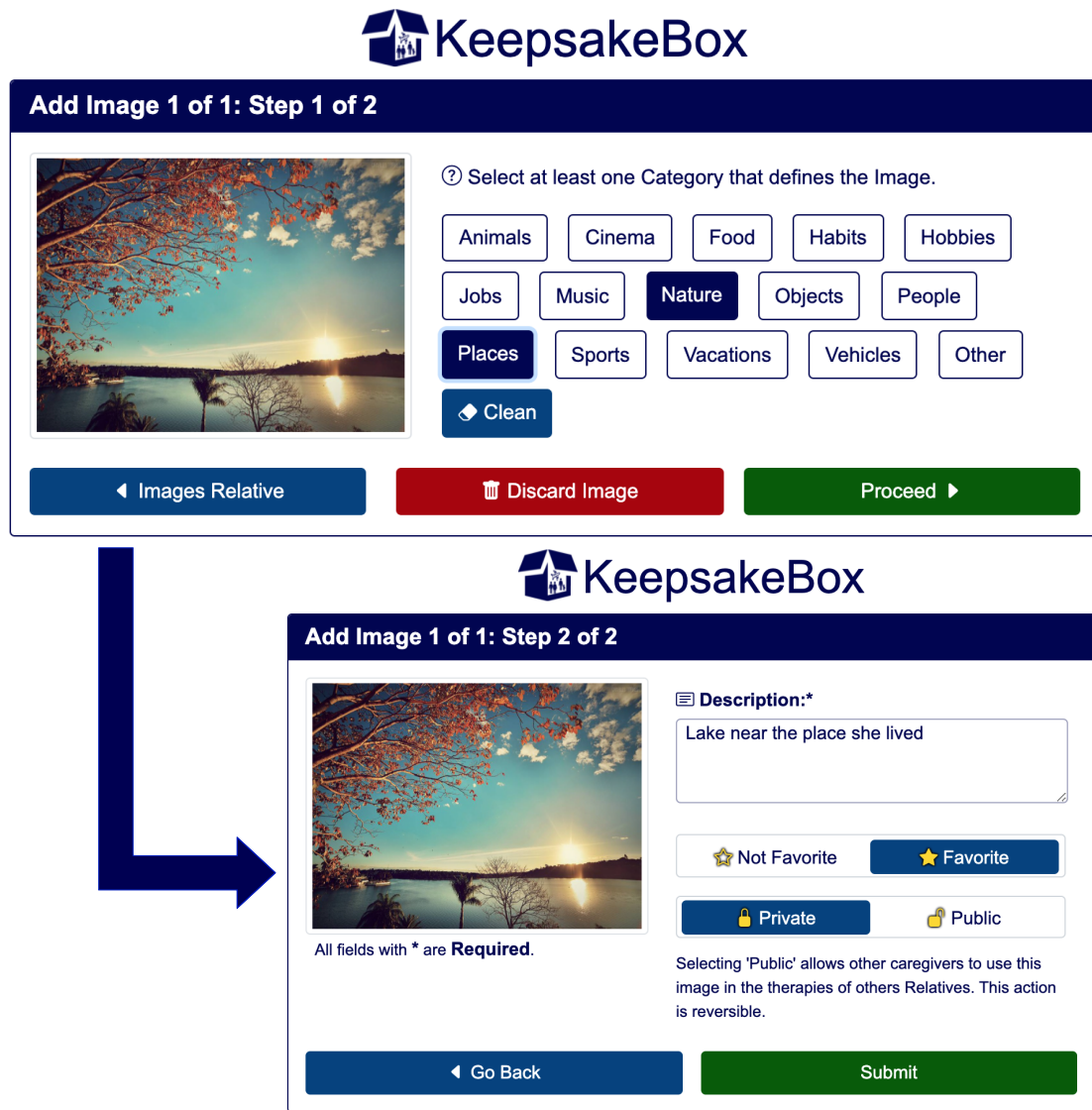


Figure 6.9: Adding a new image for a person with dementia (best seen in colour).

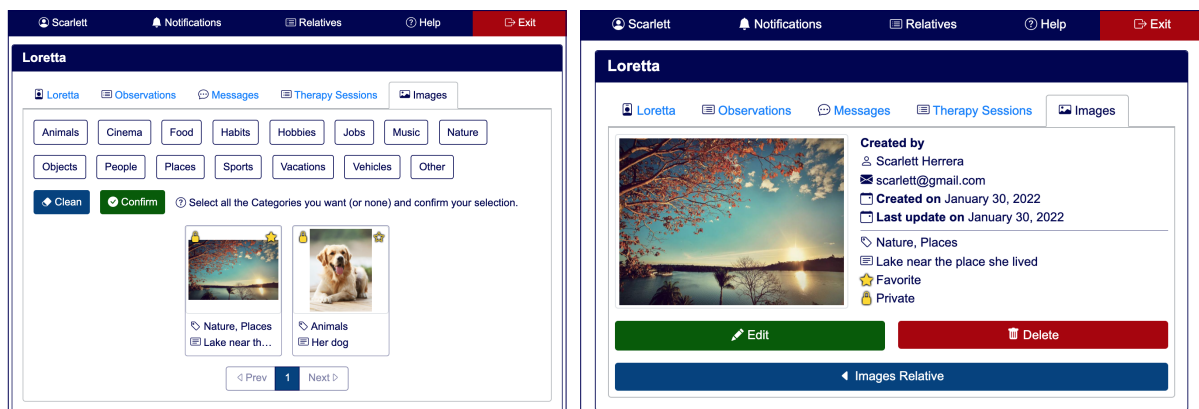


Figure 6.10: Filtering images by categories (left) and consulting image info (right) (best seen in colour).

caregiver will see the information regarding the image selected as we can see in the right screen of Figure 6.10. The caregiver can consult all the information associated to the image and if he/she is the one who added it has the possibility to edit all of its information and also delete it. As Scarlett was the one who added that image she can do that operations, as we can see in the screen we mentioned.

Also, as we referred earlier caregivers also have their images section, called MY IMAGES on their profile pages, where they can add their personal images to be used with all the persons they care for. That images section is very similar to the one we presented on this section, although the images are associated to the caregiver and there can be no other caregivers to add images on that page.

## 6.6 Caregiver Help

If the caregiver encounters some type of problem or doubts when using the platform he/she can always access the help page which we can see in the left screen of Figure 6.11 which will work like an instruction manual. By clicking in one of the topics presented another page will appear explaining the selected topic with the help of images, so we can explain each function presented in that images. In the case of the right screen presented in Figure 6.11 we have the help about the CAREGIVER PROFILE. This page has a header which has the current location on the help menu and in this case a complete explanation around the image of the caregiver profile. More images could be used to explain the functionalities better.

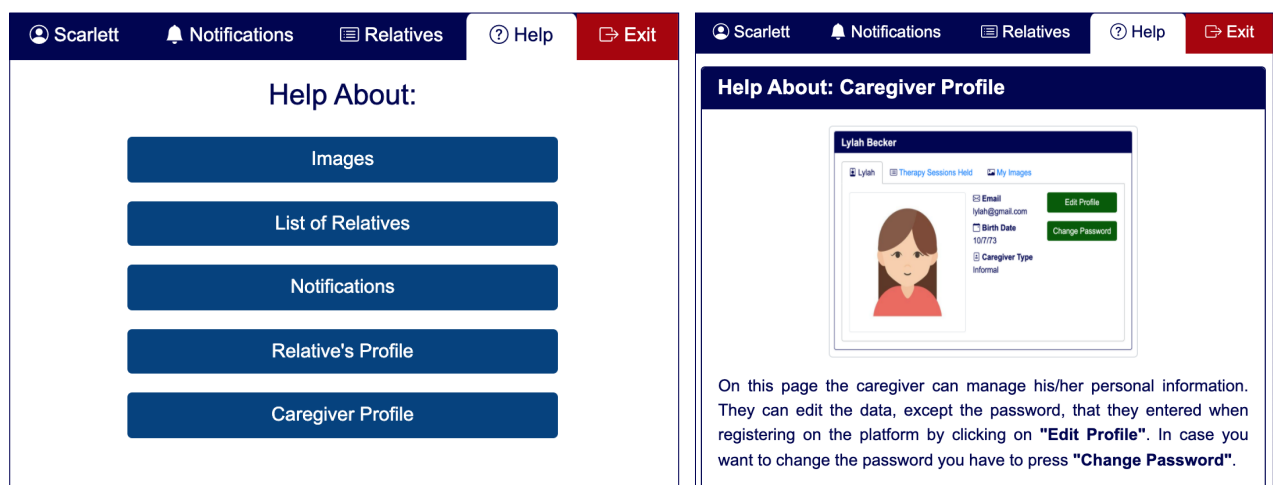


Figure 6.11: Help page (left) and caregiver profile help (right) (best seen in colour).

Although we avoided scroll in all of the platform we maintained it on this section because it will be similar to a reading file on the web which always needs to be scrolled down. To exit this section caregivers can use the principal navigator or after reading all the content on the page at its end they will have a button so they can return to the help topics page.

## 6.7 Summary

In this chapter we started by explaining our design decisions when implementing our platform's frontend. Although some of them were already considered on the guidelines referred on Chapter 2, we explained all the decisions we made considering the caregivers that participated in our requirements

gathering. We also explained how they were implemented into our platform.

After that, we started by explaining the most important use cases implemented in this work and each of their functionalities. We started by showing how caregivers could create an account on our application and what data they would need so that account could be created. We also showed the caregiver home that appears after login where they can see their list of beneficiaries or relatives, depending if they are a formal or informal caregiver respectively. They also can use the principal navigator to access their profile, where they have their personal information, their session history with the persons they care for (although not yet implemented) and also their personal images to be used with the persons with dementia at their care. The notifications and help can also be accessed through the principal navigator as well as the logout button.

After that we showed how the caregivers can create the profile page of a person with dementia so that person becomes associated to their account and also showed how they can share the care of a person between caregivers. We also presented the different sections of a person with dementia profile which are their personal information, where they also have the list of their caregivers, observations, where caregivers can register notes to help with the person's therapy, and messages, where they have a chat to talk between them.

The other section that is also on the person with dementia profile is their personal images. We showed how to insert new personal images into that person's images so they can be used in future therapies with that person. Explaining this section can also help caregivers understand their personal images section as it is very similar, although in this section the images are associated to a caregiver and no other caregiver can add images.

To finish, we showed how caregivers can access help on our application.

# Chapter 7

## Evaluation

As we explained we started our work by executing the requirements gathering and creating a prototype of the platform. This prototype was evaluated by caregivers in informal evaluations interviews, where we let caregivers remotely interact with it. In this chapter we explain what we did in that section of the interviews, how we analyzed the data, and what were the results obtained. We also detail the impact that the caregivers' interaction and feedback had on the platform's design.

With the data obtained from the requirements gathering and prototype remote tests we have improved the prototype so it became our final version of the platform. That version was tested remotely with caregivers in individual interviews and two focus group sessions. We detail both methods of evaluation, how we analyzed the data and what were its results, so we could identify what other functionalities are needed regarding caregiver needs and what needs to be changed.

### 7.1 Prototype Remote Tests

The remote testing of the platform was performed on the last section of the requirements gathering interviews. We continued the interviews on Zoom as it had a function that allowed us to give remote control to one of the pages of one of our computers so they could use the platform as if it was on their computer, so that they could interact with it freely.

Our objective with these first interactions by caregivers was to understand if we were meeting caregivers' needs in terms of design and functionalities implemented. By doing this user-centered design approach, their feedback about some aspects of our prototype influenced what we implemented in our platform, as there were some changes that needed to be considered.

#### 7.1.1 Structure

We started the tests by introducing our platform's objectives and functionalities that were already implemented and could be executed. After that, we gave the remote control to caregivers so they could interact freely with our platform and execute the given scenarios we had established. This way they would use all the principal functionalities already implemented. We also mentioned that they should comment all the process and ask when something was unclear, so we could understand what should be changed in our platform.

Our scenarios start by the caregivers accessing the platform's website for the first time and creating an account. After registering, caregivers would enter on their account's home page so they were able

to add a new person with dementia into the platform. After creating the person they should share the care of that person with a caregiver account already created. After viewing all the process regarding care sharing, caregivers were requested to add a new observation regarding the new person added. Adding a new therapy image was also asked, so they could search for it using our search tools in that page. Finally, they were requested to send a message to the other caregivers participating on the care of that person.

After trying all the functionalities available we asked some questions regarding platform's functionalities. In the first one we wanted to understand what caregivers want to register after a session is complete besides the registers we already know: feedback given after each section; images used and respective emotional reaction by each person with dementia; date and time. Also we wanted to know if caregivers would like to have an option to perform reminiscence therapies without any emotional detector by inserting these reactions manually.

Additionally to these questions, we wanted to know: how comfortable are caregivers on inserting personal materials into our platform; if they want to be able to insert more categories into an image besides the ones we had at that moment; if they would like to have a share link where caregivers not registered into the platform would be able to access that link and insert personal content of a person with dementia on the platform, that should be filtered by the primary caregiver; and finally what was their opinion regarding chatting with caregivers in real time inside the platform.

### 7.1.2 Data Analysis

We transcribed the remote tests dialogues, and we also used the software CATMA (Computer Assisted Text Markup and Analysis) [5] to do the coding, so we could identify all the important feedback that would impact our platform's implementation and also fix some errors.

Although, caregivers were able to give us feedback about the platform and try it, there were some problems that may have had an impact on the results obtained. Zoom sometimes had the cameras covering the screen which sometimes blocked the visibility of some elements of our platform. Also, the insertion of files from the operating system was not possible to see, as for security measures we were only allowing for the caregiver to use an anonymous window and the window from the file system is external to that. However, we could show them how these images would appear and how the platform manages the adding process.

### 7.1.3 Results

As similar to when we were describing interviews' results we will also show caregivers' quotes that helped us to reach the following results. Three Portuguese caregivers participated in this remote tests: a 35 year old formal caregiver (C2) and two informal caregivers with the age of 53 (C3) and 60 (C1). We started the remote tests by explaining that one of our main goals with these platform is to help perform reminiscence therapy in homes, nursing homes and day centres. After that description C2 mentioned COGWEB [9] as a very similar approach which helps to stimulate cognitive functions and that all caregivers who would perform therapy should be instructed on how to program/create one session before executing therapy alone with the persons with dementia.

After explaining our idea of the automatic session algorithm the idea was not very well accepted by the formal caregiver, in contrast to the informal caregivers opinions. When we explained that it is suppose

to be a complement to formal caregivers work and not a replacement the idea was more accepted by C2, although not totally because some knowledge is needed to manage and create therapy sessions. However, one of the main ideas of the session about removing the images that cause the most negative reactions was very well accepted.

- C2: *"We must not forget that many times the caregivers, namely informal but also formal ones, do not always have a very broad knowledge... point number one, of the diseases, their consequences and even less on how to deal with certain reactions."*

Regarding the insertion of personal materials into our platform no caregiver consider that has a problem. They also believe that other caregivers will have no problems with that. Although, C2 mentioned that some consent, even from a family member, is very important to consider when inserting personal material.

While making the register into our platform the formal caregiver C2 suggested to add a mobile contact into the caregiver's profile as it can ease the communication between them becoming more accessible. On this section caregivers had a problem introducing the birth date. The input was made using a calendar, which proved difficult to use by all caregivers because of the order in which the date was insert and some bugs of inputs. Besides this, the calendar window was small. Also there were some caregivers who had problems identifying the required fields which were only signalled by a placeholder.

- C2: *"Having a telephone contact here can also be useful... for any situation, (...) for an emergency that requires to talk to the person it ends up being an easy way to access the contact."*

After caregivers logged into our platform they saw the terms regarding the people with dementia that we had considered. We had difficulties when establishing those terms in our platform so we tried to use: LOVED ONES for informal caregivers and PATIENT for formal caregivers. The term LOVED ONES was not considered to be the most appropriate in this case so we asked suggestions to the caregivers. C1 suggested CARED PERSON and C2 RELATIVE for informal caregivers, as in their case they usually care for their relatives or friends, which normally are very closed to them. In the case of formal caregivers the term PATIENT should be completely avoided as none of the caregivers liked this term. For example, when we asked about the term patient, C1 did not like it and C2 also mentioned that they try to avoid that word as much as possible. C2 also referred that they normally use the word CLIENT although it is not the most recommended.

Regarding adding a person with dementia into the platform C2 mentioned that it is important to have the education level of that person in their profiles so principally formal caregivers know that as it can be important to consider on reminiscence therapy. Also, caregivers did not understood the difference between NICKNAME and NAME TO PRESENT which were different fields considered on the prototype. We concluded that one of them should be removed as the inputs were very similar. On the first prototype we also had a field for NIF/VAT of the person with dementia which generated a problem. On different countries it has different names and also different formats. As C3 was from Brazil, when she reached this field she asked what it meant to us as it had other name and different format on her country. Also there was a field called TREATMENT ROLE which was used to describe the role each caregiver had on the follow up of the person with dementia, which has proved to be irrelevant. Informal caregivers already

have a role of informal care associated to them and in formal cases there would need to be several different options and they already know the roles of each caregivers when they are sharing a person's care. However, in the case of informal caregiver the field `RELATION WITH PERSON` has shown relevant so formal caregivers know the relation between an informal caregiver and the person with dementia and it also can be used for statistics, like knowing the types of caregivers who use the platform most.

After adding the new person with dementia the formal caregiver C2 returned to the list of the persons she cares for and found the list too small, as she cares for more than 8 persons and this list shows only 2 per page. She did not like the fact that persons were being showed as cards instead of a table list and from all the data we were showing only the name and the last session performed were found relevant to show on this page. Also the button `MORE DETAILS` that was alongside each person with dementia's data was not understood by all caregiver that it sends them to that person's page. C2 suggested that we should call that button `VIEW PROFILE` as it is the common used in social media. However, with that change we had the problem that the caregiver's profile showed on the principal navigator will have the same word associated. To fix this, C2 also suggested to put the first name of the caregiver instead of `PROFILE`, again similar to the social media.

- C2: *"This question of the last session is important because imagine that I have 20 people to work with. I can see at the bottom who was the one where the intervention was the oldest and I would go straight to it"*

When sharing the care of a person with dementia all caregivers understood and accepted the idea of the email being the one used to make the link between accounts, as normally caregivers know the emails of one another, so they can share the care of a person by writing an account associated email. Also we noted the importance of a caregiver to accept the care of a person, so they are not caught unprepared and give their consent to participate in that person's care. Enabling this share to be between the different types of caregivers was also important as usually there is always a formal and an informal caregiver participating in the care of a person with dementia. Also, this functionality as shown to be very well implemented, easy to use and all caregivers understood its purpose.

The person with dementia observations were also very well accepted by all caregivers, and all understood its purpose. Informal caregiver C3 also mentioned that this observations can be very useful to follow the evolution of the disease. Only a text field proved to be the necessary in this section. However, when adding a new observation C3 used the search bar instead of clicking on the button first. As the button was at the right side of the search bar it could generate a misunderstanding, so caregivers thought that when clicking on the button after entering data on the search field the observation is added.

The concept of messages being a chat where all caregivers associated to a person with dementia can talk between them has proved useful and helpful to all caregivers. However we identified a problem in terms of design. On the prototype we had the requests regarding sharing the care of a person with dementia alongside with all the chats that a caregiver could access, on the notifications section. When caregivers were searching for the chat, where they would send the new message, they usually had problems finding it so this design proved not to be easy to use.

In the case of images, all of the functionalities related to inserting new images were understood. However, when performing the process of adding multiple images there were some of the caregivers



who had problems understanding the button that discards an image of that process for being added into the platform.

As session performance was not developed on this work when the caregivers accessed the page where the session history would appear we explained what was the design stipulated for the therapy session and what results should come from that. After explaining all the details, informal caregivers liked the idea of having emotional detectors to identify the reaction of a person to each image. During a session, we also thought important to be able to consult each image details. Although, informal caregivers think that it promotes a connection and more detail, the formal caregiver C2 thinks that it breaks the flux of therapy sessions and it is not recommended.

- C2: *"It takes away spontaneity and there it is, it interrupts a person who may even be at that moment in a situation where they are actually managing to have a series of reminiscences (...) people, when they are with us, they need to feel that we are fully in what we are doing with them"*

Regarding the results and feedback caregivers would like to save after a therapy session, the informal caregivers do not register any data and C1 does not even perform reminiscence therapy. On the other hand, the formal caregiver C2 does that registers and besides the feedback given by the caregiver after each session she also leaves a comment about what is the way forward for the next session. C2 also mentioned that it would be interesting that there was a way to show what images create more reminiscences. Regarding the registers when a session is being performed C2 also mentioned that it should be a way to do a posteriori registration, principally when we are talking about formal caregivers so they do not break the flux of a session and it could be easier for them as they sometimes need to make therapies with the persons one after another.

- C2: *"The first time we presented the image, the person said something, but very little. Then the second time, the person spoke more and with more memories, and then a third time the person evoked even more memories."*

After finishing the remote tests we understood that the scroll should really be avoided. Having the least possible navigation is also very important to consider. Also, C2 referred that the space between each components of the platform is small for older people and should be wider. Another thing she mentioned was that the letter should be no small than 14 pt. Bugs were also identified in this tests. By clicking ENTER some forms were skipping one step and submitting the information without caregivers seeing it. Another bug that sometimes happened was when the required fields were filled the buttons to submit or advance were not turn available without clicking out of the last field filled.

All caregivers liked our platform's idea. We also noted that, although caregivers hesitate to commit an error, they explored the platform very well and it has shown easy to use. Also, caregivers liked to be able to edit the material they inserted, as they feel more safe and comfortable when inserting it. There was no sensitive content identified on the platform during these tests. Also, the link where other caregivers not registered on the platform will be able to insert a person with dementia material by accessing it was very well accepted by all caregivers and is very important to consider in the future. Formal caregivers will be able to access more personal material of a person with this functionality and relatives or friends that are far away will be able to add material easier, so more content will be accessible.

### 7.1.4 Impact on Platform's Design

Due to the previous results the design used on the prototype was changed on our platform. As consent and privacy showed to be very important for caregivers when introducing data there should be in the future different ways to give consent about the material inserted and caregivers should be able to select which caregivers can view that information. Considering that only the persons that share the care of a person will have access to a particular person's data is not enough.

Considering the process of registering a caregiver we added the field of phone number so caregivers are able to access that information easier, although this field is optional. Also, we changed the calendar to insert a birth date, as caregivers showed difficulties to use it and did not like it. We changed it to three fields with drop-down, one for day, month and year, that always check if the given day is valid when the three fields are filled. We also added on all forms throughout our platform an hint that explains that the symbol \* represents a required field.

When logged into our platform formal caregivers will now see the term BENEFICIARY and informal caregivers will see the term RELATIVE referring to the person with dementia as it was suggested by the formal caregiver. Also the list of persons with dementia can now show 3 persons at the same time and is displayed similar to a table list instead of cards. Also, each person has now only two buttons associated: VIEW PROFILE to view that person's page; and BEGIN THERAPY to begin a reminiscence therapy session.

When adding a person with dementia there is now a drop-down field regarding the education of that person. Also, the field NICKNAME was deleted and only the NAME TO PRESENT was maintained. As NIF/VAT was not that important to person's management as each person with dementia as an ID associated we decided to remove that field from the person with dementia so there would be no problems with different countries registering into our platform. The field TREATMENT ROLE was deleted and only the RELATION WITH PERSON field was maintained only for the informal caregivers association to a person.

Regarding the button of adding an observation in the person with dementia page, as the search bar was at the left side of the button we changed it to the right side so the confusion of using the search bar as a field to add an observation will not happen again. To maintain the structure, we also changed the search bar side on all pages. In images, we made a change on the process of adding multiple images. The button regarding discarding an image is now more clear. It has a trash can icon attached to it and we also changed from REMOVE IMAGE to DISCARD IMAGE. The colour of this button was also changed from grey blue to red.

As each person's chat associated to a caregiver was being presented on notifications alongside with the requests regarding care sharing, we moved the persons' chat to persons' pages. Now it has a section called MESSAGES in each person with dementia's page where caregivers can access to talk between that person's associated caregivers.

Regarding therapy sessions we acknowledge that in contrast to informal caregiver, who would like to have an automatic session creation, the formal caregivers like to have control of the sessions they perform. So, we should offer manual creation, so caregivers could select the material they want to use on therapy before performing it. Also it is important to not break the therapy's flux to consult any data, and after a therapy session is completed there should be a way to give the feedback and consult the results later in time. We added the session follow up feedback after a session is performed to the data that should

be considered after a therapy session is complete, and feedback about each image was also considered so caregivers can detail the reminiscence obtained by a particular image.

To finish, we improved the platform's space between elements and also pushed all text to a size equal or bigger than 14 pt. Clicking ENTER in the first step of a form will no longer submit it. It will now continue to the next step, so no steps are skipped.

## 7.2 KeepsakeBox Platform Remote Tests

After finishing the implementation of our platform and implementing the changes identified in the previous section we obtained our platform's final version, which was evaluated remotely due to the pandemic situation. We performed the tests using the Zoom platform, so caregivers could interact remotely with our platform.

We contacted several institutions and the three caregivers who participated on the interviews so they could continue to give us feedback about the platform development. All institutions and caregivers contacted were Portuguese as it was easier for us to reach them and continue evaluating the terms used.

In this section we describe the structure used for the caregivers to test our platform and evaluate it. We also show how we proceed with data analysis and what were the results obtained.

### 7.2.1 Structure

We started the session by giving each participant the informed consent form along with the information brochure as it was approved by the ethics committee. They had the possibility to read all the information about the study and they gave us their digital consent about participating in the session by accepting all the conditions referred in the informed consent form.

After that, we explained our platform. We described its principal objective and also its principal users, which are the caregivers. We also detailed briefly some of the functionalities and explained that performing the therapy session was not yet possible, so they will only execute functionalities regarding caregiver's account and the management of the persons with dementia and their personal information.

Similar to the approach that we took on the previous remote tests we also defined different task scenarios to be done by the caregivers. We also asked them to comment all the process while using the platform. We now present the task scenarios defined:

1. You will start using this new platform. To use it you have to register.
2. You are currently taking care of one of your relatives/beneficiaries who is doing reminiscence therapy. Login to the platform (if you have not already done so) and add that relative/beneficiary to the platform.
3. In addition to you, someone else is caring for your relative/beneficiary. Give this person access so that he/she too can help with that person's care.
4. Once the other caregiver has accepted the request, send him/her a message asking if he/she can do a therapy session next week as you will be away.

5. During the day you noticed that your relative/beneficiary was in a very good mood and chatty. Make an observation about his/her mood.
6. The pool of photos of your relative/beneficiary that are available to use in therapy is very small, so you decide to add some photos you have in a folder.
7. The other day you found a set of interesting photos to use in therapy. Add these pictures so that you can use them with the various relatives/beneficiaries you care for.
8. Next week you will emigrate, and can no longer care for your relative/beneficiary. Stop being a caregiver of this relative/beneficiary and pass the primary care to the other caregiver.
9. After using the platform, you were curious about the features available, so you decided to consult the help.

In addition, to the scenarios used we also discussed with caregivers the functionalities we wanted to implement regarding therapy sessions. We reviewed the registers they wanted to have after a therapy session is completed and what they want to be able to regist. Also, we wanted to understand if the new idea about session programming is good for all the possible caregivers. We established three ideas to programming a session: the first one is automatically, in this session the content will be automatically selected considering the biographical information and the results from previous sessions; the second one is similar but we let the caregiver choose the themes they want to use on therapy and the platform will select materials automatically considering that themes and the information already referred; the last one is completely manual so caregivers will need to select the themes and the images that will be used on therapy.

Although most of the evaluations were individual we also did two focus groups. In those focus groups we were not able to give remote control to the participants. Instead, we shared one of our screens and demonstrate the use of the platform by performing the task scenarios. Caregivers were able to comment all the process and give their ideas and opinions while we were showing the platform.

After finishing the remote tests, or platform demonstration in the case of focus groups, we asked each participant to fill a questionnaire about the experience they had using or viewing the platform and if they would like to use it to perform reminiscence therapy. This questionnaire included the System Usability Scale (SUS) [27], regarding usability, and the first six questions regarding usefulness from the Technology Acceptance Model (TAM) [28]. This questionnaire can be seen in Appendix J. We used a Portuguese version of the SUS validated by Martins et al. [18]. As TAM did not have a Portuguese version we translated it and adapted it so it mentioned reminiscence therapy.

## 7.2.2 Data Analysis

Similar to the process made on the other interviews we also used verbatim transcription on these remote tests. However, we only transcribed the more relevant information of each sessions as there were to many data to be analyzed. So, we did not use CATMA [5] for coding, instead we analyzed all the information obtained and identified the functionalities that should be changed or implemented in future versions along with the principal comments given by caregivers about the platform.

### 7.2.3 Results

We will now present the results with the help of some of the most important caregivers' quotes that helped us achieve different conclusions regarding our platform current functionalities and future ones. From the three caregivers who participated on the previous tests of the prototype, only C2 was able to attend these sessions. We performed four more sessions with caregivers who contacted with our solution for the first time (C4, C5, C6, C7 and C19). In those five sessions, as C4 and C5 participated in the same one, although we had the task scenarios established, most of the caregivers explored the platform without needing them, which shows that our platform is easy to use.

We also did two other sessions that consisted on focus group, where we made a presentation of all the platform functionalities. The first one was made with caregivers C8, C9, C10, C11, C12 and C13, all from the same institution. On the other one the caregivers were C14, C15, C16, C17 and C18, all from another institution.

We did seven evaluation sessions in total with seventeen caregivers. C12 was the only male caregiver on these sessions. Also, we were only able to get formal caregivers due to the current state of pandemic as we were not able to reach informal ones.

Some caregivers noticed an image of an old lady with a cane on the slide show of the platform's home page, and mentioned that it was inappropriate and can send out the wrong message, referring to the more negative side of ageing. Considering these aspects will help the platform to be more attractive. Also, the content inside the slide show was considered too small for some of the caregivers to read.

On the positive side, caregivers always avoided the destructive actions in confirmation dialogues because they read the message and also because of our colour coding (red for destructive actions). Although some caregivers like C5 thought this as counter-intuitive, because normally the option YES is associated to green or blue, after we explained the logic they understood and it should be maintained. However, there were some errors regarding inserting data that need to be reviewed as when caregiver can not continue in a process they do not understand what is missing. C7 suggested that we should highlight the fields missing in this cases in red or with something that catches their attention. C6 also mentioned the importance of having bypasses, like shortcuts, in the platform. Also, when we asked C19 to logout from the session she had problems finding the button EXIT as she was searching for the button LOGOUT.

- C6: *"If there is no bypass, i.e. a way to do exactly the same thing but using another way, sometimes leaves us in a dead end. So now I can not move forward because I do not know exactly how to get around it and the fact that the same process exists but done slightly differently makes it easier."*

When it comes to the specialities of a caregiver, they suggested new options like monitor, neuropsychology, occupational therapist, social education, socio-cultural animation, social worker and speech therapist. C5 also suggested to remove the term therapy as speciality as it is over-generalised. From the ones referred, the one which stands out more was the occupational therapist as there are many who do this type of intervention, as they are the main technician who does this therapy. Regarding psychology specialities, the term psychology has shown to be broad enough.

- C6: *"I think psychology is broad enough because you can have neuropsychologists but you can also have other people who are also psychologists. Clinical psychologists for some reason will also be involved and may not have the title of neuropsychologist."*

The term therapy in our platform also raised some problems as informal caregivers are not specialized techniques. To fix this problem C5 suggested REMINISCENCE ACTIVITIES, which is more generalist and more related to the stimulating activity. After talking with C6 about this problem she also suggested the term BEGIN ACTIVITY instead of BEGIN THERAPY.

- C5: *"By therapy we mean that we are intervening in a specialised way with a certain method. The intervention made by a psychologist or an occupational therapist specialising in this area of rehabilitation or neuropsychology is very different from what a family caregiver does or can do, and what a direct action helper or an assistant in a home or day care centre can do."*

Another suggestion from C9 was to give some type of introduction about what is a reminiscence activity with a video. She also reinforced the idea of introducing how to do a therapy session.

- C9: *"For the informal caregiver to join the platform, they have to understand the benefits, what they will do and what they will gain from it (reminiscence)."*
- C9: *"Perhaps some general introductory recommendations would help. At least some limits to family members so as not to create fatigue, so as not to overstimulate, especially general recommendations connected to dementia. I think this part of the sessions is the most sensitive part of this application and that it is a very useful therapeutic tool, and in fact I think it will be an added value from what we are seeing. These issues of the therapy sessions are particularly sensitive for relatives because they do not know when to stop, what to do, how many images, and so I see this as an orientation for us to think about these issues and perhaps create some sessions that can serve as a reference and the person can use those sessions as a basis and then personalise them, but they already have a starting point. They are no longer completely lost and already have an orientation."*

When viewing the caregiver's profile, C8 mentioned that it should have some information that help intervene with informal caregivers in terms of burden. This data can also help in terms of research. The caregivers' support network is also very important to consider. A synthesis page about the caregiver intervention would be also helpful.

- C8: *"When we talk about the caregiver profile in the area of dementias, we talk about a set of information that we collect so that we can also intervene with this same person in terms of burden. Notes or, for example, some information such as how many hours per day they look after their relative, if they have other help or if they are the main caregiver of that person. In terms of research it also answers a question that we always need to know which is who is caring for dementia patients at this very moment."*
- C9: *"It may be a professional who is going to do the reminiscence therapy, but there may be other professionals who are already involved and who are not included here and who may be important later, i.e. for the intervention itself or may provide important points for the intervention itself."*
- C9: *"Serves as a bit of a profile of the work I have done with the person. When I started, when I had the last session, how many sessions I did, which themes I approached that were more successful,*

*what I should not present again as a stimulus. So, a kind of synthesis that will help me and guide me later in the intervention."*

In the context of an institutional environment C10 asked if it is possible to group all caregivers from an institution on our platform, as it is important so they can view each associated caregiver activities, regardless if they are informal or formal. An institution level above the caregiver level could also be important to consider in future versions to help with institutions' statistics. It will also help an institution track all the persons with dementia that were cared at that institution.

- C10: *"At the statistical level, it could be a reference base at the institutional level and would also allow us to work on the caregivers' data, such as gender, age, among others. If it had some questions on the level of burden, it would be important for the intervention itself."*
- C11: *"Could also allow us to monitor the status of our beneficiaries after discharge. So we can monitor care, because sometimes there are people whose connection and progress we do not lose, but there are others who, after discharge, we do not know about the continuity of care."*

Regarding privacy issues, C7 mentioned the importance of having some consent by the person with dementia, if capable of it, or by some representative of that person, as caregivers will share personal information about that person. She explained that it protects those who work and also protects the person. C10 also asked if the mobile number will be shared with everyone, showing some privacy concerns.

When viewing the page of a person with dementia the caregivers noticed a lack of notifications. C2 mention that there should be notifications in each section of that page when there is new content in a particular section. Also, on the caregiver home page only show a symbol instead of all that text. All the other caregivers agreed with this idea. The importance of using visual stimulus to represent these notifications was also explained by C6 as our visual attention tends to be quickly captured by something that has a different colour. C19 also explained that this notifications are very important to retain messages.

- C2: *"A symbol that would give us an idea that there is something pending with this patient. I think that this way it would be easier because when we enter the profile we would know if there is something pending or not, taking into account the person with whom we work."*
- C7: *"If you do not have that warning, you might not look for it either."*
- C6: *"So I come in here, this is all in shades of white, green and blue and something that is a different colour automatically catches the eye."*
- C9: *"We cannot forget the informal caregivers themselves, who may not have dementia but may have memory problems due to several factors, namely the burnout that many informal caregivers experience. Any communication process, any communicational message, is always more internalised according to the communicational channels used for this message. So, listening, reading, seeing this makes it possible to retain the message much more and so, from this point of view, I think it is always worthwhile for this channel (of notifications) to be available"*

Regarding the information on the person with dementia's page C17 suggested that we had the age of the person alongside birth date, so the caregivers do not need to calculate it. It was also suggested that we added some options to education like DO NOT KNOW as sometimes there are people who have no family network at all. The option ILLITERATE was also suggested but the options KNOWS HOW TO WRITE AND READ, KNOWS HOW TO READ and DOES NOT KNOW HOW TO READ AND WRITE were the ones that should be considered as they do not give that negative weight.

All caregivers liked the idea of being able to share a person with dementia's care. However, when sharing the care there is no feedback about if the other caregiver has accepted the request in the person's page and his/her name should be introduced in the caregiver's table replacing the action buttons by something like PENDING. Also, C13 mentioned that she could not understand if the caregivers were formal or informal by viewing the table so it could be important to explicit the caregiver type alongside with the relation with the person when it is an informal caregiver. Also, caregivers liked the idea to have always a caregiver associated to a given person with dementia so that information is not lost. They also confirmed the importance of being able to pass the primary care to a different caregiver. However, when transferring the primary care C19 had problems found it and started by looking on the profile of the caregiver she wanted to transfer the care to. As it was difficult to find a place where this option would fit, we now understand that it could be in the caregiver's profile page inside the person with dementia's page. By accessing a caregiver's profile, a primary caregiver besides having all the information and a button to remove a caregiver from that person, should have a button where they can transfer primary care to that person. This new button will ease this process and the button regarding SHARE CARE will only have that functionality associated.

- C6: *"Because there may be some period when no one is assigned to that person and losing all the data does not make much sense. The system already has the data included so you can work on them even if they are worked by other caregivers."*
- C5: *"Let us imagine even in professional terms, C4 follows a case and uses this platform and wants to pass the case to me because she will no longer follow up and thinks that this tool is an added value."*
- C8: *"Imagine that we have an inpatient here, we start the application but then we want the family member, when he is discharged, to do the continuity and we no longer have access to this application. So we transfer to the caregiver this primary care."*

Most of the caregivers also liked the idea of observations. However, C2 started by writing on the search field before clicking on the button to add an observation. When she realized that, she suggested that instead of having them side by side that they could be in a vertical sequence, like in most of the applications, which could help avoid this errors. She also suggested that the observations should be in a vertical sequence instead of horizontally, which can be a point to consider. C12 also suggested to create categories in the observations.

- C8: *"Keep here the observations for something that the person wants to write about the day. For example, the person was very sad when a session with the wedding images was done, for instance."*



*It is important that this is described so that others may understand that maybe the sessions should not go through that at the moment.”*

- C12: *”A little more oriented by levels in the sense of being easier to have the information a little more organised and being easier for the various caregivers to access the information in a more directed way.”*

The message chat between the caregivers of a person was seen with good eyes from caregivers, but most of them would like to have an option to send a message to only one or a group of caregivers. This option is even more important if the tool is shared by formal and informal caregivers. C7 also believes that private messages are useful, however she understood why we only considered a general chat with all the caregivers of a person as private messages could create some limitations in terms of transparency between caregivers. Although most of them would like to choose which caregivers they want to read the message, C19 mentioned that the chat we considered can serve to break isolation.

- C2: *”Sometimes for some issue it may be important to have an exchange of ideas just between two professionals about this person that would not involve the others.”*
- C6: *”There may be something very particular for that specific caregiver that we do not want the other one to know or that it does not make much sense to share that information, it may even be more sensitive. So the formal caregivers may want to share some information that they do not want the informal caregiver to have access to, because it is a very technical issue and the person then does not know how to manage that information because he/she does not have the knowledge.”*
- C19: *”(The chat is) very interesting for several reasons, not only to share that information but it can serve to break the isolation. This breaking of isolation, this possibility of sharing, of feeling that the person is with the others, to feel that others know what that person is thinking and what that person is doing can be very relevant.”*

Regarding the images of a person with dementia all the caregivers liked the idea of having more personalized content about the persons as they represent a very important material to reminiscence. C5 also mentioned the importance of the images representing real objects and not drawings because it removes the burden of the infantilisation of the person with dementia. Regarding the three different types of images we have on the platform they were all viewed as important. Removing an image is also very important in the cases that images can't be worked. Also, C6 liked the fact that we used different terms to discard an image on the process of adding and removing from the platform as we are talking about different processes. Being able to edit the information of an image is also very important for caregivers.

- C4: *”I think these three possibilities are important, so having a kind of image bank of the platform where I can get things, some more general images that the platform allows me to get. As a caregiver myself, I have an image bank of my own, of images that I have already selected, and then have the images of the person which, even professionals, can ask family caregivers for photographs and scan them and put them in the person's profile.”*

- C6: *"I put up x number of images and for some reason in that sequence there is one of them that is really very difficult to be worked on, either because the patient gets very upset or for whatever reason. Or because we think it is not a good image because it creates more confusion."*

Regarding how images are stored into the platform, caregivers liked a lot the idea of having categories. C7 also mentioned that they could be very helpful in terms of organization and to prepare different memory games. Also, all the principal categories needed were presented, although we could add a decades category that was suggested by C4, as older memories are more preserved and normally they present the material on the basis of the years. Also C9 mentioned that the category PERSONS is not clear and should be separated in FAMILY, FRIENDS and PERSONALITIES. C6 mentioned that the image description will also be helpful for therapy, to describe how they are important for the person. The public factor of an image was also seen with good eyes by all caregivers as it can help gather more material for therapies if they can be applied with other persons.

- C7: *"Sometimes we get lost in too many images. Even because in our day-to-day work we use images of people to play certain types of stimulation games and that (the platform) ends up helping me to refine the work here."*
- C4: *"Reminiscence therapy is mainly used in people with Alzheimer's disease because the type of memory that is most affected in people with dementia is the recent memory and therefore the remote memories, the older ones are relatively preserved and remain preserved for longer. It would be very useful to have available old images from various decades up to photographs from the 1940s, 1950s and 1960s, because we have people of various ages."*

They would like to have the generic images that were presented and selected for a person alongside with the personal ones in the person's page, so they could prepare a therapy session with the material that is important for a particular person. For that to work, we also should create a new level of filtering in the images which is the person who inserted an image. Also, we confirmed that images should be shared by all caregivers associated to a person to ease the creation of therapy sessions. C7 also mentioned that the platform could suggest or use more images that bring positive emotions. Regarding caregiver's image bank, C6 also mentioned that it would be interesting to be able to associate or send an image to a person with dementia page when they have real benefits to that person.

- C8: *"How do I know which one is the person's dog and which one is the dog that was already there on the platform's photographs?"*
- C8: *"What makes sense to me is that the photographs of the person and significant of the person whether it is added by one caregiver or another that we all have access and that they are all in the same place."*
- C12: *"If the images were all located centrally but then defined if they are generic and who added them, and then within who added them by themes, for me I think it would be more functional from my point of view."*
- C7: *"If the platform itself can even suggest them (images that bring positive emotions) to other caregivers networks. Let us imagine, that a person thinks that a particular image brings benefits"*

*to the person they care for and the platform itself gives suggestions to other caregivers of other people.”*

Although our platform uses images, several caregivers mentioned the importance of video because of being a different stimulus and some videos are well known by different people. Also, images could not be motivating for them and videos should be considered in future versions so another possible dynamic is introduced.

- C7: *”The links to some things like Youtube. For example, the ’Casa Portuguesa’, almost everyone knows and likes to sing and it can be a last minute resource that is always accessible.”*
- C12: *”There are probably some Youtube videos of visual and auditory stimulation that could eventually be included here. So we had here another level beyond the image, we had a video level with visual and auditory stimulation to work on certain aspects.”*
- C8: *”In persons with dementia defence, I challenge you to create something that is not only images because images are no longer challenging for them for the sessions. It also has to do with what C12 said that is to introduce videos, introduce sound but do not keep the application just for images because images are no longer motivating for them.”*

Regarding session results all the ideas we already had were considered important by all caregivers but some of them also suggested others. C4, for example, suggested that the person with dementia should also give feedback. C6 also suggested that is important to specify what went wrong in negative sessions by having additional information so caregivers can understand what were that points. C6 also liked the idea of the system identifying which sessions are positive and negative. C18 and C16 also mentioned that some of this information should not be available to everyone and C14 reinforced that idea saying that the information that appear should depend on the role of the caregiver. So it is very important to allow caregivers to select with who they want to share sessions’ results. Primary caregiver should be the only one with access to all the information. C18 also mentioned that the results should have an evaluation of how it went and a summary of what worked and what did not work. C14 explained the importance of having these registers shared between caregivers as it can help understand what to use in therapy sessions. Besides this, caregivers would like to print their approaches and the work they have done with people with dementia so they could share and show to other caregivers.

- C4: *”This feedback should not only be the caregiver’s subjective feedback but also something that is the person’s own feedback. In other words, if the person liked or disliked the image, the person him/herself should verbalise that.*
- C6: *”Let us imagine that the person has already had 10 therapy sessions and this all appears in a vertical line. Visually, when the person enters, they can identify if it has always gone well, so it’s green or yellow, or if on the contrary, visually, in the overall calculation, there are many more reds or many more negative smilies than positive ones. This is already worth some insight into how not only the session but the whole intervention is going and whether or not it is necessary to make some time adjustments. If nothing else, the caregiver him/herself may not be the best person to do these sessions. For the management of the therapy itself, this is useful information. If it is*

*worth continuing, if it is not worth continuing, if we have realised that it is more disruptive than beneficial for the patient.”*

- C14: *”The primary caregiver might have access to and it is like they say, not all caregivers have to have access to because it also depends on their role. One thing is the psychologist who has to do the sessions, the primary caregiver him/herself, the social worker who manages the whole process of that person and the interconnection with the family and another thing are different levels like the person who only gives him/her the bath or that kind of thing. Because there is the issue of professional confidentiality, we deal with some very sensitive information from the person themselves. This is in terms of formal caregivers.”*
- C16: *”Not everyone can share everything that has been worked out with the person, there could be an option to share with, or something like that. If it is me doing the session I could have the option of a button saying share with primary caregiver, psychologist and so on. I think then it could stay in the person’s session but only people who had that access would have access to the information from the person themselves.”*
- C14: *”If therapy is a continuous process, then it makes sense to keep and even keep the evolution of the effects of these therapy sessions or activities. I think it makes perfect sense because I think your tool can be a great asset, at least in terms of formal caregivers. Let us imagine, the psychologist plans and has a profile of what the activities are going to be, and the socio-cultural animator reinforces and carries them out and she realises that there are situations in which it is necessary to rethink because the person became too agitated, or because, on the contrary, the person became too sad, or had insomnia. It should be noted that these images cause the person a lot of sadness, or make them agitated.”*
- C8: *”It would be printing the work that was done with the person. It would also be important for the caregivers to do this because in the psycho-educational sessions they also bring us the work that they do at home with their persons with dementia and this is significant for them to share with us and also to share with other caregivers in the psycho-educational sessions.”*

Regarding the emotions registered for images, we asked C7 what she would think about having a selection where caregivers can introduce which emotions were triggered by each image. She understood the idea but suggested that instead of having this type of selection to each image, having an open field only on the most negative ones would be preferred so caregivers can explain the different emotions triggered and why that reaction happened. Having less fields is also important as some caregivers do not have the time or patience to insert several data.

- C7: *”The anxiety, agitation and apathy part are important issues to be aware of but there do not seem so many that you can not include them all. If you think it is too complicated maybe start with something much simpler, for example, if the session with this image was positive or negative. If the person wrote positive, that is fine, but if they wrote negative, maybe try to have an open field in which they can identify if there was agitation, if there was anxiety... (among others)”*

When performing sessions, formal caregivers like to be able to have some type of selection of content and preparation before starting a session. Although, automatic sessions considering the person's data would be very helpful there should always be the option to do some type of selection or completely manual preparation. Also, C7 thought useful to have automatic things although they should be personalized to the person in question, which confirms our approach. C8 also suggested that we make available some generic material to quickly do a session with a person, before caregivers add material. Moreover, the search of this material should be made based on the biographical information of the person with dementia. To ease the process of knowing about a person with dementia C9 mentioned that she would like to have information automatically gathered about the birth place of the person, for example, not only photos. C12 also mentioned that the images should have more surroundings, although the important information should be more focused and highlighted, and also be presented in the biggest size as possible. So filling all the screen should be the primary approach for presenting images in sessions. C11 also mentioned that it should be a number of photos to be presented in each session instead of considering time, as sometimes caregivers can have many reminiscences in a single image. C12 confirms the approach of a semi-automatic session because he wants to select the type of images that will appear in the session with a click and also mentioned that automatic sessions could be used in clinical practice due to lack of time for preparing sessions.

- C8: *"If they already have some material that allows them to quickly do a session with that person, even if it is not highly personalized... the ideal would be to be personalized but they do not always do personalized sessions according to the experiences and tastes of the person. So if there were already some images and some songs that are meaningful to the elderly, it would be important not only for the caregivers but also for the technicians."*
- C9: *"Everything that is significant for that person, and the place of birth, and the experiences linked to the part of the residence are very significant and are preserved memories, therefore long-term memories that will generate motivation at the level of this therapy and would make it much easier than the technician looking for it all, and putting it together, and keeping it. If this were an automated process, it would be ideal for us."*
- C11: *"Maybe we can develop some images for a longer session and others that the person does not want, or can not, or does not have the availability to develop and therefore we move on to the next image in a faster way. So, I think that the time for reminiscence activities probably does not make so much sense to me."*
- C12: *"I think that it would be good for each session to have the chance to select the images that will be in that session with a click. The fact of adding dogs does not mean that all the images of dogs appear. This allows the therapist to program the session and think and establish a video course about how they want to run the session."*
- C12: *"I think that this (automatic session) would not be the ideal model but maybe it is the one that can be used in clinical practice, at least in some contexts. This is because, in clinical practice, with the overload of sessions that sometimes exist, the caregiver does not have the time to plan a*

*session specifically for that moment and then, well, he/she does a session and guides it according to what emerges. Obviously there should be other more structured functions.”*

We found that formal caregivers would like to add the most possible details about a person with dementia into the platform, so observations are not sufficient. Besides that, to make an automatic session there should exist a Life Story Book with more information of a particular person. Also, it is important for the caregiver to know some aspects about the person like their profession, hobbies and daily living routines. So, a section where caregivers can put this information into the platform would be necessary even for the algorithm that creates a session to select generic content that meets the biographical information of a person. When we were creating a person with dementia’s profile several caregivers gave suggestions about fields that could be added regarding the life of that person, like their profession, because it is usually significant as C8 explained: *”reminiscence therapy involves getting to know the person and one of the things that marks the person’s life is their occupation”*. Other aspect that could be important is their residence and the people they live with. Describing the degree of autonomy could also be important as suggested by C12 but difficult in an initial stage. C9 also suggested the interests and motivations of the person and reinforced the idea that caregivers normally are lost in the initial phase. Another point that C8 mentioned was that informal caregivers do not know what information is important to prepare therapy sessions, so it is important to ask for them to enter that information into the platform, as mention by C16. C19 also mentioned that it should be interesting to insert a section for ACTIVITIES OF DAILY LIVING of the person with dementia somewhere in the platform as it could help caregivers know what persons need to do on their daily routines. All this information is very important for them so they are not lost on an initial phase and intervene correctly with the person. So definitely, the section about the Life Story Book is a top priority on future versions of this platform.

- C9: *”I would add the part about interests and motivations beyond the family background because I think it complements a lot the way the intervention itself is going to be implemented and this part about personal interests can even be in the form of a questionnaire or free form, I do not know which is the best option. With some options that even help the person to orientate him/herself because a technician has a notion of the questions to ask and how to address them. A caregiver is more lost in this initial phase.”*
- C8: *”Imagine that it is an informal caregiver who makes the first observations then if I want to do a therapy session I do not have the necessary information for that because he is not sensitive to the information that is necessary for me to start a reminiscence therapy activity.”*
- C16: *”So if I already have the fields with some questions that are important for this case, which is the reminiscence therapy, it already helps to direct and collect the data.”*
- C19: *”It (register the activities of daily living) can be important for caregivers to know that this actually has to happen. Imagine someone who has dementia, for example. Apart from the issue of visualisation, which may or may not be relevant, it also depends on the gradation, it is very important for them to know that they have to do those things themselves and the caregiver also has to be aware of the goal after checking whether it was done or not.”*

All caregivers liked the help within the platform and gave suggestions. C6 suggested that we should create sub-topics so the content can be more direct and that we should associate more images to the explanation to help describing a feature. She also did not recommend videos as older people may not capture all the information with that. C14 also suggested that we should make an instruction manual considering the possible errors of the platform.

- C2: *"It is adapted to the various information tabs and that makes it easier."*
- C6: *"I would put it step by step by putting the image with a little arrow or the indication on the screen where it occurs."*
- C6: *"The age groups that will use this are more older and normal ageing leads to some slowing down of thinking, it is perfectly normal, so the processes are no longer as fast. So something like a video that has movement, the person might not be able to capture everything whereas if it is static it is easier."*
- C14: *"It would be interesting to have a manual or a guide with the possible errors that can occur. What kind of errors the application can make and how we can solve them. I say this as an element of help from the point of view of the simplest user in this case, not from the point of view of those who built the whole application from scratch, so it is almost like a manual of possible errors so that we can correct them."*

In general, caregivers gave a positive feedback about the platform. They found the platform simple to use, very clear and some of them said that they would like to use it with the people with dementia. C7 also explained in what extent this platform could help them as it can ease the access and share of important information and also made us consider that, in future versions, improving the platform so it is more accessible in a mobile could be important for formal caregivers to consult a person's data. Also C9 thanked us for letting them participate in the development, as this tools normally get to them as a final product and they do not have this possibility, which reinforces the importance of an user-centered design when designing this type of applications. C19 also mentioned that the platform has good colours and contrast.

- C7: *"If I think about my experience as a professional, I think this application is interesting. It goes a little further than the records we already keep, which is more of an administrative matter, but we could use something computerised. Easy access from a mobile phone, for example, I know I am going to see that person and I do not need to be here with my paper agenda or on the computer, I can easily access it for a more urgent matter, for example, I can access this data from anywhere. For example, here in the association we have consultations but then people can go to a day care centre and the professionals there can also be integrated into this (platform) and share with everyone."*
- C19: *"This one is good enough, very nice, very contrasting without being too much. I like it a lot, it has very sober, beautiful, contrasting colours that are very important for this contrast. Both in terms of perceptual constancy, which do not change, and in terms of contrast they work very well. The background figure, technically speaking, works very well from a perceptive point of view."*

After finishing the experimental sessions we asked for caregivers to fill the form that would help evaluate our platform. As we referred the form consisted of System Usability Scale (SUS) and the first six questions regarding usefulness from the Technology Acceptance Model (TAM). This form was answered by thirteen of the caregivers who participated on the sessions. The results of SUS [13] achieved an average score of 85. Being higher than 80.3 the platform is evaluated as an A and people found it easy to use and would recommend it to other people [31]. Analyzing the second part of the form regarding TAM we found that only four caregivers answered questions above or equal to four. Since in this questionnaire the lowest values are considered the best results and the other caregivers responded equal or below three, and since the scale is from one to seven, we can assume that they found our platform useful to perform reminiscence therapy. The results obtained from these two questionnaires showed that our platform is easy to use, was accepted by all the caregivers and they would recommend it to other caregivers. Most of them also would like to use it to perform reminiscence therapy as it was considered a major help for their work.

### 7.3 Summary

In this chapter we started by describing the second part of the requirements gathering interviews, with the three caregivers. We explained how we proceed during that section so caregivers would be able to remotely try all the available functionalities of our prototype and comment it. As similar to the first part of the interview we transcribed and coded that section, so we could identify the possible changes that should be implemented on the platform. With that information gathered we made some changes to the prototype that were also detailed in the section regarding the impact on platform's design.

After explaining the first interaction that the caregivers had with our platform's prototype we explained how we evaluated the platform. After implementing all the changes identified on the prototype remote tests and finishing the other functionalities defined for the platform we proceed to evaluate it so we could understand what should be considered and implemented in the future.

We made seven evaluation sessions performed with seventeen caregivers, being two of them focus group. In the individual sessions caregivers were able to try the platform remotely. We prepared task scenarios for the caregivers to use all the functionalities within our platform, however the caregivers explored the platform without needing them.

After finishing the experiment caregivers were asked to answer to a formulary regarding SUS [27] for usability and 6 questions of TAM [28] regarding usefulness. The SUS results [13] showed good results with an average score of 85 which shows that our platform is an A in terms of usability and the caregivers found it easy to use and would also recommend it to other caregivers [31]. The results of TAM in terms of usefulness also showed great results as most of the caregivers think that our platform would help them perform reminiscence therapy.



## Chapter 8

# Conclusions and Future Work

In this work we developed a platform to support reminiscence therapy. By performing requirements gatherings and experimental sessions, with our prototypes and platform, we reached a user-centered design and were able to identify most of the caregivers' needs. Although there are some functionalities to add and improve, our solution already has a good usability. We got an average score of 85 for the SUS questionnaire which means that our platform is easy to use and caregivers would recommend it. The results from the TAM questionnaire showed that this platform will help caregivers with reminiscence therapy. The feedback given by all caregivers while using the platform was also very positive.

In the next sections we summarize all the content within this work and our contributions. We will also explain the limitations while developing our platform and the future work that should be considered to implement the missing functionalities of the platform.

### 8.1 Summary

In Chapter 1 we introduced our work. We gave a motivation about the benefits that this work will bring to caregivers as a tool to help them execute reminiscence therapy, which is also one of its main objectives. Another objective was to do requirements gathering with caregivers and perform a user-centered design. Finally, we introduced the developed solution and some of its main contributions.

In Chapter 2 we gave some background about dementia and reminiscence therapy. We described some of the technological solutions for that therapy, with a major focus on the ones that would require a digital platform. We also identified some user interface design guidelines for older people in terms of accessibility and web design, as older people will be one of the major users of the platform. An analysis about this data was made and all the digital solutions described were compared with our solution giving a set of characteristics important to consider.

In Chapter 3 we explained the objectives of our requirements gathering, which were mostly to validate the requirements gathered by the study of Alarcão et al. [1] regarding informal caregivers and also identify formal caregivers follow up with people with dementia and their needs when using this type of applications. We used two methodologies to make this requirements gathering: online surveys and remote interviews. We started by describing the procedure of this gathering. After that we explained the structure of the two surveys made with formal and informal caregivers, and the results obtained. For the interviews first section regarding questions about the caregivers' follow-up and how they execute reminiscence therapy we also described its structure and results. The main findings of this gathering along

with the requirements identified for each of the caregivers were described after that.

In Chapter 4 we described our database concepts so it could be an introduction for the terms that we would use on the next chapters and also as a knowledge base to our platform concepts. The major concepts within our platform are: caregiver, person with dementia, person with dementia chat, notification, image and session. All of them were described in this chapter along with their attributes and relations within our database.

In Chapter 5 we started by explaining how our solution will be implemented on the solution designed by Alracão et al. [1] and what components of that solution are developed in this work. After that, we described our system architecture and how each component of our platform: presentation tier (frontend), business tier (backend) and data tier (database), communicate between one another and what are their principal components. Each of those tiers were explained in the next sections of this chapter going into more detail about each of their components and the technologies used to implement our platform.

In Chapter 6 we started by describing what were the user interface design decisions considering the guidelines referred on Chapter 2 and other ones that came from the requirements gathering. After that, we described and explained all the principal use cases that can be done with our platform regarding reminiscence therapy data management. We described how caregivers can create an account, add a new person with dementia, share the care of a person with other caregivers, associate a personal image into the person with dementia's page and also how caregivers can access help within our platform.

Finally, in Chapter 7 we described both the remote tests we made to evaluate our platform and identify caregivers' needs and requirements. We started by describing the prototype remote tests made in the second section of the requirements gathering interviews with caregivers. The design and functional problems and caregivers' needs were identified in these first tests and caregivers' comments impacted our prototype design and the changes were implemented on the platform. To evaluate the platform we also did experimental sessions with caregivers remotely. In the individual sessions caregivers were able to remotely use our platform while in focus groups they only commented the platform while we were presenting it. Although those sessions were remote, we were able to gather several data regarding functionalities that should be implemented in future versions. The feedback was very positive as the platform showed to be easy to use and also useful for the caregivers to perform reminiscence therapy.

## 8.2 Contributions and Limitations

Our main contribution with this work was the requirements gathering and the user-centered design with caregivers. With the requirements gathering we were able to identify caregivers' needs while using this type of applications to perform reminiscence therapy. We also did some characterization of the caregivers along with the follow up they usually do with people with dementia. With the user-centered design we were able to identify these aspects alongside with comments that caregivers made about their intervention and how they would need some functionalities, and how they would execute it. Different aspects regarding the platform's design were identified on the first tests as being not the most appropriate and explicit. Those ones were changed, so in the platform caregivers were able to explore it without the need for scenarios. This shows the importance of the user-centered design when implementing this type of applications. Specially, when older people are involved as they have more difficulties interacting with

this type of technologies as we have seen in some cases.

As we already referred the feedback about our platform was very positive from caregivers and they also mentioned that it would be an helpful tool for them to execute reminiscence therapy. The digital platform developed will be helpful for other works to study when implementing interfaces for older people and also regarding this type of therapy, as they will be able to develop new functionalities based on the ones already structured. It is a major contribute to manage the people with dementia that caregivers have at their care along with the personal data of each person. It will be also helpful to share the care of a person with dementia as they can see the results of the therapies executed with that person, regardless the caregivers, and also communicate and share notes between them. Although, the design and the mentioned functions are well implemented and represent a major contribute of our work, to make the platform usable for this type of therapy it will need increments that we will explain on the next section.

While doing all the requirements gatherings and experimental sessions with caregivers we had problems to contact with them. As we were on a state of pandemic due to COVID-19 while developing this work, it was impossible to do in person approaches and to contact with informal caregivers, principally. Also, although the surveys were online it was really difficult to get at least fifty people, even by contacting several institutions and caregivers. It took three months to get that number of caregivers to answer, which greatly impacted the work plan. Although, we had two informal caregivers on the first interviews, on the final evaluation of our platform it was difficult to contact with them and we could not even get one informal caregiver to attend. However, we could contact at least seventeen formal caregivers which helped us a lot, principally in the final step of evaluation. Other limitation we had, was that doing this tests remotely was difficult to evaluate some aspects while caregivers were interacting with the platform as sometimes Zoom cameras got in front of the platform and some functionalities like uploading the image from the operating system were impossible to show due to security settings we used during the remote control, as the caregiver had only access to an anonymous window. However, caregivers gave a very positive feedback and could interact with all the elements designed.

### 8.3 Future Work

Future work regarding the developed platform should start by implementing the session functionalities, regarding its execution and results. We already referred that a session should have an automatic, semi-automatic and a manual mode to prepare therapy sessions, because formal caregivers like to have some control while preparing a therapy session. However, they also mentioned that they would resort to the automatic session if they lack of time. So, all these modes of creating and preparing a therapy session should be considered. Regarding messages, different forms of sending messages should be implemented, principally individually between caregivers. The Life Story Book of a person with dementia has shown a great importance to automatic generate sessions and to help caregivers intervene with the person with dementia, so it should be a top priority, and a page where caregivers can introduce different aspects regarding a life of a person should be considered in the person with dementia page. They also mentioned that different aspects regarding an informal caregiver profile would be important to introduce, like if they live with the person they care for, how much time they spend with him/her, etc. These aspects will help formal caregivers to know about the stress and burden of the informal caregiver and can also

help them intervene with them. Regarding images, caregivers would also like to see the generic images associated to a person with dementia in that person's profile.

The aspects referred were the major ones identified in the final evaluation of the platform, alongside with more design suggestions and some data that should be included in some fields, principally the selection ones. Also, these increments of the platform should be made continuing the user-centered design as it has shown very important to identify and decide about some elements' design of the platform. Also, at least formal caregivers showed great motivation to participate in the development of the platform and most of them would like to have news about it, so it would be possible to use it someday to execute reminiscence therapy and manage all the persons they care for alongside with their data. They consider it would be a major help, principally if they are involved in the development. This is another reason that supports the idea of continuing the user-centered design in the next versions of the platform.

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# Appendix A

## Ethical Committee Approval



### APPLICATION FOR ETHICAL APPROVAL OF A RESEARCH PROJECT

This application form is to be used by STAFF seeking ethical approval for non-clinical research projects/studies that involve human subjects.

Research must **NOT** begin until approval has been received from CERPDC.

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### Section 1. Applicant

Name of Researcher (Applicant):	André Filipe Matos Santana, Soraia M. Alarcão
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Telephone Number:	Click here to enter text.
Research Unit:	LASIGE
CENSUS number / Student number:	49451 / 48838

### Section 2. Project

Project / Study Title (public):	RT-Portal: Portal Web para o cuidador de terapia de reminiscência
Supervisor (if applicant is a student):	Manuel J. Fonseca
Funding:	Externally Funded <input type="checkbox"/> Internally Funded <input type="checkbox"/>
Submitted to (for funding, if applicable):	Click here to enter text.

### Section 3. Type of Project

<b>Questionnaire/Survey</b> e.g. surveys of members of particular groups / organizations; mail out questionnaires, street surveys	<input checked="" type="checkbox"/>
<b>Experiments</b> e.g. participants completing tasks under controlled conditions, use of tasks/method other than or in addition to questionnaires/surveys	<input checked="" type="checkbox"/>
<b>Observational</b> e.g. observing how people behave in a natural setting or in a laboratory	<input type="checkbox"/>
<b>Data-based</b> e.g. the use of official statistics where individuals could be identified	<input type="checkbox"/>



Other	<input type="checkbox"/>
If 'Other', please describe.	Click here to enter text.

#### Section 4. Project Details

Proposed date on which the project/study will begin (assuming, if applicable, that funding has already been granted by a funding agency):	15-01-2021
Proposed date on which the project/study will end:	31-05-2021

#### 4.1 - Project Outline & Aims

Briefly describe:

- The aims of this research
- The main tasks (or tests) that participants will be required to complete
- What use will be made of sensitive economic, social or personal data.

This description must be in everyday language, free from jargon, technical terms or discipline-specific phrases.

(No more than 300 words)

The aim of this project is to implement an application that will allow caregivers to execute reminiscence therapy with their patients with dementia and manage their data and treatment on their daily living. This project is part of a thesis named "RT-Portal: Portal Web para o cuidador de terapia de reminiscência" for Master's in Informatics Engineering. We want to study both formal and informal caregivers. Formal caregivers are usually medical professionals, therapists or nursing home assistants while informal caregivers do not have any professional qualification to treat people with dementia, but they accompany and care for them. They are normally friends or family. We want to learn the differences between formal and informal caregivers, in particular if their needs are different when it comes to functionalities and patients' management. We want to learn more about how they follow their patients and execute reminiscence therapy on them. We also want to confirm if the design guidelines that we propose meet their requirements, so we achieve better usability and accessibility. We start by executing an online questionnaire that will be distributed in institutions and social media pages to caregivers who care for people with dementia. The data collected from this questionnaire will be anonymous and will be only used to take decisions for functionalities and the application design. After that, the people that chose to participate more deeply in our study after completing the questionnaire, will be selected. We want to execute online interviews for at least 5 persons (3 formal and 2 informal caregivers) on a semi-structured format where questions about the questionnaire will be discussed more deeply, as well, as the results we obtained from the questionnaires. Also, we could ask for them to analyze our low fidelity prototypes by completing simple tasks so we can clarify some usability aspects. The data collected from these interviews will help us clarify some aspects from the questionnaires results and about our application design. These data will only be used for the implementation of our application.



#### 4.2 - Proposed Research Methods

Please provide an outline of the proposed research methods, in layman's terms, avoiding using jargon and technical terms as much as possible. Do include:

- Where and how data will be collected and stored;
- All tasks that participants will be asked to complete;
- If the research will take place outside of Portugal or in collaboration with internationally-based partners, and/or if research will take place using the Internet;
- Present an outline of the method in a step-by-step chronological order.

*(No more than 700 words)*

The questionnaires will be an online form on Google Forms available in Portuguese and English. There will be two questionnaires: one for formal caregivers that treat people with dementia in a professional way; and informal caregivers that are somehow related to the person with dementia. The data collected will be anonymous. On these questionnaires we will only ask from our participants to answer questions of multiple choice and short answer. On the end of the questionnaires, participants will have a section where they can leave their email so we can contact them later for semi-structured online interviews. This section is independent from the questionnaires to guarantee anonymity. After analyzing the results from the questionnaires, we will proceed to the interviews. We need to study these results first because there will be aspects from it that should and are supposed to be clarified on semi-structured interviews. On these interviews we will clarify the questionnaires results and will ask participants to design their perspective of pages from our application and execute simple tasks on low fidelity prototypes. If participants give consent, we will record audio and/or video of the interview so we can evaluate and codify it later. The data collected will be only used for the implementation of our application and these records will be destroyed after codification is done.

The questionnaires will take place using the Internet and we will try to get worldwide results. We will send an English version of our questionnaires to different institutions worldwide and social media pages dedicated to people with dementia and their caregivers. Also, we will send a Portuguese version of the questionnaires to institutions located here in Portugal and Portuguese social media pages. The interviews will be made worldwide, to the participants who provided us their emails. So, only the people who have said that want to continue in our study after questionnaires will be contacted.

The questionnaires do not have a complex protocol. Participants will open the link from the questionnaire they should answer (either they are formal or informal caregiver) and then there will be an introduction about the study and its objective. Also, we will ask for their consent to use their anonymous data for our study and inform that they can quit at any point of the questionnaire and withdraw their anonymous data. After that they only need to answer the questions and submit. After completing the questionnaires there will be a section completely independent from the questionnaire, where we ask for their email in case they want to be contacted to participate on an online semi-structured interview.

After analyzing the questionnaires results, we will perform online semi-structured interviews using the following protocol:

- 1) The participants will be informed about the presence of researchers, the objectives of the study, the right to quit at any time or even to withdraw their own data from the study at any point, and about any other questions that they want to ask. We conclude this step by obtaining online consent, or otherwise stopping the interview.
- 2) Upon authorization and consent, we will begin our interview by doing a set of questions that will be defined previously following a semi-structured format.
- 3) We will ask participant do design their perspective of a page of the application.
- 4) If needed, we will ask for them to complete simple tasks on a low fidelity prototype.
- 5) The participants will be thanked and debriefed, all the questions they might have will be answered and their informed consent will be reconfirmed, or otherwise data will be destroyed immediately.


**Section 5. Participant Details**

Does this research specifically target (select all that apply):

Students or staff of this institution	<input type="checkbox"/>				
Adults (over the age of 18 years and competent to give consent)	<input checked="" type="checkbox"/>				
Children/legal minors (anyone under the age of 18 years)	<input type="checkbox"/>				
The elderly	<input checked="" type="checkbox"/>				
People with intellectual or communication difficulties	<input type="checkbox"/>				
People in custody	<input type="checkbox"/>				
People engaged in illegal activities (e.g., drug-taking)	<input type="checkbox"/>				
Number of participants:	Expected at least 50 different individuals from questionnaires; at least 5 users for semi-structured interviews.				
Age from:	18				
Age to:	70				
Target populations to recruit participants, and means to select participants:	Adults, preferential above 40 years old; the questionnaires will be distributed in institutions and social media pages related to people with dementia and their caregivers; the people from the online interviews will apply to our study by leaving their email after completing questionnaires if they want to continue in our study.				
Reasons to select the required populations:	They need to be adults so they can give consent and because normally only adults are caregivers of people with dementia. We want more people above 40 so we can evaluate more our design guidelines for older people.				
Does this project require approval from an external authority (e.g., CNPD, schools, governing body)?	<table border="1"> <tbody> <tr> <td><b>YES</b></td> <td><b>NO</b></td> </tr> <tr> <td><input type="checkbox"/></td> <td><input checked="" type="checkbox"/></td> </tr> </tbody> </table>	<b>YES</b>	<b>NO</b>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
<b>YES</b>	<b>NO</b>				
<input type="checkbox"/>	<input checked="" type="checkbox"/>				
Has approval already been granted?	<table border="1"> <tbody> <tr> <td><b>YES</b></td> <td><b>NO</b></td> </tr> <tr> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </tbody> </table>	<b>YES</b>	<b>NO</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>YES</b>	<b>NO</b>				
<input type="checkbox"/>	<input type="checkbox"/>				



### Section 6. Participant Information

	YES	NO
Will you inform participants that their participation is <b>voluntary</b> ?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Will you inform participants that they may <b>withdraw</b> from the research at any time and for any reason?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Will you inform participants that their data will be treated with full <b>confidentiality</b> and that, if published, it will not be identifiable as theirs?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Will you provide an <b>information sheet</b> that will include the contact details of the researcher/team?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Will you obtain <b>written consent</b> for participation?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Will you debrief participants at the end of their participation (i.e., give them an explanation of the study and its aims and hypotheses)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Will you provide participants with <b>written debriefing</b> (i.e., a sheet that they can keep that shows your contact details and explanations of the study)?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
If using a <b>questionnaire</b> , will you give participants the option of omitting questions that they do not want to answer?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
If an <b>experiment</b> , will you describe the main experimental procedures to participants in advance, so that they are informed about what to expect?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
If the research is <b>observational</b> , will you ask participants for their consent to being observed?	<input type="checkbox"/>	<input type="checkbox"/>

### Section 7. Participant Consent

Please describe the arrangements you are making to inform participants, before providing consent, of what is involved in participating in your study:

We will give a short description of the application we want to develop. We will explain what we will request from them when it comes to data gathering like the online questionnaires and interviews. We will also explain what we want to gather from all this research and how their data will be used for the implementation of our application.

Please describe the arrangements you are making for participants to provide their full consent before data collection begins. Note that you can adapt, minimally, the template of the “*Formulário de Consentimento Informado*”, to take into account the specificities of your studies:

We will use an adapted version of the “*Formulário de Consentimento Informado*” when requesting participants full consent. This form will also be available online, so people can give online consent.

Participants should be able to provide written consent. If you think gaining consent in this way is inappropriate for your project, then please explain how consent will be obtained and recorded.



### Section 8. Participant Debriefing

Please describe the debriefing that participants will receive following the study and the exact point at which they will receive the debriefing:

At the end of questionnaires, we will give a debriefing about the current state of our application. Participants will also be thanked and reassured that their participation is confidential. At the end of interviews, we will give a debriefing about the current state of our application, what we intended with the different data gatherings and what we concluded. Participants will also be personally thanked and reassured that their participation is confidential after every intervention we have with them.

It is a researcher's obligation to ensure that all participants are fully informed of the aims and methodology of the project, and to ensure that participants do not experience any levels of stress, discomfort, or unease following a research session. Also describe any particular provisions or debriefing procedures that will be in place to ensure participants feel respected and appreciated after they leave the study. Please attach the written debriefing sheet that you will give to participants. If you do not plan to provide a written debriefing sheet, please explain why.

### Section 9. Protection of personal data of participants

Describe, in some detail, the types of personal data that will be requested to participants and how this data is going to be organized, protected, shared, and eventually backed-up. In particular, describe the anonymity procedures of the responsibility of the principal investigator ensuring that the members of the research team have no access to personal data which is irrelevant for research purposes. Address the use of internet or public / private information systems throughout the research.

*(No more than 300 words)*

Questionnaires data are all anonymous. Each participant from the questionnaires and interviews will be anonymized through a unique id. No identifiable data will be stored/distributed online. If audio and video are recorded, they will be codified and destroyed right after. It is expected that only the main investigator will access all the data. We expect the information collected to be personal and private.

### Section 10. Risk Considerations

#### 10.1 - Potential risk to participants and risk management procedures

Identify, as far as possible, all potential risks (small and large) to participants (e.g. physical, psychological, etc.) that are associated with the proposed research. Please explain any risk management procedures that will be put in place and attach any risk assessments or other supporting documents.

No risks are foreseeable.

#### 10.2 - Potential risk to researchers and risk management procedures

What are the potential risks to researchers themselves? For example, personal safety issues such as lone or out of normal hours working or visiting participants in their homes; travel arrangements, including overseas travel; and working in unfamiliar environments. Please explain any risk management procedures that will be put in place and attach any risk assessments or other supporting documents.

No risks are foreseeable.



### Section 11. Identification joint activities with the members of the Commission

Did you participate in common research projects or did you co-authored scientific papers with any of the members of the Comissão de Ética para a Recolha e Protecção de Dados Pessoais (See [Composição da Comissão](#)) in the last 24 months?

No

### Section 12. Summary of critical issues

If all the answers are NO, the Commission will follow a fast evaluation procedure.

		YES	NO
1	The project involves <a href="#">children</a> or other <a href="#">vulnerable groups</a> ?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2	The project requires the co-operation of a <a href="#">gatekeeper</a> (defined as someone who can exert undue influence) for initial access to the groups or individuals to be recruited?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
3	Is it necessary for participants to take part in the project without their knowledge and consent e.g. covert observation of people in non-public places?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
4	The project includes deliberately misleading participants in any way?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5	The project includes discussion of sensitive topics e.g. sexual activity or drug use?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
6	The project may cause psychological stress, anxiety, harm or negative consequences, beyond that encountered in normal life?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
7	The project requires prolonged or repetitive testing i.e. more than 4 hours commitment or attendance on more than two occasions?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
8	Are there financial inducements due to participants (other than <a href="#">reasonable expenses and compensation for time</a> )?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
9	The project causes pain or more than mild discomfort?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
10	The project collects and stores personal or sensitive data from participants?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
11	The project plans to transfer participants' personal or sensitive data to other institutions somehow participating in the studies?	<input type="checkbox"/>	<input checked="" type="checkbox"/>





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### Section 13. Public information

Describe the study and the populations associated to it, for public release in the site of the Commission, enabling others to contact you in case of similar activities.

*(No more than 100 words)*

Title: RT-Portal: Portal Web para o cuidador de terapia de reminiscência. The aim of this project is to develop an application that could help caregivers execute reminiscence therapy and manage their patients with dementia. This project is part of a thesis for Master's in Informatic Engineering. Researchers will conduct interviews after a questionnaire was executed. Target populations area: Adult informal and formal caregivers. The collected data will be analyzed and used as a source to implement our application so we can clarify different aspects from functionalities and design decisions.

### Section 14. Declaration

I certify that the information contained in this application is accurate. I have attempted to identify the risks that may arise in conducting this research and acknowledge my obligations and the rights of the participants.

Name of Principal Investigator:	André Filipe Matos Santana
Signature:	André Filipe Matos Santana
Date	11/02/2021



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### For office use only:

CERPD has considered the ethical aspects of this proposal. The committee recommends that the study/project be:

- Approved, without conditions
- Approved, with conditions (identified below)
- Major revision required, leading to resubmission (for reasons below)
- Not approved (for reasons below)

Click here to enter text.

Signatures:

# Appendix B

## Information Brochure



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### Information Brochure

**PROJECT: RT-Portal: Portal Web para o cuidador de terapia de reminiscência**

**INVESTIGATOR IN CHARGE: André Filipe Matos Santana**

We came to invite you this way to participate in our research study focused on collecting data to develop an application for the performance and management of reminiscence therapy.

Before deciding, we would like to present you with the details of this investigation, its reason for being, its potential utility and the implications of your participation.

#### 1 - In what consists the study?

This study aims to collect data on how caregivers currently perform reminiscence therapy with people with dementia and how they manage their treatment. To do this you will start by answering an anonymous questionnaire which will be our starting point. From the results of these questionnaires and interviews we intend with this study to identify which features of our application will be most useful and of greatest interest to caregivers, as well as the best way to design the application. We will count with the participation of the caregivers, who will be our main users, in the design of the application to obtain a greater adherence. For this we will collect information using questionnaires and interviews and show some low fidelity prototypes (first designs of the application) and ask to execute a given number of steps and comment on the process. During the data collections we will be able to collect audio and/or video recordings if the participant authorize it.

#### 2 - Do I have to participate in this study?

Participation in the study is completely voluntary. We will describe the study and present the content of this informative document, including the details of your participation. If you agree to participate, you will sign an Online Consent Form in Google Forms.

#### 3 - And if I wish to give up the study?

You are free to give up at any time without having to provide any reasons or explanations.

#### 4 - What will I have to do in the scope of the study?

The goal of the research is to understand how caregivers carry out reminiscence therapy with people with dementia and how they accompany them. In addition, we want to understand which features we should focus on and implement and how we should design the application. It is not intended to evaluate you. All recommendations and suggested improvements will allow the research to evolve and are welcome.

You will participate in an anonymous questionnaire regarding how caregivers carry out reminiscence therapy with people with dementia, how they accompany these people, and to understand what features would be useful in an application to carry out reminiscence therapy. Completing this questionnaire should take no more than fifteen minutes and you may finish at any time.

If you are available, you can eventually participate in a semi-structured interview(s) where some of the aspects mentioned in the questionnaire will be deepened and clarified. After clarifying these aspects, we will ask you to design one or two main screens of our application to give some feedback and participate in the design of our application. After this design we may also ask you to perform a few tasks on a low fidelity prototype (first designs of the application) and comment on the process. Each interview will take a maximum of 1 hour, but there is no minimum time requirement. You will participate in a maximum of



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## Information Brochure

3 interviews. Our goal is that the first one is to clarify questionnaire aspects and understand which designs we can apply in our application. The other 2 will be more to ask for feedback on the application and to execute a certain number of tasks in it, commenting on the process.

### 5 - What are the disadvantages and risks of participating?

No associated risks are foreseen, and the research team's expectation is that the sessions in which they participate will be a pleasant experience for the participants. The schedule of the sessions will be according to your availability and defined by you.

### 6 - What are the possible benefits of participating?

According to our experience, people like to participate in studies that promote communication with scientists. Their involvement will help develop a technological solution that will help all caregivers who accompany people with dementia to perform activities related to this accompaniment in a more efficient, effective, and pleasant way.

### 7 - What happens when the study ends?

The data analysis will end on June 30, 2021. The results of the study will be published in conferences and academic journals. If you wish to know details about the results and implications of the study, we will send you a copy of the study report by email, but not before July 30, 2021.

### 8 - And if any problem occurs?

If you have any concerns about any aspect of this study, you should talk to one of the responsible researchers, Prof. Manuel J. Fonseca, Soraia Meneses Alarcão or André Santana, who will do their best to elucidate you and answer your questions, by one of the emails below. If you are unhappy or would like to make a formal complaint, you can do so by contacting the Director of the Faculty of Sciences of the University of Lisbon [email: [direccao@fc.ul.pt](mailto:direccao@fc.ul.pt)].

### 9 - Will my information be kept confidential?

Yes. We will follow all ethical and legal practices and all information about you will be treated confidentially. To ensure anonymity, personal records will only be available in their entirety, to the investigator in charge, and members of the research team will only have access to the data they need to know. If your data is used for publications or presentations, it will be completely anonymized, without any reference, direct or indirect, to your identity. If pictures are taken, and it is our intention to use them in any presentation, you will be asked for prior authorization. If you are available for us to use photographs or videos for this purpose, we will first ask you to sign specific permissions for this purpose.

### 10 - Has the study passed through a revision process?

Yes. In fact, this study was reviewed by the Comissão de Ética para a Recolha e Protecção de Dados de Ciências (<https://ciencias.ulisboa.pt/pt/comiss%C3%A3o-de-%C3%A9tica-para-recolha-e-prote%C3%A7%C3%A3o-de-dados>). This commission analysed the study proposal as well as all its materials and raised no objections from an ethical point of view.



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## Information Brochure

### 11 - Who can I contact related to this study?

<b>Prof. Manuel J. Fonseca</b> Faculdade de Ciências da Universidade de Lisboa <a href="mailto:mifonseca@fc.ul.pt">mifonseca@fc.ul.pt</a>	<b>Soraia M. Alarcão</b> Faculdade de Ciências da Universidade de Lisboa <a href="mailto:salarcao@lasige.fc.ul.pt">salarcao@lasige.fc.ul.pt</a>	<b>André Santana</b> Faculdade de Ciências da Universidade de Lisboa <a href="mailto:asantana@lasige.fc.ul.pt">asantana@lasige.fc.ul.pt</a>
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Feel free to contact them on any matter related to this study.

### Thanks a lot.

Thank you for taking the time and considering participating in this study.

*André Filipe Matos Santana*  
Responsible Investigator  
André Santana

Participant



# Appendix C

## Formal Caregiver Survey

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### Formal Caregiver Questionnaire

This questionnaire is part of a project in the scope of the Master in Informatics Engineering, of Faculty of Sciences of the University of Lisbon. This work aims at the design and development of a computer application that allows the execution of all kinds of functions for the management and performance of reminiscence therapy and management of the patients of each caregiver. Reminiscence therapy helps people with dementia to remember past experiences and promotes communication between patients with dementia and the rest of the world, stimulating their memory. To support this therapy our application will allow caregivers to have an account where they can add their patients and edit their personal information. This information will be the material used in the therapies and can be of various types: images, videos, music or text. In addition to these functions, corresponding to the management process prior to the therapy, after the therapy it will be possible to consult the history of sessions performed and consult the results obtained for each one of them.

This questionnaire aims to collect information related to the performance of reminiscence therapy sessions, as well as the treatment of people with dementia, in order to understand the most appropriate design of our application and the necessary functionalities to support reminiscence therapy. We want to understand if what we have been thinking meets the expectations and requirements of caregivers, as well as understand if the design guidelines we will take into account when implementing our application are the most appropriate.

The questionnaire is anonymous and confidential, and your answers will be used only for the development of our application. It should take no longer than fifteen minutes to complete and can be completed at any time.

We appreciate your availability and collaboration!

If you have read the previous text you can proceed to the questionnaire. By clicking on the following, you consent to the use of your anonymized data for the development of our application. If you would like to see the information brochure for this study, you can consult it at:  
<https://drive.google.com/file/d/1NY866YKwJPOaBCLYGxLzdbst87kmE1K/view?usp=sharing>

---

**\*Required**

Caregiver Characterization

<https://docs.google.com/forms/d/1a92YxQT1gl0zyOOd7RGXBDM8f3uRVEQTouz3JpUMckc/edit> 1/16

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Formal Caregiver Questionnaire

## 1. 1. Gender \*

*Mark only one oval.* Female Male Other

## 2. 2. Age \*

*Mark only one oval.* Less than or equal to 50 51-60 61-70 Over 70

## 3. 3. Do you have any visual difficulties? \*

(Check all that apply)

*Tick all that apply.* None Astigmatism (distorted or blurred vision at all distances) Daltonism (difficulty in distinguishing colors) Photophobia (sensitivity to light in the eyes) Hyperopia or presbyopia (difficulty to see up close) Myopia (difficulty to see far away)Other:  \_\_\_\_\_



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Formal Caregiver Questionnaire

## 4. 4. Degree of Schooling \*

*Mark only one oval.*

- Primary School / Elementary School
- Preparatory Cycle / 2nd Cycle of Basic Education
- General Secondary Education / 3rd Cycle of Basic Education
- Complementary High School / Secondary Education
- Higher Education
- Other: \_\_\_\_\_

## 5. 5. Indicate the number of days per week that you use each of the following devices. \*

*Mark only one oval per row.*

	0 (Does not use)	1-2	3-4	5-6	7 (All days)
Computer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobile Phone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tablet/iPad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Follow-up of patients with dementia

## 6. 1. How many people with dementia do you take care of? \*

*Mark only one oval.*

- 1
- 2-3
- 4-5
- 6-7
- Over 7

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Formal Caregiver Questionnaire

7. 2. Are any of the people you care for in a severe or serious state of Dementia? \*

*Mark only one oval.*

- Yes  
 No  
 Do not know

#### Reminiscence Sessions

8. Reminiscence sessions help people with dementia to remember past experiences and promote communication between them and the rest of the world, stimulating their memory. With this in mind you are a caregiver who performs reminiscence sessions? \*

*Mark only one oval.*

- Yes *Skip to question 9*  
 No *Skip to question 23*

#### Reminiscence Sessions

Reminiscence sessions help people with dementia to remember past experiences and promote communication between them and the rest of the world, stimulating their memory.

9. 1. How many sessions on average do you perform in each patient per month? \*

*Mark only one oval.*

- 1-2  
 3-4  
 5-10  
 Over 10

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Formal Caregiver Questionnaire

10. 2. What is the average duration (in minutes) of each reminiscence session? \*

*Mark only one oval.*

- Less than 30  
 30-60  
 Over 60

11. 3. Where are reminiscence sessions usually held? \*

(Marcar tudo o que for aplicável)

*Tick all that apply.*

- Home  
 Institution (Home, Day Care Center, Hospital, etc)

Other:  \_\_\_\_\_

12. 4. The types of materials you use in the reminiscence sessions are: \*

(Marcar tudo o que for aplicável)

*Tick all that apply.*

- Images  
 Musics  
 Videos  
 Texts

Other:  \_\_\_\_\_

13. 5. The materials you use in the reminiscence sessions are: \*

(Check all that apply)

*Tick all that apply.*

- Personal (concerns the person with dementia)  
 Generic (are not directly related to the person with dementia)

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Formal Caregiver Questionnaire

14. 6. In addition to the above materials, I would like to be able to use: \*

(Check all that apply)

*Tick all that apply.*

Images

Musics

Videos

Textos

Other:  \_\_\_\_\_

15. 7. Which of the following materials trigger some kind of positive emotional reaction in the person with dementia? \*

(Check all that apply)

*Tick all that apply.*

Images

Musics

Videos

Texts

None

Other:  \_\_\_\_\_

16. 8. Which of the following materials trigger some kind of negative emotional reaction in the person with dementia? \*

(Check all that apply)

*Tick all that apply.*

Images

Musics

Videos

Texts

None

Other:  \_\_\_\_\_

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Formal Caregiver Questionnaire

17. 9. Which of the following topics related to the person with dementia do you seek to have in the material used in the reminiscence sessions? \*

(Check all that apply)

*Tick all that apply.*

- Familiar people  
 Jobs he/she had  
 Pets  
 Places where he/she lived  
 Places where he/she spent  
 Vehicles he/she had

Other:  \_\_\_\_\_

18. 10. How do you get the material for the reminiscence sessions? \*

(Check all that apply)

*Tick all that apply.*

- Family  
 Friends  
 Person with dementia  
 Search the Internet

Other:  \_\_\_\_\_

19. 11. How often do you update the materials for the sessions? \*

*Mark only one oval.*

- Daily    *Skip to question 21*  
 Weekly    *Skip to question 21*  
 Every two weeks    *Skip to question 21*  
 Monthly    *Skip to question 21*  
 Semiannually    *Skip to question 20*  
 Half-yearly    *Skip to question 20*  
 Never    *Skip to question 20*

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Formal Caregiver Questionnaire

**Reminiscence Sessions**

Reminiscence sessions help people with dementia to remember past experiences and promote communication between them and the rest of the world, stimulating their memory.

20. 11.1 Why don't you update the materials for the reminiscence sessions more frequently? \*

(Check all that apply)

*Tick all that apply.*

- Disinterest on the part of the person with dementia
- Lack of support materials
- Lack of time
- Not very useful for the person with dementia

Other:  \_\_\_\_\_

**Reminiscence Sessions**

Reminiscence sessions help people with dementia to remember past experiences and promote communication between them and the rest of the world, stimulating their memory.

21. 12. What information do you keep about the reminiscence sessions? \*

(Check all that apply)

*Tick all that apply.*

- Emotional state of the person with dementia before the therapy session
- Emotional state of the person with dementia after the therapy session
- Length of session
- Material that helped to recall past memories
- Material that induced negative emotional reactions
- Material that induced positive emotional reactions

Other:  \_\_\_\_\_

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Formal Caregiver Questionnaire

22. 13. Besides the information you keep, what other information would you like to keep about the reminiscence sessions? \*

(Check all that apply)

*Tick all that apply.*

- Emotional state of the person with dementia before the therapy session
- Emotional state of the person with dementia after the therapy session
- Length of session
- Material that helped to recall past memories
- Material that induced negative emotional reactions
- Material that induced positive emotional reactions

Other:  \_\_\_\_\_

#### Follow-up Consultations

23. The results of the reminiscence sessions, as well as the health of the person with dementia can be evaluated in follow-up consultations. With this in mind, you are a caregiver performing follow-up appointments? \*

*Mark only one oval.*

- Yes *Skip to question 24*
- No *Skip to question 27*

#### Follow-up Consultations

The results of the reminiscence sessions, as well as the health of the person with dementia can be evaluated in follow-up consultations.

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Formal Caregiver Questionnaire

24. 1. How often do you consult your dementia patients who undergo reminiscence therapy? \*

*Mark only one oval.*

- Daily Skip to question 26
- Weekly Skip to question 26
- Every two weeks Skip to question 26
- Monthly Skip to question 26
- Half-yearly Skip to question 25
- Yearly Skip to question 25
- Never Skip to question 27

Follow-up  
Consultations

The results of the reminiscence sessions, as well as the health of the person with dementia can be evaluated in follow-up consultations.

25. 1.1. Why not consult your patients more regularly? \*

(Check all that apply)

*Mark only one oval.*

- Lack of results
- Lack of time
- Not very useful for the person with dementia
- Other: \_\_\_\_\_

Follow-up  
Consultations

The results of the reminiscence sessions, as well as the health of the person with dementia can be evaluated in follow-up consultations.



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Formal Caregiver Questionnaire

26. 2. What do you usually observe/analyze when you consult patients with dementia who perform reminiscence therapy? \*

(Check all that apply)

*Tick all that apply.*

- Emotional reactions of the patient with dementia  
 Emotional well-being of the patient with dementia  
 Length of the sessions held  
 Number of sessions held per month/week  
 Results from previous sessions (for comparison)

Other:  \_\_\_\_\_

#### Other Forms of Follow-up

27. Apart from the reminiscence sessions and follow-up consultations, do you carry out other forms of follow-up? \*

*Mark only one oval.*

- Yes    *Skip to question 28*  
 No    *Skip to question 31*

#### Other Forms of Follow-up

28. 1. What other forms of follow-up do you perform with your patients with dementia? \*

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11/25/21, 11:20 PM

Formal Caregiver Questionnaire

29. 2. Do you use any kind of technology to accompany your patients with dementia? \*

*Mark only one oval.*

Yes    *Skip to question 30*

No    *Skip to question 31*

#### Other Forms of Follow-up

30. 2.1. Indicate which technology(ies) you use? \*

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#### Technology

Imagine that there is a system that allows you to register all your patients, share any of them with other caregivers with whom you work and insert materials related to the patient with dementia. These materials will then be used to perform the reminiscence sessions. The system will automatically adapt the content of the session based on the patient's biographical information and emotional reactions to the materials presented. All the sessions carried out on the person with dementia will generate results so that it will be possible to follow the evolution of the disease. All these sessions can be consulted in a history of sessions of the patient even if performed by another caregiver. Besides, the caregiver himself will have a history where he will be able to consult the sessions he has performed.

After reading the system description answer the following questions.

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Formal Caregiver Questionnaire

31. 1. Regarding the management of patients, please indicate your interest in the following features: \*

Mark only one oval per row.

	1 (Not very interesting)	2	3	4	5 (Very interesting)
Allow the creation of reminders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Notify other caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sharing patient care with other caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11/25/21, 11:20 PM

Formal Caregiver Questionnaire

32. 2. Regarding the reminiscence sessions, please indicate your interest in the following features: \*

*Mark only one oval per row.*

	1 (Not very interesting)	2	3	4	5 (Very interesting)
Automatic adaptation of the session content based on the biographical information of the patient with dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Automatic adaptation of the content of the session based on the emotional reactions of the patient with dementia to the materials presented	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consult the materials used in each therapy session	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History of caregiver sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History of the patient's sessions where all their sessions will be available, even if performed by other caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Formal Caregiver Questionnaire

33. 3. Regarding the material used in the therapy sessions, please indicate your interest in the following functionalities: \*

*Mark only one oval per row.*

	1 (Not very interesting)	2	3	4	5 (Very interesting)
Insert new material	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insert new material topics in addition to those mentioned above	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Existence of a favorites section in each patient's material	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

34. 4. Our system aims to help the user in the best possible way. To do so, we intend to provide explanation and help for the realization of the various features of the system. Please tell us how often you use or can use the following help tools when there are doubts about some functionality. \*

*Mark only one oval per row.*

	1 (Not very interesting)	2	3	4	5 (Very interesting)
Email / Telephone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help within the application	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Instruction manual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

35. 5. Our system will ensure the highest privacy and security for our users. Please let us know how comfortable you would be introducing personal content to our system. \*

*Mark only one oval.*

	1	2	3	4	5	
Not much	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Quite a lot

11/25/21, 11:20 PM

Formal Caregiver Questionnaire

Suggestions

36. If you have any idea of important features for the performance and management of reminiscence therapy and/or management of your patients, we appreciate your suggestion. If you have no suggestions you can finish and submit the questionnaire.

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# Appendix D

## Informal Caregiver Survey

11/25/21, 11:54 PM Informal Caregiver Questionnaire

### Informal Caregiver Questionnaire

This questionnaire is part of a project in the scope of the Master in Informatics Engineering, of Faculty of Sciences of the University of Lisbon. This work aims at the design and development of a computer application that allows the execution of all kinds of functions for the management and performance of reminiscence therapy and management of the patients of each caregiver. Reminiscence therapy helps people with dementia to remember past experiences and promotes communication between patients with dementia and the rest of the world, stimulating their memory. To support this therapy our application will allow caregivers to have an account where they can add their patients and edit their personal information. This information will be the material used in the therapies and can be of various types: images, videos, music or text. In addition to these functions, corresponding to the management process prior to the therapy, after the therapy it will be possible to consult the history of sessions performed and consult the results obtained for each one of them.

This questionnaire aims to collect information related to the performance of reminiscence therapy sessions, as well as the treatment of people with dementia, in order to understand the most appropriate design of our application and the necessary functionalities to support reminiscence therapy. We want to understand if what we have been thinking meets the expectations and requirements of caregivers, as well as understand if the design guidelines we will take into account when implementing our application are the most appropriate.

The questionnaire is anonymous and confidential, and your answers will be used only for the development of our application. It should take no longer than fifteen minutes to complete and can be completed at any time.

We appreciate your availability and collaboration!

If you have read the previous text you can proceed to the questionnaire. By clicking on the following, you consent to the use of your anonymized data for the development of our application. If you would like to see the information brochure for this study, you can consult it at:  
<https://drive.google.com/file/d/1NY866YKwJPOaBCLYGxLzdbst87kmE1K/view?usp=sharing>

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\*Required

#### Caregiver Characterization

[https://docs.google.com/forms/d/1vEAL8RVX3ChzVrN7D3-aOw8rPx\\_Ph54Qsr7FfoQHE/edit](https://docs.google.com/forms/d/1vEAL8RVX3ChzVrN7D3-aOw8rPx_Ph54Qsr7FfoQHE/edit) 1/16

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Informal Caregiver Questionnaire

## 1. 1. Gender \*

*Mark only one oval.*

- Female
- Male
- Other

## 2. 2. Age \*

*Mark only one oval.*

- Less than or equal to 50
- 51-60
- 61-70
- Over 70

## 3. 3. Do you have any visual difficulties? \*

(Check all that apply)

*Tick all that apply.*

- None
- Astigmatism (distorted or blurred vision at all distances)
- Daltonism (difficulty in distinguishing colors)
- Photophobia (sensitivity to light in the eyes)
- Hyperopia or presbyopia (difficulty to see up close)
- Myopia (difficulty to see far away)

Other:  \_\_\_\_\_



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Informal Caregiver Questionnaire

## 4. 4. Degree of Schooling \*

*Mark only one oval.*

- Primary School / Elementary School
- Preparatory Cycle / 2nd Cycle of Basic Education
- General Secondary Education / 3rd Cycle of Basic Education
- Complementary High School / Secondary Education
- Higher Education
- Other: \_\_\_\_\_

## 5. 5. Indicate the number of days per week that you use each of the following devices. \*

*Mark only one oval per row.*

	0 (Does not use)	1-2	3-4	5-6	7 (All days)
Computer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobile Phone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tablet/iPad	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Follow-up of patients with dementia

## 6. 1. Do you care for more than one person with dementia? \*

*Mark only one oval.*

- Yes
- No

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Informal Caregiver Questionnaire

7. 2. The person(s) you care for is/are your: \*

(Check all that apply)

*Tick all that apply.*

- Mom / Dad
- Daughter /Son
- Spouse
- Relative
- Friend
- Does not belong to my family

8. 3. Are any of the people you care for in a severe or serious state of Dementia?

*Mark only one oval.*

- Yes
- No
- Do not know

9. 4. How long on average (hours) in a day do you spend caring for a person with dementia?

*Mark only one oval.*

- 1
- 2-3
- 4-5
- 6-7
- 8
- Over 8

Reminiscence Sessions

11/25/21, 11:54 PM

Informal Caregiver Questionnaire

10. Reminiscence sessions help people with dementia to remember past experiences and promote communication between them and the rest of the world, stimulating their memory. With this in mind you are a caregiver who performs reminiscence sessions? \*

Mark only one oval.

- Yes Skip to question 11  
 No Skip to question 25

#### Reminiscence Sessions

Reminiscence sessions help people with dementia to remember past experiences and promote communication between them and the rest of the world, stimulating their memory.

11. 1. How many sessions on average do you perform in each patient per month? \*

Mark only one oval.

- 1-2  
 3-4  
 5-10  
 Over 10

12. 2. What is the average duration (in minutes) of each reminiscence session? \*

Mark only one oval.

- Less than 30  
 30-60  
 Over 60

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Informal Caregiver Questionnaire

13. 3. Where are reminiscence sessions usually held? \*

(Marcar tudo o que for aplicável)

*Tick all that apply.*

Home

Institution (Home, Day Care Center, Hospital, etc)

Other:  \_\_\_\_\_

14. 4. The types of materials you use in the reminiscence sessions are: \*

(Marcar tudo o que for aplicável)

*Tick all that apply.*

Images

Musics

Videos

Texts

Other:  \_\_\_\_\_

15. 5. The materials you use in the reminiscence sessions are: \*

(Check all that apply)

*Tick all that apply.*

Personal (concerns the person with dementia)

Generic (are not directly related to the person with dementia)

16. 6. In addition to the above materials, I would like to be able to use: \*

(Check all that apply)

*Tick all that apply.*

Images

Musics

Videos

Textos

Other:  \_\_\_\_\_

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Informal Caregiver Questionnaire

17. 7. Which of the following materials trigger some kind of positive emotional reaction in the person with dementia? \*

(Check all that apply)

*Tick all that apply.*

- Images  
 Musics  
 Videos  
 Texts  
 None

Other:  \_\_\_\_\_

18. 8. Which of the following materials trigger some kind of negative emotional reaction in the person with dementia? \*

(Check all that apply)

*Tick all that apply.*

- Images  
 Musics  
 Videos  
 Texts  
 None

Other:  \_\_\_\_\_

19. 9. Which of the following topics related to the person with dementia do you seek to have in the material used in the reminiscence sessions? \*

(Check all that apply)

*Tick all that apply.*

- Familiar people  
 Jobs he/she had  
 Pets  
 Places where he/she lived  
 Places where he/she spent  
 Vehicles he/she had

Other:  \_\_\_\_\_

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Informal Caregiver Questionnaire

20. 10. How do you get the material for the reminiscence sessions? \*

(Check all that apply)

*Tick all that apply.*

- Family  
 Friends  
 Person with dementia  
 Search the Internet

Other:  \_\_\_\_\_

21. 11. How often do you update the materials for the sessions? \*

*Mark only one oval.*

- Daily    *Skip to question 23*  
 Weekly    *Skip to question 23*  
 Every two weeks    *Skip to question 23*  
 Monthly    *Skip to question 23*  
 Semiannually    *Skip to question 22*  
 Half-yearly    *Skip to question 22*  
 Never    *Skip to question 22*

#### Reminiscence Sessions

Reminiscence sessions help people with dementia to remember past experiences and promote communication between them and the rest of the world, stimulating their memory.

22. 11.1. Why don't you update the materials for the reminiscence sessions more frequently? \*

(Check all that apply)

*Tick all that apply.*

- Disinterest on the part of the person with dementia  
 Lack of support materials  
 Lack of time  
 Not very useful for the person with dementia

Other:  \_\_\_\_\_

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Informal Caregiver Questionnaire

### Reminiscence Sessions

Reminiscence sessions help people with dementia to remember past experiences and promote communication between them and the rest of the world, stimulating their memory.

23. 12. What information do you keep about the reminiscence sessions? \*

(Check all that apply)

*Tick all that apply.*

- Emotional state of the person with dementia before the therapy session
- Emotional state of the person with dementia after the therapy session
- Length of session
- Material that helped to recall past memories
- Material that induced negative emotional reactions
- Material that induced positive emotional reactions

Other:  \_\_\_\_\_

24. 13. Besides the information you keep, what other information would you like to keep about the reminiscence sessions? \*

(Check all that apply)

*Tick all that apply.*

- Emotional state of the person with dementia before the therapy session
- Emotional state of the person with dementia after the therapy session
- Length of session
- Material that helped to recall past memories
- Material that induced negative emotional reactions
- Material that induced positive emotional reactions

Other:  \_\_\_\_\_

### Follow-up Consultations

11/25/21, 11:54 PM

Informal Caregiver Questionnaire

25. The results of the reminiscence sessions, as well as the health of the person with dementia can be evaluated in follow-up consultations. With this in mind, you are a caregiver performing follow-up appointments? \*

*Mark only one oval.*

- Yes *Skip to question 26*
- No *Skip to question 29*

Follow-up  
Consultations

The results of the reminiscence sessions, as well as the health of the person with dementia can be evaluated in follow-up consultations.

26. 1. How often do you accompany the person(s) with dementia who perform reminiscence therapy? \*

*Mark only one oval.*

- Daily *Skip to question 28*
- Weekly *Skip to question 28*
- Every two weeks *Skip to question 28*
- Monthly *Skip to question 28*
- Half-yearly *Skip to question 27*
- Yearly *Skip to question 27*
- Never *Skip to question 29*

Follow-up  
Consultations

The results of the reminiscence sessions, as well as the health of the person with dementia can be evaluated in follow-up consultations.



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Informal Caregiver Questionnaire

27. 1.1 Why not consult the person(s) with dementia more regularly? \*

(Check all that apply)

*Mark only one oval.*

- Lack of results
- Lack of time
- Not very useful for the person with dementia
- Other: \_\_\_\_\_

Follow-up  
Consultations

The results of the reminiscence sessions, as well as the health of the person with dementia can be evaluated in follow-up consultations.

28. 2. What do you usually observe/analyze to accompany the person(s) with dementia who perform reminiscence therapy? \*

(Check all that apply)

*Tick all that apply.*

- Emotional reactions of the patient with dementia
- Emotional well-being of the patient with dementia
- Length of the sessions held
- Number of sessions held per month/week
- Results from previous sessions (for comparison)
- Other:  \_\_\_\_\_

Other Forms of Follow-up

29. Apart from the reminiscence sessions and follow-up consultations, do you carry out other forms of follow-up? \*

*Mark only one oval.*

- Yes    *Skip to question 30*
- No    *Skip to question 33*

Other Forms of Follow-up

11/25/21, 11:54 PM

Informal Caregiver Questionnaire

30. 1. What other forms of follow-up do you perform with your patients with dementia? \*

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31. 2. Do you use any kind of technology to accompany your patients with dementia? \*

Mark only one oval.

- Yes Skip to question 32
- No Skip to question 33

Other Forms of Follow-up

32. 2.1. Indicate which technology(s) you use? \*

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Technology

Imagine that there is a system in place to register the person(s) with dementia, share your registration(s) with other family members or close persons and insert personal material from the person(s) with dementia. These materials will then be used to conduct the reminiscence sessions. The system will automatically adapt the content of the session based on the patient's biographical information and emotional reactions to the materials presented. All the sessions carried out on the person with dementia will generate results so that it will be possible to follow the evolution of the disease. All these sessions can be consulted in a history of sessions of the patient even if performed by another caregiver.

After reading the system description answer the following questions.

11/25/21, 11:54 PM

Informal Caregiver Questionnaire

33. 1. Regarding the management of patients, please indicate your interest in the following features: \*

*Mark only one oval per row.*

	1 (Not very interesting)	2	3	4	5 (Very interesting)
Allow the creation of reminders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Notify other caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sharing patient care with other caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11/25/21, 11:54 PM

Informal Caregiver Questionnaire

34. 2. Regarding the reminiscence sessions, please indicate your interest in the following features: \*

*Mark only one oval per row.*

	1 (Not very interesting)	2	3	4	5 (Very interesting)
Automatic adaptation of the session content based on the biographical information of the patient with dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Automatic adaptation of the content of the session based on the emotional reactions of the patient with dementia to the materials presented	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Consult the materials used in each therapy session	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History of caregiver sessions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History of the patient's sessions where all their sessions will be available, even if performed by other caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11/25/21, 11:54 PM

Informal Caregiver Questionnaire

35. 3. Regarding the material used in the therapy sessions, please indicate your interest in the following functionalities: \*

Mark only one oval per row.

	1 (Not very interesting)	2	3	4	5 (Very interesting)
Insert new material	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insert new material topics in addition to those mentioned above	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Existence of a favorites section in each patient's material	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

36. 4. Our system aims to help the user in the best possible way. To do so, we intend to provide explanation and help for the realization of the various features of the system. Please tell us how often you use or can use the following help tools when there are doubts about some functionality. \*

Mark only one oval per row.

	1 (Not very interesting)	2	3	4	5 (Very interesting)
Email / Telephone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Help within the application	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Instruction manual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

37. 5. Our system will ensure the highest privacy and security for our users. Please let us know how comfortable you would be introducing personal content to our system. \*

Mark only one oval.

	1	2	3	4	5
Not much <input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Quite a lot <input type="radio"/>

11/25/21, 11:54 PM

Informal Caregiver Questionnaire

Suggestions

38. If you have any idea of important features for the performance and management of reminiscence therapy and/or management of your patients, we appreciate your suggestion. If you have no suggestions you can finish and submit the questionnaire.

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Google Forms

# Appendix E

## Informed Consent Form

11/26/21, 12:19 AM Formulário Consentimento Informado

### Formulário Consentimento Informado

PROJECTO: RT-Portal: Portal Web para o cuidador de terapia de reminiscência  
INVESTIGADOR RESPONSÁVEL: André Filipe Matos Santana

Desde já agradecemos o seu interesse e colaboração neste estudo. Ao assinar este formulário confirma que:

- Foi informada(o) do estudo em questão e lhe foi disponibilizado o folheto informativo.
- Foi-lhe dada a oportunidade de esclarecer qualquer dúvida em relação a este estudo, e que estas foram respondidas de forma satisfatória.
- A sua participação é voluntária, logo é livre de desistir do estudo em qualquer altura, sem ter de dar quaisquer explicações e sem quais quer consequências.
- Autoriza que os dados recolhidos durante o estudo sejam partilhados com os restantes membros responsáveis pelo estudo. Se a investigação for publicada, todos os dados serão mantidos anónimos e nenhuma informação será identificável como sendo sua.
- Declara que não comunicou nenhuma razão potencial de qualquer natureza que constitua um eventual fator de risco para a sua saúde ou integridade física.
- Declara que participa neste estudo sem qualquer remuneração ou contrapartida.
- Declara que aceitou que as suas entrevistas sejam gravadas em áudio e vídeo ou captura de ecrã, excluindo a cara.
- Declara que toma a sua decisão de forma inteiramente livre.
- Concorda participar neste estudo.

Assinatura do investigador responsável:  
André Filipe Matos Santana 14/07/2021

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**\*Obrigatório**

1. Assinatura do participante \*

\_\_\_\_\_

2. Insira o seu email caso queira que lhe seja enviado o relatório final do estudo.

\_\_\_\_\_

<https://docs.google.com/forms/d/127KB7yawOV5T90Ce2U7-r0VObR7ZurT-Nd977TorGwE/edit> 1/2

11/26/21, 12:19 AM

Formulário Consentimento Informado

3. Insira o seu email caso queira ser contactada(o) acerca de sessões ou estudos adicionais relacionados com este estudo.

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Google Formulários



# Appendix F

## Interviews Script

1. Filling the Informed Consent Form.
2. Ask permission to record. After permission start recording.
3. Caregiver Characterisation:
  - Age?
  - Cares for how many people with dementia?
  - What is the relationship with this person(s) (relative, friend, etc.)?
  - Does he/she Currently conduct reminiscence therapy with the person(s)?
  - If not, do he/she know what it is? Has he/she ever done it?
  - If yes, how long are these sessions?
  - **IF FORMAL CAREGIVER:** Do you hold group reminiscence sessions? What is its importance for the person with dementia?
  - Does he/she use new technologies? Which ones does he/she use most?
4. If he/she does Reminiscence therapy:
  - What materials does he/she uses?
  - Does he/she has help in choosing materials?
  - Are the materials he/she uses personal (does it relate to the person with dementia, something they have lived through, own, know or experienced), generic (does it help improve the mood of the person with dementia but is it nothing that relates to them) or both?
  - If both, is there a difference between the emotional reaction shown by personal and generic material?
  - In the event of a more negative reaction from the person with dementia, how does he/she proceed?
  - Does he/she usually update the material you use in therapy
  - If not, why not update?
  - What is his/her opinion about updating therapy material more often?

- Does he/she records the patient's emotions throughout the therapy?
  - If yes, how does he/she record them?
5. Explain application (in this part the user can stop if he/she has any comments or does not understand the purpose of the functionality)
- The main objective is to have a platform to store all the information to perform the therapy, to store the information of all the therapies performed and also to perform the therapy.
  - The application will have automatic mechanisms to generate and manage the therapy sessions, so that they adapt to the reactions of the person with dementia and are different from each other.
  - In this application the user is the caregiver and can add all the people with dementia they care for to the platform and manage their information as well as their caregivers, being able to share a person's care with other caregivers.
  - In the person's information you can insert images that will be used in therapy. If you are a formal caregiver you can add images to be used in the therapies of all people with dementia at your responsibility.
  - It is also possible in this application to send messages to other caregivers so that you can have quick and necessary conversations about a person with dementia (you can inform them of something that has happened or a therapy that you have not carried out with a person).
  - The application will also have a help section that will serve as an instruction manual, but there will also be tips throughout the application.
6. Application testing (through descriptive testing the user will describe/comment their experience while using the application):
- **REGISTER:** Imagine that it is the first time you access the platform in a real scenario and that you create an account on the application.
  - **ADD PERSON WITH DEMENTIA:** Now that you are logged in, imagine that you want to add one of the people with dementia at your responsibility to the platform (NIF=504079050).
  - **SHARE CARE:** now imagine you have another caregiver involved in that person's care and you want to share the person's care with him/her (andre@gmail.com).
  - **ADD OBSERVATION:** imagine that during therapy you observed an important signalling reaction and you want to record it in the person's observations in order to inform other caregivers and note that it happened.
  - **ADD IMAGE:** you now have an image that you want to use in the person's therapy and you want to add it to the platform.
  - **SEARCH IMAGE:** now you need images about x and want to filter them by that category.
  - **SEND MESSAGE:** now you intend to talk to the person's caregivers and send a message saying that you cannot do the next therapy.

7. In the session history when clicking on a session the following information about the session will appear:

- feedback given by the caregiver who carried out the session;
- images used and the respective emotional reaction of the patient to each of these;
- session date;
- duration.

Do you know of any other data that might be important to show in the summary of a reminiscence session?

8. After testing the application:

- How comfortable are you with inserting personal images of yourself or the person with dementia on the platform?
- Would you like to be able to insert more image categories than those shown?
- Would you like to allow people not registered on the platform, such as family and friends, to insert images for the person with dementia via a secure link? These images would then be confirmed by the primary caregiver.
- When conducting therapy sessions would you like to have the option not to use any other device (such as emotion detection bracelet or camera) and enter the person with dementia's emotions throughout the session manually?
- What is your opinion regarding the usefulness of being able to chat with other caregivers in real time within the application?



# Appendix G

## Interviews Affinity Map

- Technical Problems
  - Zoom’s cameras stay in front of the prototype
  - It is not possible to test all the functionality of inserting images with the Zoom remote control (choose folder/file)
- Characterisation
  - Ages of interviewees (35-F,53-I,60-I)
  - Use of new technologies
    - \* Difficulty with laptop touchpad
    - \* Skype
    - \* Zoom
    - \* Mobile phone
    - \* Computer (when larger screen is necessary )
    - \* Cogweb
  - Informal caregivers usually only look after one person
  - Formal caregiver cares for several people with dementia (more than 8)
- People with Dementia
  - There are fewer and fewer emotions
  - Do not easily adopt new technologies (the older ones)
  - Not all seek to isolate themselves
  - Pulling up when the person is feeling down
  - Confused feelings of jealousy
  - Complicated reactions
    - \* Not challenge ideas and divert the subject when the person is too fixated on a particular issue
    - \* Deal through speech and explanation

- \* Many of them only happen once because the person forgets
- \* Create a differentiated environment
- Follow up of People with Dementia
  - Resort to Dementia Support Centres
  - Cognitive stimulation
  - Physiotherapy
  - Games
  - Hippotherapy
  - Promoting the accomplishment of as many tasks as possible in daily life, slows down the process and encourages the person with dementia to maintain his/her autonomy
  - Follow all suggestions of the person with dementia to carry out tasks that promote his/her well-being and autonomy
  - Informal caregiver has many uncertainties during follow up
  - Informal caregiver shows an increase in despair and fatigue over time
- Reminiscence Therapy
  - Some informal caregivers carry out therapy intuitively (do not know they are doing it)
  - Formal caregiver carries out therapy on average 2 to 3x per week
  - Duration - 30mins-1h
  - There is a preference for the use of personal material
  - Formal caregiver prepares the session in advance with his/her chosen material
  - Generic material is used when there is a lack of personal material
  - Generic material has to be filtered
  - The group therapy sessions held are between 2 to 4 people (5 exceptionally)
  - Formal caregiver records emotions on a Word sheet he/she has for each person. On this sheet he/she records the therapy sessions as well as cognitive performance. The emotional part is also always mentioned.
  - Informal caregiver does not register emotions (never thought about it)
  - Material update
    - \* Depends on the experience and knowledge of the caregiver
    - \* Family members provide the new materials
    - \* Doing other different things (activities)
    - \* It depends on the person and the stage of disease
      - Update material can confuse a person when in a state of major forgetfulness
      - They use older photos in a greater state of forgetfulness

- \* Formal caregiver sometimes does not receive new material from family members
- Music is referenced for therapies
- Application
  - The aim is to help deliver therapy at home/day centres/nursing homes
    - \* Reference to Cogweb when that is explained
    - \* Instruct others to carry out therapy
  - They have no problems entering personal information into the application
    - \* Believes that other people will not have problems either
    - \* Since there is consent when the material is from third parties
  - Session algorithm not well accepted by formal caregiver
    - \* Highlighting that it is a complement, helped to be accepted.
    - \* Idea of removing images with negative reactions accepted
    - \* A certain knowledge is required to manage the sessions (a bit against)
    - \* Therapy not being repetitive is well accepted
  - Problems with the term of reference for people with dementia
    - \* "Loved one" is not suitable for informal caregiver.
    - \* Suggested "Cared person" for informal caregiver.
    - \* "Patient" is not a good term
    - \* "Client" is also used in the formal context but in this case it is meaningless.
    - \* Formal caregivers use "Beneficiary"
    - \* Formal caregiver suggests 'Relative' for informal caregivers.
  - Idea very well accepted overall
  - User hesitates, so he/she does not make a mistake
  - The user explores the platform well
  - Overall intuitive
  - Idea of using biographical information to fetch material accepted
  - Idea of unique identifier for the caregiver being the email accepted
  - Caregivers like to be able to edit anything they are allowed to
  - It does not have any sensitive information
  - Secure link for adding images by unregistered caregivers
    - \* Idea very well received
    - \* The main caregiver should filter the inserted images through this link
    - \* Formal caregiver wants very much this feature
- Design

- Enter birth date
  - \* Calendar does not work very well
  - \* It is not intuitive and people prefer to write
  - \* New idea of birth date very intuitive (allow writing)
- Misunderstanding of the paging buttons
- Person's "Edit Info" button is perceptible
- Indication of important mandatory fields
- "Name to show" and "Nickname" in the same place is confusing
- Scrolling problems (to be avoided as much as possible)
- More spacing between the various components of a page
- List of caregivers of a person with dementia very well accepted
  - \* "Treatment role" could be relevant here
  - \* "Relation with person" could have a lot of relevance here
  - \* There is nothing more to add
- "More Details" button is not intuitive
  - \* "View Profile" instead of "More Details"
  - \* To avoid repetition, replace "Profile" of the caregiver with his/her first name.
- Less browsing and clicking as possible
- Suitable font but should not be smaller than 14pt
- Caregiver's Profile
  - Add mobile phone to caregiver profile
  - "Treatment role" not well understood
    - \* There is no need
    - \* It should be different among the various professionals (formal caregivers)
    - \* For the informal caregiver it does not make any sense.
- Person with dementia's profile
  - Add schooling to the patient profile
  - NIF as unique identifier of the person with dementia
    - \* Ideal because normally these people do not have email
    - \* The NIF is different in every country and always has another name
    - \* No problem of putting the NIF in the application
- Share Care
  - It is assumed that they know the email address of the other caregiver for sharing



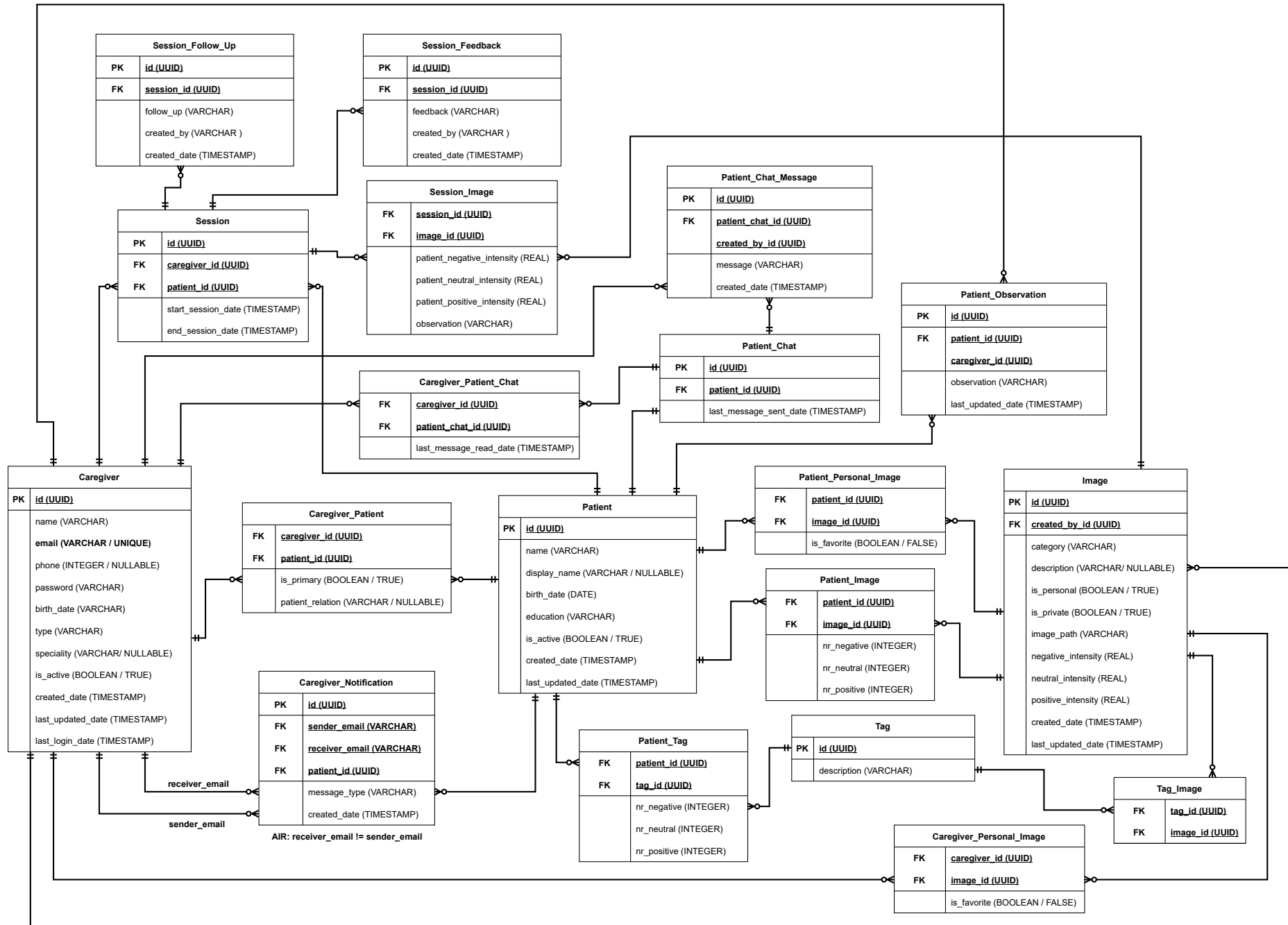
- Stop caring associated with a more tragic outcome rather than transfer of care
- Instead of "Primary Caregiver" use "Reference Caregiver"
- "Primary Caregiver" might be a good term for informal caregivers
- Importance of caregivers accepting the request
- It is relevant that other caregivers can post content and edit their own content
- Care sharing can and should be between both types of caregiver (formal and informal)
- The person's page only disappears if there is no caregiver
- Very intuitive
- People with Dementia List
  - It is too small for formal caregivers
  - There is too much information
  - Only the "Name" and "Last Session" is required in this part
  - Present list as if it were a table
- Observations
  - Similar to the notes in the person's chart
  - Registers will help follow up the evolution and those who do not make registers miss it
  - Only one text field is enough
  - Have used the search bar for "Add Observation" instead of button
  - Idea very well accepted
  - Very intuitive
- Messages
  - First version not easy to use
    - \* "Requests" and "Messages" in the same place is confusing
    - \* It should be easier to create a new message
    - \* There should be a button saying "New Message"
    - \* "Requests" can appear on the caregiver's profile
  - Chat idea accepted
  - New version easy to use and idea understood
  - Useful and very good
- Feedback during sessions
  - The first idea for the session screen will have the image and buttons to move forward and maybe also buttons to react

- Emotional reaction by image
- Emotional detectors are welcome to adapt therapy
- Show image details/observations
  - \* It promotes more connection through detail
  - \* Difficulty for professionals to provide such detail
  - \* Formal caregiver does not like the idea as it is not helpful to the flow of the session
- It is difficult to take notes during sessions
- One should not break the flow of the session as the person doing the therapy would not feel the commitment of the caregiver
- The caregiver is the best to dictate a reaction
- Sessions Performed
  - Informal caregiver does not take many notes
  - Caregiver important feedback/notes about a session
  - Being able to say which way to go in the next sessions
  - Be able to edit/analyze therapy data later
  - Importance of the reaction to each image
  - Highlight when an image shows more and more reactions/remembrances
    - \* If it is made from notes it should be requested at another time than during the session
    - \* Depending on experience the caregiver may be able to remember the most important things some time after the session
    - \* Which images appeared should be presented
    - \* Do afterwards, at the end of sessions showing each image that appeared to the caregiver
    - \* Through reaction button + note.
  - Adding a mood chart might be a good idea
  - Notes on positivity or negativity of the session
- Bugs
  - "Enter" makes submission and jumps a few steps
  - "Continue" is not immediately available when valid data is available.

## **Appendix H**

# **Database Entity Relationship Diagram**

Diagram in next page.



# Appendix I

## Experimental Evaluation Script

### I.1 Individual Sessions

1. Filling the Informed Consent Form.
2. Ask permission to record. After permission start recording.
3. Explain application (in this part the user can stop if he/she has any comments or does not understand the purpose of the functionality)
  - The main objective is to have a platform to store all the information to perform the therapy, to store the information of all the therapies performed and also to perform the therapy.
  - The application will have automatic mechanisms to generate and manage the therapy sessions, so that they adapt to the reactions of the person with dementia and are different from each other.
  - In this application the user is the caregiver and can add all the people with dementia they care for to the platform and manage their information as well as their caregivers, being able to share a person's care with other caregivers.
  - In the person's information you can insert images that will be used in therapy. If you are a formal caregiver you can add images to be used in the therapies of all people with dementia at your responsibility.
  - It is also possible in this application to send messages to other caregivers so that you can have quick and necessary conversations about a person with dementia (you can inform them of something that has happened or a therapy that you have not carried out with a person).
  - The application will also have a help section that will serve as an instruction manual, but there will also be tips throughout the application.
4. Testing the application (using the think aloud technique where the user will describe/comment their experience while using the application):
  - **Before starting tell the caregiver that they can click on everything so that we understand how they would interact with the application in a real life scenario.**
  - **REGISTER:** You will start using this new platform. To use it you have to register.

- **ADD PERSON WITH DEMENTIA:** You are currently taking care of one of your family members/beneficiaries who is doing reminiscence therapy. Login to the platform (if you have not already done so) and add that family member/beneficiary to the platform.
  - **SHARE CARE:** In addition to you, someone else is caring for your family member/beneficiary. Give this person access (andre@gmail.com) so that he/she too can help with that person's care.
  - **SEND MESSAGE:** Once the other caregiver has accepted the request, send him/her a message asking if he/she can do a therapy session next week as you will be away.
  - **ADD OBSERVATION:** During the day you noticed that your relative/beneficiary was in a very good mood and chatty. Make a note/observation about his/her mood.
  - **ADD PERSON WITH DEMENTIA IMAGES:** The pool of photos of your family member/beneficiary that are available to use in therapy is very small, so you decide to add some photos you have in a folder.
  - **ADD CAREGIVER IMAGES:** The other day you found a set of interesting photos to use in therapy. Add these pictures so that you can use them with the various family members/beneficiaries you care for.
  - **LEAVE PERSON'S CARE:** Next week you will emigrate, and can no longer care for your relative/beneficiary. Stop being a caregiver of this relative/beneficiary and pass the primary care to the other caregiver (Andre Santana).
  - **HELP:** After using the application, you were curious about the features available, so you decided to consult the help.
5. Ask the caregiver to fill in the application evaluation form: SUS <https://measuringu.com/sus/> + TAM (6 answers about usefulness) <https://measuringu.com/usefulness/>

## I.2 Focus Groups

1. Filling the Informed Consent Form.
2. Ask permission to record. After permission start recording.
3. Explain application very briefly:
  - **OBJECTIVE:** The main objective of this application is to support reminiscence activities.
  - **CAREGIVER IS THE USER:** The caregiver will be the main user of the application.
  - **MANAGE BENEFICIARIES:** Allows you to add beneficiaries to the application to create a page for each of them, where you can manage their data.
  - **MANAGE BENEFICIARIES' CAREGIVERS:** On these pages you will be able to manage that person's caregivers and share care as well as all the information entered about the person with dementia
  - **REMINISCENCE ACTIVITY:** In the future it will be possible to carry out reminiscence activities considering the data entered for each person with dementia.

4. Before showing application:

- **Before starting tell the caregiver that we will be taking comment breaks where they can say whatever they like about each part of the application.**
- **I SHOULD ALWAYS COMMENT THE PROCESS.**
- **Take breaks during each scenario.**
- **Create the informal caregiver Soraia before the session.**

5. Show application:

- **CREATE ACCOUNT:** Let us imagine that I am a formal caregiver and I want to start using the platform. For this I will start by creating an account.
- **CAREGIVER HOME:** We are now on our home page where you can add beneficiaries to the application.
- **PROFILE (POINTER):** In addition, in the top menu you can access your profile, which we will explain later.
- **NOTIFICATIONS:** The notifications where you will be able to consult all requests related to the people you care for.
- **HELP:** And the help that will work as a manual of instructions divided into sections. You will also have an email address available in case you need it.
- **ADD BENEFICIARY:** Now let us imagine that we want to add one of the people we care for to the platform. To do so, go back to the main page and add the beneficiary.
- **BENEFICIARY'S PAGE:** After finishing the process, the beneficiary's page will then appear where you can consult your main information and associated caregivers, as well as start the reminiscence activities.
- **PRINCIPAL CAREGIVER:** Since we were the caregiver who added this person to the application we will be the principal caregiver of this person, i.e. like an administrator. We are the only ones who can edit all the information entered on this page, even if it is not by us, and manage the caregivers.
- **SHARE CARE:** Let us imagine that we would like a relative of this person to participate in their care. To do this, we will share the care with another caregiver. That caregiver will need to be registered in the application, as we will use their email address to do this sharing which should be associated to their account.
- **CHANGE ACCOUNT AND ACCEPT:** Now let us imagine that Soraia goes into the application to accept the request we sent. When she logs into her account she immediately sees the main page and notices that there is a new notification. She clicks on it and then has our sharing request, which she will accept. On acceptance the person's page will then appear, however she can only perform the reminiscence activities as she is a secondary caregiver. She can only edit the information that she entered for that person, and she can see all his/hers information.

- **CHANGE ACCOUNT AND SHOW DIFFERENCE:** Back to our account we can see that Soraia already appears among the caregivers and that we can remove her and consult her profile. (Besides that, since there is already another caregiver taking care of this person we can already transfer the principal care). We can now consult Soraia's profile where we can see her information as well as her phone number, in case we need to contact her in an emergency.
  - **MESSAGES:** However, if it is not urgent you can use beneficiary's messages to talk to all the caregiver associated to him/her.
  - **SEND MESSAGE BETWEEN ACCOUNTS:** Exemplify the messages with the 2 accounts and ask if they think this method is enough or if they would also like to be able to send messages individually or in groups.
  - **OBSERVATIONS:** Exemplify observations process. Add 2 in each of the accounts and use search bar.
  - **SESSIONS HELD:** Explain the purpose but do not put too much emphasis on it as it is not developed.
  - **IMAGES:** Here we will be able to add the images to be used in the reminiscence activities with this beneficiary in order to have more personal images.
  - **ADD IMAGE PROCESS:** Explain the whole process and terms.
  - **ADD FOLDER:** To add more images and show the filters.
  - **CAREGIVER'S PROFILE:** Quick overview of what is in the caregiver's profile.
  - **CAREGIVER SESSIONS:** Explain difference between these and those of the beneficiary.
  - **CAREGIVER IMAGES:** Explain difference between these and those of the beneficiary.
  - **END SESSION:** End caregiver session and ask for final notes.
6. Ask the caregivers to fill in the application evaluation form: SUS <https://measuringu.com/sus/> + TAM (6 answers about usefulness) <https://measuringu.com/usefulness/>



# Appendix J

## Experimental Evaluation Form

11/26/21, 12:28 AM Avaliação Experimental da Aplicação KeepsakeBox

### Avaliação Experimental da Aplicação KeepsakeBox

Após ter experimentado a aplicação KeepsakeBox, pedimos-lhe agora mais 5 minutos no máximo para preencher o seguinte formulário. Daqui para a frente iremos referir-nos à aplicação como o produto desenvolvido e o objetivo deste formulário é perceber se este produto é fácil de utilizar e útil para dar suporte à realização da terapia de reminiscência. Desta forma iremos perceber a opinião das pessoas que experimentaram o produto e assim poderemos tirar conclusões e fazer as melhorias necessárias.

Mais uma vez agradecemos imenso a sua disponibilidade!

**\*Obrigatório**

**Questionário de Usabilidade**

Nesta secção pretendemos avaliar se o produto desenvolvido é acessível e de fácil utilização. Para isso, responda às seguintes perguntas mediante a escala apresentada.

1. Acho que gostaria de utilizar este produto com frequência. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

2. Considerei o produto mais complexo do que necessário. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

[https://docs.google.com/forms/d/1Miko6KgB\\_yWXXVYXY5doPviWsy3aT1YeMj3lvENpTYE/edit](https://docs.google.com/forms/d/1Miko6KgB_yWXXVYXY5doPviWsy3aT1YeMj3lvENpTYE/edit) 1/5

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Avaliação Experimental da Aplicação KeepsakeBox

3. Achei o produto fácil de usar. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

4. Acho que necessitaria de ajuda de um técnico para conseguir utilizar este produto. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

5. Considerei que as várias funcionalidades deste produto estavam bem integradas.

\*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

6. Achei que este produto tinha muitas inconsistências. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

11/26/21, 12:28 AM

Avaliação Experimental da Aplicação KeepsakeBox

7. Suponho que a maioria das pessoas aprenderia a utilizar rapidamente este produto. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

8. Considerei o produto muito complicado de utilizar. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

9. Senti-me muito confiante a utilizar este produto. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

10. Tive que aprender muito antes de conseguir lidar com este produto. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	
Discordo Totalmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Concordo Totalmente

### Questionário de Utilidade

Nesta secção pretendemos avaliar se o produto desenvolvido é útil para dar suporte à terapia de reminiscência. Para isso, responda às seguintes perguntas mediante a escala apresentada.

11/26/21, 12:28 AM

Avaliação Experimental da Aplicação KeepsakeBox

11. A utilização deste produto na realização da terapia de reminiscência permitir-me-ia realizar tarefas mais rapidamente. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	6	7	
Provavelmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Improvável

12. A utilização deste produto melhoraria o meu desempenho na realização da terapia de reminiscência. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	6	7	
Provavelmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Improvável

13. A utilização deste produto na realização da terapia de reminiscência iria aumentar a minha produtividade. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	6	7	
Provavelmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Improvável

14. A utilização deste produto iria aumentar a minha eficácia ao realizar a terapia de reminiscência. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	6	7	
Provavelmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Improvável

11/26/21, 12:28 AM

Avaliação Experimental da Aplicação KeepsakeBox

15. A utilização deste produto facilitaria o meu trabalho na realização de terapia de reminiscência. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	6	7	
Provavelmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Improvável

16. Eu acharia este produto útil para a realização da terapia de reminiscência. \*

*Marcar apenas uma oval.*

	1	2	3	4	5	6	7	
Provavelmente	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Improvável

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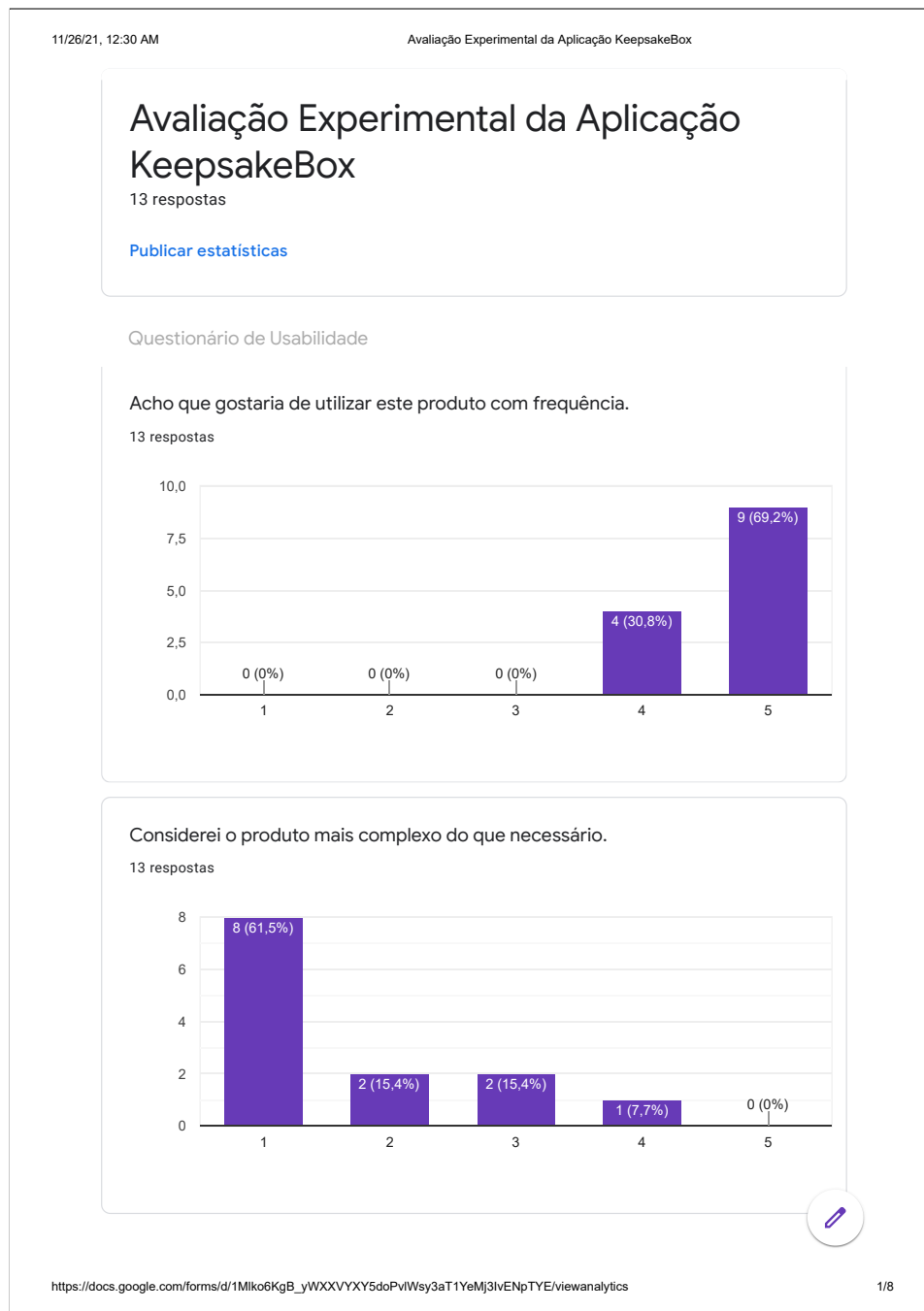
Este conteúdo não foi criado nem aprovado pela Google.

Google Formulários



# Appendix K

## Experimental Evaluation Form Results

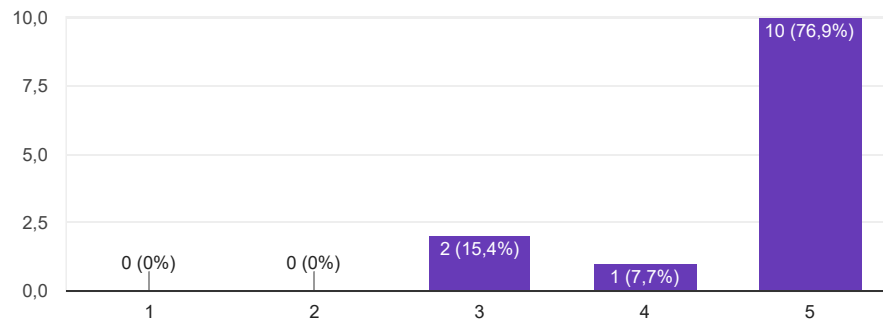


11/26/21, 12:30 AM

Avaliação Experimental da Aplicação KeepsakeBox

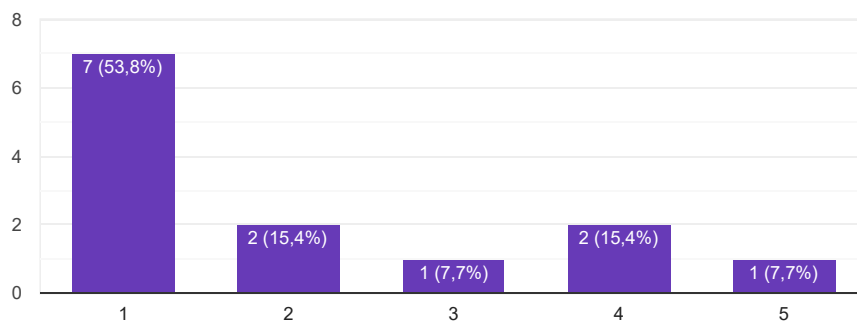
Achei o produto fácil de usar.

13 respostas



Acho que necessitaria de ajuda de um técnico para conseguir utilizar este produto.

13 respostas



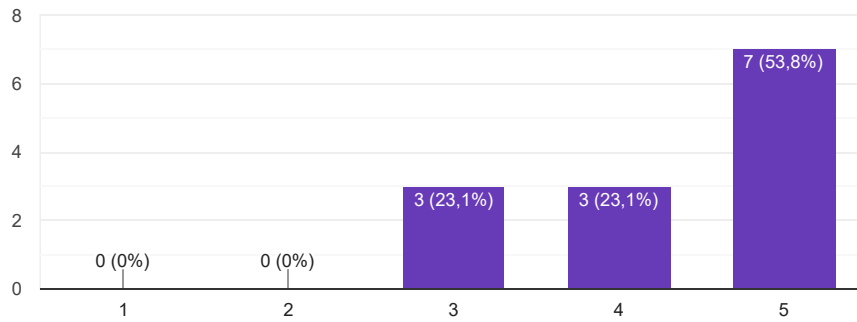


11/26/21, 12:30 AM

Avaliação Experimental da Aplicação KeepsakeBox

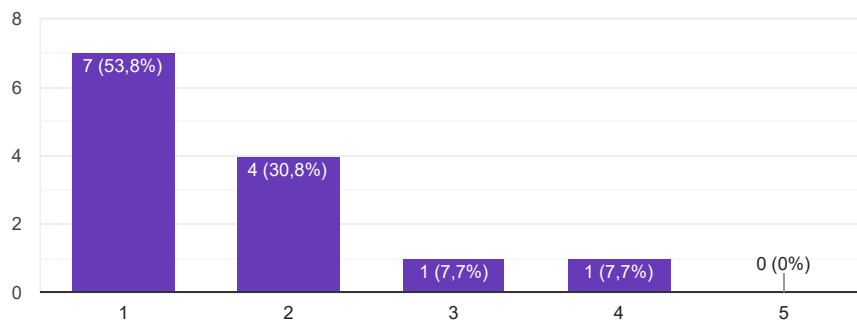
Considerarei que as várias funcionalidades deste produto estavam bem integradas.

13 respostas



Achei que este produto tinha muitas inconsistências.

13 respostas

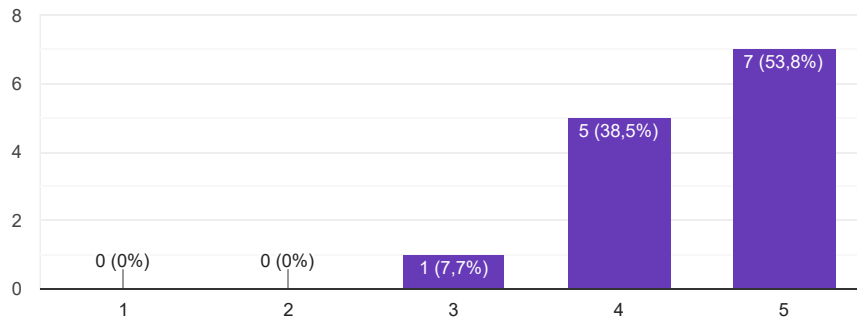


11/26/21, 12:30 AM

Avaliação Experimental da Aplicação KeepsakeBox

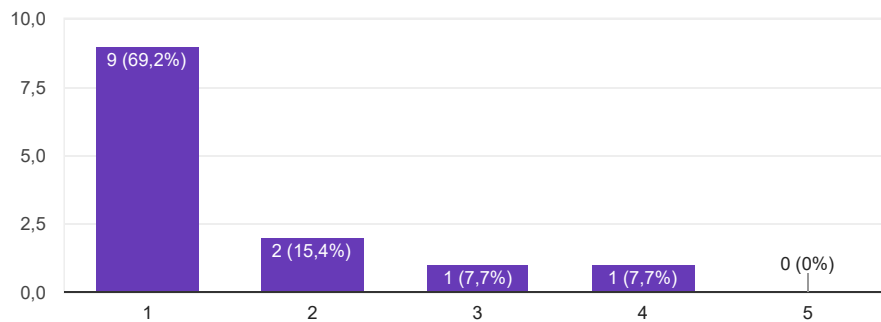
Suponho que a maioria das pessoas aprenderia a utilizar rapidamente este produto.

13 respostas



Considereei o produto muito complicado de utilizar.

13 respostas

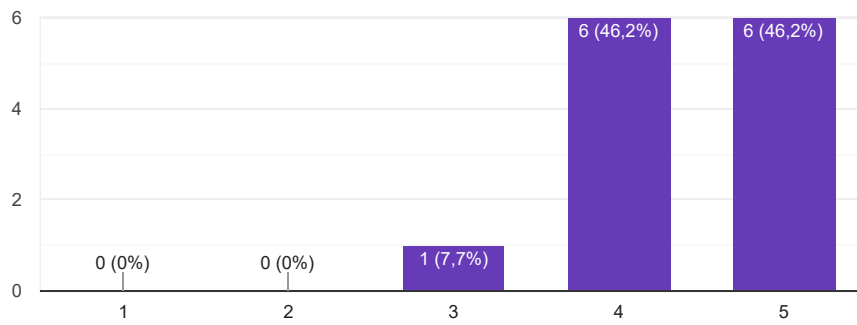


11/26/21, 12:30 AM

Avaliação Experimental da Aplicação KeepsakeBox

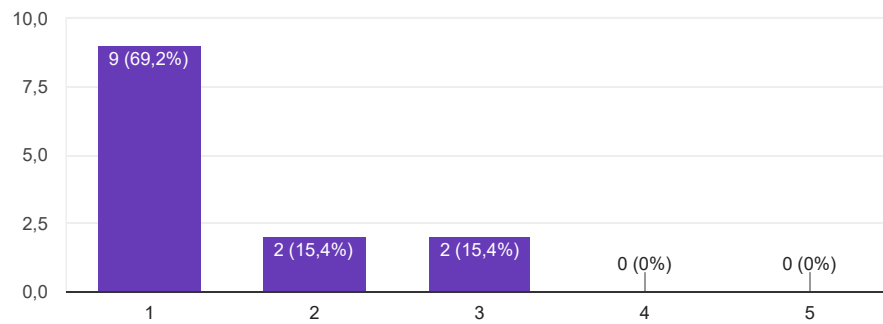
Senti-me muito confiante a utilizar este produto.

13 respostas



Tive que aprender muito antes de conseguir lidar com este produto.

13 respostas



Questionário de Utilidade

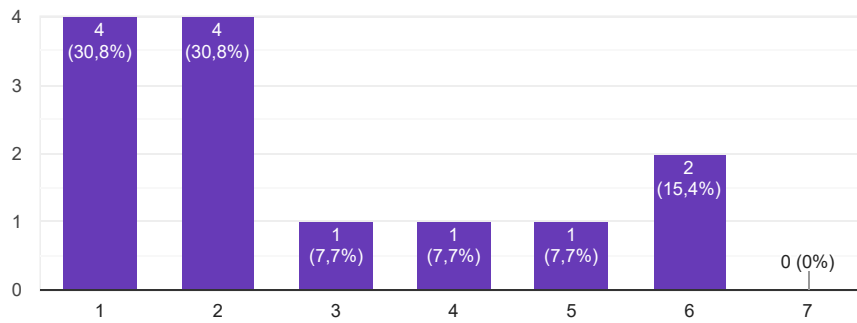


11/26/21, 12:30 AM

Avaliação Experimental da Aplicação KeepsakeBox

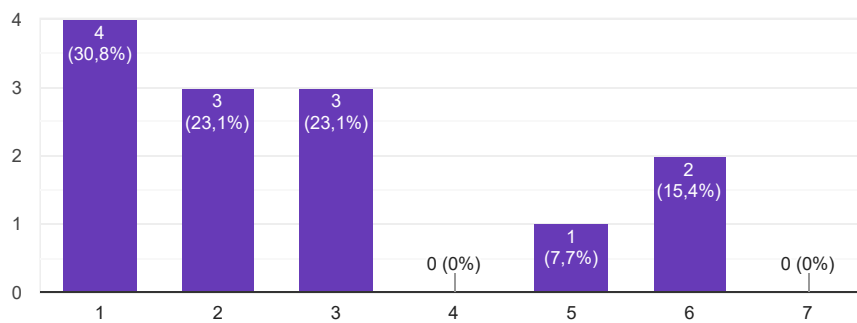
A utilização deste produto na realização da terapia de reminiscência permitir-me-ia realizar tarefas mais rapidamente.

13 respostas



A utilização deste produto melhoraria o meu desempenho na realização da terapia de reminiscência.

13 respostas

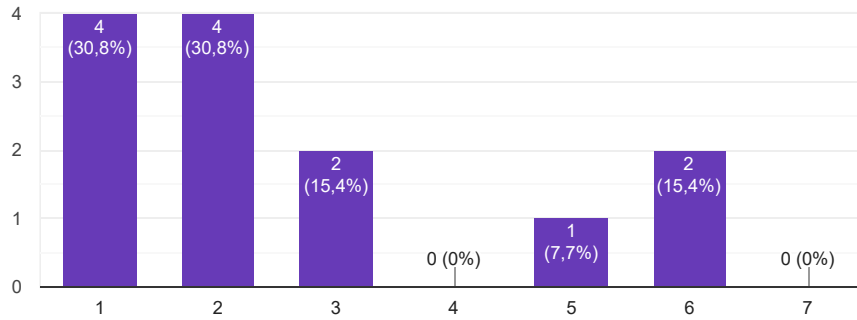


11/26/21, 12:30 AM

Avaliação Experimental da Aplicação KeepsakeBox

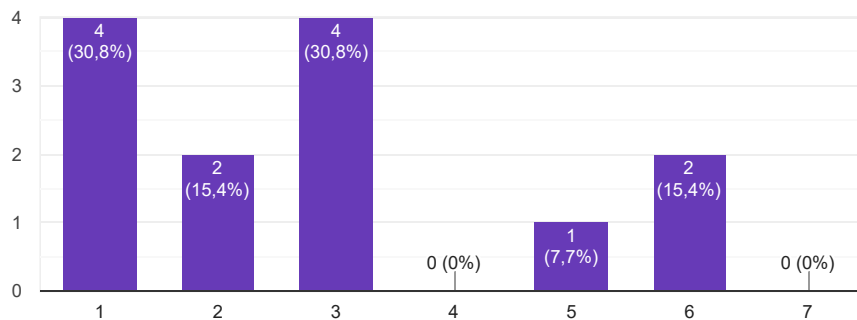
A utilização deste produto na realização da terapia de reminiscência iria aumentar a minha produtividade.

13 respostas



A utilização deste produto iria aumentar a minha eficácia ao realizar a terapia de reminiscência.

13 respostas

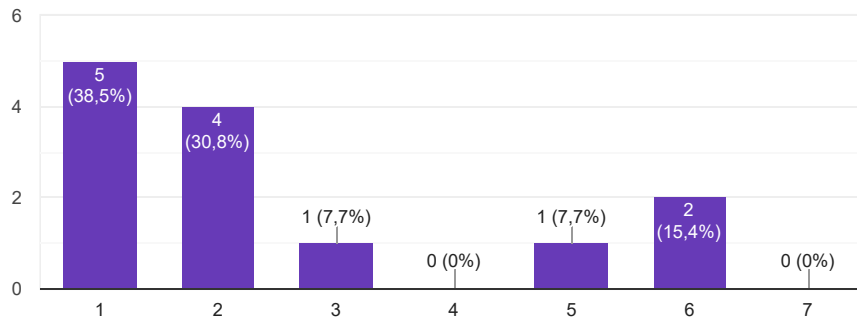


11/26/21, 12:30 AM

Avaliação Experimental da Aplicação KeepsakeBox

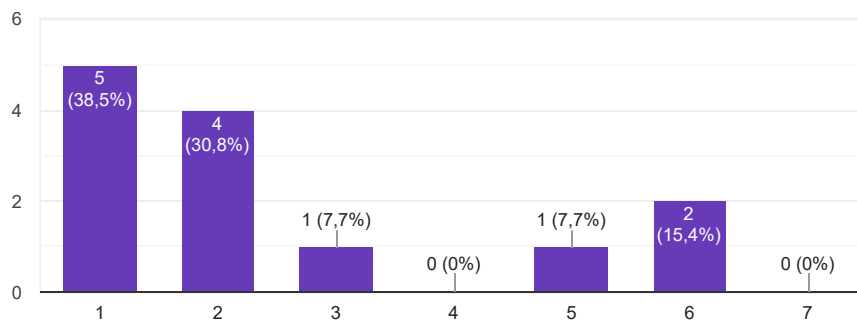
A utilização deste produto facilitaria o meu trabalho na realização de terapia de reminiscência.

13 respostas



Eu acharia este produto útil para a realização da terapia de reminiscência.

13 respostas



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