D2.2 User requirements report

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Use of version numbers (DELETE BEFORE RELEASING):
- v0.1, 0.2, etc.: Status =concept for internal review (to be sent to reviewing partner)
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Acronyms

Term	Explanation
TAM	Technology Acceptance Model
UTUAT	Unified Theory of Use and Acceptance of Technology

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Summary

In this document we describe the outcomes of those activities in Workpackage 2 in which we involved the target groups. By means of qualitative interviews with both older persons with dementia, their informal caregivers, (grand)children and professional caregivers in the Netherlands and Austria we aimed to explore the preferences and wishes of our target groups with regards to the use of technology, the maintenance of important close relationships, keeping engaged in society and recalling and sharing memories.

The interviews show that most of the persons with dementia do use a certain type of technology. This use of technology is often related to engagement in important passions, hobbies or society in general; to keep feeling connected to important others or to replace activities that were previously (before decline occurred) done before.

When we asked whether people like it to recall and share memories, persons with dementia responded very differently. Some of them mentioned that they liked this, but most of them told us that 'the past is over' and therefore should not been recalled again. The ones around them, however, told that they talk about the past with the persons with dementia by watching (personal or general) photobooks or video-material or by – for instance – visiting a historical museum. These activities, however, mainly are initiated by the persons around the one with dementia.

We used two books (one with pictures from the fifties, one like a diary of the past to be filled in by the user) and an existing app with photos from the past to ask the respondents whether they would use these to recall memories. Although many of the respondents initially indicated they didn't like to talk about the past, especially the book with pictures did recall a lot of memories and triggered interesting conversations about the past - both with the persons with dementia, their relatives and professional caregivers.

In this user requirement study we learned:
- When we develop a digital tool for persons with dementia – we should develop this in a way that fits well in the lives of this target group. For instance by including elements related to their hobbies/passions; by letting the tool facilitate personal contact with important others or facilitating activities that are difficult offline.
- Although older people with dementia say they do not like to talk about the past, they kept sharing stories about their earlier years once they were triggered with the right materials. This might be caused by the fact that the perception of time for these people has changed. A recommendation would be not to emphasize the part of recalling memories, but rather introduce a tool like this as a conversation starter/facilitator.
- (Grand)children turned out to be very important for the persons with dementia. This could be integrated in a tool like MI-Tale in different ways. First the tool can include or facilitate to add pictures from important persons as a trigger to use the tool. Second the person with dementia can use the tool together with relatives from younger generations. The interviews namely also showed that the caregiving persons (both formal and informal) are often more sceptical about the technology use of the people with dementia, while the younger relatives are more positive and optimistic with regards to the abilities of their (grand)parent.

1 Introduction

1.1 Background

The personal history of dementia patients is a valuable source of information for a personalized care approach. The values they have formed in their early adult years are especially important for dementia patients, as they often resurface as guiding values in their current behaviour. Understanding these values and the memories of the experiences that shaped them, are the basis of dementia care according to a growing number of dementia care systems. Mapping these memories is important to develop a personalized care approach. However, it is also a challenge because the process is time consuming and complicated.

The fading of memories of their personal history is difficult not only for those who need to work professionally with dementia patients. Also the informal caregivers, partners, children and friends find it increasingly difficult to communicate in a meaningful way with their loved one when memories start to fade.

Turning the mapping of memories into an interactive device; most likely an app based activity - which is the main goal of the MI-Tale project - has many advantages. It is a good way to access emotional, personal experiences, copings and values, other than memories from an average photo album. It may help both the elderly people with dementia and the social network around them to spend time together in a meaningful and pleasant way. In day-care or residential care, such an activity might be a also be an interesting way to have a group session with elderly who have lived in a similar time period or region and who can share emotional memories. This provides an 'at-home' feeling and self-esteem

However, although there are indicators (derived both from theory and practice), that recalling and sharing memories together may have several benefits for different involved actors and technology may play a relevant role in facilitating this process, we do not exactly know the preferences of the involved actors yet with regards to sharing memories (topics, with whom, under which conditions etc.), the use of technology (frequency of technology use, use of devices, purposes for technology use, facilitators and barriers etc.) and the potential of technology to get and keep in touch with other generations.

1.2 Research question

The central question in this user requirements study was:

'How should a device, e.g. an app look like for elderly people with dementia and their beloved ones to recall, share and record memories according to their wishes and preferences?'

1.3 Set-up

The MI-Tale project started with a collection of user requirements to investigate the preferences and wishes of the primary end-users (seniors with early dementia) and several groups of secondary end-users (informal caregivers of the primary end-users; relatives from other generations such as (grand)children and formal caregivers). Requirements were collected by the means of qualitative, semi-structured, face-to-face interviews.

1.4 Reading guide

Chapter 3 gives an extensive overview of the target groups in this study. Since we aim to develop an app to get and keep in contact, several groups of persons are involved. This chapter describes the groups the MI-Tale project primary focuses on.

Chapter 4 describes relevant theory and literature in the domain of aging, life-review, dementia and technology and provides the theoretical framework, which was used in the interviews conducted.

Chapter 5 elaborates on the methodology used in this user requirements collection. It motivates why it was decided to use which methods to map the preferences and wishes of the different user groups. Besides, it describes the recruitment of participants, as well as the ethical steps that were taken.

Chapter 6 & 7 describe the results of respectively the literature study and the qualitative interviews conducted in Austria and the Netherlands.

Chapter 8 provides a conclusion of the document and reflects on the results in relation to the used literature and theory.

Chapter 9 contains the translation of the results into applicable specifications of the app to be developed. Besides, it contains several use case scenarios to illustrate how the app eventually could be used in practice.

2 Description of targeted user groups

In a first step during the kick-off workshop the entire consortium identified the specific target groups. Defining these groups helped us to distinguish between the groups the app would be developed for and the group to include in this user requirements study. Furthermore we distinguished between primary end-users, who shall be motivated to share their stories, and secondary end-users, who are the ones these stories will be shared with. Finally, we also described the involved persons in the envisioned multi-user mode.

2.1 Primary end-users

The primary end-user group of the eventual innovation as well as of this user requirements collection consists of elderly people.

(Healthy) Elderly people

Who? Seniors in general, living alone or together, independently. The app will be most interesting and attractive for those who like to look back on their life (for instance just entering a new stage in their life, such as retirement or getting grandchildren) and who like to collect, record and share memories with others (see secondary end-users). Next to that, seniors with any interest in/affinity with technology may be interested in the app to be developed.

Why? Literature describes how the recalling of personal memories plays an important role among people in the final years of their life. Butler (Butler, 1963) introduced the concept of 'life review' as a '*progressive return to consciousness of memories and unresolved past issues for re-evaluation and resolution'*. He explains this evaluative process as a universal development, occurring in all persons in their final life stage. Technology cannot only help to facilitate and ease this important process, but also to make it more 'fun' for elderly people to share memories with their beloved ones from different generations.

Elderly people with (early) dementia

Who? In this study we focused on people at the age of 55+ with early dementia, either diagnosed or still in the process of diagnosis. The app will be mainly interesting for those within the target group with any affinity with technology. In order to investigate facilitators and barriers, also elderly people with dementia were involved with less interest in technology and innovation were involved in this exercise. Elderly people with dementia who also suffer from other (psychiatric) diseases, which may influence their mental state, will be outside the primary focus of this project. However, once the product is launched and available, they might benefit from it as well.

Why? Although looking back on life is a process all elderly people experience, the MI-Tale project does have a particular focus on elderly people with dementia, since for these persons memories play an even more important role. The values they have formed in their early adult years often resurface as guiding values in their current behaviour. However, recalling and sharing memories as a skill does decrease during the process of dementia. Technology can play an important role in compensating these diminishing cognitive skills. Therefore an app to support elderly people staying in contact with the ones around them, should specifically take into account the preferences and wishes of this end-user group.

2.2 Secondary end-users

The secondary end-user groups include the persons who use the app together with the primary users. The elderly person tells his/her story, the secondary user triggers and challenges her/him to come up with stories and memories to share.

Informal caregivers of elderly people with dementia

Who? The first group of secondary end-users includes the informal caregivers. These can differ from spouses, children, siblings, but they have in common that they are the main caregivers from the informal network.

Why? Besides to the fact that the app can provide fun and facilitate social interaction, it can help the informal caregiver to get a better understanding of and more respect for how the person in need acts and reacts.

Social network, same generation

Why? Although we may also consider these persons as primary end-users as well, we really need this group to motivate the elderly person and to act as secondary end-users. Especially for elderly persons with dementia, it is very important to be addressed by persons from their own age, having the same memories from the past. This will give the (primary) user the feeling that s/he is involved in an equivalent conversation rather than an interrogation. Next to that, people from the same generation can trigger reactions by mentioning own experiences and memories instead of only using the materials in the app. Initially, we proposed/aimed to develop the app primarily to connect generations. However, the first conversations and interviews with elderly people with dementia did show the importance of getting in touch with people from their own age in sharing memories. These persons are triggers themselves as they remind the elderly people with dementia of their (common) past.

Who? Siblings who grew up together with the (primary) end-user, as well as friends from the past who still or again play a role in the life of the elderly person (with dementia). Next, this category also includes 'new' social contacts/friends who (preferably) have a common background in terms of e.g. region of origin, religion, profession or hobbies.

Relatives from the new generations

Who? Children, grandchildren, grand-grandchildren, all belong to this category of secondary end-users. However, based on our first experiences with the target group, we think we can make a distinction between new-generation relatives who are able to start and maintain a conversation, ask questions, listen to grandparent's story etc. and those who are not. The youngest relatives (we cannot specifically determine an age, but in the interviews children aged under 7) turned out to be very important for a feeling of connectedness, simplicity, energy and vitality. They may be interested in using an app as well. However, since it may be hard for them to ask questions (which may not even be desired by the people with dementia: they like these children especially since they do not ask difficult questions), they are not the main target group as secondary end-users. They may play, however, a role in the background. For instance, when their parents use the app with their grandparents.

Why? These relatives from new generations are very important for elderly people in general and those with dementia more specifically. They feel connected by their family ties and elderly people feel very proud of them. However, the elderly persons often have the feeling that these younger generations are not interested in stories of the past, since they live in the present. However, at the same time the new generation says to be interested, but not to know what to talk about, since the elderly person doesn't show enough initiative to show what's in their mind. This app will help to bring these two groups together, help them to facilitate conversation and spend quality time together.

Professional caregivers

Who? Professional caregivers working with elderly people with cognitive impairments, either in a nursing home, home-care setting or as day activity, who take care of the elderly person in an individual setting.

Why? Similar to the case of the informal caregivers, the app may also help the professional caregivers to get a better understanding of and more respect for how the person in need acts and reacts. Understanding the past of a client will help to provide personal care in the present: they are an important base for a growing number of dementia care systems such as Dementia Care Mapping and the Psychobiography Care Model. This app may help professionals in this process, make it more fun and easier to record and save stories and insights.

Böhm-certified professionals

Who? The specific group of professionals who are trained through the ENPP training-program for the Böhm care method and work in officially ENPP-certified organisations like day-care centres (e.g. care farms) and nursing homes.

Why? The device or app is specifically based on the methodical approach of Professor Erwin Böhm. This means, that theoretically Böhm-certified organisations should benefit most from the device/app. These specific organisations requested in the first place for this development.

2.3 Playing in a group

A second application of the device/app will be group activities. In that case there will not be a sharp distinction between primary and secondary end-users, since all of them play together and share their stories, while at the same time listening to other ones' stories.

This application focuses on seniors in a group setting to share stories (for instance in a nursing home or at a day care centre, or healthy elderly coming together).

There may be someone present (e.g. a professional caregiver), who facilitates the process, moderates the conversation, asks questions and (in case of professional setting) make notes.

3   Theoretical Background

3.1   Life review of aged people

Life review is a very important process for people in the final stages of their lives. The process differs per individual, depending on life experiences and characteristics of a person. This means that life review can either lead to satisfaction and acceptance or to pain, resentment and feelings of guilt. Although life review is a naturally occurring phenomenon, it may also be influenced by as well as used in interventions. Guided life review can be used e.g. in psychotherapy and investigate, based on memories, how current issues go back to experiences earlier in life (e.g. Lewis & Butler, 1974; Haight & Webs, 1995). End-of-life review applied in palliative care can also be used as a way of validation of the life someone has lived and a way of saying goodbye to loved ones (Aylor & Grimes, 2008).

3.2   Reminiscence and recalling memories

Research of (e.g.) Ernst Bohlmeijer (Bohlmeijer, 2007) focused on reminiscence, a less structured way of recalling memories than life-review. In his review he gives an extensive overview of the application and effects of this concept. Although life-review can be considered as a part of reminiscence, reminiscence is a broader concept that includes more elements, including problem solving, teaching/informing, conversation, boredom reduction, bitterness revival, death preparation and intimacy maintenance. Reminiscence has both intra- and interpersonal functions and the content is influenced by present circumstances. Reminiscence may enhance successful aging by strengthening identity, increasing meaning and coherence in life, preserving a sense of mastery and control, and promoting reconciliation and acceptance. According to this review, reminiscence as autobiographical memorizing can be seen as a reconstructive process and as an effective method for enhancing psychological wellbeing and diminishing depression.

3.3   Recalling memories with dementia: Böhm

The Böhm-care method doesn't discuss above-mentioned theory, but includes some 40 years of study in practise with people in dementia. The theory of the originally Vienna-based practice is not accidentally based on famous Austrian science or surrounding German speaking countries. The classic school for depth-psychology is one of the main sources, many times partly based on Sigmund Freud. Alfred Adler, Viktor Frankl, Carl-Gustav Jung end Rüdiger Dahlke are many times quoted, but also studies from Konrad Lorenz and Luc Chiompi are involved. Apart from that, Böhm did have intensive contacts with Tom Kitwood, founder of the internationally rewarded Dementia Care Mapping method.

The most important outcome of this mix of practice and theory is the conclusion that people in (most varieties of) dementia suffer from a mental regression, that leads them back to their past in which they were not yet adults. In the beginning of dementia, they will re-experience their life in early twenties. Later, they will go back to earlier stages. This conclusion is in line with theory from Professor Erik Scherder (VU, NL), who discovered, that people with cognitive impairments will appeal to their so called frontal cortex, which is a part of the brains that is developed from day one in someone's life, until they are mentally grown-up. It is a back-up system for difficult moments in life. In there, you know to cry when you are sad, to flee from danger or to fight danger, and to smile when you like something. It's a collection of emotional memories, values and copings in a way

someone stored them personally. While cognitive functions are damaged in dementia, it is the only memory left. There is nothing more, nothing else. All other things around, are strange and most likely frightening. Within the collection of memories of a frontal cortex however, there are enough aspects to fill a personally experienced meaningful day. The challenge is to collect the memories of the frontal cortex, because no-one else knows them. With deep knowledge of the related time-spirit, one can only have a bit of a clue.

Taking both of above-described approaches into account, it seems relevant to further investigate the use and effects of the recalling of memories among elderly people with cognitive impairments, such as dementia. However due to the impairments related to dementia, it takes these patients and the ones around them a lot of effort to keep these memories alive. Although the long-term memory stays intact, recalling them is not always easy for these patients since consciousness of time and order are decreasing.

Suitable triggers are needed to help recall these valuable stories and memories of dementia patients. Based on earlier research, tools helping dementia patients recalling memories may not only have positive effects on the patients themselves but also on their caregivers (Woods et al., 2005 in Bohlmeijer, 2007). However, since the initiative of these elderly is decreasing and most of the people in the close environment were not part of these early memories, it is often hard for the social network to find the right triggers.

3.4 Sharing memories in a digitalized World

Digital innovation is rapidly taking over daily life. Whereas banking, buying products and sending messages were offline activities in former times, nowadays these are increasingly done online. The older generation also participates in this transition. In 2016, from the Dutch population aged 75+, 60% did have an Internet connection at home and made actively use of it. About 30% of the respondents did have a smartphone (CBS, 2016).

This new online dimension does not only influence daily activities, it also is used on a big scale for recording and sharing experiences, memories and life-stories. In the Netherlands, from the people aged 12 or up, about 80% declare to use social media (CBS, 2016). These new media, such as Facebook, Twitter or Instagram introduced new ways of sharing life by facilitating the posting of messages, pictures and the organizing of social events. Also the older generation is participating in this trend: from the people aged 75+, 22% mention to make use of social media (CBS, 2016).

3.5 Acceptance of technology

Although we may consider the dissemination of available social media as a rise of possibilities to use technology to share life stories, it does not necessarily mean that seniors will also use technology for this purpose. As the statistics mentioned above indicate, only a small percentage of the older generation does use social media and the numbers do not say anything about their motivation. Besides, the distinction was based on age solely and these numbers do not say anything about specific groups of elderly people.

Of course, abovementioned statistics only illustrate a specific part of the use of technology. However, they confirm what can be found in other literature as well, namely that the use of technology among older adults stays behind compared to other age groups (e.g. Porter et. al., 2006; the Digital Future Report, 2004; Fox, 2004; Lenhart et al., 2003; van Boekel et al., 2017).

Explanatory models

Models that are frequently used to predict or describe the acceptance of technology, are the Technology Acceptance Model (TAM) (Davis et all, 1989) and the extended version, the Unified Theory of Use and Acceptance and Technology (UTUAT) (Venkatesh, 2003). These models describe the determinants influencing the acceptance of a certain technology by a person. The most important elements are:

- *Perceived usefulness (TAM) or Performance expectancy (UTUAT)*: to what extent does a person expect the technology to be useful and of added value in his/her life? If this factor does increase, someone will be more likely to accept and use the specific technology.

- *Perceived ease of use (TAM) or Effort expectancy (UTUAT)*: how easy does a person expect the specific technology to be to use? How much effort will it cost the potential user to use the technology? The easier a person will consider the use of a technology, the more likely s/he will use it.

- *Perceived social norms (TAM) or Social influence (UTUAT):* What do people around a person say about a certain technology? Do they recommend it or even try to convince a person to use it? Or are they negative and discouraging him/her to use the technology? Their opinion will be taken into account in their considerations to accept and use technology or not.

3.6   Social Aging

As described above, different factors are of influence in someone's decision to accept and use technology. Although these factors do play a role in the considerations of potential users of all ages, several studies show that people from higher ages score lower in the acceptance and use of technology and so do people with cognitive impairments (including people with dementia).

If older adults score lower on the acceptance and use of technology, we may assume, based on the described models, that they don't see enough added value of the product, they do not expect the technology to be as easy to use or the people around them influence their decision.

To understand how older adults perceive usefulness and ease of use of technology as well as the role of the social network in their decision making, theories of social aging (e.g. Charles, 2009) do provide valuable handles. These theories describe what is important for people in the process of aging as well as how they select where to focus on. Although some of these theories 'disclaim' to be applicable to people with cognitive impairments (which could include people with dementia), we may assume at some points, that these theories also describe our target group.

Socioemotional Selectivity Theory

This theory describes how the awareness of a constrained life period left, influences goals. When people age, this theory says, goals increasingly focus on emotional wellbeing, meaning and satisfaction. Activities and relationships that not contribute to these, are paid less attention to. People do select well considered on which activities they do focus on and they will shape their lives around these.

Memories

As described earlier, memories and experiences of the past play an important role for people with dementia. Theories about social aging confirm that memories of the past strongly influence how people appraise and evaluate their lives. Memory of adults is often less negative or even more positive than that of younger adults. They are even 'biased storytellers', recalling their past more

positively than they reported at the time (Kennedy et al., 2004; Ready et al., 2007 in Charles, 2009). However, when asked to focus more on the facts and details, these increases in positivity of past memories disappear, which indicates the importance of sharing personal stories and experiences rather than factual information.

Relationships

As described, elderly people focus more on relationships contributing to their emotional wellbeing. Less important relationships are discarded to create time and energy for the important relationships in life. Next to that, older adults report more satisfaction when interacting with family member than younger adults (Carstensen 1992, Charles & Piazza 2007 in Charles, 2009).

Selective optimization with compensation

According to this model, when aging, people become increasingly aware of age-related gains and losses. Because social, cognitive and functional reserves are often diminishing with age, resources are carefully allocated. As a result people select goals that are important and can be realistically obtained in later life.

4 Methodology

In order to answer the formulated research question and to define the user requirements for the app to be developed, end-user requirements were collected on different levels and using different methodologies.

4.1 Literature study

Before the start of the project, the consortium proposed to execute a quantitative survey in order to prepare the qualitative interviews properly. However, due to several reasons, we decided to replace this survey by a literature study.

In the first place the target group, elderly people with dementia, are not suitable to act as respondents in a quantitative survey. Many of them would need assistance (from formal or informal caregivers) while in this user requirements research we explicitly would like to make distinction between the different involved actors (people with dementia, (in)formal caregivers and relatives). Next to that the information we would like to collect was more about motivations, opinions and ways people spend and spent their lives, which is not easy to investigate by a quantitative survey. First, the background and personal stories of the respondents will be needed to understand the information, next, the research aimed to be so explorative that every respondent should have the opportunity to come up with his/her own story and formulation of answers.

Next, a lot of research was already done on the topic of elderly, aging, dementia, technology and the recalling and sharing of memories. Therefore we decided to prepare the qualitative research part with a literature study to replace the quantitative survey.

4.2 Qualitative interviews

Based on the literature study, qualitative semi-structured interviews were executed both in the Netherlands and Austria. The development of the interview topics will be described in Chapter 5, where the results will be discussed. Interviews took place with elderly people with dementia, visiting the care farm as a day activity, their informal caregivers, (grand)children and professional caregivers. Healthy elderly people were not involved separately, since in the development of the app we mainly focus on the elderly people with cognitive impairments. The app should in the first place be suitable for this group. Eventually we will make sure that the app will be as attractive and challenging enough as well for healthy elderly people. However, many of the informal caregivers involved in the study were seniors themselves, which allowed us to collect their own preferences and wishes as well.

The Netherlands

In the Netherlands interviews were conducted in the summer of 2017 by the National Foundation for the Elderly (NFE) in collaboration with the subcontracted partner Samenwerkende Zorgboeren Zuid (SZZ), an umbrella of care farms in the South of the Netherlands.

Approaching the target group
As a first step, early July, SZZ sent out a letter on behalf of NFE to care farms in Noord Brabant and

Gelderland (N = 35) to explain the project and invite them to take part in the project by participating in an interview and asking their clients and their informal caregivers as well. An English version of this letter can be found in Annex I. Some of the farms responded negatively on the e-mail for several reasons: their clients were not interested in technology or not able to participate in an interview; the summer period made it complicated to join or the person from the care farm was not able - for private reasons- to organize this. Two farms responded – preliminary – positive.

After two weeks, all care farms were called by NFE for a more personal introduction. Most of the care farms responded positively on this phone call. Some asked for a specific information letter for clients. Eventually the care farms asked clients to participate, provided their contact information and NFE called them to plan an appointment for the interviews. Contact took most of the times place via the informal caregiver. During the interviews we explored which persons were important for the participant and should be invited for another interview.

Criteria for primary end-users
- Age of 65+ ;
- Visiting the care farm regularly;
- Suffering from a type of dementia (either diagnosed or in the process of diagnosis);
- Able to express their opinion, especially when it comes to technology and communication;

Criteria for secondary end-users
- Age 18+;
- Knowing the person with dementia already since before complains appeared;
- At least one of the secondary end-users would preferably be the main informal caregiver;

Respondents (N=35)	Relationship	Sex	N
Care farms / professionals (N=5)		Females	N = 5
Elderly people with dementia (N=11) ➢ **Age 59-93** ➢ **Alzheimer, Lewy Body, Vascular Dementia, Mild Cognitive Impairments**	Primary respondent	Females	5
		Males	6
Informal caregivers (N=11)	Spouses	Females	4
		Males	2
	Children	Females	3
		Males	1
	Sibling	Female	1
Third person from network (N=8)	Children	Females	2
		Males	1
	Grandchildren	Females	3
		Males	2

TABLE 1 SAMPLE OF PARTICIPANTS

The eventual sample existed of 11 primary end-users, visiting the care farm. Respondents were aged between 59 and 93. Since the project was about technology, many care farms mentioned that there were also younger people (<65) with dementia interested to participate. Therefore the age criteria was decreased to 55+.

Primary respondents suffered from different types of dementia: Alzheimer disease, vascular dementia, Lewy body and less defined mild cognitive impairments . In eight of the cases there was an official diagnosis. In three cases the process of diagnosis was still running. In the last case, there was no diagnosis, since both the respondent and the family were not interested in testing, since it wouldn't make a change for them. In all cases, professionals from the care farm did consider the respondent as a senior suffering from dementia, even when there was no diagnosis (yet).
A twelfth person was recruited, but during the interview with his informal caregiver (wife) it turned out he also suffered from schizophrenia already from his childhood on. Since this disease influenced his life for a serious part, he deviated too much from the aimed target group and we decided not to include him as a case.

The informal caregivers (N=11) were in six cases a spouse, in four cases an adult child (three and in one case a sister with her husband.

The third person interviews (N=8) took place with three – adult- children and four. In three cases we couldn't find a third person two interview. In two cases, the primary respondent didn't have children, in one case we asked the primary or secondary end-user multiple times by e-mail and telephone, but although they gave a positive response, they did not come up with a third person.

Additionally, representatives from the care farms (N=5) were interviewed. Four times the owner and main responsible person at the farm, in one case a professional involved in practice.

Execution of interviews
Interviews with the seniors with dementia and their informal caregivers mainly took place at the care farms, with a few exceptions. Interviews with (grand) children mainly took place at their homes.

Interviews on average took 45 minutes. The shortest interview took about twenty minutes, the longest one and a half hour. The audio of the interviews was recorded with an iPhone, with permission of the participants.

In almost all cases, the interviews were individual. In one case, a sister of a client of the care farm and her husband did the interview together; in one other case, a son of a primary end-user did the interview together with his wife. In one case, the primary end-user was also present at the interview with her husband, in another case it was the other way around: a daughter was present at the interview with her mother (who was the primary end-user). In these two last cases it was mainly for practical reasons that it went like this: the primary end-user was not mobile enough to go to another place. In all described cases, it was emphasized that we'd like to have individual opinions.

Afterwards, the participants received a little present as thanks for their participation: a gift card and a knitted little owl, the symbol of the project, which was knitted by the knitting clubs of NFE.

FIGURE 1. LITTLE PRESENT TO THANK RESPONDENTS

Analysis

The interviews were all recorded and transcribed ad verbum (in Dutch), using the software OTranscribe. Transcriptions were as anonymous as possible; names were replaced by codes. After transcription, the interviews were coded in several steps, using the program Atlas.ti. This helped to easily find all the passages in the interviews talking about the same topics.

Ethics

All the participants were asked to sign an informed consent to declare that they were well informed about the project and that they took part voluntarily. They also declared that they were aware of the fact that the interview was recorded and that they knew what their information was being used for. One of the grandchildren who participated was younger than 18. In this case, also his mother signed for consent. During one interview photographs were made from the elderly person. Both this person herself as her daughter (informal caregiver) signed for permission to use this picture. The Informed consent was used in Dutch, but can be found in English as Annex II.

Austria

The partner LFTL took care of the collection of additional preferences and wishes of professionals in Austria. Since we were - additionally to the collection of data in the Netherlands – specifically interested in the opinion from professionals working according to the Böhm methodology , ENPP certified professionals (N=6) were invited for an informal interview/conversation during the annual meeting of Böhm-certified institutions in Innsbruck.

5 Results – Literature study

5.1 A firm base for interviewing

The literature study first was meant to prepare the interviews and to explore which questions to ask the respondents. We explored the domain of recalling and sharing memories among elderly people in general and among elderly people with dementia more specifically; we had a look at the literature about social aging and the things and persons that are important for elderly people when aging and we dived into the knowledge already available in the domain of elderly and technology.

We believed that these topics would tell us more about how to investigate wishes and preferences of elderly people with dementia and their social network with regard to the use of technology to recall and share memories. Therefore, we derived the interview guidelines from the described theory.

5.2 Indicators for designing the app

As expected, the literature taught us a lot about how to investigate the topic. Additionally, the literature also told us a lot about how to develop an app for elderly people to recall and share memories. Some of these statements would be confirmed or further explored by the interviews, other were considered to be interesting indicators for the development stage of the app.

Digital skills

Based on the Technology Acceptance Model (TAM) as well as its extended version, the Unified Theory of Use and Acceptance of Technology (UTUAT), a new digital tool for elderly people should fit to their digital skills and should be easy to use.

Relevance

Based both on the models, which describe acceptance of technology, as well as the literature about social aging, we can recommend to design the app in such a way that it is relevant for the user, has added value. People will focus more intensively on less different things. If the developer of an app is aware of these important things in life for the elderly person, the target-group will be more likely to use it. Another important way to make a certain technology to be considered as useful, is to make it a 'tool' that helps elderly people to keep doing things that aren't they able (anymore) without this specific technology.

Family

One of the things that would become more and more important in older life, according to the social aging literature, is family. The models about acceptance of technology say, that the social network plays an important role in the decision-making around technology. One developing technology for elderly people, should give the closest family a role in the use of it. This can either be the use of a certain app together, or use the family as an influencing actor to convince the senior to use it.

6 Results – Qualitative interviews

6.1 The questions

Based on the studied literature, we developed a semi-structured questionnaire for the different described end-users (See Annex IV) in which we aimed to further elaborate on these theories among this target group as well as (even more important for this study) on the implication and application of this information for/on the app to be developed.

Considering the fact that older adults evaluate the past differently than younger ones, as well as the fact that people with dementia live in their own specific world of experiencing, we found it even more interesting to involve younger people around the people with dementia in the interviews. Next to that, the literature stated that relationships with family are more important for older adults than for younger people. However, in the MI-Tale project we would like to develop an app to connect generations. The interviews with secondary end-users may help us to investigate under which circumstances younger adults would invest in the relationships with family members, such as (grand)parents. Aim was both to include the perspective of the primary end-user from the other point of view as well as to collect wishes and preferences of the secondary target groups.

Questions were –amongst others- about:
> Important things in life for the primary end-user from different perspectives, such as hobbies, persons etc., both in the present and the past (socioemotional selectivity).
> The way people with dementia maintain these important things, when cognitive and practical skills decrease (optimization with compensation).
> Important persons in the life of people with dementia in the past and the present.
> Preferences of the primary end-users as well as the other interviewed people with regard to talking about the past as well as triggers that are helpful to recall stories of the past.
> The use of technology (devices, purposes, motivations, change over time, digital skills of the primary end-users from different perspectives).

6.2 The stories

Important things in life

Family
As expected, most important things in life for the primary end-users include in the first place family. Partners and (adult) children are mentioned to play an important role, for social and emotional but also for practical help and support in the process of dementia. An interesting group of important family members does consist of the youngest generation: the grandchildren and grand-grandchildren aged under (+/-) seven. The best explanation for this, mainly mentioned by informal caregivers, is that these little kids represent energy and vitality, maintain relationships just by being there and they do not ask difficult questions - which other relatives are tending to do. Finally, these children also give the seniors the feeling of usefulness, as these little human beings are still dependent on the older generations (such as parents and grandparents).

Hobbies

Next to the family, almost all participants mentioned one specific important hobby or interest from the past (in some cases even better defined as 'obsession') which was still very important to them. In the first place, they maintain these hobbies just because they (still) like to do these. A second and maybe even more important motivation is because it gives the elderly person with dementia a feeling of self-control, usefulness, still being part of society and still having the skills to do what they were used to. When the respondents did not have enough skills to execute the hobby in the way they initially did, they looked for alternative ways to do so. Hobbies that were mentioned differ and include (amongst others) doing creative things; singing in a choir; watching baseball on the television (American lady); birds; using the tablet or watching soccer games.

Lady, 81 (Alzheimer disease): '*The Yankees are my favorites! I find it great! Sometimes I go to bed even at 2am.. My oldest son is baseball player and my youngest son is technical, so.. It gives me a lot of pleasure, a lót!***'**

Important persons

Social network

As expected, the social network of people with dementia decreases. As mentioned, most important persons currently in this social network are family members.

Next to (grand-grand) children and partners, also siblings are mentioned. These are important since they have the same experiences from the past.

Most persons with dementia also have a few (one or two) friendships going back to their early years. However, both these respondents as well as their informal caregivers say that it becomes more difficult to maintain these relationships.

Also persons from the farm are mentioned as important persons. Although the elderly persons do not know their fellow-visitors for so long yet, they feel connected somehow. Most of the times they share a common background in terms of region of origin.

Finally, also neighbours are mentioned. Sometimes by the primary end-users, sometimes by their informal caregivers, as they give social and practical support. The primary end-user is not always aware of this so well, but his or her informal caregiver most of the times is.

Maintaining relationships

Most of the people with dementia experience difficulties in maintaining existing or starting new relationships. Persons with dementia find it hard to take initiative in general and in relationships as well. In most of the relationships, the other person takes initiative.

Another reason is that the social sensibility decreases with dementia, which may lead to troubles every now and then. They are suspicious and say things to others that are not socially accepted. Another obvious reason is that people with dementia forget a lot of things, including names and backgrounds of people, which makes it difficult for them to have social contacts. Some respondents mention to avoid coincidental meetings in the supermarket, since they know they will not be able to have a normal conversation. The same counts for telephone calls or visits.

A final reason for not having a lively social live is a more practical reason. Many of the respondents are not allowed anymore to drive a car and not able to go by bike, which makes them very dependent on others to meet other people.

Lady (81, Alzheimer disease): *'And then the forgetfulness.. The fact that.. ehh.. the names of people you should.. you see a face.. Well, I don't know how many times I thought: 'Let's see, I shóuld know her..'.*

Lady about her husband (69, Vascular dementia): *'The neighbours do not talk to us anymore. My husband told to the guy next door: 'You're too lazy to work'. Although we think he is a bit lazy ourselves, a normal person wouldn't say that to him.. but my husband did. He said: 'You're a scrounger!'. Well.. and then the neighbour came back to me..'*

Talking about the past

Preferences and assumptions

To start about this topic, we asked just right away whether the respondents did like to talk about the past. For some of the respondents, this turned out to be a difficult question. The ones who did answer the question quite easily, most of the time immediately answered that they didn't like to do so: Since the past was over and it didn't make sense to keep hanging in those times. The stories of the past are known already, something new would be more attractive to talk about. Next to that, they said the past was not always a good period (poorness, war, diseases) and recalling this again wouldn't make one happy.

However, although most of the respondents didn't say to be interested in talking about the past, most of them radically turned, when questions were asked about the past, without specifically labelling them so. We showed for instance a book with images of the fifties, which made them talk a lot about their early years. A daughter of one of the primary respondents had a tablet with pictures of her early life, which *'was worth gold'* according to her mother, who started talking and sharing stories about her past once she watched the photographs. Something similar happened when we asked about their passions and hobbies, which were often closely related to their earlier life. It seemed that the past and present were divided by a sharp line when we asked directly about it, but not anymore when we started to recall memories together.

With whom

If we asked right away with whom the respondents do or would like to share memories of the past, they surprisingly didn't come up with the persons they earlier considered as the most important persons in their life. In principal they would like to share memories with (-grand-grand) children, but they were convinced these wouldn't be interested in the past or in them as grandparents in general. The elderly people with dementia rather would recall and share memories with people of their own age, including siblings, friends or people they meet at the care farm. This would help them exchange memories instead of only telling them their selves.

However, when we asked the yóunger respondents whether they would like to hear the stories from the primary end-users, most of them responded much more enthusiastically than we would expect based on the estimation of their (grand)parents. They regret these do not talk about the past so much, find it difficult that they often don't have so much to talk about but don't know what questions to ask or triggers to apply either.

Lady (86, Alzheimer Disease): *'Well, I don't think they [grandchildren] are interested in the past, they do live in the present. [..] No, honey, that's life! It's over. I have my own memories and every now and then they ask something, but I cannot say they are really interested in my past and what*

I did and what happened to me'.

Mister (husband of lady, 62, with Alzheimer Disease): *'Well, we were at a birthday lately, at a sister, or brother. And some of her family members think that there's not so much wrong with her. [..] And she was talking a lot.. and everything gets out and she's laughing and making jokes. And the brothers and sisters don't notice anything bad. And all stories are right!'*

Triggering the past
For this question first two books were used. One did contain pictures from the fifties in all kind of categories; the other was a book with questions to be filled in by grandparents to write a book about their life for their grandchildren. Most respondents agreed that the book with pictures would help better to facilitate a conversation than the questions. These questions would be hard to read, to understand and to answer, which would make the people with dementia feel insecure.

FIGURE 2. BOOK ABOUT THE FIFTIES

FIGURE 3. BOOK TO FILL IN LIFE STORY

After that, two digital tools, with the same idea behind it, were shown: A reminiscence app at a tablet, which showed pictures from the early years of the respondent and a digital tool at a laptop to facilitate a life story digitally.
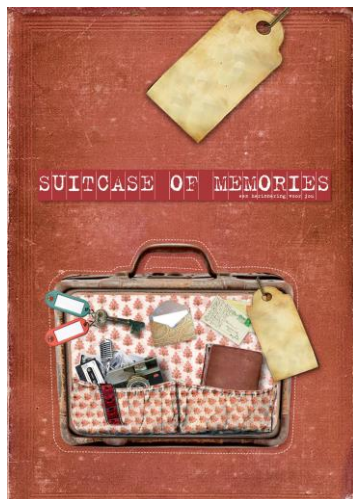
FIGURE 4. REMINISCENCE APP

FIGURE 5. WEBSITE FOR MAKING UP LIFE STORY

Triggers already used

When we asked the respondents (both primary and secondary) which 'triggers' they use to recall stories from the past, an amount of examples came across.

Photographs are mentioned the most as good triggers to recall memories. However, these were not only mentioned to trigger experiences from the past, but also to recall short-term memories or to facilitate conversation (for instance, watching pictures when children come back from holiday).

Next to personal photographs, general images in books, as well as from Google images or Google Maps/Street view were mentioned (by respondents with dementia as well as those around them) to get memories above.

Other triggers mentioned were personal letters (one lady still had a box with old love letters from her husband that had passed away); obituaries (a daughter told how her father reads the entire (regional) newspaper but only really processes the obituaries which reminds them of people he knows from the past; visits to a museum or important place from the past (in which the entire surrounding sometimes 'breathes' the past) and specific persons (meetings with important persons

D2.2 User requirements report

who remind them of specific past events). One daughter makes notes of all interesting quotes of her mother in a specific notebook, so she can use them as conversation starters in talking to her mother.

Use of Technology

Frequency of use

Although most of the primary respondents do use technology in a certain way, it differs from hardly no technology use daily use. Besides, it holds true for all respondents that they do use less technology than they were used to. One of the reasons for this may be that the practical skills of the people with dementia decrease while many technologies become more complex over time – such as TV's with one button transferring into smart TV's with many buttons and several remote controls. In most of the cases, the respondents didn't respond quite positively on the question whether they use technology or not. However, when we talked about how the elderly people with dementia shaped their daily life, examples of technology use came across.

Use of devices

A big variety of devices was mentioned by the primary end-users and the ones around them. Most frequently mentioned device was the television, almost all of the respondents do have and use the television.
Next device was the telephone, landline or mobile phone. Sometimes even a smartphone was used. Furthermore the laptop, tablet and regular computer were mentioned as well as radio and CD-players. Sometimes the perception of the primary respondent and the others wasn't the same. In most of the cases, the primary respondent mentioned to still use technology, while the informal caregiver denied this.

Digital skills

As mentioned, the primary respondents all make less use of technology than in the past. One reason is that some of them used to need it for their work, which is no longer the case. However, most important reason is the decrease of digital, (fine) motoric and social skills, which are all important when using technology.

The different perspectives on this topic are interesting. In most of the cases, the primary respondents tell to be still able to use technology, but s/he is no longer interested in it. Their (in)formal caregivers, however, most of the times say, s/he is not able to use it at all. Grandchildren, in general, think their grandparent with dementia is still able to learn new things and are enthusiastic to try the new app with him/her.

Purposes of use

As expected based on the literature and theory, the respondents mainly use technology for the most important things in their life, rarely 'just for the fun'. These most important things in life include, as described, family members and specific hobbies/passions.

Hobbies

Although we can relate these hobbies to 'fun' as explained above, for most of the respondents these hobbies mean a lot more than just fun. One lady learned how to handle her digital TV because watching baseball meant a lot to her; One man keeps using his computer for making music scores for the choir he sang in; a lady who worked in a kindergarten and misses the creative activities, still

uses Pinterest to keep up-to-date about the latest 'Do It Yourself'-trends; A man who used to cycle a lot now tries to figure out how to watch the Tour de France at his tablet etc.

Family

With regard to important persons, respondents use technology in different ways. The ones who are still able to use What's App or have a phone do so to keep in touch with the family. One man, for instance, told us how he keeps in touch with his son by using the chat function in Wordfeud. However, most of them do make more passively use of these devices: the partner receives messages and pictures from the children, the one with dementia looks indirectly as well. Although many of the respondents are not able to maintain relationships so well anymore, they absolutely like to watch pictures from their (grand-grand) children and also use, if necessary, technology for this.

Man (77, Vascular Dementia): *'I'm not such a computer.. But I can use it. I was member of a choir for about 16 years. And we got these music scores, with music and text. But these were very bad readable. Then I said: 'I have a program on the computer and I can remake these'*

Man (69, Vascular Dementia) *'I see my son every week. We talk by using the chat function of Word feud. I find it difficult to talk, so it is easier for me to talk'.*

Son*: 'Well, it are no big stories, but because it is my dad, I often understands what he does mean'*

The professionals' point of view

Using technology

When we asked the professionals about their opinion on the use of technology by their clients, a general response was scepticism. Most of the clients would not be familiar with devices such as tablets or similar technical devices. But the generations of elderly to come will be better prepared. A central device such as a smart TV or 'Tovertafel' (a Dutch concept in which moving images/games are projected on a table by a beamer) would work better as a group activity, since giving every participant an own device may be difficult.

One respondent was sceptical about the fact, that the app shall be web based, as having to be online when using it might be too much of a restriction (because of e.g. lacking a fast internet connection)

Response on the idea of the new app

Although technology might be difficult or new, the idea of sharing memories by photo's or music was received positively. However, probably the elderly end-users with dementia would need assistance from the professionals.

The respondents also think the tool can help professionals to gain a better understanding of clients with dementia and their (emotional) biography.

However, the content should really be good, as existing alternative apps are not always of good quality. Images and other materials should be of good quality, the app should be user friendly (easy to edit and adapt) and the content should make sense for the aimed end-user group. National archives and personal collections of elderly people would be a good source when defining the content.

Finally, the technical functionalities would be good. If an Internet connection is needed, for instance, this would work properly.

Recalling memories as a group activity
Like we did in the interviews with the elderly peoples and their family members, we also asked the professionals how they recall memories with their clients. Books with historical pictures from the region are popular, as well as different games (using dices with categories, memory cards etc.) to talk about the past. Next to that, using old objects in the care setting also triggers the visitors to talk about their past, while just doing daily activities.

The professionals also mentioned video and music to stimulate people. Interestingly, these instruments were not mentioned by the other respondents, even not when specifically asked. However, a reason might be that they are just not aware of this being a way to share memories in the same way they didn't prefer initially to talk about the past, until the right triggers were there.

7   Conclusions

In this user requirements study, the following research question was elaborated on:

'How should an app look like for elderly people with dementia and their beloved ones to recall, share and record memories according to their wishes and preferences?'

We addressed the question by studying existing theory and literature and conducting qualitative interviews to collect new information.

Models in the domain of acceptance of technology show us the factors that are of influence in the process of the acceptance and use of technology by different groups of users. The factors in this model gave interesting indicators on how to study our own target group.

Social aging theories show us what is important for elderly people when aging. The theories explain which persons are important, how aging people cope with decreasing skills in certain domains and how they, on the contrary, stay focused on the things they are still able to do. The theories also explain which persons and relationships are important in the process of aging and how elderly people maintain these relationships.

We predicted, based on the literature, that elderly people would be more likely to use technology if it adds value to their life and contributes to the most important things left and to the relationships with the most important people in their network.

We can conclude that this is mainly true. The respondents with dementia use technology for hobbies/passions being there already from their early years and which are still important to them. They like to use it to keep in touch with their family members or are convinced to use technical devices to feel connected with their family – for instance by watching photographs. Technology may help elderly people with executing tasks, which have become more and more difficult. As a final conclusion, using technology gives people with dementia a feeling of self-control, usefulness and belonging to society. Technology does not only need to be useful in itself but also help the user to feel useful.

However, this study did not only give us the great opportunity to test the theories with our target group, it even more helped us in formulating functionalities and specifications for the envisioned app. These will be described in the next chapter.

8 Application

The conducted study provides us many handles for the development of an app for elderly people with dementia to recall and share memories with the ones around them. This chapter describes the implications of the results for the development of this app.

8.1 Content

Triggers
An app to motivate the user to recall and share memories may include a big variety of triggers. It may include general and personal photographs, offer the possibility of adding own material (such as obituaries and birth announcements, letters) and include music and videos and pictures of relevant persons.

Quality of content
A result from the interviews with Böhm-professionals in Austria is the advice to take special care of the quality of the provided material (photos, video, music) with regard to time period, social background and nationality.

Family
One of the categories in the app should definitely be 'family'. Even the respondents who found it hard to answer questions (about any topic), did talk about their family and especially the youngest members. Also those who were not interested in technology were willing to use a tablet or smartphone if it would help them to keep up-to-date about and in touch with their family.

Passions
If an activity is related to something already important for the targeted end-user, s/he will be more likely to be motivated to join. Although skills decrease, most people with dementia seem resourceful to find new ways to keep doing the things that are important to them. If the app provides the opportunity to talk about their passions and hobbies, they will be more willing to use it.

Sharing life
Many of the respondents indicated not to prefer to talk about their earlier life. Therefore the app should not primarily focus too obviously on talking about the past, but rather emphasize the added value of sharing experience and building relationships. This would make it more interesting for the primary end-users to accept and adapt the app. Moreover it may also increase the likeability they will play it with people of other ages.

8.2 Playing the app

Playing with the little ones
Although an app aiming to share and record stories may be difficult to use for children aged seven and younger, the developers should consider this group as well. One of the sons for instance mentioned that his little daughter likes to play (digital) games with her grandfather, e.g. on a tablet or smart TV. Although it is hard for this group to share and listen to real stories, it may provide both of them a valuable time together.

Playing with brothers and sisters

Initially we didn't consider brothers and sisters as a specific secondary end-user group. However, many respondents indicated these persons as important communication partners. They have the same background and common experiences. The developers may consider functionalities, which may be specifically interesting to recall common memories. Furthermore, the consortium may focus on brothers and sisters in the branding of the app.

8.3   Use of technology

Device

It is important to use a device that the users already know or which is easy to learn. A tablet may be a suitable choice when an older person plays alone, but when two people use one device together a smart TV may work better. Many elderly people mentioned to have motoric decrease or decreased sight, which makes it more attractive to use a bigger screen/device.

8.4   Bringing the app to the target group

As people with dementia are often insecure in social relationships, the app should primarily focus on the people around them. If the secondary end-users will take the initiative, it is more likely that the app actually will be used. An additional benefit is the use of the app with (grand-grand)children. Since grandparents often assume that the young ones are not interested in their stories, it could be the younger generation that proposes to use the app.

8.5   Using the app in a group

Device

When using the app in a group setting, the app should preferably run on a central device. Both professionals and other respondents mention the obstacles of giving every group member a separate device, such as a laptop or tablet. Apart from high costs, it would mean too much effort to lead the process, solve problems, ensure everyone is looking at the same screen etc. A smart TV or 'Tovertafel' would work better.

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10 Annexes

I   Invitation care farms

To: Care farms SZZ
Date: July 2017
Topic: Participation project 'life stories and elderly people with technology'

Dear contact person of the care-farm,

In May, the National Foundation for the Elderly started, together with partners from the Netherlands, Austria and Cyprus a new project: MI-Tale. In this project we will develop, in the next couple of years, a digital and interactive game for elderly people with (early) dementia. Samenwerkende Zorgboeren Zuid is partner in this project as well. Via [name contact person SZZ] we understood that you are interested to participate. In this letter we'd like to explain the project a little more, as well as our expectations if you decide to participate.

What is MI-Tale?
Memories from the past play an important role in how elderly people with dementia feel and act. However, often it is hard for the social environment of the elderly (both formal and informal) to discover what's on their beloved one's mind. In the MI-Tale project we'd like to develop and app to help elderly people to recall and record personal memories, together with the ones around them. For instance with photographs, video's or letters. On the one hand, the app will contain existing material to trigger the players; on the other hand, the player can also add own material to generate a personal document.

Approach
To make sure that the app fits as best as possible the preferences and wishes of the aimed end-users, we start with this user requirements research. We'd like to do this by the means of interviews with elderly people visiting your care farm as well as important persons around them. We'd like to know with whom the elderly people share memories; which issues of their life they share with others; what's important for them when talking about their life and which tools (either analogue or digital) could help them in this.

What do we ask from you?
We'd like to visit your care farm in the next couple of months (July-September) to interview one or more of your visitors. Next to that we'd like to interview two persons who are important for him or her. Preferably an informal caregiver and someone of another generation (child or grandchild). Finally, we'd also like to interview you or a colleague from the care farm. The interviews will take about 45 minutes. The participants will receive a goodie for their participation.

What if you'd like to participate?

In the coming weeks, we will call you to ask whether you would like to participate and to answer eventual questions. We can then make further appointments. You would help us greatly if you could connect us to informal caregivers of elderly people who visit your care farm. We would like to appointments with them about how to reach the person with dementia and to discuss the details.

We also have a specific invitation letter available for (potential) participants, which you could find as an attachment. It would be great if you can invite potential respondents (people with dementia or their relatives) with this letter.

To summarize

- We would like to visit your farm this summer for interviews with your clients;
- We are looking for elderly persons (65+) with (early) dementia who'd like to participate in an interview about the sharing of memories and technology;
- We are preferably looking for people with any affinity with technology;
- Next to the person with dementia, we'd like to interview two persons from their network;
- The interviews are part of the European project MI-Tale.
- We will call you in the coming weeks to answer your questions and make additional appointments.

When you already have questions yourself, please don't hesitate to ask them! You can always call us (030-XX of 06-XX) or send us an e-mail.

With kind regards,

Marije Blok – project leader MI-Tale (m.blok[at]ouderenfonds.nl)
Manon van Dijk – project officer MI-Tale (m.vandijk[at]ouderenfonds.nl)

The MI-Tale project is part of the European programme AAL (Ambient Assisted Living) and is next to that in the Netherlands financed by ZonMw. This study is executed by the National Foundation for the Elderly, in close collaboration with the VU University Amsterdam, department of Sociology.

II   Informed consent participation interview project MI-Tale

Dear participant,

Thank you for participating in this interview for the **MI-Tale** project, we really appreciate that. Before the start of the interview we would friendly like to ask you to sign the informed consent. By doing so, you declare that you participate voluntarily and that you are aware of how your information will be used. This document will give you more information about the project in general and your participation more specifically. The last part of the document does contain the actual consent.

The development of MI-Tale
In the MI-Tale project, the National Foundation for the Elderly will develop, together with partners from the Netherlands, Austria and Cyprus, a **digital** and **interactive** game for elderly people (65+) and their social network. The app helps elderly people to recall and record personal memories, together with their beloved ones. This can be for instance with existing photo and video material which is already available in the app, or by adding own material. To make sure that the app, which still needs to be developed, fits properly to the wishes and preferences of the aimed users, we conduct these interviews with visitors of the care farm and their beloved ones in the starting phase of the project. In this way we can map the communication between elderly people and those around them from different perspectives.

Participation in this interview
We'd like to ask your opinion in this interview. The researchers of the National Foundation for the Elderly together with you picked a moment for this interview which will take about an hour and which will elaborate on the share of memories and life-stories and the potential use of technology to support this. We will ask you for instance with whom you share memories, about which issues in life you talk with others (and about which not) and which tools –analogue or digital- you use or would like to use.

The rights you have as a participant
- You are allowed to quit the participation at any moment. If desired, we can make sure your answers and information will not be used in the study;
- Your data will be processed anonymized and confidential; Your answers will not be traceable; - You have the right to receive a summary of the interview afterwards, to give your response and to indicate incorrect things;
- You can ask your question at any time. We will always do our best to answer these;

Importance of data protection
The National Foundation for the Elderly and the Vrije Universiteit Amsterdam find it very important to treat your personal information carefully. We ensure you that you we process your information anonymized and confidentially. The results will only be presented in processed way and will not be traceable to you as a person. The material will be used within the MI-Tale project to develop the mentioned app and for related (scientific) publications.

Consent participant

Hereby I declare that I participate in this interview voluntarily and that I am well informed about the goals and consequences of the project. With my signature I give permission for the use of the answers I give during this interview. All of my questions were answered to my satisfaction. I am aware of the fact that I can quit my participation at any moment, without giving a reason.

Place and date:

Name:

Signature:

Consent of the interviewer

Hereby I declare that I duly informed the respondent about his/her participation in the project. If during the project new information will come up which may influence the permission of the respondent, I will always inform the participant.

Place and date:

Name:

Signature:

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IV-A Interview guide elderly person with dementia

Introduction: (+/- 5 minutes)

Introduction researcher/background and aim of the project (very brief), namely to explore.. what is important for you in life in general and in the contacts you have with others more specifically. We are also interested in your use of technology and your wishes and preferences in that.

- Ask for permission to make recordings (audio, video?)
- Emphasize anonymity and confidentiality
- Emphasize open conversation
- Emphasize that no answers are wrong
- Ask for additional questions of participant

Part 0: General questions (+/- 5-10 min)
Aim: To get insights in the context of the respondent, ice breaker, to make the respondent feel comfortable.
- For how long do you already visit this care farm? Do you like to be here? Do you have any affinity with the farmers' way of living? Do you have pets? Do you live close by?
- May I ask you what your age is?
- What about your family situation? Do you live alone, with a partner, do you have (grand)children?

Part 1: Technology use in general: (+/- 10 min)
As I told you, I would like to get to know, among others, something more about your use of technology. When we continue the conversation, I will mention several examples and ask additional questions, so if you do not know everything immediately it is no problem.

1A. Use of technology
- First I am interested whether you have experience with the use of technology. Which technology do you use? You can think of a laptop, smart/telephone, computer, tablet?
- (if not clear yet) Do you also use technology to get and keep in touch with others. Can you mention examples of that? What would you rather not use for this purpose? Why not?

1B. Promoting factors and thresholds
- What was for you the most important reason to use these technologies?
- What are, on the other side, thresholds to use new technologies?

Part 2: Socioemotional Selectivity + Selective optimization with compensation (+/- 15 min)
I would now like to talk with about what you find important in life and how that has changed over the years – if you still can remember that of course. First I will ask you some questions about what you think is important in life in general, afterwards I will ask which persons are important for you.

2A. Aims in life
- What is important for you in life?
- How do you spend time on these things that are important for you? (technology?)
- Are there things you still would like to do in life?
- Are there things that were important for you in the past but not anymore?
- Are there things that were important but you are not able to do anymore? (compensation)

2B. Friendships and social contacts
- <u>Who are important /mean a lot for you?</u> Do you see these people often?
- Do you ask them to <u>advice</u> you when making important decisions?
- Who were important for you <u>in the past</u>? Has this <u>changed</u>?
- How do you <u>keep in touch</u> with these important persons? (live, <u>technology</u>, different)
- Are you <u>satisfied</u> with this? Are you <u>happy</u> with these contacts? Why (not)?
- Reciprocity, exchange: how has the balance changed over time?
- Functionality vs. emotional connectedness.

Part 3: Intimacy/ Self-disclosure (+/- 15 min)
We just talked about who are important for you. I now would like to ask some more questions about how you experience the contact with these important persons.

3A. With whom?
- With <u>whom</u> do you share things about yourself? (family, friends, new contacts or persons you already know for longer..) Are these the same persons you mentioned at question 2?
- With whom would you <u>not</u> talk about yourself? Why is that?

3B. About what?
- <u>About what</u> do you share things with others about yourself? (what makes you proud, what makes you feel ashamed, positive/negative experiences/memories, the past/the present etc.)? Are you happy with how you do this?
- How important is is a <u>response from the other person</u> for you if you share things about yourself? In which way? (-non-verbal, physical, text, voice, distance, instantly, later)?

3C. Tools to help you to share things about yourself?
- Which <u>tools</u> do you use to share things about yourself? And which <u>not</u>? (media, technology, face-to-face)?
- Emotional vs. factual information
- Have these <u>things changed</u> over the years?

Part 4: Talking about the past (+/15 min)
We just talked about <u>with whom</u> you share things about yourself. I now would like to elaborate more specifically on <u>'talking about the past'</u>. What your preferences are, which tools you (like to) use etc.

4A. With whom and about what?
- Do you like to talk about <u>the past</u>? About what (not)? Why (not)?
- With <u>whom (not)?</u> Who initiates these conversations?
- What do you use in these conversations? (photo's, video's, old objects)

4B. Capturing a life-story
- Would you like it to <u>capture your life-story</u> and share it with others? Why (not)?
- Could other persons (you just told me you tell a lot to XX about yourself) help you to make you enthusiastic about this?
- Do you think the following <u>'tools'</u> could help you with this? (examples: paper books and digital app)
- Which functions should such a tool have (not)? (think of usability, gaming elements, digital/analogue).

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- Could other persons (you just told you tell a lot about yourself to XX) help you to become enthouasiastic?
- Do you think the following tools could help you in that? (show examples: books and digital tools)
- Which functions should such tools have? Which not? (think of user friendliness, game elements, digital/analogue, interaction with others, together or remotely, triggering questions, images etc.).
- If you would capture your life-story, either digitally or on paper, with whom would you then like to share it? And with whom not?

We are at the end of the questions I wanted to ask you. Is there anything else you'd like to tell or ask me? (..) Then I like to ask you friendly for participating in this interview. Would you like to receive a summary of this interview? Then I will send it to you.

IV-B   Interview guide social network elderly person with dementia

Introduction: (+/- 5 minutes)

Introduction researcher/background and aim of the project (very brief), namely to explore.. from the network point of view: explore what is important for elderly people with dementia and how this may be of influence on their acceptance of technology. Next: explore what is important for respondent him/herself in the communication with the person with dementia.

- Ask for permission to make recordings (audio, video?)
- Emphasize anonymity and confidentiality
- Emphasize open conversation
- Emphasize that no answers are wrong
- Ask for additional questions of participant

Part 0: General questions (+/- 5-10 min)
Aim: To get insights in the context of the respondent, , to make the respondent feel comfortable.
- What is your relationship with the person who visits the care farm?
- For how long does XX already visit this care farm? What was the reason for coming here?
- How is the health status of XX? How did this develop over time?
- May I ask you what your age is?
- What about your family situation? Do you live alone, with a partner, do you have (grand)children?
- What about your work situation?
- What does your care for XX include?
    * most personal questions about XX only ask from the most important person?

Part 1: Technology use in general: (+/- 10 min)
As I told you, I would like to get to know, among others, something more about the use of technology of the person visiting the care farm. I'm interested in your opinion on this. When we continue the conversation, I will mention several examples and ask additional questions, so if you do not know everything immediately it is no problem. If something additional pops up in your mind later on, please feel free to share it.

1A. Use of technology
- First I am interested whether XX, according to you, has any experience with the use of technology. Which technology does XX use? You can think of a laptop, smart/telephone, computer, tablet? Which are, according to you, most important for him/her?
- For which purpose would XX, according to you, use technology which s/he doesn't do yet?
- For which purpose would XX, according to you, never use technology? What's your opinion about that?
- Does XX use technology to get/keep in touch with other persons? And with you?

1B. Promoting factors and thresholds
- What was for XX, according to you, the most important reason to use these technologies?
- What are for XX, according to you, on the other side, thresholds to use new technologies?
- How important are you, according to yourself, in the decision XX made in these domain?

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Part 2: Socioemotional Selectivity + Selective optimization with compensation (+/- 15 min)
I would now like to talk with about what <u>you think</u> is important for XX in life and if you think this is different than in the past – if you still can remember that of course. First I will ask you some questions about <u>important things in life</u> in general, afterwards I will ask <u>which persons</u> are important for XX.

2A. Aims in life
- What is, according to you, <u>important</u> for XX in his/her life?
- How does XX <u>spend time</u> on these things that are important for him/her? (technology?)
- Are there, according to you, things XX <u>still would like to do</u> in life?
- Are there, according to you, things that were <u>important for XX in the past</u> but not anymore?
- Are there, according to you, things that were important but XX is <u>not able to do anymore</u>? (compensation)

2B. Friendships and social contacts
- <u>Who are</u>, according to you,<u> important /mean a lot for XX?</u> What do these persons mean for XX, does XX see these people often?
- Does XX ask you for <u>advice</u> when making important decisions? And others?
- Who were important for you <u>in the past</u>? Has this <u>changed</u>?
- How does XX, according to you, <u>keep in touch</u> with these important persons? (live, <u>technology,</u> different)
- Are you <u>satisfied </u>with this? Are you <u>happy </u>with these contacts? Why (not)?
- Reciprocity, exchange: how has the balance changed over time?
- Functionality vs. emotional connectedness.

Part 3: Intimacy/ Self-disclosure (+/- 15 min)
We just talked about who are important for XX. I now would like to ask some more questions about how XX, according to you, experiences the contact with these important persons.

3A. With whom?
- Does XX share things about his/herself with you?
- With others? (family, friends, new contacts or persons XX already know for longer..)
- With <u>whom not</u>?

3B. About what?
- <u>About what</u> does XX share things about his/her self with you? About what does s/he like to talk, about what not? (what makes him/her proud, what makes his/her feel ashamed, positive/negative experiences/memories, the past/the present etc.)?
- Do you like to share things about yourself with XX? How does XX respond on this? About which issues do you share things? Do you have the impression this enriches your relationship?
- Emotional vs. factual information

3C. Tools to help you to share things about yourself?
- Which <u>tools</u> does XX, according to you, use to share things about his/herself? And which <u>not</u>? (media, technology, face-to-face)?
- Which tools do <u>you use</u> to share things about yourself with XX? Did the feeling of intimacy between the two of you change?

Part 4: Talking about the past (+/15 min)

We just talked about whether XX shares things about his/herself with you, if you share things about yourself with XX and <u>about what</u>. I now would like to elaborate more specifically on <u>'talking about the past'</u>. If you like to do that with XX, if you think XX likes to do that with you, what tools you ('d like to use etc.).

4A. With whom and about what?
- Does XX, according to you, like to talk about <u>the past</u>? About what (not)? Why (not), do you think?
- Who initiates these conversations?
- What do you use in these conversations? (photo's, video's, old objects)

4B. Capturing a life-story
- Would you like it to <u>capture the life-story of XX</u> together to help you to talk about him/her?
- Do you think XX would like to do that? Why (not)?
- To what extent do you think the following <u>'tools'</u> could help you with this? (examples: paper books and digital app)
- Which functions should such a tool have (not)? (think of usability, gaming elements, digital/analogue, triggering questions/photo material etc.).
- Could such a tool help you in a certain way in your care for XX?

We are at the end of the questions I wanted to ask you. Is there anything else you's like to tell or ask me? (..) Then I like to ask you friendly for participating in this interview. Would you like to receive a summary of this interview? Then I will send it to you.

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IV-C Interview guide professional

Introduction: (+/- 5 minutes)

- Introduction researcher/background and aim of the project (very brief).

Aim of this study is multiple:
- First we would like to explore what is important for elderly persons with dementia when it comes to maintaining/deepening relationships and how this influences their acceptance of technology.
- Next the interviews will serve as input for a digital app/game we would like to develop to help elderly persons with (early) dementia and their social network (spouse, family, friends, care professionals) to recall personal memories and capture these in a digital life-story book. Not only working towards a final deliverable, which is a personal life-story book with the overview of someone's life, but even more to promote and improve the communication between elderly persons with dementia and their beloved ones.
- The reason I would like to interview you as a professional, is first to collect insights about the elderly respondents with dementia from your point of view. Next we would like to hear your opinion on the application of the aimed app/game in the setting of the care farm.

- Ask for permission to make recordings (audio, video?)
- Emphasize anonymity and confidentiality
- Emphasize open conversation
- Emphasize that no answers are wrong
- Ask for additional questions of participant

Part 0: General questions (+/- 5-10 min)
Aim: To get insights in the context of the respondent, ice breaker, to make the respondent feel comfortable.
- What is <u>your function</u> at this care farm?
- For <u>how long</u> do you already work here?
- What is, according to you, <u>unique</u> of the setting of the care farm?
- Can you give an impression of <u>another day at the care farm</u>?

Part 1: Technology use in general: (+/- 10 min)
As I told you, I would like to get to know, among others, something more about the use of technology of the person visiting the care farm. I'm interested in your opinion on this. When we continue the conversation, I will mention several examples and ask additional questions, so if you do not know everything immediately it is no problem. If something additional pops up in your mind later on, please feel free to share it.

In the last couple of weeks, I conducted interviews with several visitors of this care farm, namely mister XX and misses XX.
- Why do you think these persons participated in this study?

The next questions partly concern the persons I just mentioned. We already had a conversation with them, as well as with the persons around them. In this interview with you I am mainly interested to these persons in the setting of the care farm.

1A. Use of technology

- To start, I am interested whether XX & XX, according to you, has any experience with the use of technology.
- Which technology do they use according to you? You can think of a laptop, smart/telephone, computer, tablet? Which are, according to you, most important for them?
- Do you use technology in daily practice of the care farm? Individual, with support, as a group activity? Who takes the initiative?
- How do XX & XX like such activities? Do they, in your opinion, like these activities?

1B. Promoting factors and barriers
- What are, in your opinion, for visitors of the care farm, important reasons to technology?
- What are, in your opinion, on the other hand, important barriers to use technology?
- Would you be able to say something more specifically about considerations of the persons I talked to in the last couple of weeks?
- How important are you, in your opinion, when it comes to the use of technology?

Part 2: Socioemotional Selectivity + Selective optimization with compensation (+/- 15 min)
I would now like to talk with you about what you think is important for elderly people with dementia. First I will ask you some questions about important things in life in general, afterwards I will ask which persons are important for elderly person with dementia in general and XX & XX more specifically.

2A. Aims in life
- What is, in your opinion, important for persons with dementia? Is this different compared to other people? (youngsters, healthy elderly people)?
- Are there, in your opinion, things that were important in the past for the elderly visiting your care farm, but not anymore?
- Or: that they are not able to do anymore? Are there other ways they now do these things?
- Do you have any specific information with regards to the persons I interviewed?

2B. Friendships and social contacts
- Who are, in your opinion, important for XX & XX? What do these persons mean for them? How is this visible?
- How do XX&XX, according to you, keep in touch with these important persons? (live, technology, different)
- Is there a feeling of belonging to a group among the visitors of the farm? Are the visitors open to each other? Are they interested in each other?

Part 3: Intimacy/ Self-disclosure (+/- 15 min)
We just talked about who are important for XX & XX. I now would like to ask some more questions about how they, in your opinion, experience the contact with these important persons.

3A. With whom?
- Do XX & XX share things about themselves with you?
- With others? (family, friends, new contacts or persons XX already know for longer..)
- With whom not?
- Do XX & XX also share things with other elderly visitors of the care farm?

3B. About what?

- <u>About what</u> do XX & XX share things about themselves with you? About what do they like to talk, about what not? (what makes them proud, what makes them feel ashamed, positive/negative experiences/memories, the past/the present etc.)?
- To what extent are the contacts at the care farm <u>reciprocal</u>?
- Emotional vs. factual information

3C. Tools to help you to share things about yourself?
- Which <u>tools</u> do you use in the <u>farm setting</u> to invite visitors to talk about their selves?
- Which tools do XX & XX like to use to share things about themselves? And which <u>not</u>? (media, technology, face-to-face)?

Part 4: Talking about the past (+/15 min)
We just talked about whether XX & XX share things about themselves with you and <u>about what</u>. I now would like to elaborate more specifically on '<u>talking about the past</u>'. If you like to do that with the visitors XX, if you think XX likes to do that with you, what tools you ('d like to use etc.).

4A. With whom and about what?
- Do XX & XX, according to you, like to talk about <u>the past</u>? About what (not)? Why (not)?
- Who <u>initiates</u> these conversations?
- What '<u>tools</u>' do you use in these conversations? (photo's, video's, old objects)

4B. Talking about the past in a group
- To what extent do you think 'talking about the past' is suitable as a <u>group activity</u>?

4C. Capturing a life-story
- Do you think XX & XX would like to <u>capture their personal life story</u> to talk about it with you and others at the farm? <u>Why</u> (not)?
- To what extent do you think the following '<u>tools</u>' could help you with this? (examples: paper books and digital app)
- Would this work as a <u>group activity</u> or rather as an <u>individual</u> activity? (or with support)
- To what extent could these tools help <u>you</u> to communicate/feel connected with the visitors?
- Which functions should such a tool have (not)? (think of usability, gaming elements, digital/analogue, triggering questions/photo material etc.).
- Could such a tool help you in a certain way in your care/work for the elderly persons with dementia?

We are at the end of the questions I wanted to ask you if there is anything else you'd like to tell or ask me? (..) Then I like to ask you friendly for participating in this interview. Would you like to receive a summary of this interview? Then I will send it to you.