MANYME

SOCIAL INTERACTIVE CARE SYSTEM TO SUPPORT THE WELLBEING OF PEOPLE LIVING WITH DEMENTIA

D1.1 USER REQUIREMENTS ANALYSIS

AAL
PROGRAMME

Published in the framework of:

Many-Me – Social Interactive Care System to support the wellbeing of people living with dementia
Many-Me website: www.stage-aal.eu

Authors:

Julia Nuss, terzStiftung
Pawel Nowakowski, ASM
Co-Authors:

Sotia Nicolaou, Materia
Jan Michiel Meeuwsen, MOB

Revision and history chart

Version	Date	Editors	Comment
0.1	29.08.2017	Julia Nuss (terzStiftung)	First version
0.2	20.09.2017	Sotia Nicolaou (Materia), Jan Michiel Meeuwsen (MOB)	Survey analysis updates
0.3	21.09.2017	Eva Reithner (EURAG)	Review and recommendations
0.3	21.09.2017	Sotia Nicolaou (Materia)	Recommendations
1.0	22.09.2017	Julia Nuss (terzStiftung)	Final version
1.1	28.09.2017	Julia Nuss (terzStiftung)	Final version
1.1	5.11.2017	Bjorn Bekkers	Review
1.2	10.11.2017	Julia Nuss (terzStiftung)	Final version 2.0

Disclaimer:

Short description

In contrast to the current European healthcare model where older adults were removed from their homes into long-term care facilities, people suffering from dementia benefit from aging in environments to which they are accustomed. To support these people and their caregivers digital systems can be helpful.

Many-Me develops a support system for people with dementia and their informal and formal caregivers. This document contains a description of the user-centred process applied in the project and reports the findings concerning the end-user requirements. As a result, the findings and recommendations for Many-Me are listed, which are taken as inputs for the elaboration of the system requirements and the development of the Many-Me system.

Content

List of figures:

List of charts

1. Introduction

1.2. Objectives

This deliverable describes the requirements of the primary and secondary targeted user groups of the Many-Me solution, the user requirements activities and procedures of four partner countries (AT, CH, CY, NL) that are involved in the user requirements analysis.

The document will be structured as follows: Section 1 gives an introduction and short background information about the Many-Me system. Section 2 describes the definition of the Many-Me user group and shows the personas that build the basis of the user idea. Section 3 contains the state of research that gives a status quo of the current use of digital solutions and the daily challenges with memory problems or dementia. The user requirements analysis was done with the help of three different methods: pilot interviews, interviews and an online survey that are described in section 4 to 6. Section 8 provides a summary and conclusion.

1.3. Scope of the deliverable

The major goal of D1.1 is to give a summary about the definition of the user groups targeted and their requirements related to memory problems / dementia and overcoming of related challenges. User requirements were analysed from three different points of view involving primary users (older adults with memory problems) and secondary users (informal and formal caregivers caring for people with mild or moderate dementia). The main results are listed in a requirements table at the end of this document.

2. Users and Context of use

2.1. Target user specification

To create a system that will be accepted by end-users, it is necessary to understand who those users are. It is important to know in which context they live, what problems and challenges they face in their daily lives and how they will use the new system solution to overcome some of those problems, improve their quality of life and stay independent as long as possible. In order to develop a system that fits to the needs of the future end-users the target group needs to be defined. Therefore, we first identified the potential users of the Many-Me system internally in the consortium and together with the end-user organizations and some experts in the field trying to characterize the user groups as close as possible.

One useful tool are personas that indicates a fictional character of each target user group. A persona represents all relevant characteristics of the final user of the system. The consortium created ten personas that represent the future users of the Many-Me system. All personas contain a short prose text with some personal data in a table at the beginning.

In the following section, the three different main user groups are presented and shortly characterised. Afterwards one persona of each group is shown and how Many-Me could be implemented in their daily life.

2.2. User types

For Many-Me the following user types have been identified:

- **Older adults**: This user group includes older adults who suffer from memory problems or mild to moderate dementia. The person is still living alone, with his partner or other family members in a private home. We consider the primary user aged between 60 and 80+ years and interested in technical assistive solutions.
- **Secondary end-user**: This target group contains informal and formal caregivers who care for a person with mild or moderate dementia. This group can be subdivided on the one hand into partners, relatives, friends, neighbours and other trusted volunteers and on the other hand into professional care givers and people working for mobile care services. A typical secondary end-user can be an adult around 30-70 years old that knows how to use a simple information and communication technologies (ICT)-device without being very fond of it.

2.3. Personas

The following three personas are examples created by the involved end-user organisations. Each represents one user type.

Persona 1 describes a typical primary end-user. The person suffers from memory problems or mild cognitive impairment and is interested in modern communication devices. Mr. Cheng is 92 years old, but still active. He is widowed and has 5 children with whom he tries to stay in close contact.
Using Many-Me could help him feel safer when he goes outside or when he loses the orientation in his environment. Although he lives independently in his own apartment of a nursing environment he sometimes feels insecure when he forgets something. Many-Me helps him to remember.

Name	Mr. Cheng
Age	92
Marital status	widowed, 2 sons, three daughters
Work/job role	Retired. Worked until his retirement at one of the biggest companies in the Port of Rotterdam
Education	No formal education. Only courses related to his work in the port of Rotterdam needed for his work.
Computer knowledge	No computer knowledge, uses a smartphone
Goals/wishes	Health, closer contact to his family
Hobbys	Taking care of pigeons, playing Mahyong with friends (Chinese game with stones/tiles)
(Health) Restrictions	Mild dementia

Family and social contact
Mr. Cheng lives in a modern nursing environment for Chinese elderly with his own house/room in this jointly space. His wife died 16 years ago. He has five children (2 sons, 3 daughters) and a lot of grandchildren he loves a lot.

Memory problems and Dementia
A few years ago, he recognized some memory problems, had them checked and discovered he suffers from dementia. He is aware that his mental health is deteriorating. Early stages dementia causes complaints and sometimes threatening situations (for example, if he goes for shopping on his own).

Media and Communication
Mr. Cheng does not have much computer knowledge, but he knows how to use a smartphone. He uses WhatsApp frequently to communicate with his sons and daughters.
Mr. Cheng wants to have a video and image communication channel with his family. When he feels unsure he wants to see one of his sons or daughters.

Self-image
Mr. Cheng is open minded, honest and outgoing. He likes having other people around, so he does not feel lonely.

Persona 2 describes a typical informal care giver who cares for a relative with dementia. Hans Kleber is 74 and cares for his wife who suffers from dementia for one year. They are living in their own house where his wife Ilse finds her way around easily. Nevertheless, Hans wants an independent life for his wife as long as possible. With Many-Me he has a useful system that helps his wife with her memory and relieve himself a bit.

Name	Hand Kleber
Age	74
Marital status	married, 1 daughter
Work/job role	Retired
Computer knowledge	Owns/works with laptop/smartphone since many years, interested in new technologies
Goals/wishes	Health, live as long as possible together with his wife
(Health) Restrictions	No major health restrictions

Daily challenges while caring for a person with dementia
Hans is 74 years old and has noticed lately that his wife Ilse, also 74, always forgets appointments etc. Even when she goes shopping, she often does not bring half of the desired things and stays away for a long time. When Hans asks her where she has been, Ilse cannot really remember and gives slightly aggressive answers.

Help by Many-Me
Hans talks to his daughter Hannah about these problems and during her research, Hannah comes across Many-Me. With the help of the Many-Me solution, Hans can set up functions that remind his wife, when it is time to do certain things, etc. He can also monitor her when she is on her way for grocery shopping and does not return in time. He can guide her via remote and help her find her way back home. Hans is much more relaxed due to this solution and can easily leave his wife alone without the fear that she gets lost. Many-Me also helps Hans to better understand the disease and gives him the opportunity to train the memory together with his wife.

Persona 3 stands for a formal caregiver who works in a care/nursing home/mobile care service for persons with dementia. Karin Lampe is 45 years old and working for a care institution for people with dementia. She uses the Many-Me service to structure her day to day work in a more efficient way.

Name	Karin Lampe
Age	45
Marital status	married, 2 children
Work/job role	Works in a care/nursing home with PWD
Computer knowledge	Basic computer knowledge, uses her smartphone to communicate with her family and colleagues
Goals/wishes	Wants to structure her work more to work more efficiant
(Health) Restrictions	No major health restrictions

Daily challenges and help from Many-Me

Maria just adopted Many-Me. She is a formal caregiver who works hard, struggling to provide good care for all her patients. The service intelligently arranges her daily caregiving schedule based on patients' needs, their situation, her availability and specific context (e.g. location, hour, task). She finds it very useful to receive alarms when help is urgently needed as well as relevant information from informal caregivers, so she can easily monitor patient's condition. She loves the collaboration and coordination capabilities Many-Me provides, helping her learn and be more effective as part of a support network.

3. Status Quo

The aim of this chapter is a literature review in order to provide a solid background for the user requirements analysis in the Many-Me project. The chapter outlines the state of the art on the subject, addressing particularly the use of digital devices by older people; challenges of caregivers and proposed solutions; and interaction requirements for assistance devices supporting people with dementia and their caregivers.

3.1. Use of digital solutions and assistance devices

We are living in the digital era for quite some time now and we can say that information and communication technologies (ICT) are a natural environment of the Western region and of a significant part of the Asia Pacific. Digital devices and solutions are continuously developed and improved, but there is also a very important social dimension of the whole phenomenon, namely that ICT are increasingly oriented towards groups of people that have not been particularly addressed by high technology before. Among them there are elderly people and people with different impairments or diseases (Cf. Alexandrakis 2017; EPHA; Ferreira et. al. 2014).

Digital solutions are more and more used not only in a traditional medicine as a support in a diagnostics and treatment[1], but also to help people to improve and/or to sustain their quality of life, cognitive

---

[1] *Medical Devices and Systems: ICT and the Future of Healthcare*,
https://www.rvo.nl/sites/default/files/2016/04/ICT%20and%20Healthcare%20Japan.pdf [access: 15/08/2017].

skills and independency[2] . Furthermore, the elderly and diseased people's relatives and/or caregivers are also increasingly offered ICT solutions supporting them in their roles as caregivers.

One of the key facts that should be taken into consideration when addressing a usage of high technology by older people is that they are a heterogeneous group represented by persons with very different experience and attitudes towards new technologies. This variety stems from the fact that old age encompasses more than 30 years which means that depending on age the elderly people have different needs, as well as different physical, cognitive and intellectual problems, financial situations and social resources. Another important factor is living arrangements, e.g. whether one lives alone, with family or in a care institution, and types of attitudes towards new technologies represented by relatives, friends, social workers, doctors, caregivers, etc. Also, tutorial training affects acceptance of ICT. Subjective factors naturally matter, too, like personal experiences, familiarity with technology/computers and one's expectations. Nevertheless, besides those societal and personal aspects, we should be aware of political and legal factors. All those conditions influence a usage of new technologies by the older people in terms of ability, interest and confidence in using ICT (Georgantzi et al. 2014; Adelman et al. 2011; Aronson et al. 2013; Wilkowska, Ziefle 2009).

It is now common and well documented knowledge that:

"People designing technical interfaces, (…) need to take this sensitive relation between usability and acceptance serious. It should be kept in mind that any devices' technical genius and the promised advantage for users' daily needs can only be recognized and highly valued, if the human properties and cognitive specificities are properly recognized, and highly valued. Thus, whenever the knowledge of both the technical and the human factors are incorporated into current design, the devices may meet the demands of users, designers and manufacturers at the same time" (Wilkowska, Ziefle 2009).

Furthermore, a few interesting conclusions were made by the Home Sweet Home project's field studies (Georgantzi et al. 2014) on the older people's attitudes towards new technologies:
1) when people are not very interested in the benefits of technology experience, they are likely to use it;
2) "openness to learn and adopt new things is essential in the process of introducing new technologies to an older person's home";
3) the desire to be healthy and to improve social life is not enough to accept ICT;
4) the very familiarity and interest in new technologies, though possibly increasing acceptance of digital devices, are not necessarily correlated with active using them;
5) assistance devices are more attractive to people who live alone and have no access to supporting ICT solutions;
6) social dimension of using ICT is very important for users (contacts with people);

---

[2] A good example is Active and Assisted Living Programme built around the idea "ICT for ageing well". For detailed examples of assistive technology see https://www2.health.vic.gov.au/ageing-and-aged-care/dementia-friendly-environments/assistive-technology [access: 17/08/2017].

7) people, who are in touch with a doctor or a nurse, or live in sheltered housing are not as interested in supporting ICT systems as others;
8) personalization of services is very important;
9) accessibility of new applications is necessary, however also a support from trusted people is crucial;
10) assistance devices must be reliable;
11) lack of affordability is very frequent problem;
12) when it comes to installation of the devices at homes, important aspects are aesthetics and privacy.

At least some of those findings, i.e. 1), 2), 9), 10), 11) 12) are confirmed by other research on the topic (Wilkowska, Ziefle 2009; Willemse et al. 2015; Preliminary guidelines [...] 2014). When it comes to social dimension, though, it should be added that some of older adults' state that using ICT would negatively influence their social contacts in real life (Willemse et al. 2015). Also, not all research results indicate that older people consider new technologies as costly (Alexandrakis 2017).

Another important, though rather underrated, factor influencing the uptake of assistance devices by older people is that they tend to be relatively present-oriented and not willing to take the effort of learning how to use the devices that might be useful for them in the future. They tend to think it is not worth the costs (time, frustration etc.). Therefore, presenting the benefits of proposed solutions seems to be even more crucial. It appears, then, that usefulness is more important for the uptake of technology than the easiness of using (Wilkowska, Ziefle 2009; Willemse et al. 2015).

On the other hand, main reasons given by the elderly people for their willingness to use ICT are needs for:
1) controlling their lives and living independently;
2) living safely at home and around the house;
3) increasing social contacts;
4) performing different activities on the Internet, like internet banking, financial administration, exchanging e-mails, searching for information, playing games and online shopping (Willemse et al. 2015; cf. Alexandrakis 2017).

Eurostat data indicate that the percentage of people between 65 and 74 years, who use computer on a daily basis, has significantly increased in the EU. From 2010 to 2015 the growth was by 14 percentage points – usually by 3 percent yearly – up to 33 percent. It means that within five years the number of older people, who use computer every day, increased from a fifth to a third. Importantly, when comparing these results to data for people aged 25 to 64, it appears that the growth is much more rapid in the case of older people which can be observed in the Figure 1. Within five years the proportion between the first group (older people) and the second group (25-64) decreased from 1:3 to 1:2. When it comes to the Internet, in 2015, 41 percent of older people used it at least once a week[3].

---

[3] A look at the lives of the elderly in the EU today,
http://ec.europa.eu/eurostat/cache/infographs/elderly/index.html [access: 15/08/2017].
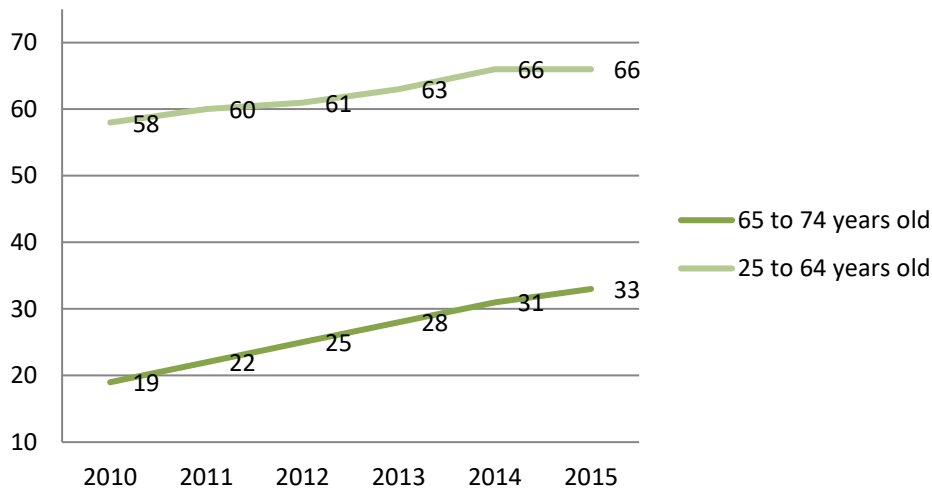
Figure 1: Percentage of individuals in the EU who use computer daily

Source: own elaboration based on Eurostat data

One of the reasons might be that the increasing number of people reaching 65 has used the Internet before or was confronted with the internet due to their professional career (probably also daily).

However, it should be also noted that there are still many older people in the EU who have never used a computer. According to Eurostat, in 2015, it was 45 percent, in comparison to 13 percent among people aged 25 to 64. This, naturally, hinders a successful implementation of digital solutions and assistance devices oriented towards older users (Willemse et al. 2015).

Nevertheless, in this area, too, the gap between the two groups has been decreasing. Moreover, within five years the percentage of older people having no experience of using computer decreased by 15 percentage points.
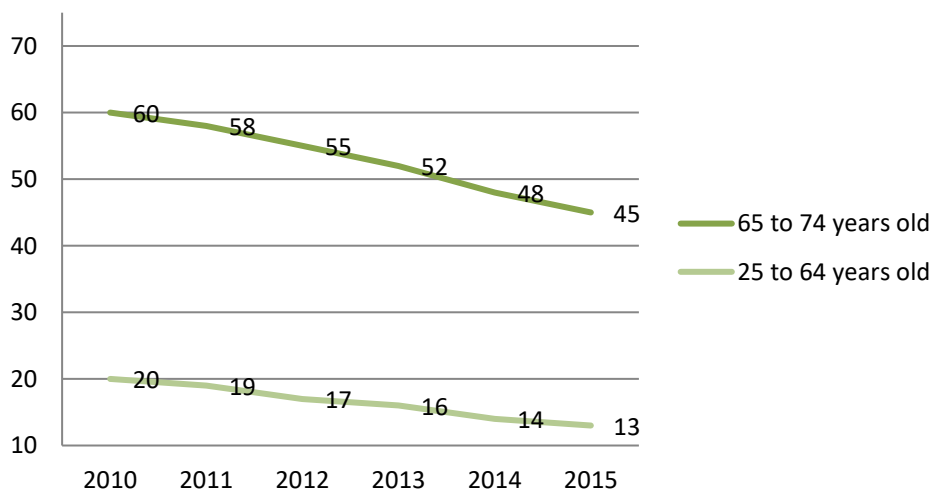
Figure 2: Percentage of individuals in the EU who have never used computer

Source: own elaboration based on Eurostat data

3.2. Review of daily challenges for informal and formal caregivers and solutions for it

People with dementia are cared by both formal and informal caregivers, however, as the number of dementia patients is rapidly growing, much more than the number of formal carers, there will be an increased need for informal caregiving in the future. On the other hand, caring for a person with dementia is a difficult task and is likely to cause psychological and physical symptoms (van Knippenberg et al. 2017).

Among the most important daily challenges for caregivers, the following can be mentioned (Cf. The Dementia Guide 2017):

1) stressful conditions and need for being resistant to stress;
2) high responsibility for a person under care;
3) continuous alertness in order to ensure the safety of a person under care;
4) little free time or no free time which hinders looking after their own help;
5) not enough sleep (sometimes);
6) dealing with changed behaviour and mood of a person under care;
7) dealing with own different emotional states (e.g. loss, guilt, anger vs satisfaction from supporting a person under care);
8) helping a person under care to maintain possibly good quality of life and stay at home as long as reasonably possible;
9) being very patient with a person under care (e.g. being prepared to repeat, remind and explain as well as to talk with a person who repeats himself or herself);
10) being physically tired or depressed;

In general, it is claimed that family carers "carry a disproportionate burden of responsibility in the absence of a comprehensive and integrated public response" (O'Shea, Monaghan 2016).

As a response for those challenges, main advices for caregivers in terms of their own wellbeing are (The Dementia Guide 2017):

1) to look after own health and wellbeing (among other, to visit a GP);
2) to eat a balanced diet and to get enough sleep and exercise;
3) to have some free time, to relax, to get out regularly, to meet friends, to be socially active;
4) to have short breaks, if possible;
5) to consider day care or replacement care (a temporary supporting care);
6) to exercise a right to a carer's assessment and to support in a caring role (sometimes it is possible to have support from local authorities, although not necessary free of charge);
7) to use available information and advices;
8) to take advantage of support from family, friends, health professionals, memory services, social services, talking points, carers' support groups and organizations (there are numerous support workers who can give practical information, guidance, support; they can visit a carer's home or get in touch via phone);

9) to develop a good relationship with a patient (trying to understand him);

10) to make eye contact, listen carefully and speak clearly while communicating with a person under care[4];

11) not to ask lots of questions to a person under care at once and give this person enough time to answer;

12) not to take personally the difficult behaviour of a person under care; this can be a way of trying to tell something important, e.g. about pain or frustration; it is a good idea to contact with a doctor or a representative of a special institution;

13) to try to keep positive attitude (which has a positive influence on a person under care) and remember how valuable is a carer's help;

14) to spend quality time together with a person under care, e.g. going for a walk, to the cinema, etc.;

15) in the case of a working carer, to try to arrange flexible working.

When it comes particularly to care for a person with dementia, there is also a possibility to contact with a dementia specialist nurse (Admiral nurse) who can provide varied support: practical, clinical and emotional. There are also dedicated discussion forums for people who care for a demented person (The Dementia Guide 2017).

The evaluation report of HSE & Genio Dementia Programme (Cullen et al. 2016) shows that ICT/telecare programmes supporting people with dementia were particularly helpful for their caregivers. Among the most valued benefits were reassurance and alerting a carer when the assistance for a person with dementia was needed, for example in the case of falls. Another important benefit for some caregivers was the feeling that due to assistance devices they could help the diseased persons to stay at home longer. Also, having more and better sleep was evaluated as a significant benefit as well as – in the case of full-time caregivers – having some free time for themselves. The report also showed a couple of negative aspects, like noisy alarms, over-sensitive sensors, invasion of privacy of a person under care. Nevertheless, caregivers were very satisfied with using telecare.

As already mentioned, caregivers are also offered tailored technological support. There are dedicated ICT solutions for persons caring for people with dementia, too.

One of such solutions is the experience sampling method (ESM), which is a "structured diary method that can be used to self-monitor subjective experiences in daily life". Importantly, ESM measures a carer's emotional states daylong which enables a dynamic assessment of the experience from the whole day, and not only from the perspective of the strongest emotions which might be emphasised by a carer's memory. Thus, ESM provides caregivers with possibility to better monitor their experience and stress positive emotions. As a result, caregivers' motivation might be strengthened as well as they may be prevented from becoming overburdened (van Knippenberg et al. 2017; 2016).

---

[4] See also https://www.med.unc.edu/neurology/divisions/memory-and-cognitive-disorders-1/dementia-1/family-concerns-1/communication-challenges [access: 15/08/2017].

Another solution is remote mode telecare which enables a caregiver, who does not live with a person he/she cares for or is often outside the house, monitoring that person. The system is based on sensors installed in the house or worn by a demented person. In case of emergency, an alert is triggered. There are also similar systems managed by a monitoring centre. Via a call centre, text message or even through logging into the system a carer is informed when something critical happens (Cullen et al. 2016).

It should be noted that not only persons under care but also caregivers, particularly informal, often lack advanced ICT literacy. They themselves are often older people who need to be caregivers for their spouses or relatives. Therefore, they also need training and support with using the telecare and assistance devices. That was the aim of the Carer+ programme which developed "Toolkit for developing the Digital Competences of Carers" (Cullen 2015).

Paradoxically enough, according to a study on care planning in dementia, another challenge for informal caregivers is their "low to moderate agreement with PwD[5] [person with dementia] on preferences for end of life treatment" (Harrison Dening et al. 2016). The study concludes:

"This underscores how planning for care at the end of life is beset with uncertainty, even when the carer and PwD perceive the care-giving/receiving relationship is good. Families affected by dementia may benefit from early and ongoing practical and emotional support to prepare for potential changes and aid decision making in the context of the realities of care towards the end of life" (Harrison Dening et al. 2016).

3.3. Review of interaction requirements – Communication/information/visualization

Provision of adequate care for older people is one of the main challenges of the present day. It concerns particularly people with dementia (Meiland et al. 2010). The idea of ICT for ageing well is based on many-sided adaptation of the developed solutions for older users – since they face many barriers, from medical and cognitive to societal and cultural, it is a sine qua non for a successful employment of the assistive devices and digital solutions for elderly users.

It is especially the case for people with dementia, who additionally are a heterogeneous group, meaning that different persons live in different conditions, face varied disabilities and have different needs (Meiland et al. 2010; see chap. 3.1.). One of the main challenges for designers is communication with seniors, in particular with those having speech or hearing problems and with people with dementia. In such situations designers must rely on their intuition and experience. On the other hand, most of them are not familiar with the specifics of ICT services and products oriented towards older people (Jiang et al. 2015).

---

[5] PwD = person with dementia

Fereira et al. (2014) define the user requirements for the purpose of the application "Medical Assistant", however their conclusions are universal. According to them, such an application should[6]: (1) inform users in an everyday language; (2) provide touch and speech interaction for everything in order to facilitate user interaction since some users may have physical or cognitive limitations; (3) be reliable and credible because the user must trust its advices and alerts; (4) as elders usually have low proficiency with technology and vision problems it is crucial that the application avoids overloading content and small icons; (5) have extra care with language and dimension; (6) adapt to the user and the context; (7) provide personalization; (8) be able to provide more information when the user wants it; (9) provide help to the elder when they present difficulties interacting with the application; (11) provide a group of guides".

These conclusions are confirmed by other researchers. Moreover, when it comes to not particularly medical assistance devices, but to assistant devices for elderly people as such, Dröes et al. (2010) state that it is required and claimed that:

1) textual reminders should be as simple as possible;
2) reminders should be personalized with text and clear pictures;
3) when a phone is provided, it should be a picture-dialling phone, and the dialling procedure should include as little steps as possible;
4) option for personal configuration of music/radio is welcomed;
5) it is a good idea to add a clearly visible clock and day indicator;
6) text reminders can be added with flashing screens and/or sound signal in order to communicate messages more efficiently;
7) external design of devices is important for the users; it is important that the devices blend with furniture etc.;
8) good readability on mobile devices should be assured.

Wallace et al. (2010) added to this list other important requirements:

1) lower sound frequencies are better for older people;
2) human – computer interactions should be simplified (however too simplified solutions are not welcomed by more experienced users): simplified structure, contrast between text and background, increased text and target sizes;
3) most informative information should be presented first.

Moreover, instructions should be neither too weak nor too strong, because a person might respectively ignore it or oppose to it (Teipel et al. 2016).

When it comes strictly to electronic spatial assistive devices, a large panic button in a signal colour is required in order to request help. The button should be situated on a point where it cannot be pressed by accident. Furthermore, the preferred dimension of the device should not extend 50 x 50 x 20 mm and should weigh not more than 100 g. A preferred shape of a device is a bracelet. Also voice channel is required in order to enable a communication with a caregiver (Schneider, Henneberger 2014).

---

[6] Quoted almost *in extenso*, in a bit compressed form.

4. Requirements analysis: pilot interviews

Before the interviews were asked to a huge amount of people a pilot test phase was seen as useful. Whereas, some information can be used from further studies and out of the literature, there are issues that need to be directly addressed for the Many-Me project. The Many-Me project seeks to overcome physical and psychological problems related to progressive intellectual deterioration, which is a characteristic symptom for dementia, a clear requirements analysis to this subject needs to be done. It is important to understand the special daily challenges and circumstances of those people and their caregivers.

4.1. Goals

To make sure asking the correct questions and especially in a way that the results are useful for the analysis and further development of the Many-Me system a pre-test is useful. We used this method to figure out what questions can be answered by elderly people suffering from mild to moderate dementia and which questions are most useful for the further user requirements analysis. To develop a system for people with dementia means to find out their needs, behaviour, routines and how to cope with the disease. The first insight in this topic and becoming acquainted with the fact of dementia is of major concern for the present pilot study.

4.2. Research questions

The research questions were structured in five parts that describe the major parameters. The five parameters are integrated as followed:

Daily life

These questions consider the difficulties and challenges of daily life when suffering from dementia. Especially routines and situations where assistance is required that could be supported by the Many-Me project were of huge interest.

Care activities – problem-solving, assistance, procedures, measures

This question part sheds light on the role care activities play in the daily life of people suffering from dementia. Both self-help in terms of problem solving/coping with challenges and assistance by third persons and assistance technology shall be covered. This also includes measures taken for prevention, recovering or training.

Social aspects – partaking, information sharing, involvement of communities

This parameter should identify the readiness of the involved target groups to exchange information about (aspects of) the impairment and in what way they approach and make use of each other and each other's knowledge. Therefore, it is important to know, what people are being consulted for assistance and how far different stakeholders are being admitted into the confidence zone of affected individuals. Information sharing attitude, open-mindedness and transparency in the handling of the impairment are additional interests.

Motivation and learning

We want to find out what people are curious about to learn in order to avoid memory problems and what their attitude is regarding prevention and training. This includes both motivational and content-related aspects.

ICT – types, acceptance, areas of application

The familiarity with and acceptance of assistance technology shall be investigated, and areas of application identified. Areas of deployment of assistance technology and chances of adoption of potential features should be included.

4.3. Method

4.3.1. Target Group

The target group for the pilot interviews was defined as elderly people with mild or moderate dementia and informal or formal caregivers from people with this impairment. People that were known by the end-users' organisations were chosen to guarantee an honest and useful feedback. At the end, a total of 20 people were asked by all end-user organisations (5 per organisation) that cover all end-user groups.

4.3.2. Research design and implementation

The research design was developed using the input from the description in the project plan. Based on the above-mentioned research parameters, all partners were invited to state their opinion from the perspective of their background and experience. All questions need to be seen as a guideline for an open conversation and may not be taken literally. Nevertheless, all question groups needed to be covered in each interview.

4.3.3. Language

As the interview guideline was carried out in the mother language of each partaking country, translations in other languages needed to be made by each end-user organisation.
Questions were not literally translated but in line with their sense. After ending the survey, all results were converted back into English and qualitative comments were translated by each included partner according to their sense.

4.3.4. Limitations

As some of the current interviews are addressed to people with dementia, the data gathered here shall be taken with care. Although responses can give indications about preferences and requirements by the respondents, some of the questions may be subject to interpretation and different experiences or the simple dealing with cognitive impairment. For example, the participants may have individual ideas or associations regarding specific assistance, which could provoke different reactions on their part depending on their point of view. Moreover, primary users may have a different perception about their cognitive impairment.
Besides this, some questions were too complex for people with dementia, so they could not answer them.

4.4. Findings

The results described in the following section are structured in the same order as in the questionnaire. This manner was chosen because a lot of answers were similar in all end-user groups.

4.4.1. Daily life

One important parameter that was nearly named by all respondents is the problem to find the way back or losing orientation about what day and what date it is. Besides this, the capacity of remembering things, e.g. words, events and relocated things decreases. The respondents reported that this causes stress to the concerning person as well as to the relative or caregiver. But not only the difficulties in remembering things is getting a problem but also losing mobility and the motivation to get up in the morning and doing the daily routines.
These challenges imply a lot of assistance that the older person requires. People suffering from moderate dementia need help with their basic daily routines like eating, drinking and daily hygiene. People with mild dementia need support with reminding on dates, medication intake and appointments. Here the respondents caring for a person with dementia show that the disease manifests differently per each person and that people with dementia are in some case not able to stay alone or even live alone. The consequences are that the person with dementia never goes out alone and therefore often stays at home.

4.4.2. Care activities

For understanding the care activities that PwD make use of and the caregivers provide, a closer look should be taken on the assistance and assistance technology that is already used or can be envisioned. Most PwD with mild or moderate dementia life with their family members or in a nursing home. They help them with the daily routines and give them a feeling of security which is very important for both sides.

Most people in distress use an emergency button where they can call for help from outside. This is the only tool people know and that is seen as helpful. Other assistance technology is less known or not available yet. In addition, some PwD cannot imagine using any kind of assistance technology, because it looks too complicated at a first glance. The respondents named that the forthcoming assistance technology need to be very easy to use and not overwhelming with too many functions that are not necessary.

4.4.3. Social aspects

An important part of Many-Me is the social interaction and in addition the information exchange and involvement of stakeholders. All respondents reported that information about any kind of medical data is confidential. They answered that all health information should only be shared within the family or care institution. All information shared with the PwD and their informal caregivers is regarding how their lives will be influenced by the impairment in every stage and anything that they will have to undertake and deal with. There is a clear transparency between the stakeholders. The informal caregivers and the PwD are consulted basically by the doctor who provides guidelines to the rest of the health care professionals who are involved in the patient's care.

The formal caregivers responded that information about the patient is kept in a formal care file that every involved and authorized person can read. Some of them exchange the information by phone to get quick information.

4.4.4. Motivation and learning

As we know from other projects that older people are motivated to stay fit and healthy and therefore doing some exercises. But the caregivers told us that there are other people that can only be hardly motivated doing some exercises. In those cases, the informal caregivers and the persons with dementia themselves resign easily especially in eating and drinking.

A very important point for the development of a new technological system is the learning behaviour of older adults. The participants responded that it is easier to learn new things where you already know something. To learn total new things is very complicated, because sometimes the older adult has not enough knowledge to learn new (technical) things.

But not only the older adults themselves need to learn to work with modern technical devices, but also to attend seminars in order to enhance their knowledge and skills, which is indicated by some healthcare professionals.

One point that is especially important when developing a system for people with dementia is the structure of the system. Their relatives and other caregivers remark that you must avoid decision making while using modern technology.

The professionals have a positive attitude towards technology and believe that the ICT will be very useful since they will be able to communicate with other professionals involved in their cases as well as to enhance their knowledge and skills through the platform by exchanging knowledge. The ICT can be helpful for monitoring patients' medication adherence and any other important aspects that they need to pay attention to, according to the importance of each aspect: checklist, charts and reminders will be helpful features to be included in the ICT. Mainly any changes on the physical aspects and changes in behaviour will be important to be included in the platform.

4.4.5. Information and communication technology

The people with dementia were asked in this interview session regarding their technology knowledge and they responded that they have hardly no experience with modern technology, because most of them have less experience with modern technology in their further working life, which was also confirmed by their relatives. In addition, they cannot envision where modern technology can be utilized in care situations can be helpful. In contrast, their relatives and caregivers use smartphones and other modern devices and have quite a positive attitude towards modern technology.

The professionals do not currently use any kind of assistance technology for the monitoring of the PwD. They usually use messenger programmes (Viber, WhatsApp etc.) for the in-between communication of the professionals on case updates. The professionals are very interested in trying to use ICT for their work, since it will enable various professionals to get informed about their patients and monitor closely their health, symptoms and any changes that may occur so as to intervene as soon as possible.

4.5. Recommendations

The findings from the pilot interviews give a first insight in the daily life of people with dementia and their informal and formal caregivers. According to the experience gained from these interviews, it is hard to work with people with moderate cognitive impairments. They have quite a lot memory problems that makes it relatively difficult to work with them in the test phase. Furthermore, the disease is unpredictable.

This leads to a first decision of only questioning people with mild dementia and memory problems in the next interview session.

Nevertheless, some recommendations can be made from the findings.

Daily life

Most people suffering from dementia have problems with their orientation, regardless of whether they are outside or inside their home. The developers must make sure to offer a secure system that is accepted by the elders themselves and easy to handle especially in a stressful situation.

Care activities

The question about caring activities can be better answered by the caregivers than by the older persons themselves. For the following interviews, it only makes sense to ask the challenging questions to the caregivers.

Motivation and learning

As the learning behaviour is an important aspect when developing applications for older adults, it is necessary to ask thorough questions about the technical knowledge that the end-user have. It is imperative that the system is easy built and with less functionalities, so that less stress can occur.

Information and communication

Because of older people suffering from dementia scarce interaction with modern communication devices, it is necessary to find out in what way they can be introduced to it. This point should be taken into account by the developers when building the system.

5. Requirements analysis: Interviews

5.1. Goals

The second wave of end-user input took place in July 2017 and focused on the aspects that were identified in the previous pilot interviews. The aim of this interview section was to capture the findings from the initial interviews, to gather furthermore information about living and coping with dementia. This method was used to get insight in the topic and to discover issues that were not known yet.

5.2. Research questions

The research questions were structured in the same way as in the pilot interviews; thus, they were also divided into five parts. The first one covers the daily life, including challenges, routines and emotional as well as mental conditions. The second section focuses on care activities such as problem-solving, assistance, procedures and measures to find aspects in these activities which could be optimized the usage of ICT technologies. The next section treated the social aspects like partaking, information sharing and the involvement of communities. Motivation and learning was the subject of the fourth section which included education, consulting, problem-solving attitude and incentives. The fifth and last section gave attention to the ICT, especially its types, acceptance and areas of application.

5.3. Method

5.3.1. Target Group

In total 50 older adults with dementia and their informal or formal caregivers participated in the interviews. 32 older adults with mild dementia with an average age of 77, 9 informal caregivers with

an average age of 60 and 9 professional caregivers aged between 21 and 57 were questioned about their needs, requirements and challenges.

5.3.2. Research design and implementation

The research design was developed by using the input from the pilot interviews and the description in the project plan. Based on these research parameters, all partners from the end-user organisation team stated their opinion and helped in developing the questionnaires. The interview need to be seen as a guideline for an open conversation and may not be taken literally. Nevertheless, all question groups needed to be covered in each interview if possible.

5.3.3. Language

As the interview guideline was carried out in the mother language of each participating country, translations in other languages needed to be done by each end-user organisation.

Questions were not literally translated but they were in line with their sense. After ending the survey, all results were transformed back into English and qualitative comments were translated by each included partner according to their sense.

5.3.4. Limitations

As some of the current interviews are addressed to people with dementia, the data gathered shall be taken with care. Although responses can give indications about preferences and requirements of the respondents, some of the questions may be subject to interpretation and different experiences or the simple dealing with cognitive impairment. For example, the participants may have ideas or associations regarding specific assistance, which could provoke different reactions on their part depending on their point of view. Moreover, primary users may have a different perception about their cognitive impairment.

We acknowledge the difficulty of people with dementia to answer to some questions, however their input is important, thus we decided to include them in the interview process. This circumstance leads to the decision to address people with memory problems when putting forward the user requirements survey.

5.4. Findings

5.4.1. Primary end-users

Daily life

To understand the daily life of older adults with memory problems, a closer look should be taken on the challenges that they confront.

Regarding the everyday life, most respondents stated to have no serious memory problems, but sometimes forgetting they forget things like the place where they left their glasses. Others reported that they cannot recall names or persons/places they knew before. Another instance mentioned by the PwD was that they sometimes forget why they are going to the kitchen. To overcome the effects of the impairment the affected people make use of lists, agendas to remind them of appointments, birthdays and daily activities. Even if they find some solutions to deal with the impairment in their daily life, some of them are still annoyed by this condition.

In this connection, the emotional drain should not be forgotten. The primary users stated that they are afraid of being embarrassed, others declared that they get angry, which leads to stress and even worse results. Some users cannot accept the situation, some say they do not have any special emotion while others get nervous, restless or doubtful, confused or feel helpless and alone when they forget or misplace something.

As it is known from the literature discoveries, suffering from memory problems or dementia can cause stress to the affected people. To overcome such stressful situations people named four different methods: use old memories to calm down, ask other people for help, strict organisation of the day, do not change any routines.

Care activities

When asked which caregiving activities are more important than others, the majority of participants do not have any preferences. Others think that the personal care like hygiene morning routines and help with eating and drinking are most important to them, while some stated that physiotherapy is the most important element in order to stay mobile and fit.

Social aspects

As already reported above an important part of the Many-Me system is the social interaction between different end-user groups. Therefore, the system must make sure to work in a very safe way in regards to personal data. While the majority of the questioned primary end-users do not want to exchange medical data, some are open to talk about their impairment and would like to exchange even medical data. Concerning the handling of the impairment within the family or friends, the clear majority is completely open minded, mostly because their friends have the same or similar impairments. Only five out of twenty-nine respondents, state that they do not talk much about it, mostly because they are scared to be rejected or excluded.

Another objective of Many-Me is to connect people but this is not as easy as it may seem. Nearly all questioned people state that they are not interested in making new friends because they already have

a lot or only need their family. Only three seniors can imagine getting in touch with new people with the same impairment or would get in touch with professionals if the impairment would get worse. About half of the users say that the contact with friends and families is very important for them but at the same time they state that it is hard to find new friends.

Motivation and learning

When developing a new technical product that covers an aspect that is quite new for the users it is important to find out the level of participants' willingness to learn to use it or if they are in the position to learn it. Most of the participants are highly motivated to stay active and fit or to continuously train their memory. They do this because a well-trained memory is helpful to stay independent. Moreover, the importance of emotional support was highlighted by the participants, especially when loosing brain function. The primary end-users declared, that they need someone they can trust and whom they can talk to in an honest and open manner about their fears and impairments. Besides this, they need comfort of feeling that they are still important and needed by the family or other close persons. The most named motivation using modern technology is the feeling of safety and not being worried about forgetting too many things. The improvement of daily life as well as the contact with medical doctors and also a reminder function would be an additional motivation for utilizing modern technology.

Information and communication technology

In contrast to the answers in the initial interviews, the use of tablets or smartphones as a reminder (with sound) or the function to write down memories, is now stated as to be helpful. Furthermore, the participants can envision using memory-training-programs and tracking-functions, if they are not already doing so.

When it comes to the improvement of care activities by technology the respondents stated that technology and modern devices should be easy to use so that they can remember effortlessly how to run through.

Summary

In conclusion, the interviews show that the majority of participants is forgetting appointments, their intake of medication or where they put things. Furthermore, they use strict routines to avoid stressful situations. They often get angry or upset when they forget anything. Regarding the use of technologies, more than 50% already use/own smartphones, tablets or computers and would also use wearables if they are useful but will not bother them. According to the findings, an app should contain a calendar, an acoustic reminder function, a diary and a tracking function as well as a surveillance function which informs caretakers in case of emergency or if something unusual happens. In addition, it is crucial that the app is easy to use and to include an emergency button.

5.4.2. Informal caregivers

Daily life

Discovering the daily challenges from the view of informal caregivers gives us a similar picture. The most frequent situation of people with dementia is the lack of orientation, being confused in unfamiliar or hectic situations, the neglect of daily basic routines, appointments and actions, etc. Furthermore, the care recipients get irritated and often aggressive when they forget something, and they keep asking the same questions repeatedly. When asked in which situations the care recipients need support concerning the daily life, the care givers stated, that they either do not need any support at all, or that they need support in all activities of the daily life like cooking, cleaning and orientation. The acceptance of the situation seems to be another problem among people with dementia. Furthermore, they stated that the recipients get angry regularly, which is stressful for the informal caregivers and affects their relationship.

Care activities

Considering the impairment-related restrictions of the PwD the informal caregivers reported that the personal hygiene and medical activities have the highest priority. Sometimes the informal caregivers get support by professionals that visit the family on a regular basis. When asked about the effectiveness of this external help, the interviewee is content as, the assistance technology used in the form of the emergency button is very important for the patient that knows well how to use it.

Social aspects

When caring for a person with dementia it is important to exchange information about that person. In this section it can be recognized that medical information as well as information about changes in the behaviour are only exchanged between the carer, the patient and the medical personnel.

Regarding the satisfaction of the stakeholders with the information exchange and their involvement in the different aspects of the impairment and potential improvement of the condition, the survey shows that the awareness within the society needs to be improved. Family and friends seem to be open minded about the handling of impairment, as rated in the survey.

Motivation and learning

The motivation of the caregivers to engage in education and learning of new aspects in order to improve the caring skills, looking quite significant. They stated that increasing knowledge about the impairment and the learning of new facts, improves the care-quality and helps both, the caregiver and recipient. But it is complicated to find an appropriate training that really helps. Another problem is the information search without internet access, but this was reported as a problem in only one case.

Information and communication technology

The target groups experience with any kind of technology covers the usage of smartphones, tablets and emergency buttons. When it comes to the acceptance of monitoring their health conditions, the safety of personal information is essential, and the acceptance of wearables is reported as moderate. The feeling of safety and independence would motivate the caregivers to use the new technology.

Summary

To sum up, according to the findings from informal caregivers, the lack of orientation, forgetting appointments and medication are the biggest problems when it comes to the daily life of the PwD. Furthermore, the care recipients need a highly structured life to avoid stress. Personal hygiene and medical activities have the highest priority among care activities. The majority of informal caregivers are highly motivated to engage in education to improve their care quality and to handle stressful situations better. When it comes to ICT, an emergency function as well as a tracking function and a reminder, would be very useful.

5.4.3. Formal caregivers

Daily life

Regarding the daily life, the formal caregivers stated that most patients have problems with forgetting appointments or information like names, places etc., misplacing things and with the acceptance of their own impairments. Furthermore, they get depressed, restless, anxious or aggressive/angry when they forget something and eventually lose their self-confidence. These problems cause stressful and difficult situations in relationships with their families and formal caretakers. In addition, the impairment affects the activities of the daily life, like doing the groceries, going outside alone, dressing, taking care of personal hygiene and household activities such as cleaning. These stressful situations can be overcome by special techniques that the patients learn in therapies, by talking to them and further questioning if they have misplaced something or simply reassuring the client. To avoid such situations and problems, people with dementia start writing a diary, asking for transportation so they do not need to go by themselves or using reminders for medication etc., but nevertheless, they cannot find solutions for all problems.

When it comes to situations in which support is needed, the caregivers stated that patients need assistance especially with medication and reminders and they, seek help mostly from their families, caregivers or medical personnel. Assistive technology could be helpful in reminding them for medication intake, drinking, eating and appointments as well as in emergency situations. But the caregivers also declared that it will be complicated for the patients to use modern technologies if they did not use them before the impairment.

Care activities

Concerning the importance of caregiving activities, the areas of eating and medication aspects are the most important.

Regarding the caregiver, professional assistance is mostly needed when it comes to medical issues and physical support. Most patients get visits from professional caregivers daily, in addition they use doorbell screens and emergency buttons to feel safe. When it comes to the role of assistive technology in external help, it can be seen, that a connection and a knowledge transfer between the different caregivers and medical personnel would improve the quality of the external help and care activities.

The medical information is either only shared between the medical personnel, the formal caregivers and families in avoid alarming the patient, or it is either shared directly with the care recipient, but never with other (external) persons; with the prerequisite, however, that the involved persons are

authorized. The patients are slightly open-minded in the handling of their impairment but often do not want to talk about it.

Social aspects

In regard to the social life of the patients, the interviews show that their involvement often decreases, however some patients still partake in group activities or meet up with people in the same situation or with friends. The formal caretakers state, that it would be good and useful to arrange activities and also to offer incentives, either with other patients or with their families or caretakers to offer incentives.

Motivation and learning

Most elderly people with dementia are motivated to use modern communication devices so as to stay in touch with their family and to have a feeling of safety.

Information and communication technology

Most people suffering from dementia have problems with their orientation, regardless of whether they are outside or inside their home. The developers must make sure to offer a secure system that is accepted by the elderlies themselves and easy to handle especially in a stressful situation. The skills that need to be acquired for the Many-Me system must be very easy to learn in order to be used more often and not to alienate the patient.

The caregivers often use seminars, brochures and e-learning methods to develop new skills for when coping with the impairment. Nevertheless, it is difficult for the caregivers to find professional information online. Concerning the need of emotional support, the majority of participants stated, that empathy and interaction as well as talking about the impairment and spending time with the patients are crucial aspects of emotional support.

Summary

The questionnaire shows that from the formal cares view, forgetting appointments and persons, the misplacing of things and the general acceptance of the impairment as well as the lack of orientation are the biggest problems in the daily life of their patients. When their clients forget something they get depressed, stressed, aggressive and even angry. Nevertheless, stress can be overcome by special techniques learned in therapies, furthermore it can be avoided by starting a diary or the use of reminders. The impairment affects daily activities like grocery shopping, going outside alone, dressing, personal hygiene and keeping the household. Their patients need help with their medication and reminders, so that a reminder for medicine, eating and drinking, appointments and names as well as an emergency function would be helpful; even though, it will be hard for the patients to learn to use technical devices if they have never learned before the impairment. The assistance technology in external help should support the connection and knowledge transfer between different caregivers and medical personnel as well as family members in order to improve the quality of care activities. To this point, caregivers use seminars, brochures and e-learning to improve their work, but they also complain about the lack of professional information. Regarding their expectations of

an ICT emergency and guiding tool, an emergency function to help inform them immediately in case of an emergency it is necessary.

5.5.   Summary and recommendations

According to all three groups participated in the interviews, the problems of forgetting to take medicine, misplacing things and forgetting basic matters, as well as the lack of orientation are the most serious ones. The impairment affects daily activities like going out alone, doing the groceries or the personal hygiene. The best way to avoid these stressful situations is to keep a strict daily routine and to use reminders as well as diaries and calendars. From the interviews, it was found that an ICT emergency and guidance tool should definitely contain an acoustic reminder, a calendar and a diary, a tracking and surveillance function and an emergency function which immediately contact the care giver in case of emergency. Furthermore, the connection and knowledge transfer between the caregivers and families as well as their education must be improved in order for the quality of care activities to be improved too.

Caring for people with dementia is very complex and time-consuming. The developers must take into account that the solution is unable to replace care activities like hygiene, eating and drinking and medication intake. The system should address more to the early stage of dementia, in order to support the people with special designed agendas or memory help functions.

Besides this, the system must be very easy to interact with, so that persons with dementia and caregivers can adapt to it easily even if they do not use it every day. The developers must make sure to consider the user requirements when building up the proposed solutions, addressed to the elderly people.

6. Requirements analysis: Online surveys
6.1.   Goals

Although, a lot is already known from the personal interviews about the practise and some technological possibilities of an e-health-system supporting people with memory problems and caregivers from dementia persons, a detailed analysis about the user requirements is necessary. To develop a new technical solution for their daily challenges their environment and behaviour needs as well as to be taken into closer account. The Many-Me project seeks to develop a solution for the specific needs and routines of older adults with memory problems and their caregivers, providing them with assistance where necessary and possibly in their daily life. To develop a new system that fits best in the daily life and work of the targeted user-group, a deeper analysis was needed to gain further information about the specific needs, preferences and habits of the older adults and the caregivers from their role as potential users.

Even though a lot of information was gained from the interviews regarding the use of technical assistance devices, we do not know which behaviour or habits are mostly used (prevailed) by the target groups and what kind of technical assistance could be helpful. It is important to find out more about

the users' daily challenges and how they deal with them. In addition, ways of communication and the general usage and acceptance of ICT will be important for the development of the system.

6.2.   Research questions

The questions for the survey were developed out of the results from the preceding interviews. Since we have three different target groups (older adults, informal caregivers and formal caregivers) the survey contains three different questionnaires. Each questionnaire was developed in the light of their answersand five major parameters were identified.

Dealing with memory problems / Strategies or methods of counteracting
This parameter is important to understand the general behaviour of the primary target group. Asking questions about how they try to avoid or to counteract to their memory problems will help the developers to get deeper insight on the behaviour of this target group.

Use of technical devices / Knowledge about ICT
This parameter focuses on the current familiarity and usage of the target group with different devices. Issues such as habits, experiences and preferences are important to trigger the interest and openness towards modern technical devices. This includes a basic knowledge about a technical impression.

Expectations from a technical assistance device
A general and important parameter is what users expect from a technical device that should support them. Getting insight on the users' imagination and expectations is useful when developing new solutions.

Modes of organizing informal and formal care (alone or with other persons together)
Another focus of the Many-Me project is the assistance of informal and formal caregivers. This parameter considers the daily routines and organization of the target group regarding the caring of dementia person(s). The mode of organization can be apprehended by the new solution and shall be further analysed.

6.3.   Method
6.3.1. Target Group

The target group for the users' requirements analysis was defined as elderly people with memory problems, informal caregivers and formal caregivers working with people with moderate or mild dementia. The survey was carried out by all end-user organisation partners in Austria, Switzerland, Cyprus and the Netherlands.
One important strength of the online survey was the collection of information from a greater amount of people related to the target group that is addressed by the Many-Me system which will help in validating the interviews' results.

Besides this, Many-Me also focuses on the form of assistance of by caregivers to people with dementia and therefore the survey also considers the daily challenges and habits of informal and formal caregivers.

6.3.2. Research design and implementation

The research design was developed by using input from all consortium partners that are involved in the user requirements analysis. Based on the research questions regarding the specific objectives of the Many-Me project, all involved partners were invited to state their opinion and give some input from the perspective of their background and former experience.

Both primary and secondary users were recruited for conducting the survey in Austria by EURAG, in Switzerland by terzStiftung, in the Netherlands by MOB and in Cyprus by Materia. The recruitment was done by using existing databases and networks (older adults, members of charities, networks) and contacts from other projects and activities. Besides this method, the partners get to acquire new contacts by using diverse strategies (e.g. newsletter, homepage, contacting self-help-groups, etc.).

Formal caregivers, which are working for care institutions were mainly recruited by MOB and Materia, because they have direct contact to this group.

For the selection of primary and secondary users of Many-Me, even users with at least a bit of access and openness towards modern technology and modern communication devices, were recruited for the online survey. The survey was structured into three different parts, each addressed to one user group and containing the five major parameters mentioned above.

6.3.3. Language

As the survey was carried out in different countries with different languages, the original questionnaires were designed in English and translated to all required languages (German, Dutch, Greek). Questions were not literally translated but in line with their sense. After finalizing the survey, all results were converted back into English and qualitative comments were translated by each included partner according to their sense.

6.3.4. Sample

At the end 306 people answered the survey. 111 people answered that they have some memory problems. 105 of them finished the questionnaire (6 stop the survey in the thick of it) (*Chart 1*).

122 respondents have no memory problems, but only 41 care for another person with mild or moderate dementia. 63 do not care for someone and 18 did not answer this question. Conclusively there are 14 informal caregivers and 11 formal caregivers that finished the questionnaire and 16 participants did not answer whether they are formal or informal care giver, thus they fall out of the following statistics.

A) Do you have the feeling that you forget more things in the last time?
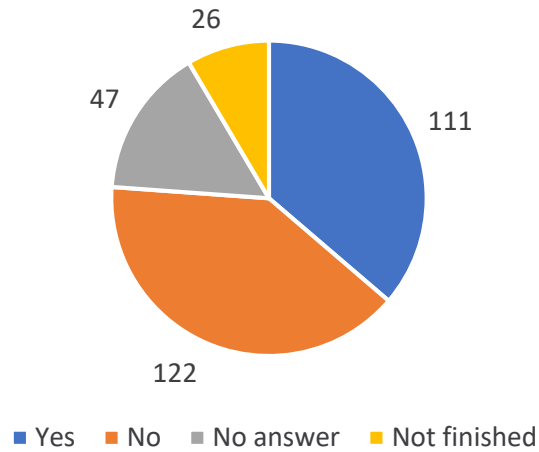
Chart 1: Number of persons taken part in the online survey

B) Do you care for another person that suffers from MCI or mild/moderate dementia?
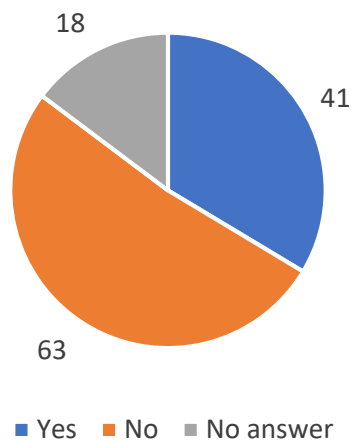
Chart 2: Number of persons that care for a person with cognitive impairments

C) If Yes
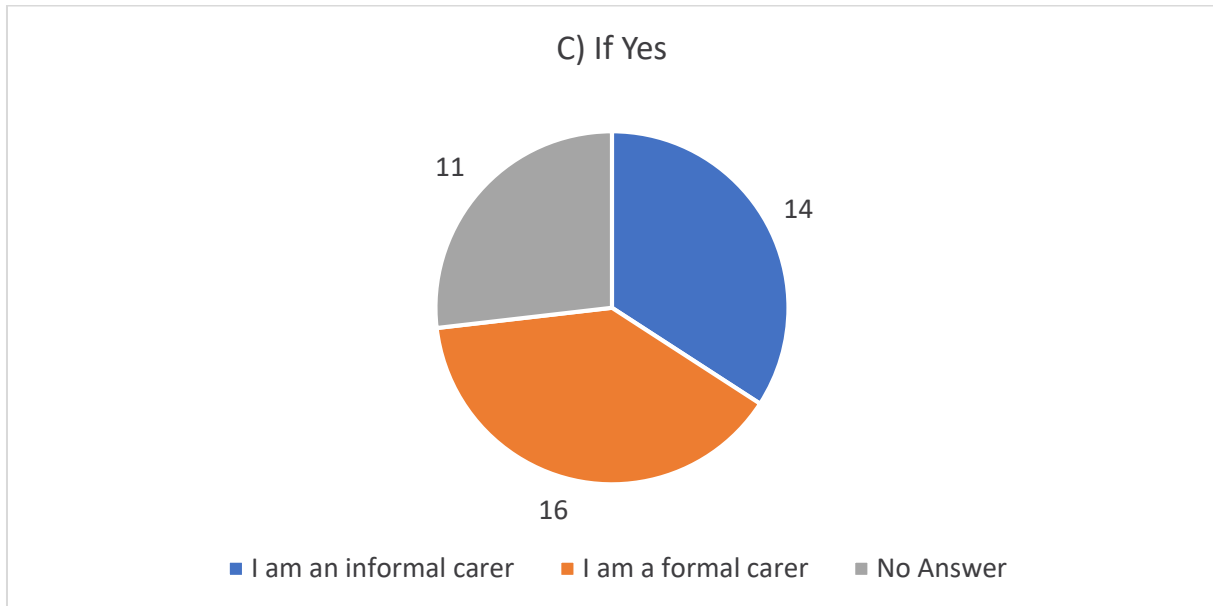
Chart 3: Number of informal and formal caregivers

Information about the sample of older adults

More than 50 percent (55 persons) of the respondents that have memory problems are male, about 40 percent are female and 6 percent did not answer this question.

11) What is your gender?
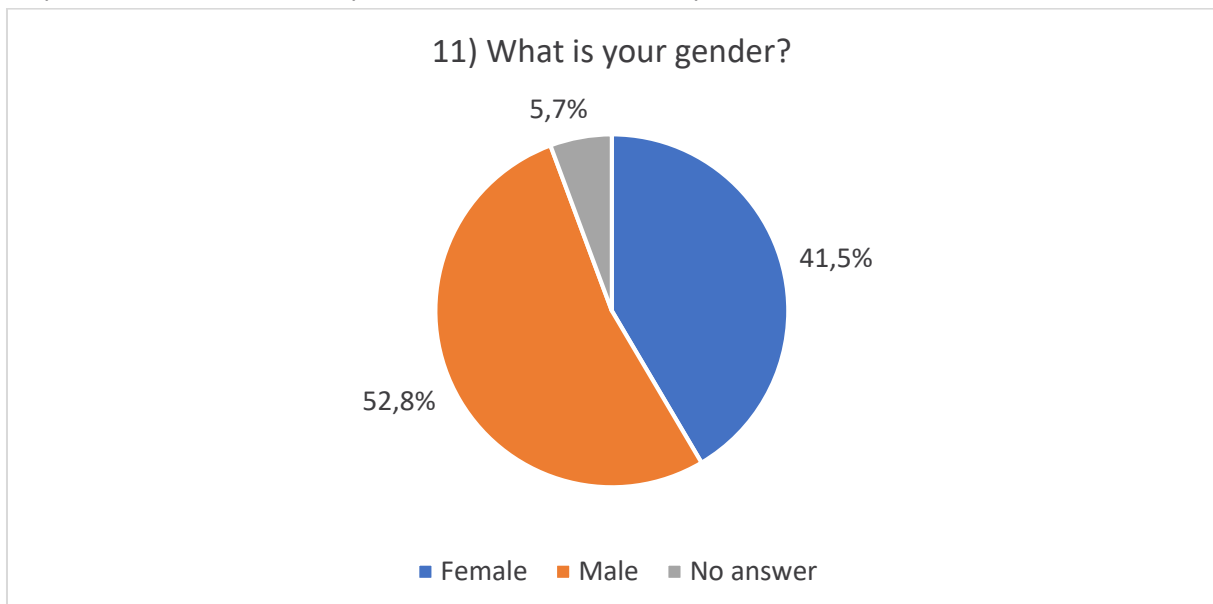
Chart 4: Gender of older adults

The majority of the respondents can be found in the age group 70 – 79 years (53,1%), followed by 15,3% in the group between 65 – 69 years old and 11,2% in the group under 60 and between 60 – 64 years old. A minority of the respondents is older than 80 years old (7,1%). None of the respondents is older than 90 years old.

12) How old are you?
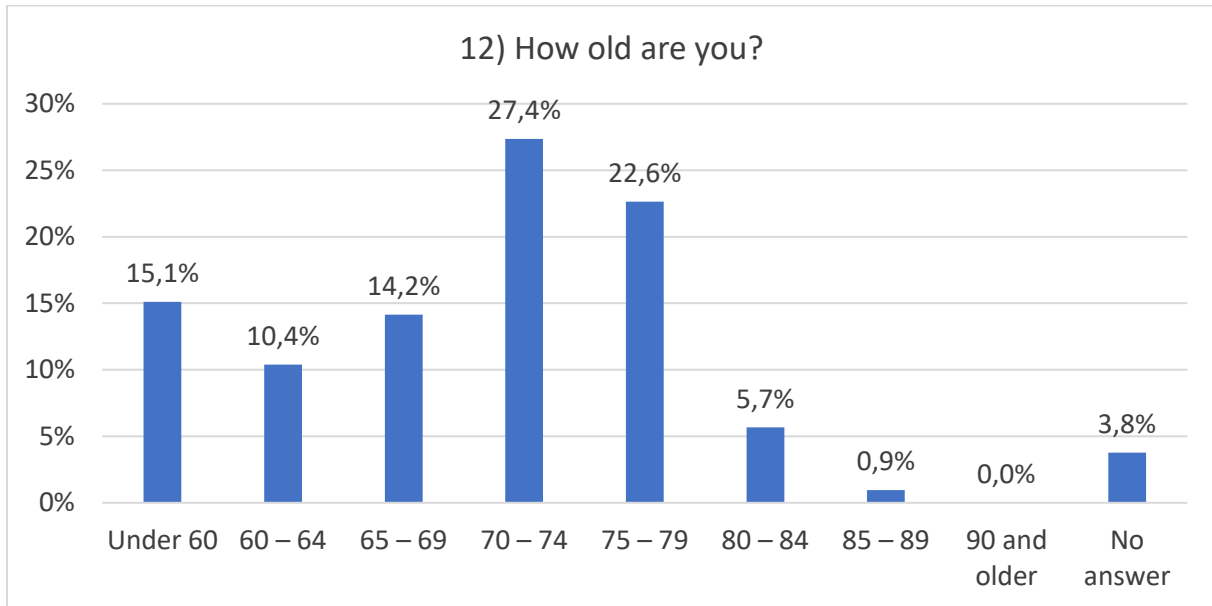
Chart 5: Age of older adults

The living environment is an important factor for the underlying analysis considering that the Many-Me project pursues for the targeted audience to live independently for as long as possible in their own home. Only a minority of the respondents live together with their family (other family members excluding their partner) (2,0%) or in a senior residence (2,0%). 91,8% of the respondents from the older adults' survey reported to live in a private house or apartment.

13) How do you live?
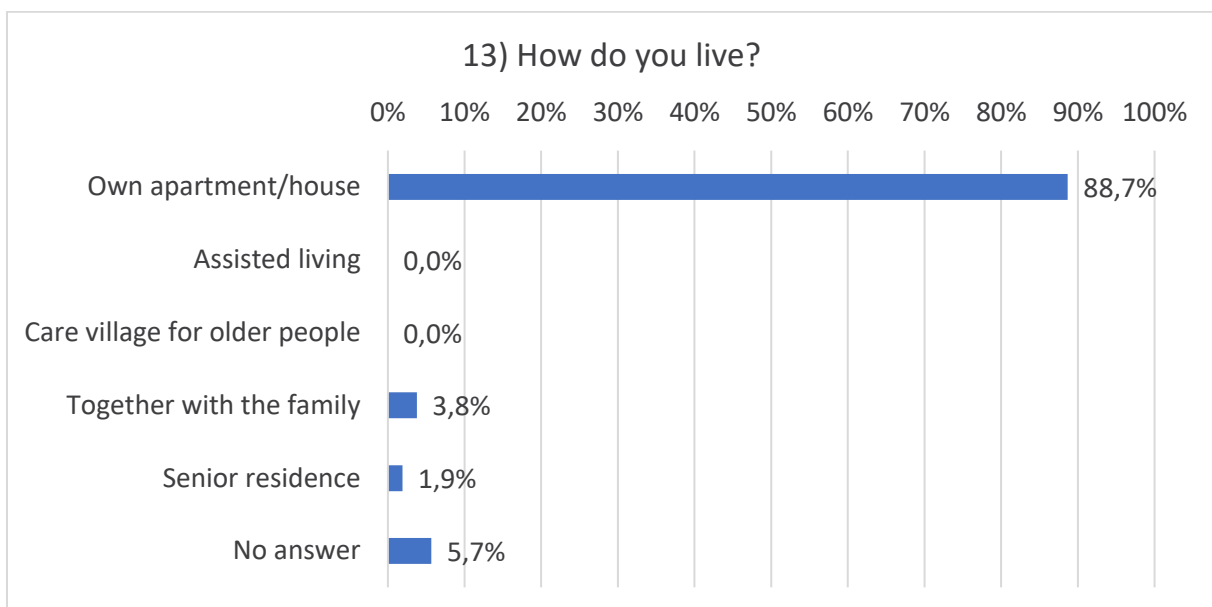
Chart 6: Living area of older adults

Information about the sample of informal caregivers

Chart 29 and 30 demonstrate that half of the respondents who are in the group of informal caregivers are male and (50%) are elderly persons themselves between the ages of 70-79 years old. Most likely these informal caregivers are the partners of those who they care for. This is important to keep in mind when developing the Many-Me solution.

11) What is your gender?

16,7%

33,3%

50,0%

■ Female   ■ Male   ■ No answer
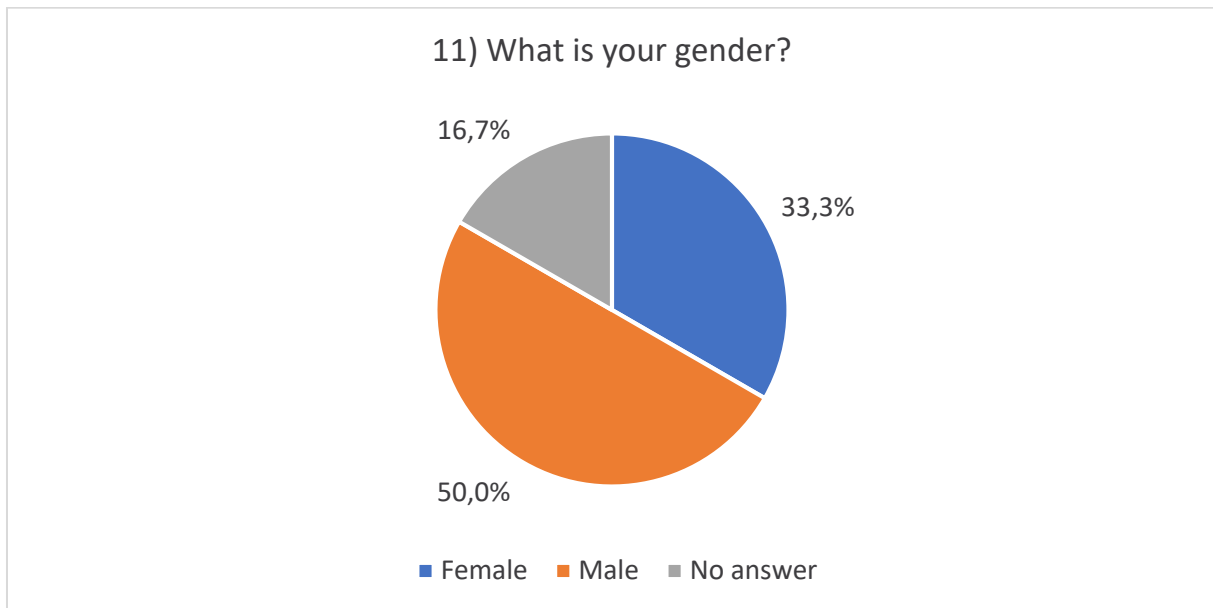
Chart 7 Gender of informal caregiver

12) How old are you?

Under 40	8,3%
40 – 49	8,3%
50 – 59	8,3%
60 – 69	8,3%
70 – 79	50,0%
Older than 80	0,0%
No answer	16,7%
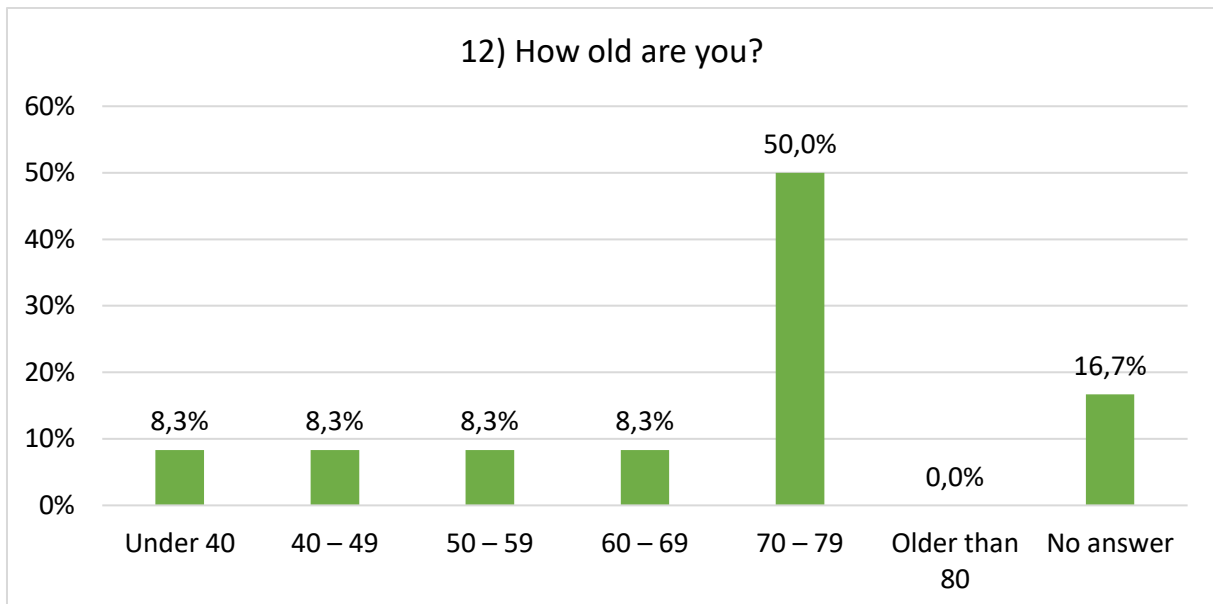
Chart 5: Age of informal caregiver

Information about the sample of formal caregivers

The gender of formal caregivers who respondent to the survey was equivalent: 44% of the respondents were male and 44% were female. The remaining percentage of the participants did not report their gender.

10) What is your gender?

13%

44%

44%

■ Female ■ Male ■ No answer
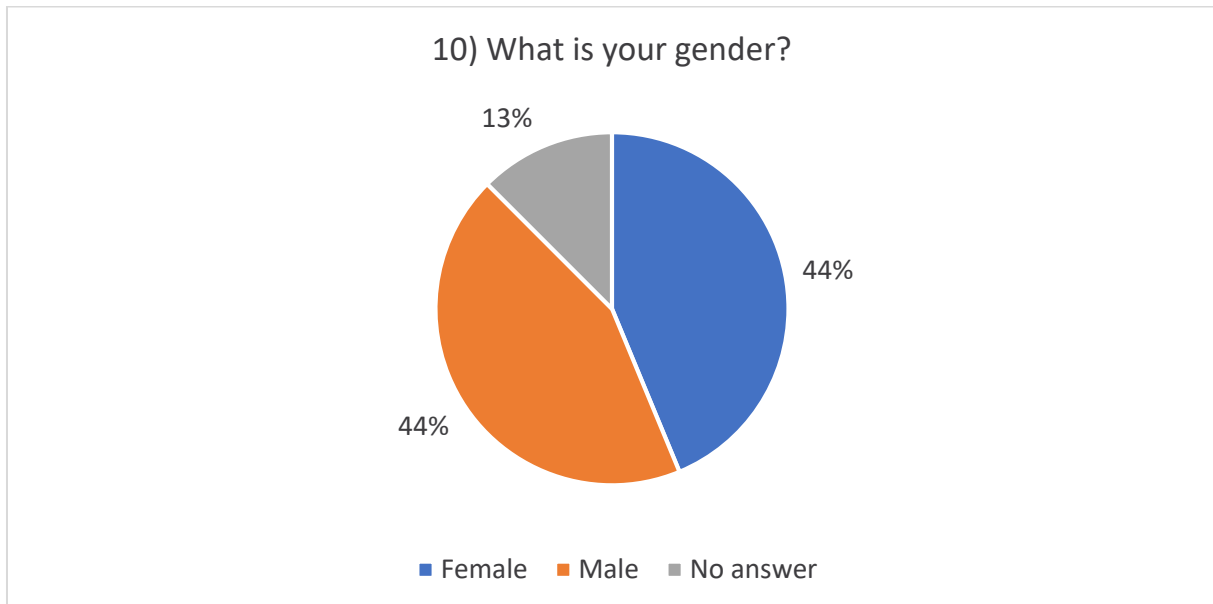
Chart 8: Gender of formal caregivers

The majority of the respondents reported an occupation that was not listed in the survey, thus, a variety of answers were given for this question: the participants' occupation are, among others, activity consulting, caregiver and consulting. 13% of the participants were nursing staff and an equivalent percentage (13%) did not provide an answer. Geriatric nurses, medical doctors and speech therapists were represented with 6% each.

11) How old are you?
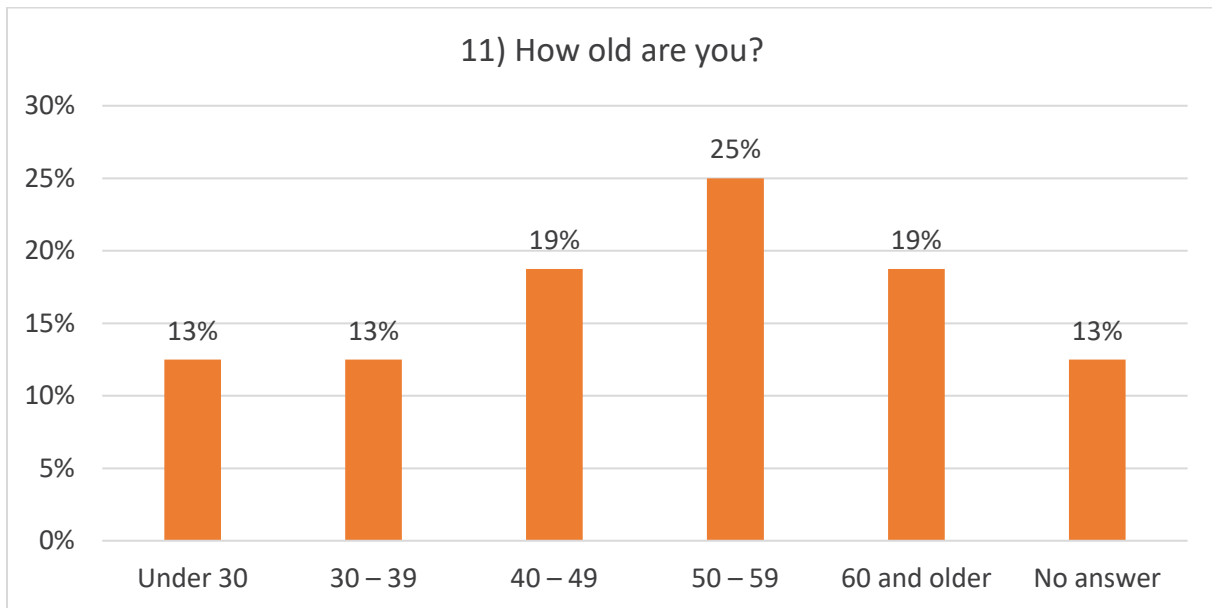
Chart 9: Age of formal caregivers

Furthermore, the formal caregivers were asked to report the device they use and the majority reported smartphones, followed by the pc/laptops with 24% and then mobile phones and tablets with 16% each. This indicates that the assistance technology has to be compatible with any type of smartphone and to have a mobile friendly appearance in order to increase the possibility of usage.

12) As what do you work?
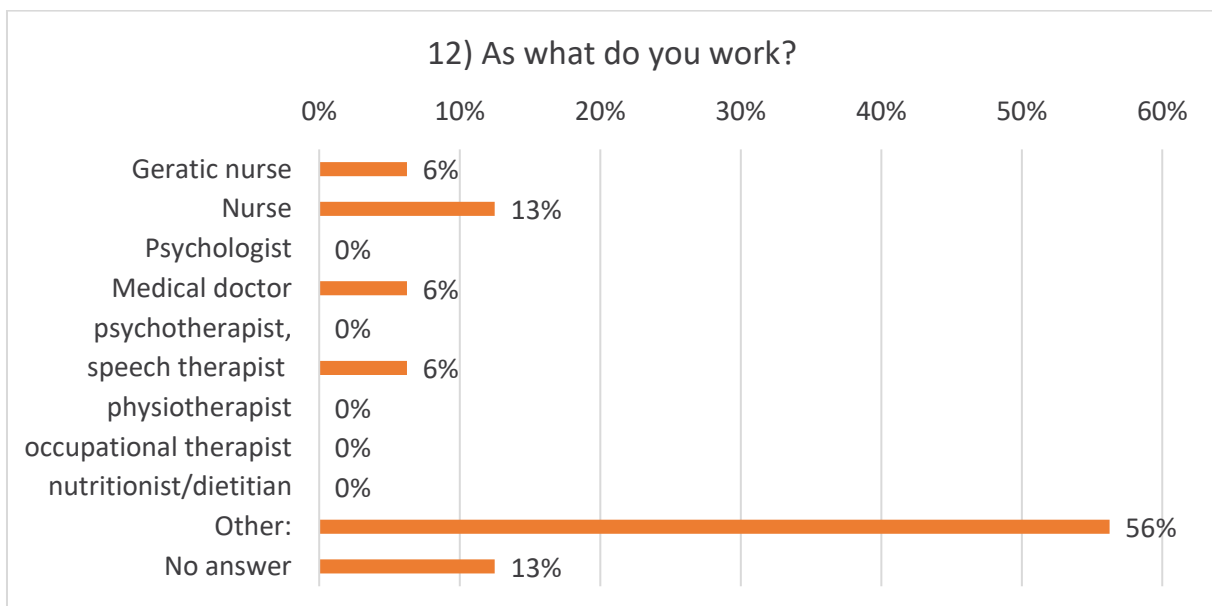
Chart 10: Work qualification of formal caregivers

6.4. Results

To guide the users to the right questionnaire an opening question was used. First, all participants were asked if they have the feeling that they have some memory problems. 37,1% answered this question with "yes". Those who answered the question with "no" got linked to the question for care givers.
The first question of caregivers' questionnaire was to choose whether they are an informal or a formal caregiver. Those who did not answer this question finished the survey without former results. 28,6% of those who answered this question are informal carers and 46,9% are formal carers (each of them was guided to the appropriate questionnaire).

6.4.1. Results primary users' survey

The results show an interesting picture of the respondents that expressed having a feeling of forgetfulness. Nearly 50% stated that had forgotten things again and again during the last four weeks, about one quarter of the participants, had forgotten things only one or two times but 22,9% had the feeling of forgetting something every day. This result shows, that even if older people suffer from memory problems they still fit enough to work with the computer.

1) If you have the feeling to forget more things, how often does this happen within the last four weeks?

Category	Percentage
One or two times	23,8%
Again and again	46,7%
Nearly every day	22,9%
I don't know	2,9%
No Answer	3,8%
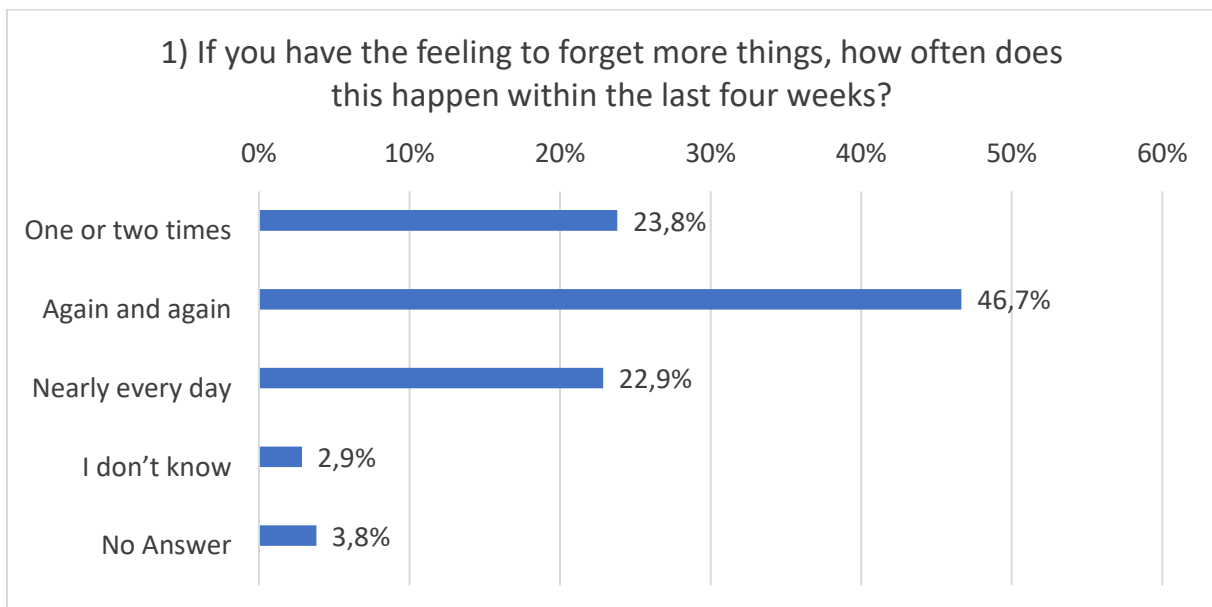
Chart 11: Feeling of forgetfulness

Most people suffering from memory problems, make notes on a piece of paper to get reminded of the important things. This result is not very surprising because this generation is used to handwritten notes. Two other factors are very interesting: (a) 17,1% use their mobile phone or smartphone to make some notes for reminders, which shows that some of the users we want to address knows how to use the modern technology as an advantage in their daily life; (b) but 21,0% have not found the right solution yet, which shows that the available on the market technology is not usable for all older adults with memory problems. Here Many-Me should draw on and develop a solution these people could use.

2) How do you try to avoid such situations?
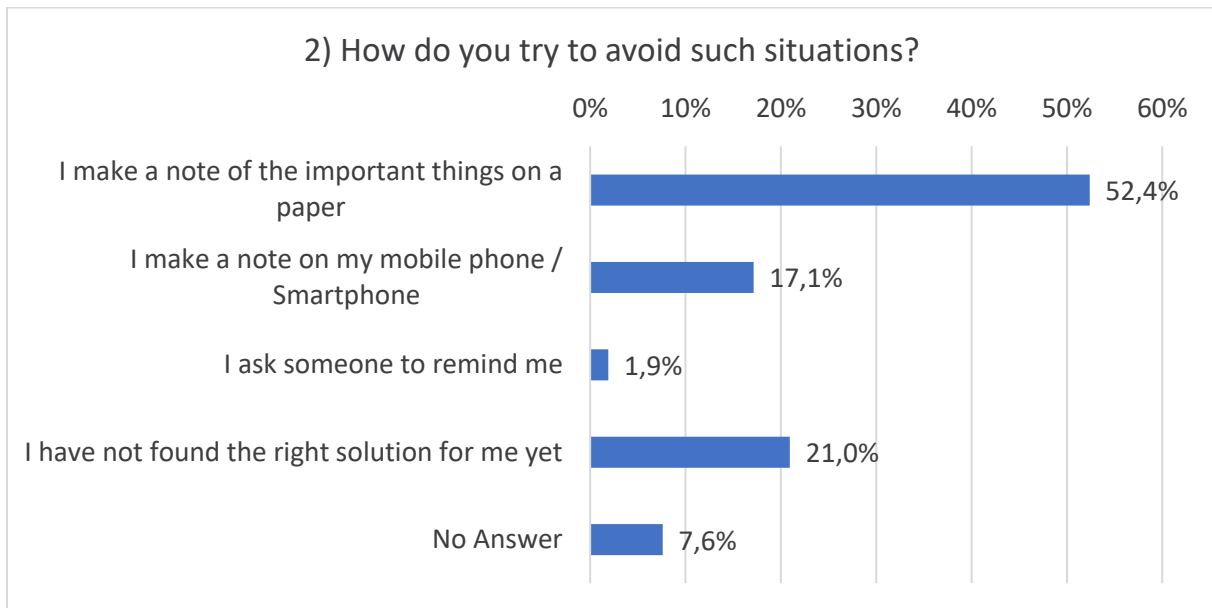
Chart 12: Avoid situation of forgetfulness

Chart 16 shows in which situation the participants have to deal with their forgetfulness. Most of them have problems when they are at home doing their daily activities (26,8%) and one fifth has difficulties to learn new things. This can be an indicator for the primary target group of Many-Me. It seems like that a lot of people have problems learning something new, so Many-Me can consider addressing people that have at least some basic knowledge about technical communication devices. Nevertheless, this should not imply making it very complex because this would involve a learning process which can prove difficult for the users.

3) In which situations do you have the most problems with your forgetfulness?
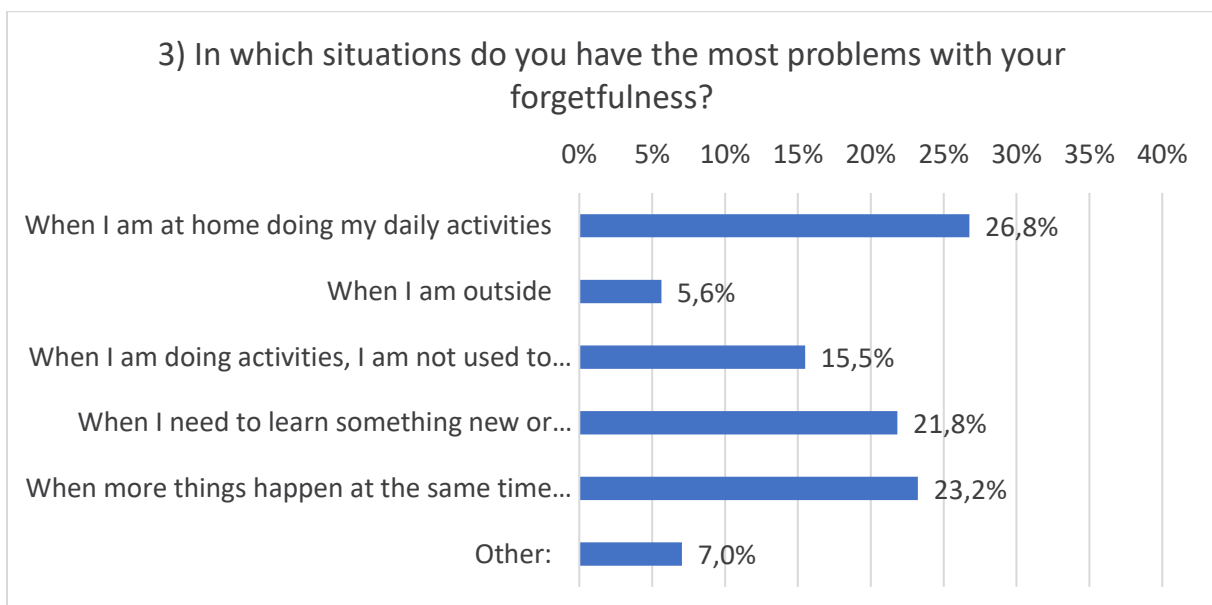
Chart 13: Situations of forgetfulness

Psychological effects are an issue to be considered when developing a system for people with mental impairments. Regarding this, it is necessary to ask potential users about their emotional state. The results clearly indicate sharp differences in attitude when asking primary users about their feelings towards their memory problems.

About half of the respondents (45,7%) answered that it is not so bad and that they laugh about it. There is a clear openness and acceptance among these participants towards their mental impairments. As the results in *chart 17* shows that, 42,8% are bothered by their impairment, 15,2% get angry when they realised that they forgot something even when they decided not to forget it. As indicated in the following chart, only 13,3% gets stressed by this mental state. Nevertheless, the results show that this impairment causes stress to every seventh person suffering from memory problems. This suggests that it is necessary to avoid additional stress for the future users when using the Many-Me solution. In contrast, a minority of participants reported, sadness (5,7%) or feeling insecure and to be afraid (8,6%) of the memory problems they have. These results also show the sensitivity of working with older adults with memory problems which is an important factor that needs considered when developing a system for older people with memory problems.
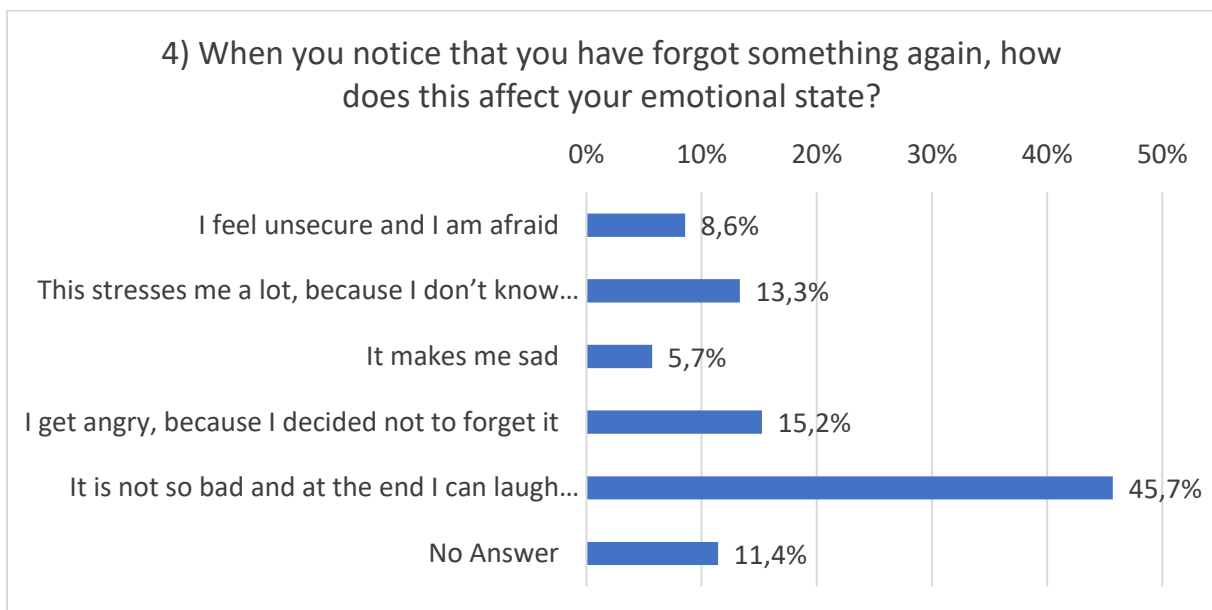
Chart 14: Emotional state

Looking at the handling of daily issues, the question about specific auxiliaries is necessary. When primary users where asked about the specific methods used for remembering dates wo which end users are currently used to, most of them use their agenda to make some notes (67,6%). Besides this tremendous amount, 16,2% use their mobile phone or smartphone to install some reminders.

5) What do you do, to remind your dates?

Answer	Percentage
I make a note in my agenda	67,6%
I make a note on a paper and put it on the door of the fridge/ main door	6,7%
I get assistance from another person	1,9%
I set the alarm on my mobile phone/ smartphone, that reminds me	16,2%
I don't have any special method	1,9%
No Answer	5,7%
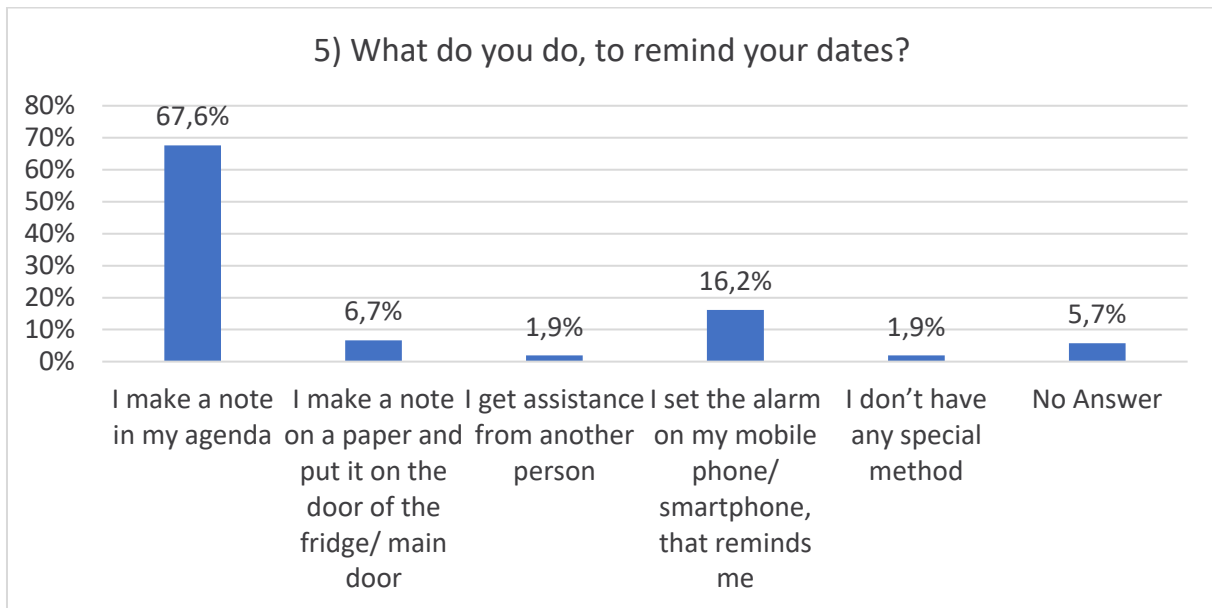
Chart 15: Reminding dates

Taking a closer view at the use of the calendar or agenda the users are using as presented in the chart above, the elderly people mainly use a pocket or book calendar to remember their appointments. 26,6% acknowledged that they use their agenda on the mobile phone, 19,0% still use a kitchen calendar. 9,5% use the calendar on their computer, like outlook, to remind them of their appointments and dates.

6) Which kind of calendar are you using?

Answer	Percentage
Wall calendar/ kitchen calendar	19,0%
Pocket calendar/ book calendar	38,1%
Calendar on the computer (e.g. outlook)	9,5%
Calendar on the mobile phone/ smartphone	28,6%
I don't use a calendar	0,0%
No Answer	4,8%
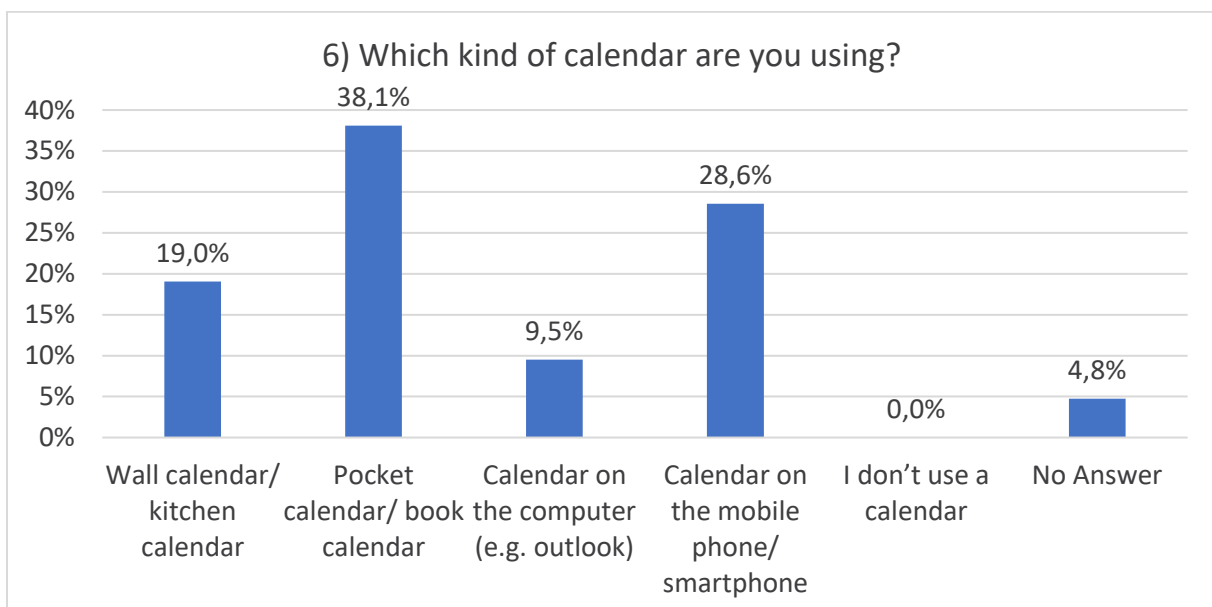
Chart 16: Calendar using

To get a better understanding of the life of primary users a question about leisure activities was included. Most respondents are interested in information procurement like reading the newspaper, magazines or books (19,9%). There is no activity that covers more than 20% of the answers. Even if this

question was a multiple-choice question it looks like that the respondents only answered one of the possible answers. They had the possibility to choose more than one answer, but did not do so. This could be an explanation for the low answer rate in each category.
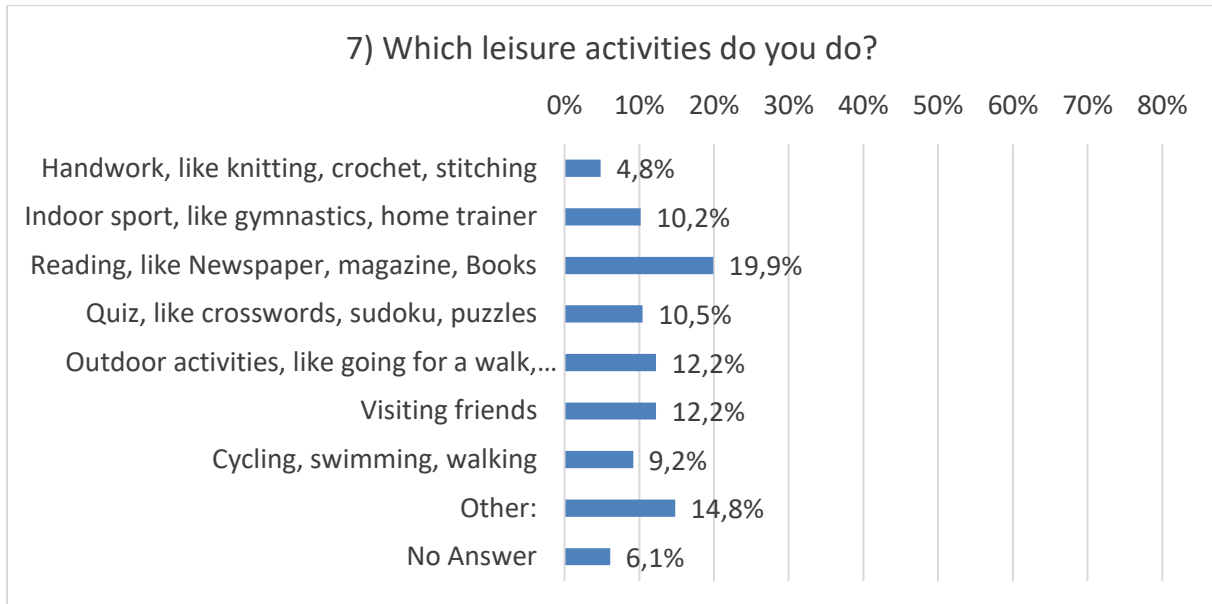
Chart 17: Leisure activities

In order to tailor the Many-Me system to the current needs of the target group, it is important to take a closer look at the activities that need to be reminded mostly. As we know from the previous interviews, most of the people with memory problems need to make a reminder for appointments, like at the doctor or hairdresser (46,6%). As illustrated in the chart below, nearly one third needs to set a reminder for appointments with the family or friends (28,5%). Only 14,5% remind themselves with a note on doing the shopping or going to the bank (14,5%) and a minority of the participants needs to remember by themselves to take their medicine. Even if this is reported by a minor number of interviewees, Many-Me needs to make sure to adapt this to its system.

8) For which activities do often make a reminder?

Activity	Percentage
Appointments, like doctor, hairdresser,…	46,6%
Appointments with friends, family	28,5%
Transactions like shopping, banking	14,5%
Taking the medicine	3,6%
Drinking or moving	1,0%
Nothing from that	3,1%
Other:	2,6%
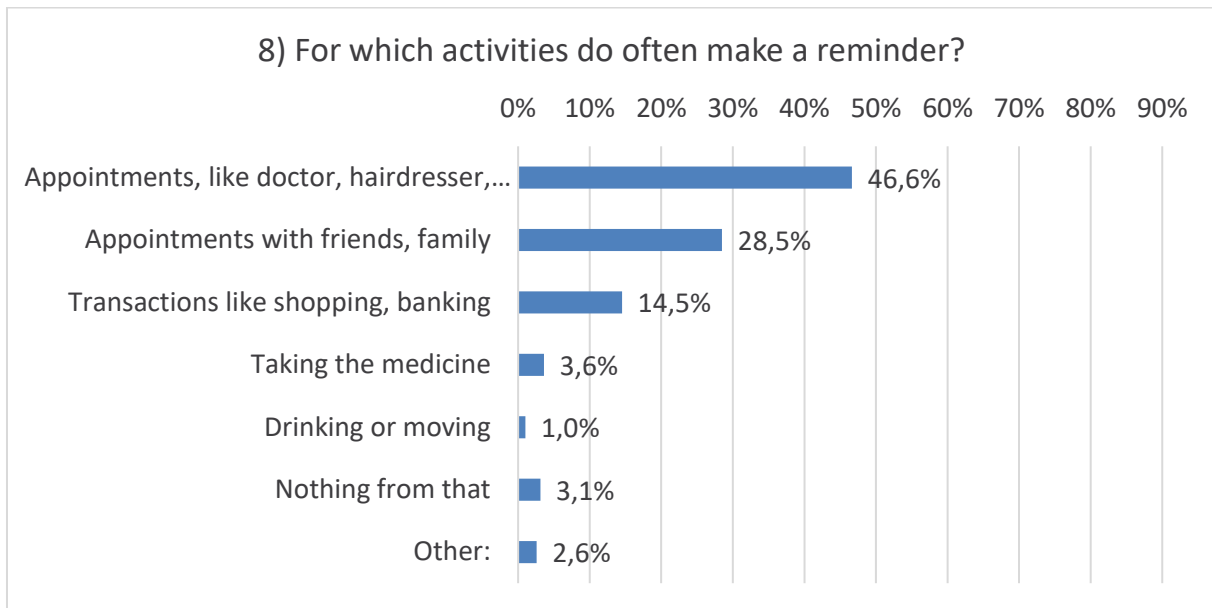
Chart 18: Reminder for activities

When developing a system for people with memory problems and dementia it is important to ask their level of knowledge regarding modern communication devices and modern technology. As it can be seen in the interviews above and the literature research it is very difficult for people suffering from MCI to learn something new. Therefore, it only makes sense to provide the Many-Me system to people that are already familiar with some technical expressions and have some knowledge about modern technology.

Before the results are analysed, it needs to be pointed out the fact that the respondents might not recognize the possibility of selecting multiple answers.

In general, the respondents have some knowledge about modern technology and communication. The items "online" and "website" are known by 14,7% and 14,2% of the respondents, respectively. The expressions "Wifi", "Link" and "homepage" are known with about 13% each by the participants. Only "blog" and "virtual reality" are less known.

Nevertheless, the results show that some older people have a basic knowledge about technical expressions. This can be a needed basis for developing a system for people with dementia. If the participants know these expressions now, it is more possible that they will remember them when the memory problems get worse.

9) How familiar are you with the following items? Which do you know?

Item	Value
Online	14,7%
Wifi	13,5%
Blog	10,6%
Link	13,0%
Homepage	13,6%
Emoticons	11,4%
Website	14,2%
Virtual Reality	8,3%
Nothing from there	0,6%
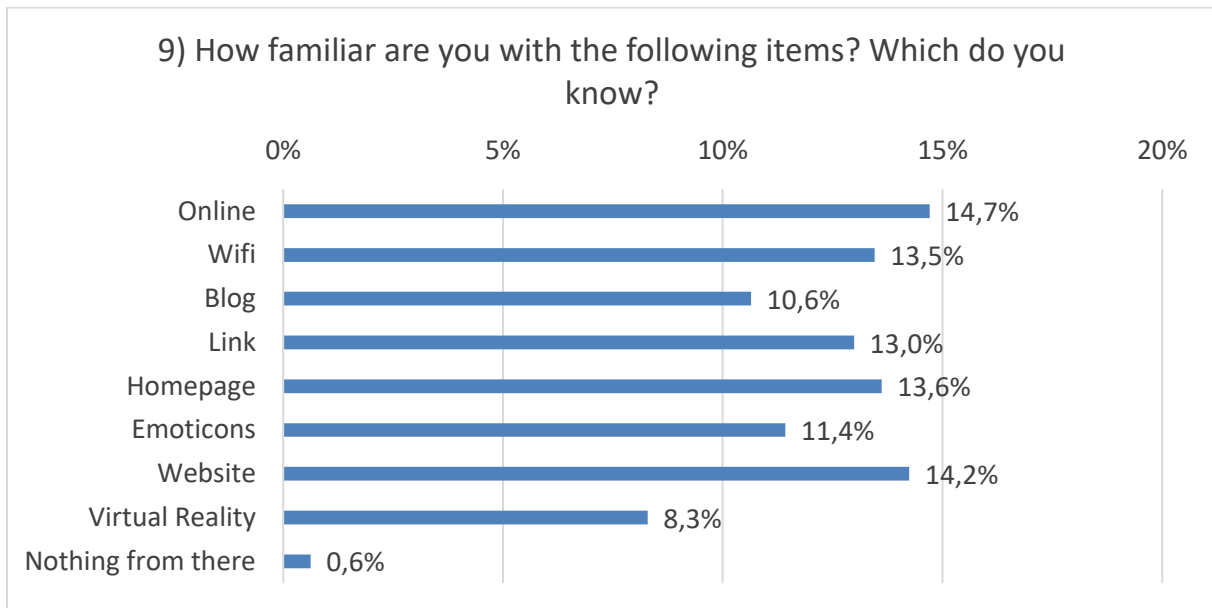
Chart 19: Technical expressions

The Many-Me system should be a system that support people with dementia in their daily life, involving some monitoring functions of the person using the app. When asked if they could imagine having a system that calls for help in certain emergency situations nearly 40% can imagine getting help from such a system when they fall. 15,3% can imagine getting a note when they are tired or restless. Only 11,7% think it can be helpful to get a note when they leave the house going for a walk. In contrast to those positive answers, one third answered that they cannot imagine getting help from a system like that.

10) Imagine there exists a technical device that "cares" for you, what do you think is helpful?

Item	Value
When I fall, it should alarm a person I defined.	39,6%
When I leave the house going for a walk and don't find back home any more.	11,7%
When I am tired or restless, it should give me some suggestions (e.g. go outside) so I feel…	15,3%
Nothing of these suggestions would be helpful.	33,3%
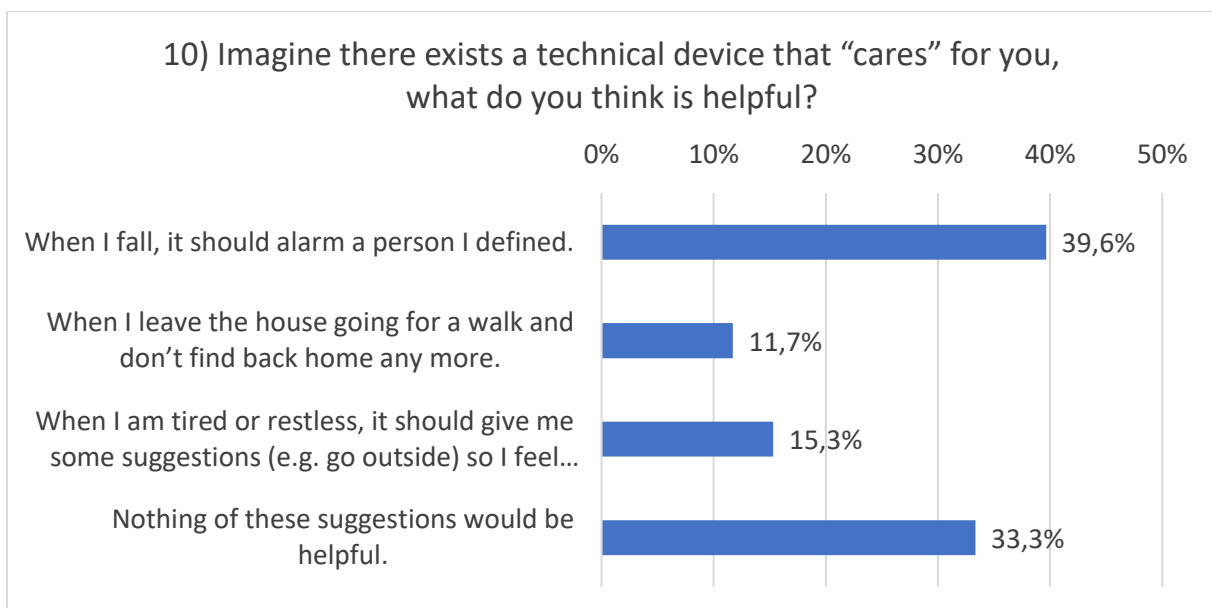
Chart 20: System that „cares" for you

We decided to send the survey to older adults in general. With the opening question, if they have the feeling of forgetting things more than they are used to, we wanted to select a group of people with early stage of memory problems or even dementia. To make sure that there are people in the sample that have serious memory problems we asked them, if they already have consulted with a professional for diagnosis. About three quarter did not visit a doctor yet, but 12,3% did so. This is a significant amount of people if the total number the survey's participants are considered.

15) Did you already visit a doctor to check your forgetfulness?

14,2%

12,3%

73,6%

■ Yes ■ No ■ No answer
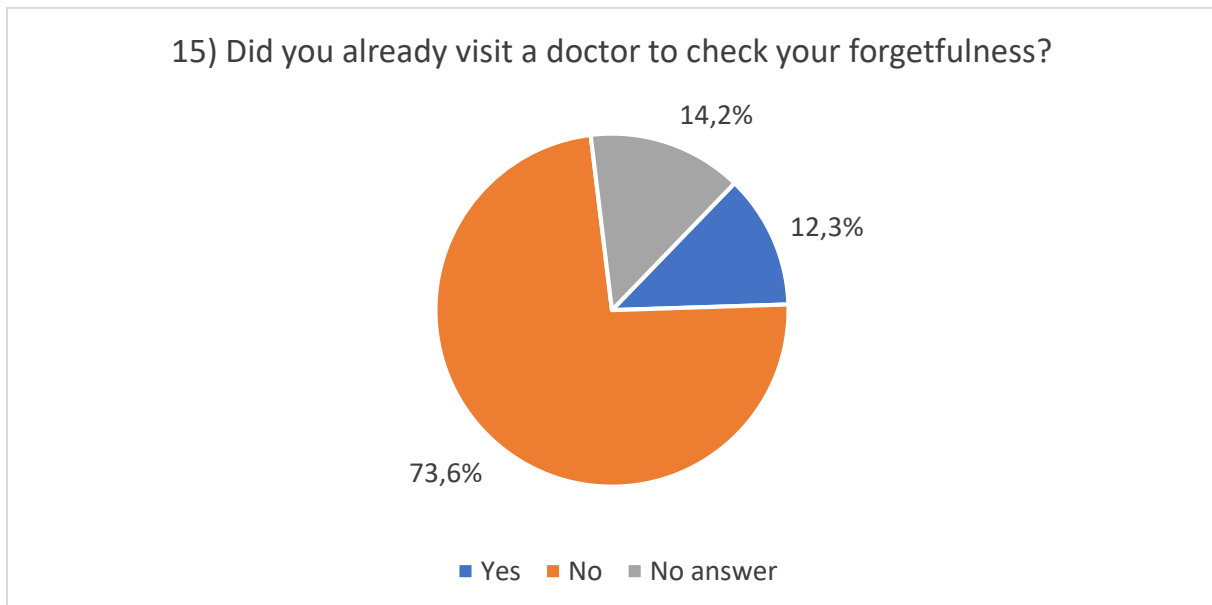
Chart 21: Check forgetfulness

Summary

In a nutshell, the present survey among older adults with memory problems gives valuable indications for a number of aspects relevant to the further development of the Many-Me solution. In the first place, the great variety and distribution of responses among the participants clearly indicates the requirement for adaption capabilities. It confirms the diversity of lifestyles, requirements and preferences for both usage of ICT and the dealing with the impairments.

Regarding the dealing with the impairment most people with memory problems make a note of the important things on a paper, but there is a moderate amount of people that use their smartphones to make some notes. Globally, the target group can be expected to have little knowledge about modern technology. But they are more inclined to make use of long-known and safe methods.

Most of the people with memory problems have problems when doing their daily activities, especially learning new things can be a big challenge; this point is important when developing a new system.

6.4.2. Results informal caregivers survey

Only 12 informal caregivers have finished the survey, therefore we should not jump to strong conclusions based on their answers, given by the small number of respondents. However, some interesting aspects occur. *Chart 26* shows that informal caregivers sometimes have the responsibility of more than one person. Moreover, half of the informal caregivers share their tasks with others (*Chart 26*) and if they share this care, half of them do this with 3 persons (*Chart 27*) and a third with two persons. This means that for about of one client/patient a considerable number of informal caregivers are circling and offering assistance. Clearly, this means that regular and reliable communication between informal caregivers is crucial in order to ensure that the caregiving process remains stable.

1) For how many people with mild cognitive impairment or early stage dementia are you providing care?

16,7%
0,0%
8,3%
75,0%

■ 1 person ■ 2 persons ■ More than 2 persons ■ No answer
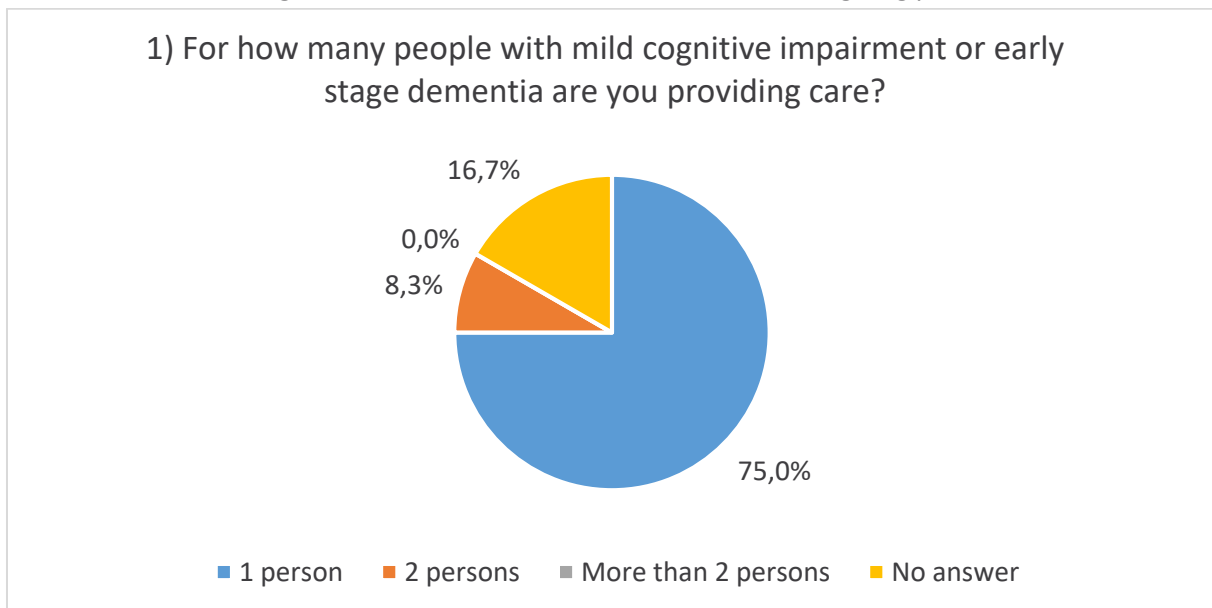
Chart 22: For how many people do you care?

2) Do you share your care with other persons (e.g. siblings)?

25,0%
50,0%
25,0%

■ Yes ■ No ■ No answer
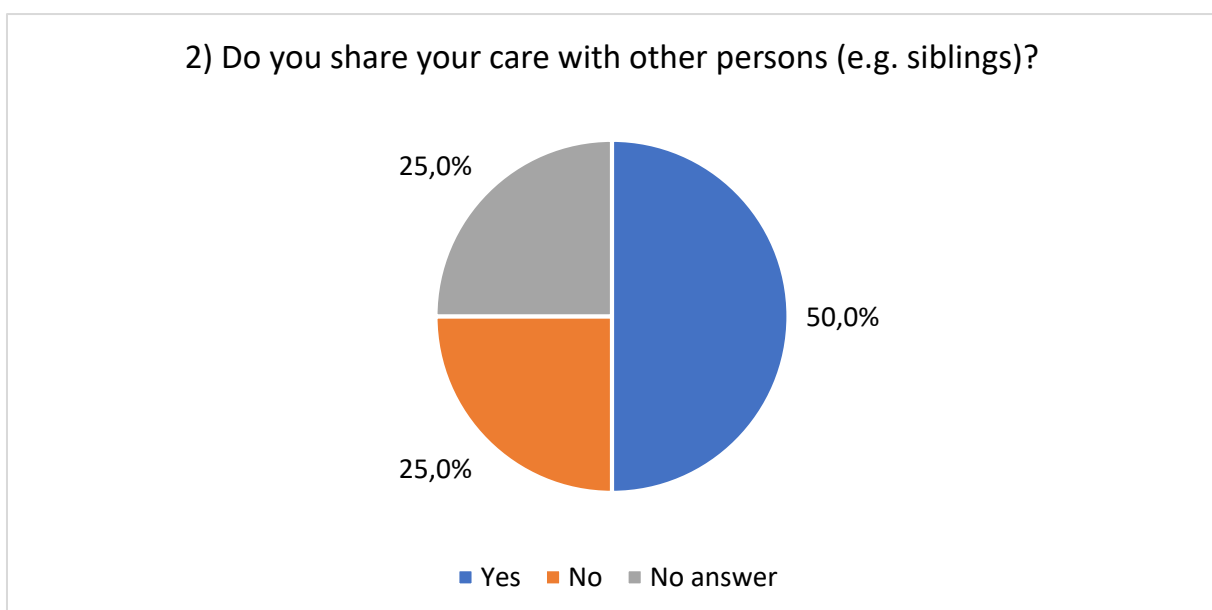
Chart 23: Sharing care with others

3) If yes, how many people share the care?

16,7%

0,0%

33,3%

50,0%

■ 2 persons ■ 3 persons ■ 4 persons ■ More than 4 persons ■ No answer
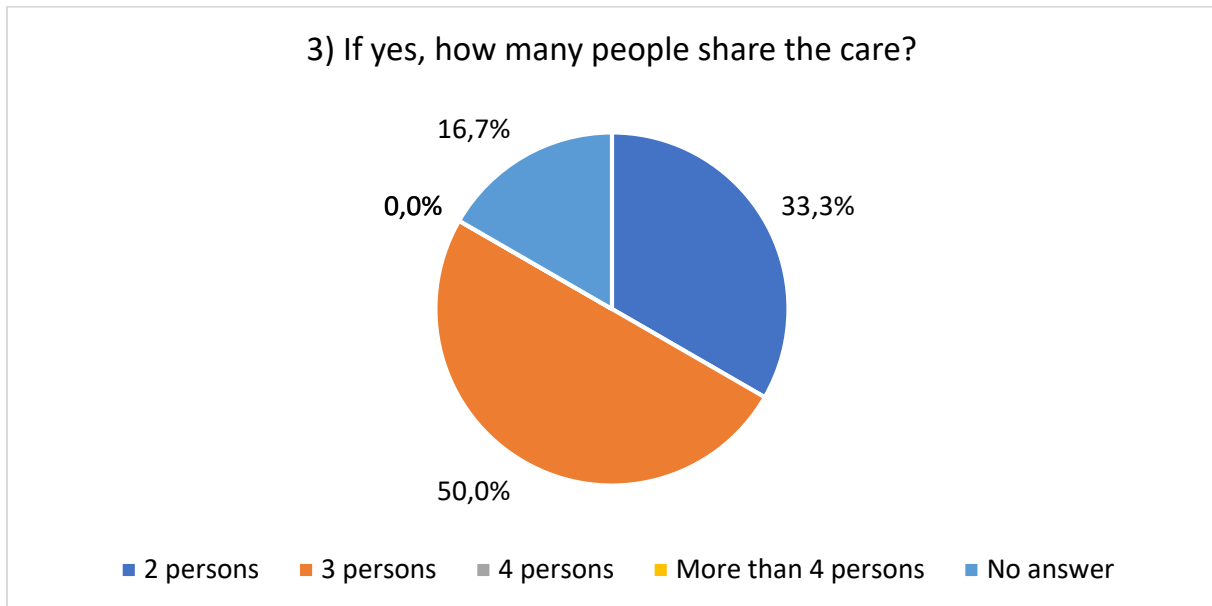
Chart 24: How many people share the care?

Based on this clear communication requirements amongst informal caregivers, simple telephone calls or personal meetings are by far the most common means of communication (*Chart 29*) and also in getting organised 75% relies on personal meeting (*Chart 30*). In a way, it is surprising to see that a relatively easy way of getting organised through a WhatsApp group is not mentioned at all (*Chart 30*), although in chart 4, under communication WhatsApp is mentioned by 10% of the respondents.

4) If you share the care, how do you communicate?

Telephone call	40,0%
Email	0,0%
Short text message (SMS) by phone	10,0%
WhatsApp	10,0%
Personal meeting	40,0%
Application provided by the care providing institute; please mention the name: …	0,0%
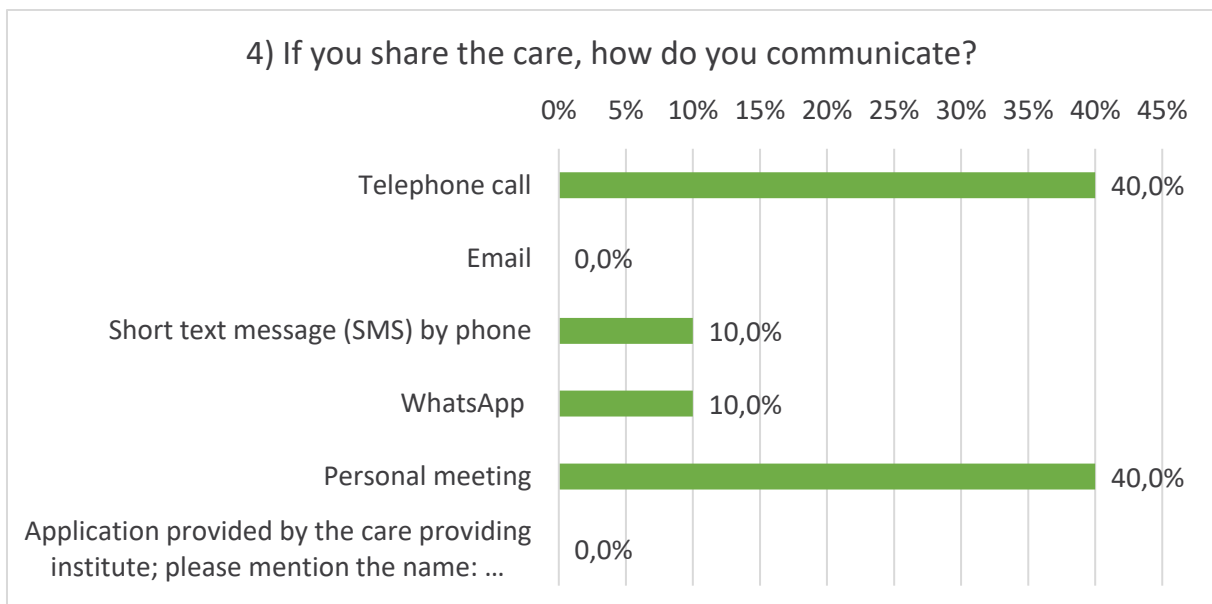
Chart 25: Way of communication

5) If you share the care, how do you get organized?

	Percentage
We use a common (digital) agenda	0,0%
We write ourselves messages within a short message service	25,0%
We make use of a WhatsApp group	0,0%
We use a telephone tree	0,0%
We meet each other on a regular basis	75,0%
Application provided by the care providing institute; please mention the name: …	0,0%
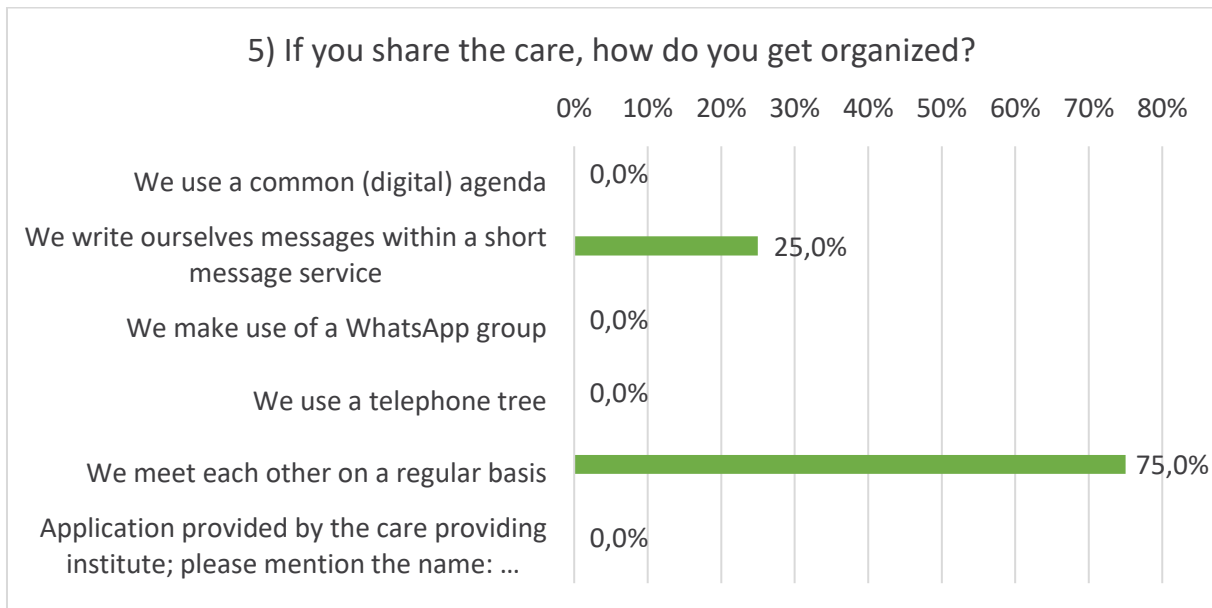
Chart 26: Getting organized

A digital exchange platform, such as Many-Me, would be useful for mainly managing appointments concerning the patient and to-do-lists clarifying the division of tasks between the informal caregivers (*Chart 31*). Obviously, the last functionality is useful if two or more persons care for one patient.

6) Imagine there exists a program, that is a digital exchange platform. Which functionalities would be useful?

	Percentage
To-do-list, where you can see who is doing which task (cleaning, shopping, go to the…)	29,4%
Appointments concerning the patient (doctor, pedicure…)	35,3%
Appointments concerning the informal caregiver(s) (information event, vacation…)	17,6%
Which caregiver is on duty.	17,6%
Other:	0,0%

Chart 27: Helpful functionalities

Additionally, one third of the respondents would favour a functionality of a digital platform that makes use of GPS location and helps to locate what informal caregiver is closest to the patient at a given moment in time (*Chart 32*).

7) Imagine there exists a platform that registers your location (GPS). How helpful would it be to schedule acute activities to the informal caregiver that is located nearest to the patient?
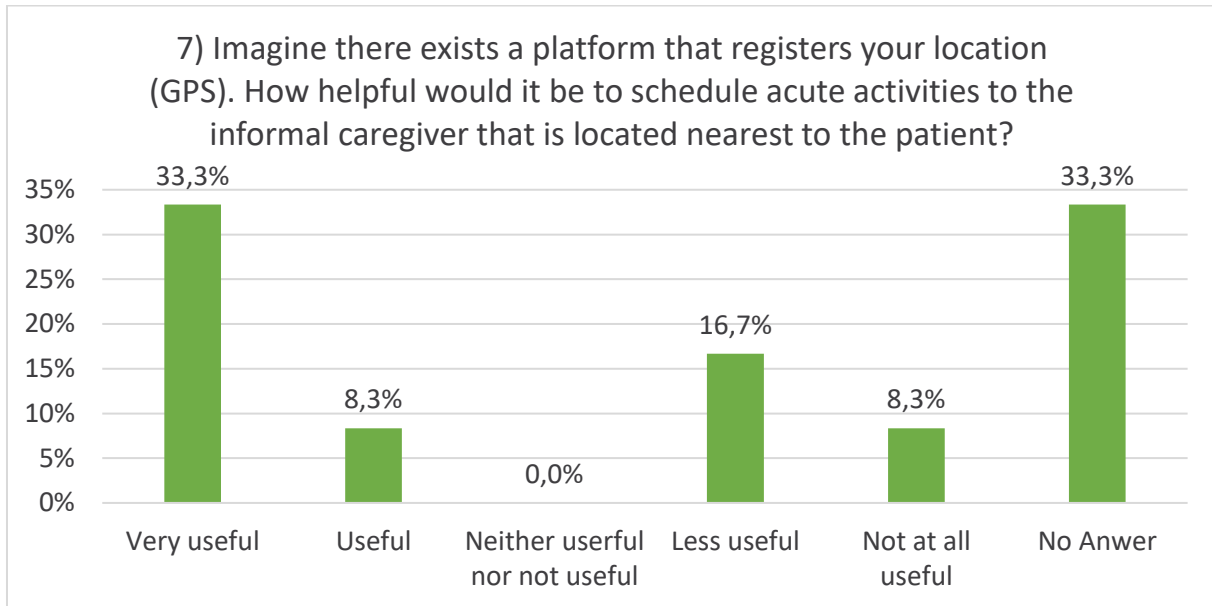
Chart 28: Schedule acute activities

The vast majority of informal caregivers (70%) exchanges experiences with other caregivers (formal and informal) in personal talks (*Chart 33*). Clearly, more advanced approaches through the internet or self-help groups are less favoured or possibly unknown.

8) Do you exchange your experience/work with other caregivers? If yes, in which way?
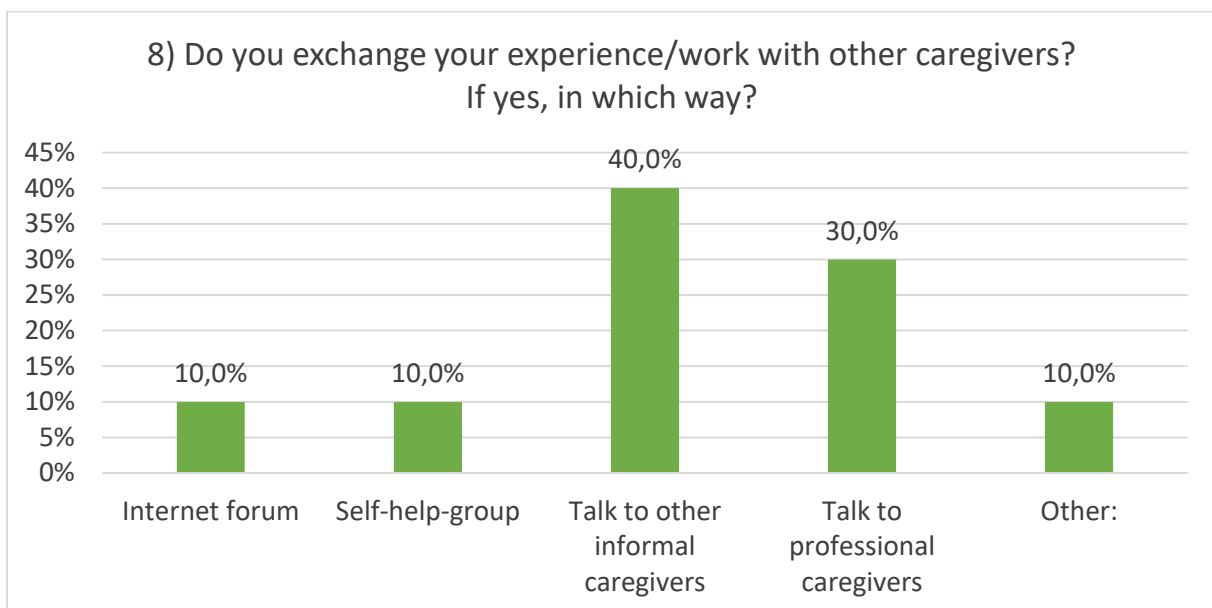
Chart 29: Exchange experience

Chart 32 shows that most of the respondents are familiar with terms related to computer and internet use. Though, less familiar with more advanced use such as emoticons, virtual reality or even blogs. Consequently, the Many-Me solution should depart from this basic internet skills and knowledge respondents show and not to indulge in too fancy functionalities.

9) How familiar are you with the following items? Which do you know?
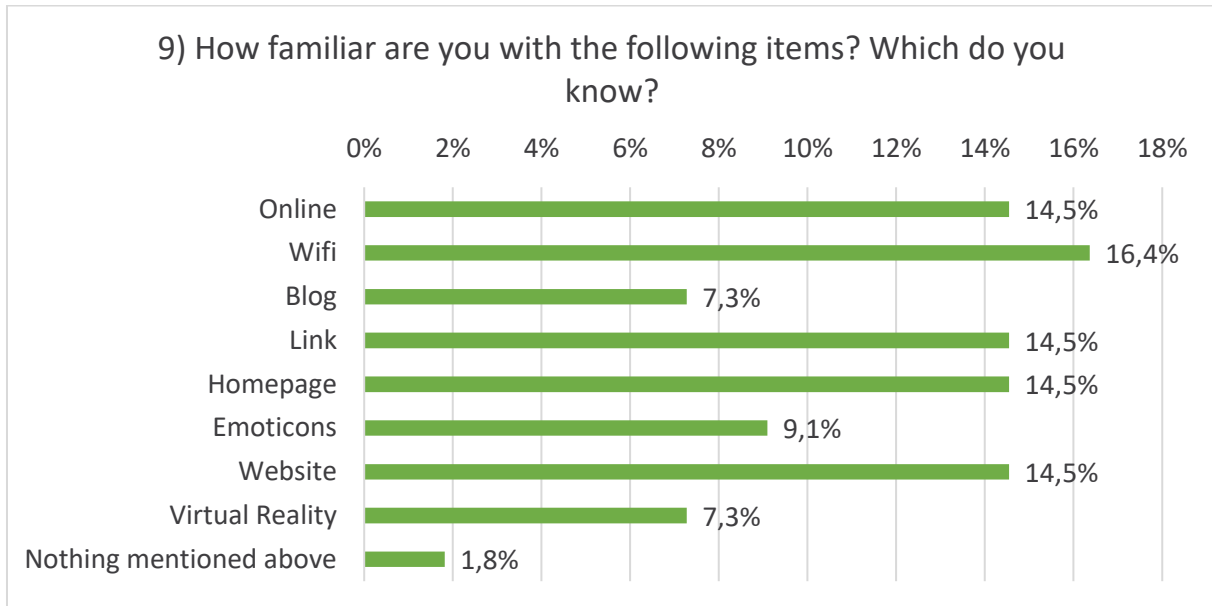
Chart 30: Technical expressions (informal caregivers)

The most useful functionalities of a 'technical device' seem to be solutions to assist when someone gets lost or falls (*Chart 35*). Clearly, the respondents focus here on life threatening and alarming situations a patient might end up in. However, other functionalities are not mentioned in the survey and therefore unknown to the respondents. Therefore, if the Many-Me solution, offers at least a credible solution for the two life threatening situations mentioned or others that we can think of, it meets the needs of informal caregivers.

10) Imagine there exists a technical device that "cares" for your relative. What do you think can be helpful?
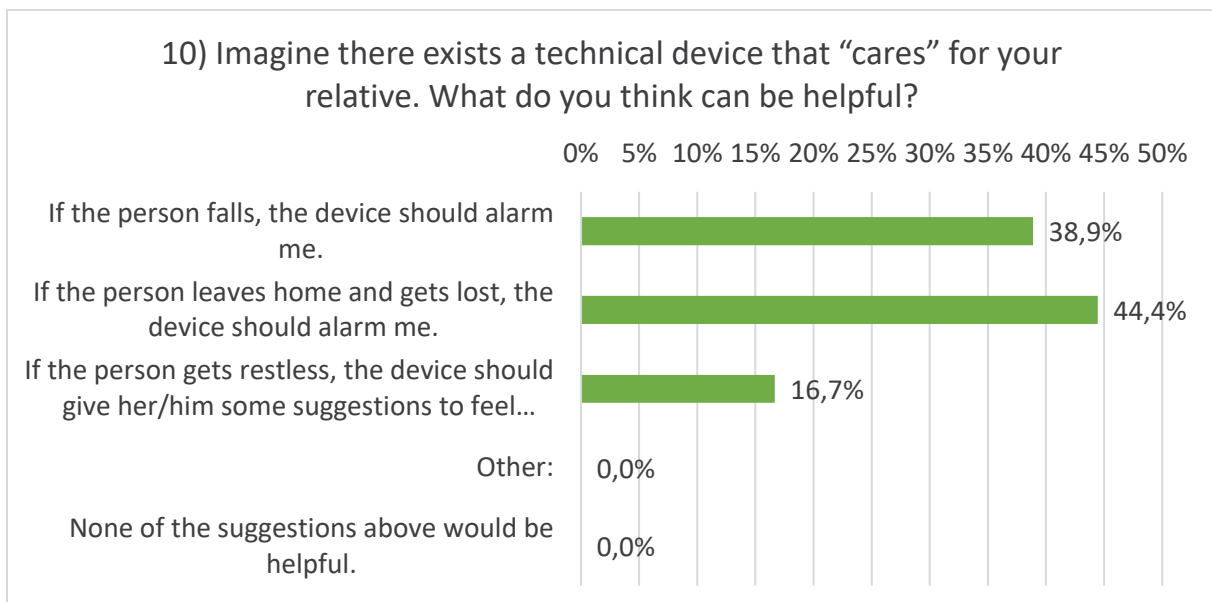
Chart 31: System that „cares" for person with dementia

13) What technological device do you currently use?
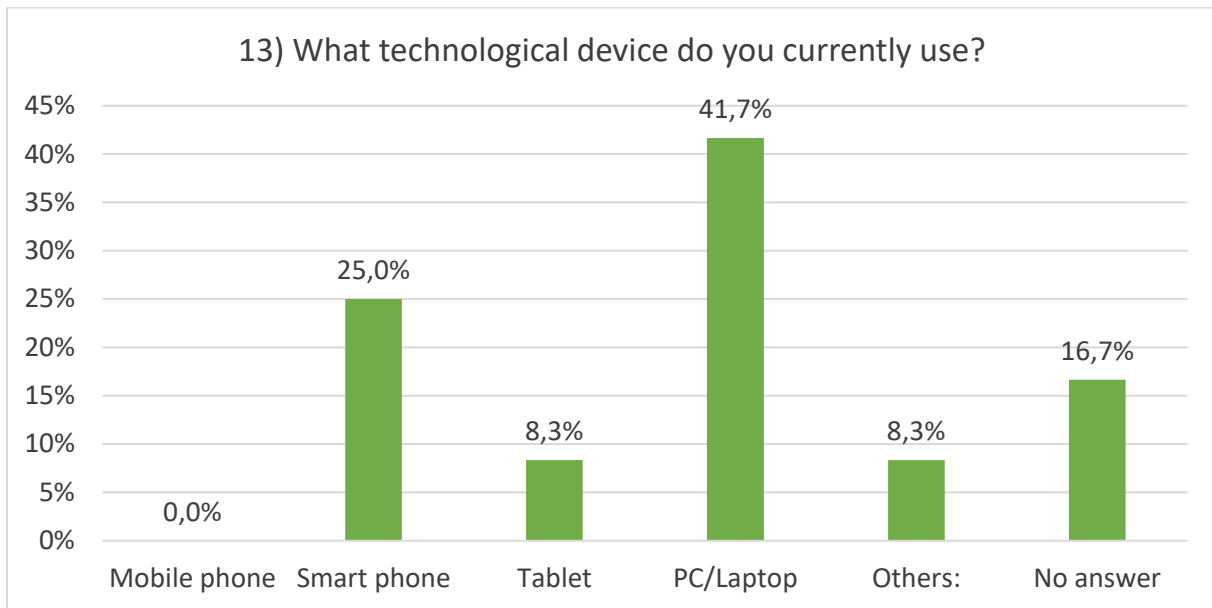
Chart 32: Use of technical devices

PC/laptop and smart phones are the most common devices used amongst this group of informal caregivers (*Chart 37*). Therefore, the Many-Me solution should take this into account and develop the platform in a way that is easily accessible through these devices.

14) How does the person you care for lives?
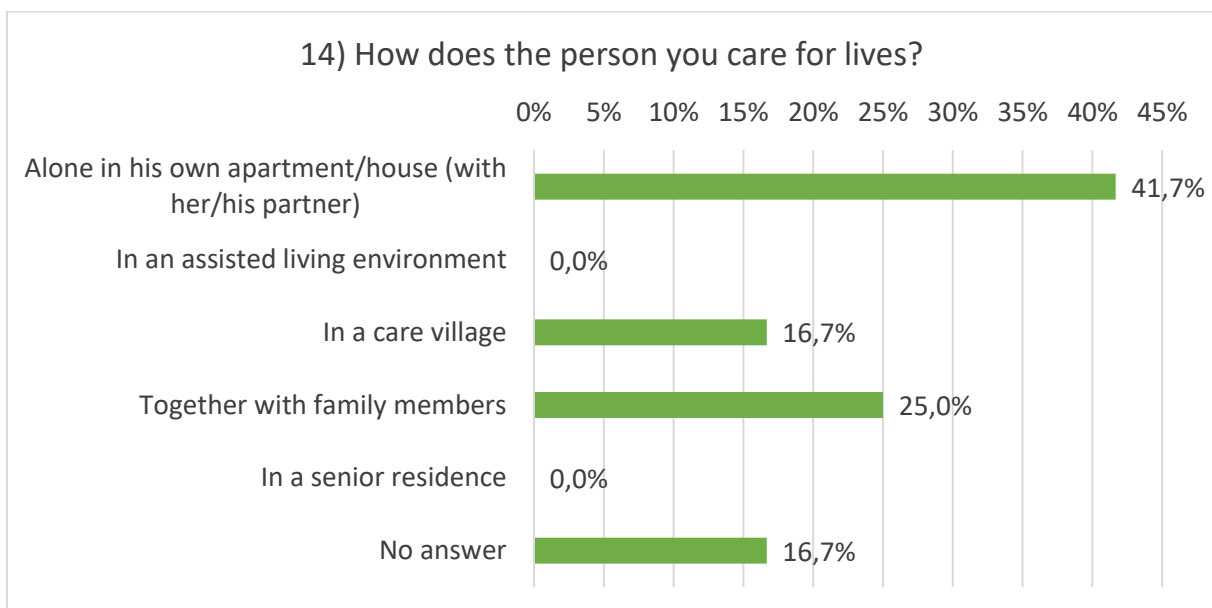
Chart 33: Living environment of person with dementia

Chart 38 shows that most of the clients/patients (42%) live alone independently and a considerable 25% lives together with family members. In one third of the cases the informal caregiver lives together with the client/patient.
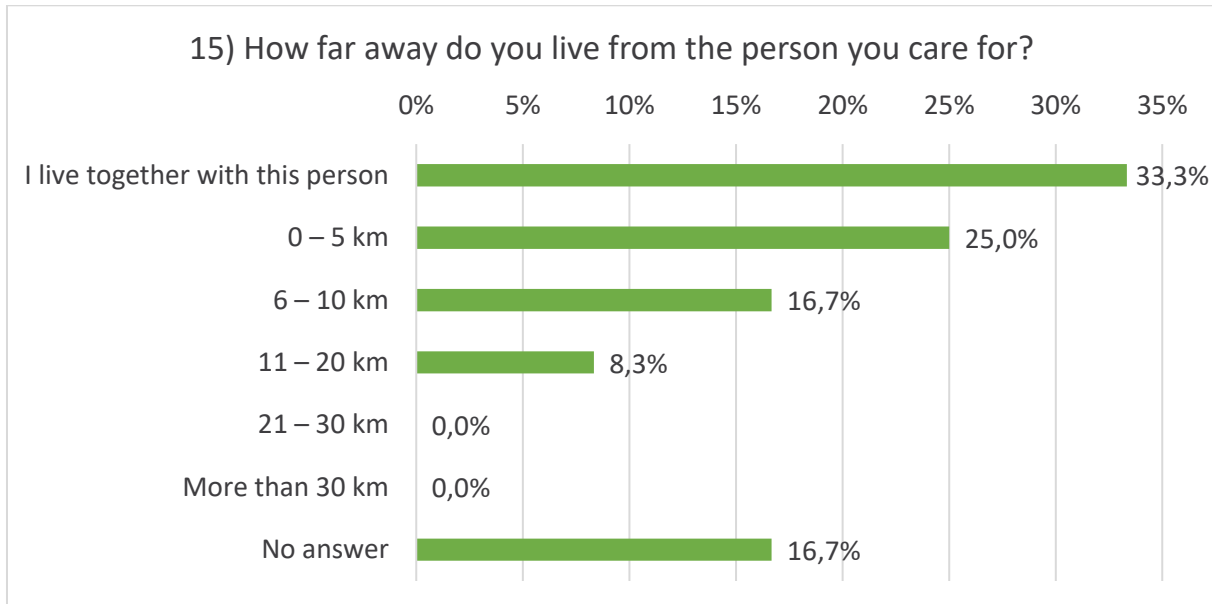

15) How far away do you live from the person you care for?

I live together with this person	33,3%
0 – 5 km	25,0%
6 – 10 km	16,7%
11 – 20 km	8,3%
21 – 30 km	0,0%
More than 30 km	0,0%
No answer	16,7%

Chart 34: Distance between informal caregiver and person with dementia

Summary

Given to the small number of respondents, strong conclusions cannot be made. Nevertheless, some important points can be summarized.

Informal caregivers share their task with other formal caregivers which requests reliable communication on the division of work. Therefore, they use telephone calls and personal meetings as the most common means of communication. Here the Many-Me system should support managing appointments of the patient and the division of tasks between informal caregivers. A very strong point can be made regarding the communication, personal talks are the most common communication to exchange experiences between informal caregivers.

Besides this technical support, the use of GPS to locate which informal caregiver is closest to the patient, is considered to be useful. Especially life treating situations such as getting lost or falls of patients are mentioned as the most urgent situations where a "technical device" should provide a solution. Most of the persons that are being taken care of, live alone independently.

Concerning to the old age of the informal caregivers, most of them have only some basic knowledge about modern technology. PC/laptop and smartphones are the devices most frequently used by informal caregivers. The new system must make sure to be very easy to understand and easy accessible.

6.4.3. Results formal caregivers survey

Formal caregivers have significant involvement in the daily care of patients with dementia who live independently in their home; thus, their perspective in building the Many-Me service is valuable. Unfortunately, the number of participants in the survey does not allow generalisation, however, the survey's results are additional to the in-depth interviews conducted by the consortium prior to the survey and all together can provide the direction for the development starting point of the development of the Many-Me service.

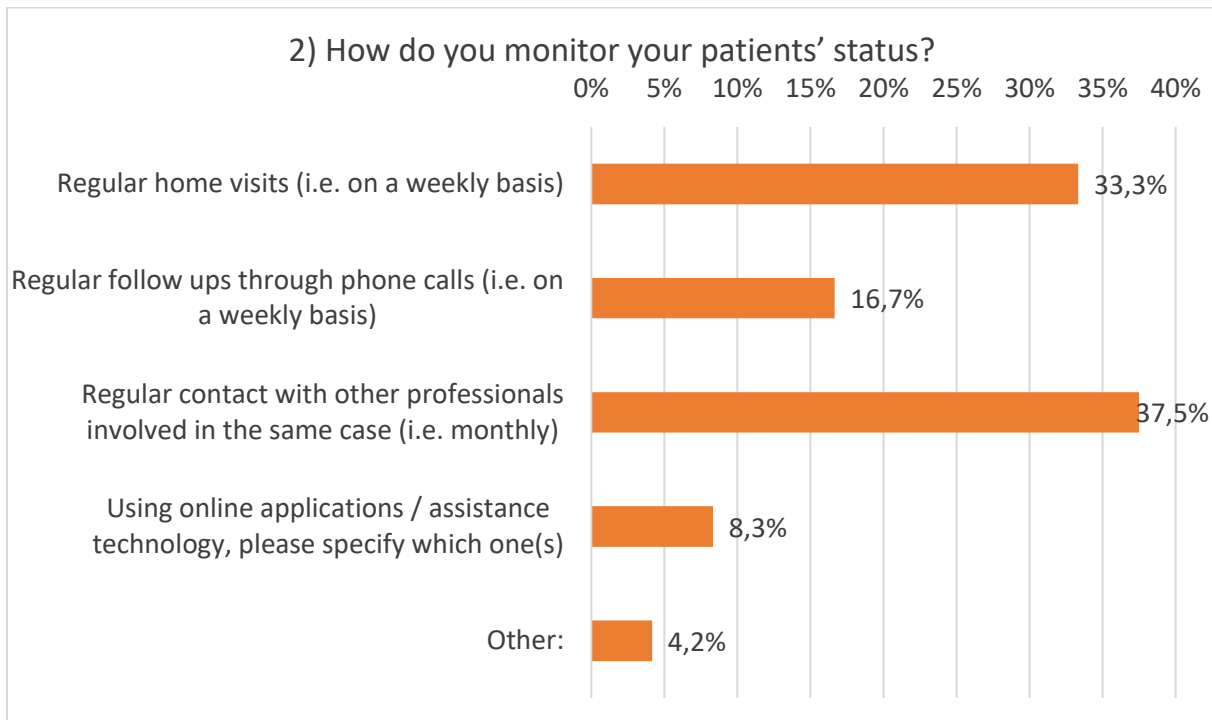The first question asked to the formal caregivers was the number of patients they take care since the needs of the formal caregivers may change accordingly. Most of healthcare professionals who respondent to the questionnaire reported to have 1 to 5 patients (23.5%) and more than 20 patients (23.5%) whereas, approximately a third of the respondents have from 11 to 15 patients. The rest of the participants reported to either have from 6 to 10 patients or 16-20 patients. However, a significant percentage of the respondents (17.6%) did not provide an answer.

1) How many patients per week do you visit/ care/ have sessions/meetings with?

Category	Value
None	5,9%
1-5 patients	23,5%
6-10 patients	5,9%
11-15 patients	17,6%
16-20 patients	5,9%
More than 20	23,5%
No answer	17,6%
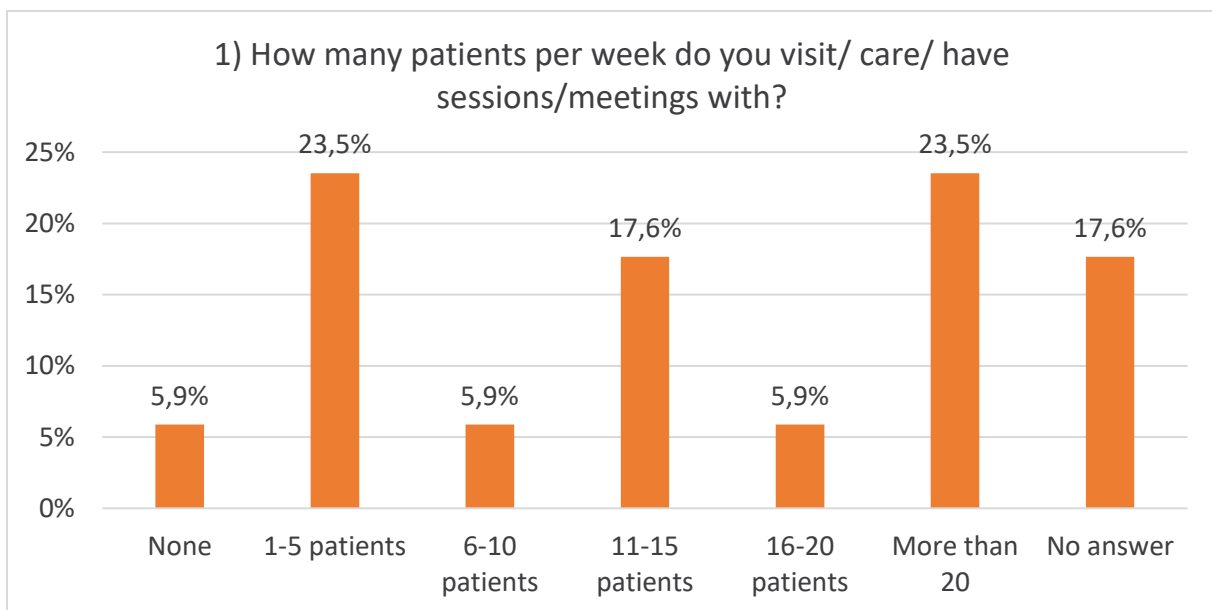
Chart 35: Number of patients

Regular contact with other professionals who are involved in the same case is the most dominant way that formal caregivers use to monitor their patients' status. Moreover, regular home visits, i.e. on a weekly basis, is another common method used by health professionals in order to monitor their patients. Whereas, regular phone follow-ups and online applications or assistive technology are less common methods used by professionals for monitoring patients' status. This question shows the importance of regular in-person contact between the professionals and their patients.

2) How do you monitor your patients' status?

Regular home visits (i.e. on a weekly basis)	33,3%
Regular follow ups through phone calls (i.e. on a weekly basis)	16,7%
Regular contact with other professionals involved in the same case (i.e. monthly)	37,5%
Using online applications / assistance technology, please specify which one(s)	8,3%
Other:	4,2%

Chart 36: Monitoring patients' status

The below question investigates the current daily practices used by professionals for keeping track of their tasks for each case. The graph reveals that the most common technique used for keeping track of their tasks is to keep a hand-write calendar, the second most used method is the online application, then the use of mobile calendar / to-do list and a small percentage reported that they can remember their tasks by heart. Therefore, keeping track of the tasks is important for formal caregivers; hence, an assistance technology should include a type of application designed to help care professionals to apply and use it in everyday tasks.

3) How do you keep track of the tasks that you need to do for each of your patients?

|	
Keep a calendar where I write by hand my appointments and tasks that need to be…	35,3%
Use a mobile calendar / to-do list, Smartphone to remind me	17,6%
Use online application, please specify	23,5%
I just remember	5,9%
No answer	17,6%
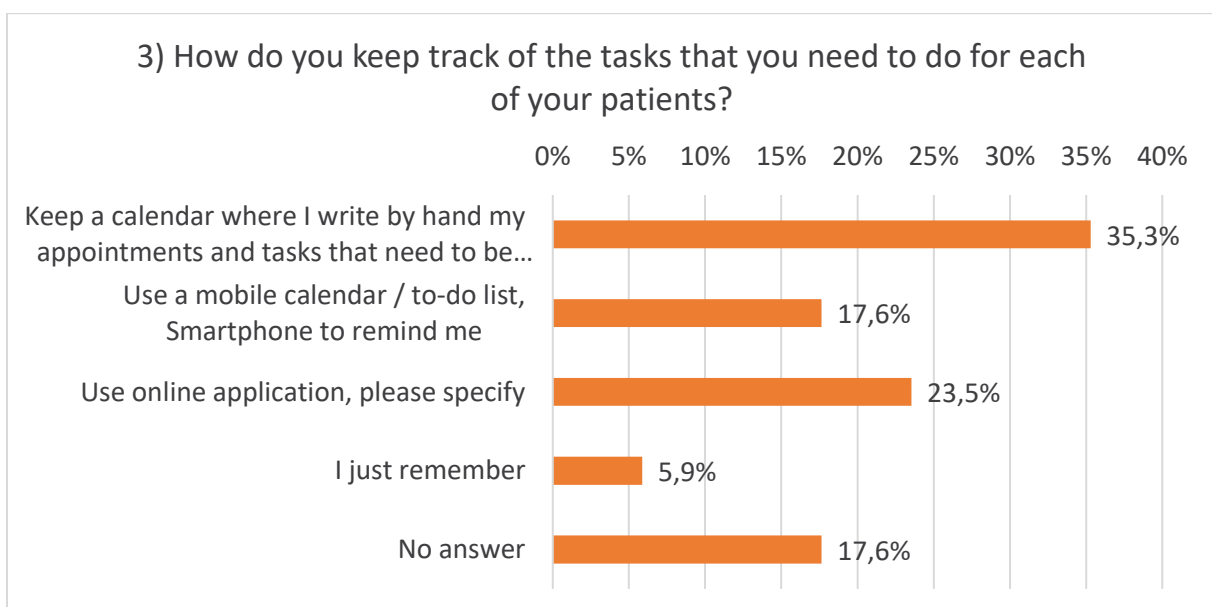
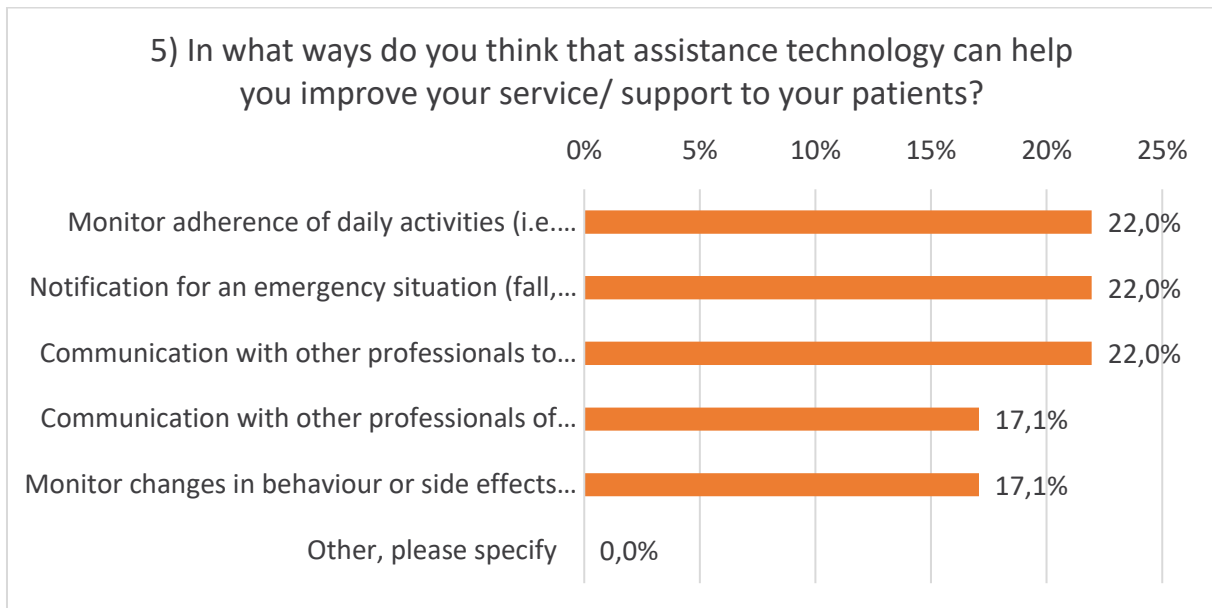*Chart 37: Keeping trak of the tasks*

Moreover, the majority of the respondents reported that online applications can be helpful in improving their services, either by choosing the "very helpful" or "helpful" options in the below question. A tenth of the respondents reported that online applications are little help for the improvement of their service or support, whereas a small percentage (5.9%) believe that these applications will not help them at all.

These two last questions provide contradicting information about the preference of professionals in methods used for their services and support towards their patients. On the one hand, most of the professionals use hand-written calendars instead of online tools and application for keeping track of their tasks and on the other hand, most of the professionals support that online applications can improve their support and services to patients. This can lead to two conclusions: (a) either the professionals are not informed of the available online applications or (b) the existing applications do not meet their needs.
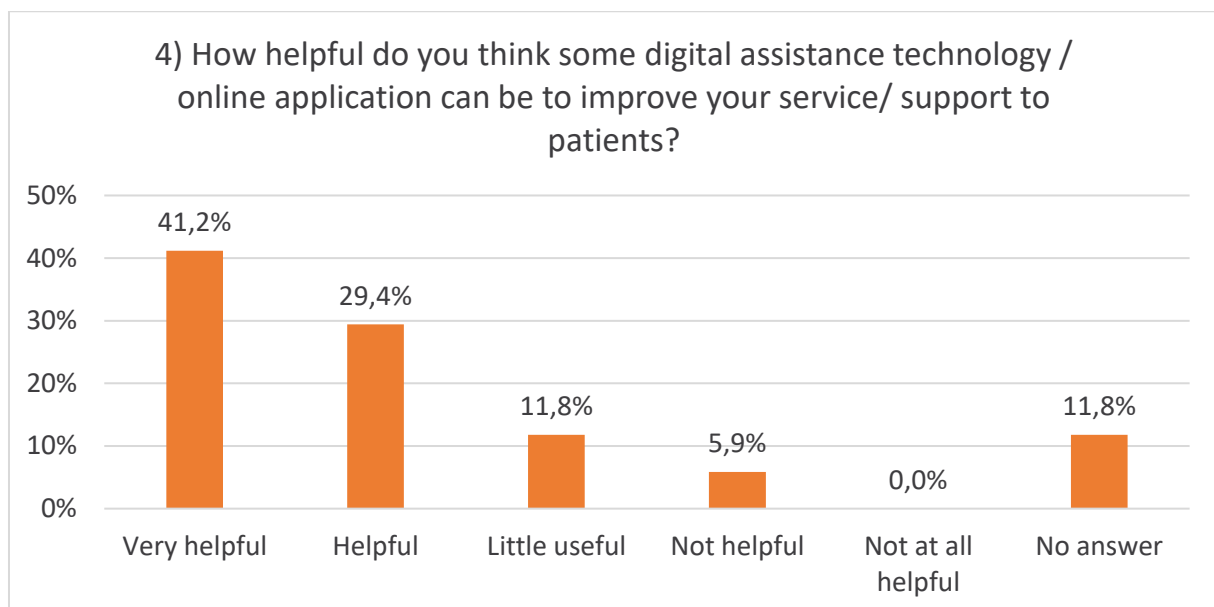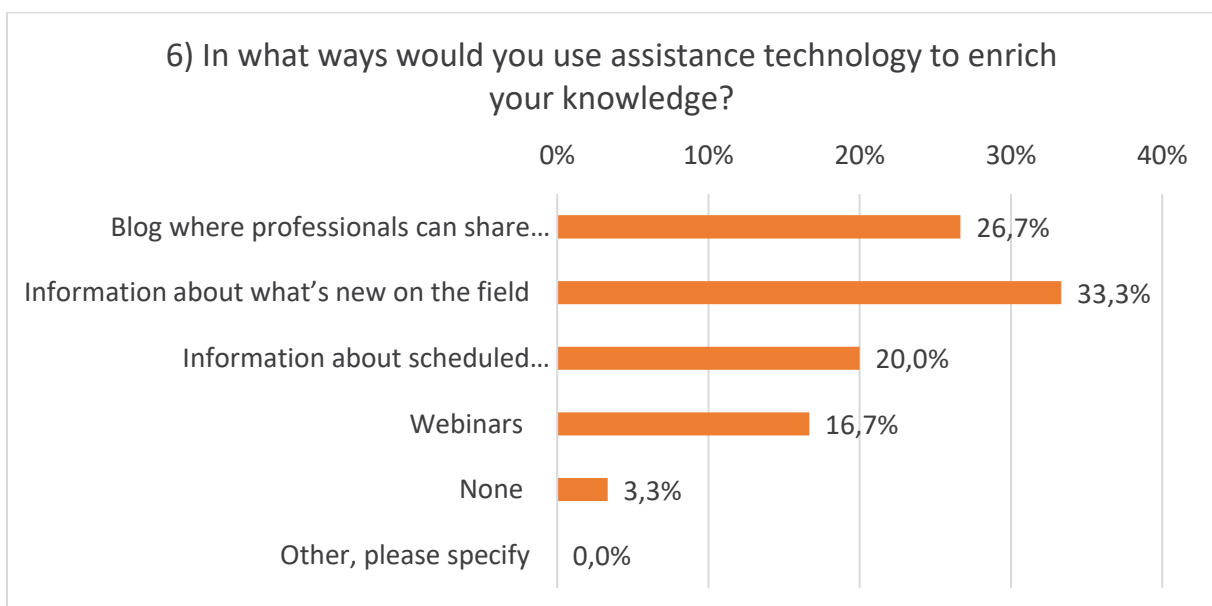

Chart 38: Helpful digital assistance technology

The following question provides more specific information regarding the usage of the assistance technology and the professionals' needs. The three equivalent and dominant ways in which assistance technology can help in the improvement of healthcare professionals' services and support towards their patients are in: (a) monitoring adherence of daily activities, (b) receiving notifications for emergency situations and (c) communication with other professionals who are involved in the same case. However, the communication with professionals of the same field for enhancing their knowledge as well as the monitoring of behaviour changes or side effects are reported to be significant functions for an assistance technology as well, since approximately a quarter of the respondents have reported those functions as important.

5) In what ways do you think that assistance technology can help you improve your service/ support to your patients?

Monitor adherence of daily activities (i.e.…	22,0%
Notification for an emergency situation (fall,…	22,0%
Communication with other professionals to…	22,0%
Communication with other professionals of…	17,1%
Monitor changes in behaviour or side effects…	17,1%
Other, please specify	0,0%

Chart 39: Assistance technology for improving the service

The professionals were also asked to specifically address the ways in which assistance technology will be used to enhance their knowledge. Approximately a third of the professionals identified the need to learn what is new on the filed through the assistance technology, and the second most important usage in the enhancement of their knowledge was indicated to be a blog through which professionals will share their best and worst practices. Moreover, providing information regarding forthcoming seminars is marked as the third most important by the respondents and later the professionals chose the option of watching webinars through an assistance technology tool. This question indicates the increased need of the professionals to get improved through the exchange of knowledge and good practices.

6) In what ways would you use assistance technology to enrich your knowledge?

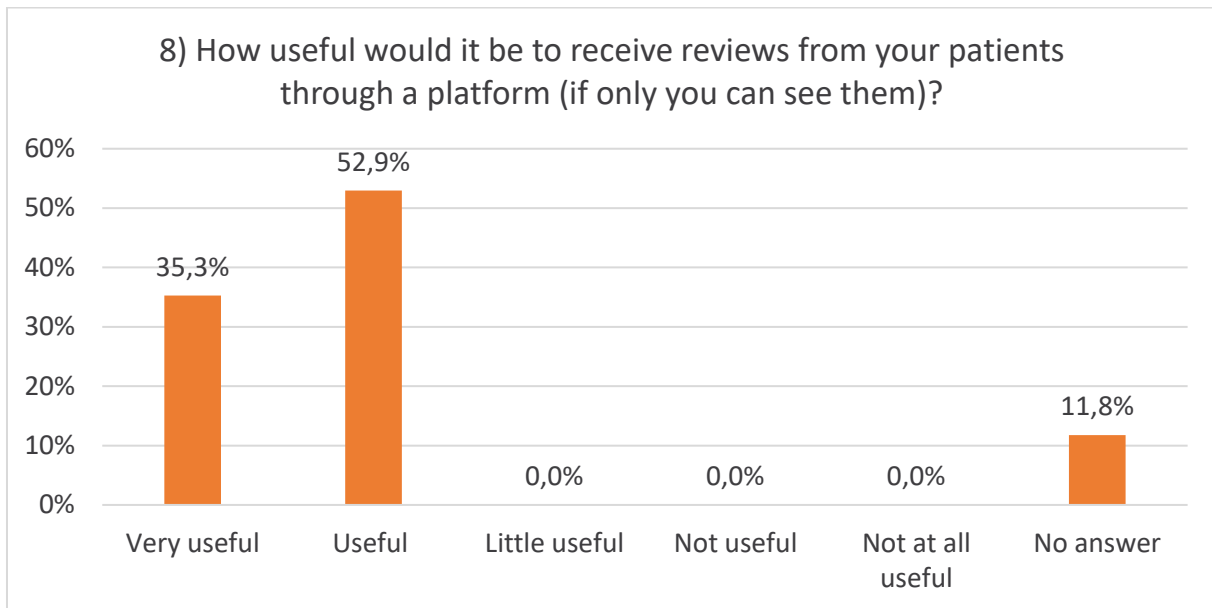|	
Blog where professionals can share…	26,7%
Information about what's new on the field	33,3%
Information about scheduled…	20,0%
Webinars	16,7%
None	3,3%
Other, please specify	0,0%

Chart 40: Assistance technology to enrich knowledge

Likewise, this question indicates the need of professionals to connect and learn from each other, since approximately 80% of the respondents reported that it would be either "very useful" or "useful" to connect with other professionals in order to accomplish a more complex task or case. Whereas, almost 6% reported that it would not be useful at all to connect with other professionals for the accomplishment of a complex task and almost 12% did not provide an answer.
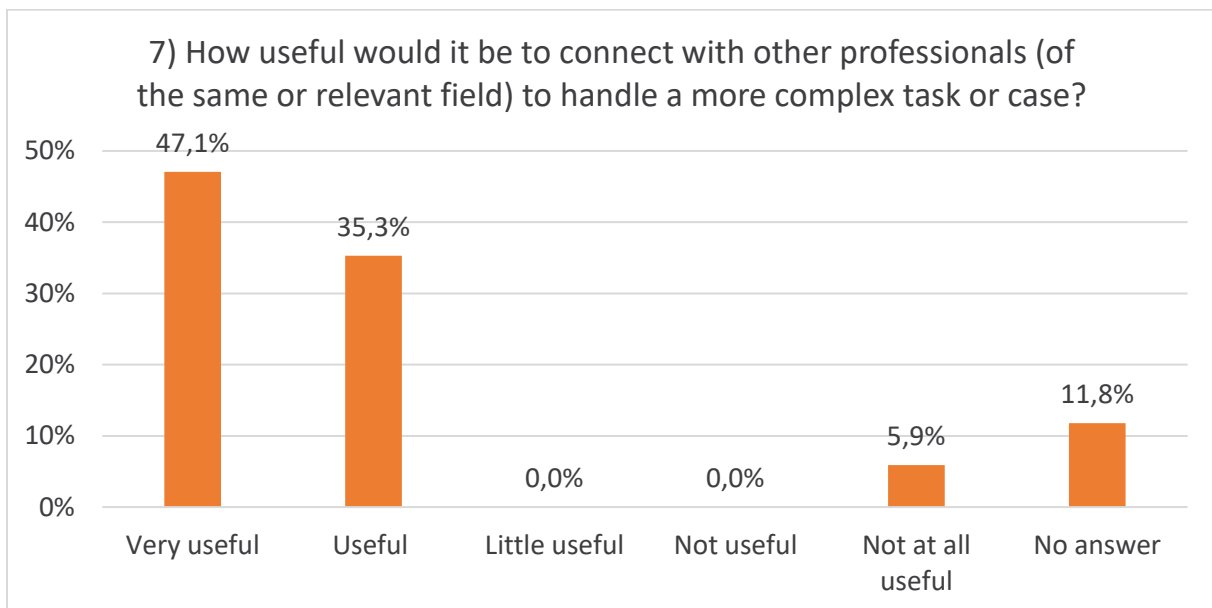
Chart 41: Connect with other professionals

Additionally, the formal caregivers were asked whether receiving reviews from their patients through the platform would be useful and all of the respondents reported either "very useful" or "useful" and approximately a tenth of the respondents did not provide an answer. Therefore, this question indicates the significance of including a feedback or review function in an assistance technology.

8) How useful would it be to receive reviews from your patients through a platform (if only you can see them)?

Very useful: 35,3%
Useful: 52,9%
Little useful: 0,0%
Not useful: 0,0%
Not at all useful: 0,0%
No answer: 11,8%

Chart 42: Receive reviews from your patients

Health care professionals were also asked about the usefulness of registering their position in order for the system to automatically schedule activities according to different factors; approximately a quarter of the respondents believe in the helpfulness of such a function and 17.6% reported that it would be very helpful. Only a minor percentage said that it would be little to not at all helpful. However, a significant percentage, approximately a third of the respondents, did not take a stand to the question. Taking these responds into consideration, one can infer that the significant percentage of "no answer" means that it is an unknown function that has not been used by the professionals before and it can also be suggested that they are positive about trying to use this function.

9) Imagine there exists a platform that registers your position (GPS). How helpful would it be to schedule activities automatically based on the availability of other caregivers, the patients, their preferences and location?

Very helpful: 17,6%
Helpful: 41,2%
Little helpful: 5,9%
Not helpful: 0,0%
Not at all helpful: 5,9%
No answer: 29,4%
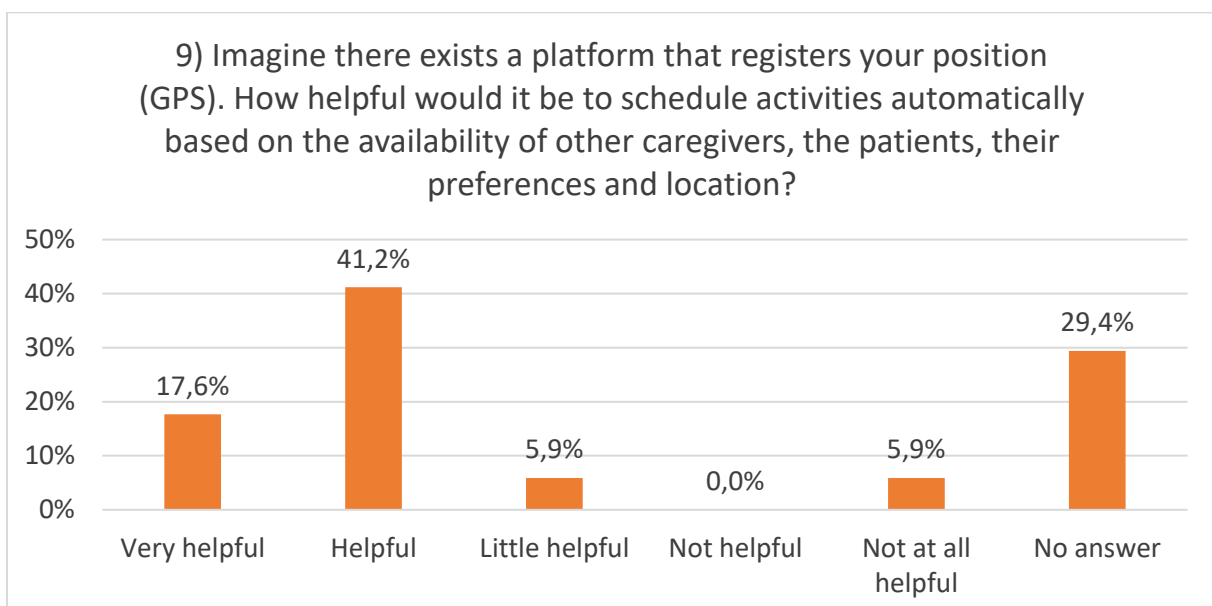
Chart 43: Schedule activities automatically (formal caregivers)

The above results help in defining the requirements of the formal caregivers in order to develop the Many-Me service, which will be based on information and communication technologies (ICT), according to their needs and preferences in order to improve their services and at the same time to increase the likelihood of using it in their daily routines at work.

13) What technological device do you currently use?
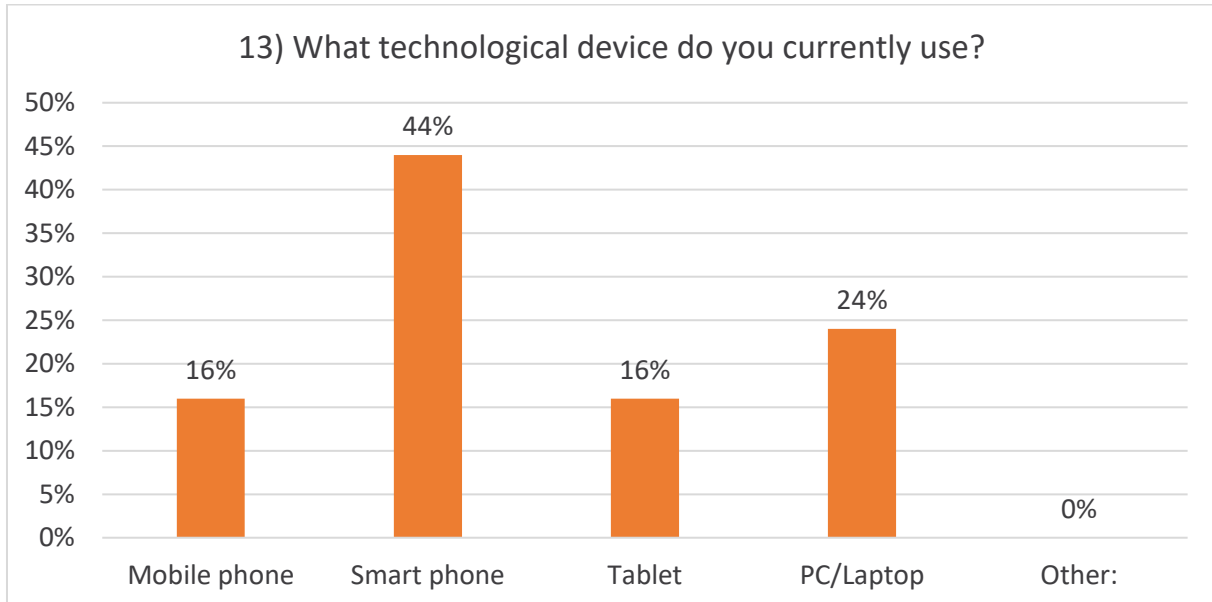
Chart 44: Currently used technological devices

Summary

To sum up, all formal caregivers that participated in the survey care for a significant amount of people, each of them requiring a great deal of attention. To monitor the patients' status most of them do regular home visits and stay in touch with other care professionals that care for the same person. To organize their activities most of them use a paper calendar, only a small amount uses their smartphone. This can lead to two conclusions, either the formal caregivers are not informed of the available online applications or that the existing applications do not meet their needs.

When exchanging information about the patients, communication with professionals of the same field for enhancing their knowledge and monitoring of behaviour changes or side effects are reported to be significant functions for an assistance technology.

As regards the function of the Many-Me solution for formal caregivers most of them would be interested in information about what's new on the field and to read a blog where professionals can share their experiences. In addition, getting better and more efficient organized solutions of scheduling activities automatically is seen as helpful.

7. Conclusion and recommendations

This document analysed the needs of the different target groups of the Many-Me project. The project considers two main user groups: the primary users, who are the older adults with cognitive impairments, and the secondary users, who are informal and formal caregivers.

The analysis has been executed by means of a mix of qualitative and quantitative methods. As a qualitative instrument, interviews were selected. As a quantitative instrument, an online survey was applied, focusing on the daily challenges and situations where support is needed.

According to the findings stated above, a list of recommendations can be made for the further development of the Many-Me system. These recommendations are intended as guidelines for the upcoming development process and are subject to validation. They must be read in conjunction with the findings that are directly inferable from the interviews and charts listed above.

7.1. Recommendations from primary users

Functionality/issue	Recommendations
Device	Develop the Many-Me system for smartphones. This device has a high degree of utilisation and can be taken with the users easily.
Surface	Older people can have difficulties with their fine motor skills. The Many-Me system must make ensure that buttons and scroll bars are big enough and easy to use. Avoid using bright colours and a small/thin font. The users need to see/read the content clearly. In addition, it must be possible to change the font size, so that users with visual impairments can adjust the system to their needs.
Alarm function	People are afraid of getting lost or loosing orientation. To support them the Many-Me system must include an emergency function or an emergency button and the possibility of GPS-tracking to help them in difficult situations and giving them a feeling of safety.
Reminders	Use simple reminders and build them referring to the procedures that older people are familiar with (e.g. set the reminder in the same way as the alarm) The reminders should include a function for making notes for appointments and medication adherence.
Special finding function	Implement a function that helps the person to find the device. If they do not find it, all functions on the Many-Me system are useless.
Learning new things	Learning new things can be difficult for users with cognitive impairments and can cause stress. To avoid this, it is important to work with functionalities the users are used to and that motivates them (e.g. collecting points when doing some cross words, reaching a higher level when solving a memory game successfully).

User focused design	Older people should not be treated as children and are to be taken in all seriousness and attentively. People with dementia should not be reduced to their impairment. The Many-Me system should not use a geriatric design! Here the system should address people with cognitive impairments, but it should be appealing to everyone. It is very important to design a "serious" platform and easy accessible application.
Personal and medical data	The system must make sure to allow transparency over the data, which should be easily accessible by the end-user, as well as possibilities for personal control by the end-user. This also includes the possibility to switch on and off functionalities intended for the collection and sharing of information. Different forms of access and feedback to the end-user (e.g. rough vs. consolidate data) should be considered in the design process. In addition, the users must be informed where their data is stored and who has access to it.

7.2. Recommendations for informal caregivers

Functionality/issue	Recommendations
Calendar	Considering that several informal caregivers share the care, it can be useful to have a simple calendar used by all involved informal caregivers and the primary users.
GPS location	The Many-Me system should make use of GPS location and helps to locate what informal caregivers is closest to the patient at a given moment in time. That can be a helpful function for emergency situations.
Exchange experiences	Since informal caregivers are mostly non-professionals it is considered to be useful to have a platform where they can exchange experience between other informal caregivers. Here the Many-Me system can develop a forum.
Alarm function	Provide an alarm function to the informal caregivers that calls them when the person they are caring for has an emergency situation (e.g. falling, being not at home for a long time).

7.3. Recommendations for formal caregivers

Functionality/issue	Recommendations
Functional aspects	The system must make sure to support the formal caregivers in a best way. As it can be seen in the results, three main functions should be included: - Possibility to keep records of their tasks - Have notifications for emergency situations - Having a platform for a regular communication between professionals involved in the same case
Staying up to date	As caring for dementia people implies tremendous work for the caregivers to keep up to date with the continuous new insights associated of the disease. Therefore, the Many-Me system should insert a newsfeed about the work of the formal caregivers, giving them the possibility to share experiences between professionals
GPS location	The Many-Me system should make use of GPS location and to help locate what formal caregivers is closest to the patient at a given moment in time. That can be a helpful function for emergency situations.

8. References

A look at the lives of the elderly in the EU today,
http://ec.europa.eu/eurostat/cache/infographs/elderly/index.html [access: 15/08/2017].

Adelman et al. (2011), "Ageing and Public Health," in *PublicHealth in the 21st Century*, vol. 1: Global Issues in Public Health, ed. M. E. Finkel, Preager.

Alexandrakis D. (2017), "Factors Affecting the Usage of ICT by Older Adults: Results of an Empirical Study in Greece,"
https://www.researchgate.net/publication/313023114_Factors_Affecting_the_Usage_of_ICT_by_Older_Adults_Results_of_an_Empirical_Study_in_Greece [access: 15/08/2017].

Aronson et al. (2013), Social psychology, Wellesley College.

Cullen J. (2015), D6.1 Toolkit for developing the Digital Competences of Carers, Carer+ project,
http://www.carerplus.eu/sites/all/libraries/Toolkit_developping_digital_competences.pdf?dl=0 [access: 15/08/2017].

Cullen et al., 2016, Telecare and Assistive Technology Evaluation, Work Research Centre and Genio.

Dröes et al. (2010), "Dementia-Related and Other Factors to Be Taken into Account When Developing ICT Support for People with Dementia – Lessons from Field Trials," in *Supporting People with Dementia Using Pervasive Health Technologies*, Advanced Information and Knowledge Processing, Springer-Verlag London Limited.

EPHA (2017),"Digital Solutions for Health and Disease Management," https://epha.org/wp-content/uploads/2017/05/Digital-solutions-for-health-Discussion-Paper.pdf [access: 15/08/2017].

Ferreira et al. (2014), "Elderly centered design for Interaction – the case of the S4S Medication Assistant," *Procedia Computer Science* 27.

Georgantzi et al. (2014), "ICT for ageing well: Listen to what older persons think!", https://www.age-platform.eu/images/stories/Publications/HSH_publication_webversion.pdf [access: 15/08/2017].

http://ec.europa.eu/eurostat/cache/infographs/elderly/index.html [access: 15/08/2017].

https://www2.health.vic.gov.au/ageing-and-aged-care/dementia-friendly-environments/assistive-technology [access: 15/08/2017]

https://www.med.unc.edu/neurology/divisions/memory-and-cognitive-disorders-1/dementia-1/family-concerns-1/communication-challenges [access: 17/08/2017].

Harrison Dening et al. (2016), "Advance Care Planning in Dementia: Do Family Carers Know the Treatment Preferences of People with Early Dementia?," *PLoS ONE* 11 (7).

Jiang et al. (2015), Human Aspects of IT for the Aged Population. Design for Aging. First International Conference, ITAP 2015 Held as Part of HCI International 2015 Los Angeles, CA, USA, August 2–7, 2015 Proceedings, Part I, eds. J. Zhou, G. Salvendy, Springer International Publishing.

Medical Devices and Systems: ICT and the Future of Healthcare, https://www.rvo.nl/sites/default/files/2016/04/ICT%20and%20Healthcare%20Japan.pdf [access: 15/08/2017].

Meiland et al. (2010), "Identifying User Needs and the Participative Design Process," in *Supporting People with Dementia Using Pervasive Health Technologies*, Advanced Information and Knowledge Processing, Springer-Verlag London Limited.

O'Shea, Monaghan (2016), An Economic Analysis of a Community-Based Model for Dementia Care

in Ireland: A Balance of Care Approach, National Centre for Social Research on Dementia, http://www.age-platform.eu/sites/default/files/Genio_ECONOMIC_ANALYSIS_OF_DEMENTIA_COMMUNITY_CARE.pdf [access: 15/08/2017].

Preliminary guidelines for design and implementation of technologies (2014), Deliverable 2.4, FARSEEING project, http://farseeingresearch.eu/wp-content/uploads/2014/07/Preliminary-Guidelines-V1.0-Public.pdf [access: 15/08/2017].

Shneider, Henneberger (2014), "Electronic Spatial Assistance for People with Dementia:

Choosing the Right Device," *Technologies* 2014, 2, 96-114

Teipel et al. (2016), "Information and communication technology solutions for outdoor

navigation in dementia," *Alzheimer's & Dementia* 12.

The Dementia Guide 2017, https://www.alzheimers.org.uk/download/downloads/id/1881/the_dementia_guide.pdf [access: 15/08/2017].

van Knippenberg et al. (2017), "Dealing with daily challenges in dementia (deal-id study): process evaluation of the experience sampling method intervention 'Partner in Sight' for spousal caregivers of people with dementia," *Aging & Mental Health*.

van Knippenberg et al. (2016), "Dealing with daily challenges in dementia (deal-id study): effectiveness of the experience sampling method intervention 'Partner in Sight' for spousal caregivers of people with dementia: design of a randomized controlled trial," *BMC Psychiatry* 16:136.

Wallace et al. 2010, ICT Interface Design for Ageing People and People with Dementia, in *Supporting People with Dementia Using Pervasive Health Technologies*, Advanced Information and Knowledge Processing, Springer-Verlag London Limited.

Wilkowska, Ziefle (2009), "Which Factors Form Older Adults' Acceptance of Mobile Information and Communication Technologies?", in *HCI and Usability for e-Inclusion. 5th Symposium of the Workgroup Human-Computer Interaction and Usability Engineering of the Austrian Computer Society, USAB 2009, Linz, Austria, November 9-10, 2009 Proceedings,* eds. A. Holzinger, K. Miesenberger, Springer.

Willemse et al. (2015), e-Inclusion in Ageing Europe: Barriers and Needs in ICT Use of Older People, Trimbos Institute.