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USER REQUIREMENTS REPORT

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Table of Contents

List of Figures

List of Images

List of Tables

1. Introduction

Seniors with mild cognitive impairments are (to a certain degree) dependent on caregivers such as family careers and home care. The support and care by caregivers enables these seniors to continue living in their own home for as long as possible. However, these seniors might experience barriers towards moving around in outdoor environments when their caregivers are absent. The MyGuardian project aims for a product or service that facilitates safe and secure mobility of seniors with mild cognitive impairments. Not only seniors, but also caregivers (whether formal or informal) are likely to be users of this future product or service. Therefore, this research explores the needs and experiences of three different stakeholders:

1.1. Seniors with mild cognitive impairments

MyGuardian aims to facilitate safe and secure outdoor mobility of the seniors with mild cognitive impairmentswhile preserving their autonomy and dignity, and thereby enable seniors to increase their mobility (while increasing their self-confidence) and consequently to take part in the self-serve society. By removing the barriers towards autonomous mobility, MyGuardian ultimately improves physical health, wellbeing, and social life of seniors. At the same time, MyGuardian improves wellbeing and efficiency of voluntary caregivers (e.g., family and friends) by ensuring their peace of mind and keeping them informed when the senior is experiencing confusion states and risk situations when out and about, and improves efficiency of professional caregivers by providing them with up-to-date information and by supporting coordination of their care efforts. Third, MyGuardian enables new business models for professional caregivers by enabling them to assist voluntary caregivers and to step in when needed.

1.2. Informal Caregivers

Informal caregivers are the persons who take care of the patient in their daily life. The informal caregivers are often partners or other close family members of the patient. They are the ones who make decisions and take care responsibilities regarding a loved one who lives in a constant state of illness. Making these kind of decisions is an activity of great importance, more when the caregiver should decide not only for actions of daily life, but even to decide of the prognosis for the disease. Caregivers arise from the need to help a loved one, a child, a parent, etc.., who have a disease and are in need of constant care, other caregivers spontaneously respond to this need because they feel an unconditional love for that person; others become family caregivers because there is no other person to assume that role. In many cases, women take on the role of informal caregiver. They often have to combine caregiving with being a mother and housewife and/or their job. The important thing is that the caregiver needs to decide where and when to invest efforts in view of their availability and their responsibilities.

Caregiving experience involves making changes in lifestyle and reorganize work and social life; this makes a tendency to isolation, because the caregiver must distribute personal and economic resources. Strong emotions and feelings can be caused by the caregiving responsibility, especially when there is a conflict in between the desire to care for her family and their tiredness. The caregiver is many times forced to change the settings of their home, which becomes a small hospital where they must reorganize beds, chairs and furniture to install the tools and medications that the senior uses and must rearrange schedules depending on the senior’s needs.

The experience of being a caregiver brings positive feelings: satisfaction for the care of their loved one seeking wellbeing, but unfortunately there are often more intense negative feelings of overload, depression, helplessness, sadness and guilt, especially when important decisions need to be made for seniors or themselves. Moreover, there is some structure and claims of other family members, which often criticize the management of the caregiver. Caregivers, therefore, have a number of needs: reassurance, social support, knowledge of the illness of the senior they take care of, financial support, and recognition of both their family, and the one who they are caring for.

All things considered, MyGuardian empowers the senior, as well as has a potential to increase the caregivers’ confidence and improve their efficiency.

1.3. Formal Caregivers

Formal caregivers are the professional home caregivers who take care of the senior being a patient.The care may include care inside the home of the patient and care away from the home. In-home services include, but are not limited to, visiting nurse services, homemaker services, respite care, and home health aide services. Care away from the home involves services such as care provided in a physician's office, day care provided in a nursing facility or other bureaucratic facility, congregate housing, senior center activities, nursing care provided in residential settings, and transportation.

These persons received theoretical courses to provide practical day-to-daycare to the patients and their family. They could be at the patient's house or in hospitals, residential or specialized services. They also cover wide range of professions working together with doctors, nurses, psychologists, social workers and health technicians.

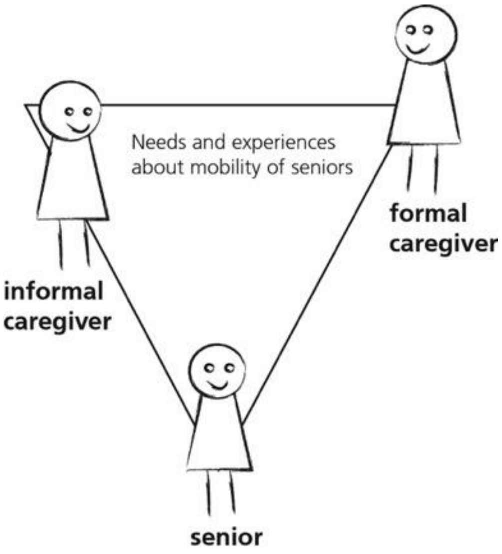


Figure 1: Stakeholders

2. User Research Objective

This user research aims for insight into the needs and experiences about mobility of seniors from the perspective of the three stakeholders above. This insight serves to inform and inspire the concept development of MyGuardian. As a next step in the MyGuardian project, user requirements and use cases will be defined based on the outcome of this user research.

This research will be conducted in different countries participating in the MyGuardian project (France, Spain, the Netherlands). The socio-cultural context of the stakeholders may result in different needs and experiences.

We have to take into account that for this study the countries involved have large cultural differences among themselves, on the basis of the welfare state in each, like in the Netherlands they have the Nordic model a high level of social protection from the state, in France they are governed by the continental model they also have a high social spending for pension protections. In Spain, by contrast with the Mediterranean model, is the involved country with lower spending on social services market.

To all this is added the fact of cultural difference in each country, in Spain the tradition dictates that younger generation takes care of elders, and bring them to live with. In fact Spain is one of the European countries that use most of the informal caregivers. By contrast, in France and the Netherlands it is widely accepted that a senior with certain kind of needs has a special care by a professional.

3. Methodology

In order to bring out the needs and experiences about the senior's mobility of the three stakeholders, we use probes, semi-structured interviews, and focus groups. We use a different methodology for each stakeholder, because they have different capabilities (see figure 2).

3.1. Data Collection

Participants are 4-6 seniors, 4-6 informal caregivers, and 4-8 formal caregivers per country. The seniors and informal caregivers are related. In this way, we utilize the available relationships, which enable us to listen to the experiences about the senior's mobility from multiple perspectives, and help us to connect them to the situation, and thereby better understand what the experiences mean.

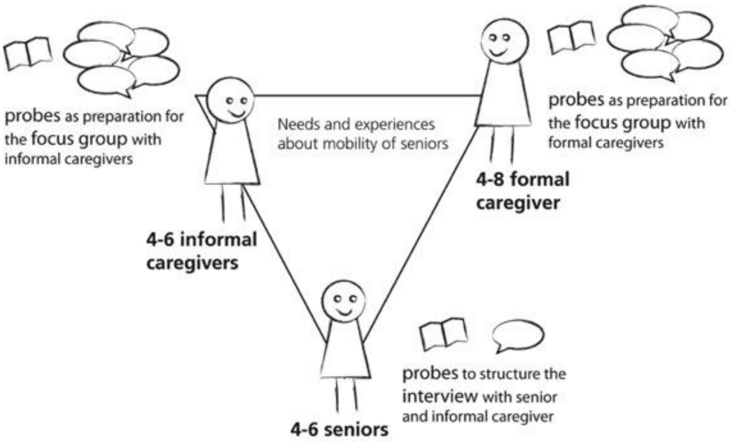


Figure 2: The three stakeholders and the Methodology

3.1.1. Seniors

We conduct a semi-structured individual interview with 4-6 seniors per country. A caregiver is present, but only helps out if needed. The interviews take place at the senior's house, enabling the researcher to observe the senior's living environment.

The seniors have been selected and recruited in close consultation with the local participating end user organization (Careum for NL, AGIM for FR and Cetiex for ES). Selected seniors currently suffer from mild cognitive disorders and are currently being supported by informal cares and professional care.

3.1.1.1. *Semi structured interview*

We use a *probe* to prepare participants for the interview, and to make them aware of issues they are generally not aware of (see appendix 1). Whereas the caregivers complete a probe in the absence of the researcher, the researcher is present when the senior fills in the probe. This way, the researcher is able to help the senior with completing the probe. At the same time, the researcher gets a feeling for the capabilities of the senior. The assignments in the probe serve as structure to provide topics to discuss. After the interview, when analyzing the results, the probes provide us a *persona* and a summary of the conversation. These probes can be shared within the consortium.

The probe addresses the following topics:

- Personal (age? Gender? Disability level?. ….?)
- A day in their life
- An overview of who takes care of them and how close they are to them
- A story of their last adventure outside
- Insight into how often they go outside and where to (week overview)
- If needed to extract more information, they can be made more concreted questions
    - Do you buy in a big market or a small one?
    - How often do you go out to buy bread? Where exactly do you go for?
- The objects and people they bring when going outside, and how they find their way
- Their feelings, emotions, concerns about going outside
- Their favorite or dream locations and what is so nice about this place
- The ingredients that stimulate or prevent them from going outside (e.g., safety, people, walking stick, a map, bad weather conditions).

  Interface – In order to know how they feel about technologies:
    - Do you have a computer? Do you use it? How often and what for?
    - Do you have a mobile phone? Do you use it? How often and what for?

3.1.2. Informal Caregiver

We conduct a focus group with the 4-6 informal caregivers who were present at the interview with seniors. This focus group takes place after all interviews with seniors are completed. In this way, the participants are more at ease with the researcher and the researcher knows the caregiver's situation and the senior they take care of. In addition to the interview, participants can now discuss and bring out topics that were too sensitive for the senior to hear about.

The informal caregivers have been selected and recruited in close consultation with the local participating end user organization. Selected informal caregivers will either be actively involved in providing care to a senior with mild cognitive disorders, or have recently been actively involved in providing care to a senior with mild cognitive disorders.

3.1.2.1. *Probe as preparation for focus group*

As preparation for the focus group, the participants complete a probe a week after the interviews (Gaver et al., 2003) containing open questions about their experiences about the senior's mobility. In utilizing probes, participants can freely think about the topic, without the researcher around. Moreover, the assignments sensitize the participants for the upcoming focus group (SleeswijkVisser et al., 2005). Again, this probe can be used as persona and easily shared within the consortium. It addresses the following topics:

- Personal
- A day in their life with an indication of what they do for the patient during the day
- Their story about their relationship with the patient before and now
- The things they love to do in their free time
- Their needs and experiences when the patient goes outside.

3.1.2.1.1. Focus group

The focus group consists of three main parts.

Part A. Informal caregivers discuss their experiences about the mobility of the dependants. This group discussion involves the following questions:

- What are your experiences concerning seniors going outside?
- What are the positive and negative aspects about this?
- How does the senior experience mobility?
- How do formal caregivers experience mobility according to you?
- What is your role in the mobility of the senior?

Part B. In the next part we employ the generative technique ‘cognitive map’ (SleeswijkVisser et al., 2005). For this exercise, we prepare an expressive toolkit with arrows, words, and images. This toolkit helps the participants to express what stimulates and hinders seniors in going outside. Next they explain what they made to the rest of the group.

Part C. Each participant makes an ideal “device” to support the patients in going outside and explains what their device does to the rest of the group.

Note: these explanations help the researcher to filter the most important criteria. We do not aim to use these exact solutions in the development of MyGuardian.

3.1.3. Formal Caregiver

We conduct a focus group with 4-8 formal caregivers.

The formal caregivers have been selected and recruited in close consultation with the local participating end user organization. Selected formal caregivers will be actively involved with the day-to-day care of seniors with mild cognitive disorders. The goal will be to select a diverse group of caregivers, with different roles in the care process.

Each end user organization will be free to select themselves caregivers and seniors, as they are different cultural context, we cannot define the same profile for each, so it will be open to the local end user organization to choose theme.

3.1.3.1. *Probe as preparation for interview*

Again, each participant completes a probe as preparation a week before the interviews (see appendix for example). This probe addresses the following topics:

- Personal
- A day in their professional life
- An overview of who they take care of

3.1.3.1.1. Focus group

The focus group consists of three main parts, similar to the one with the informal caregivers.

Part A. The participants discuss their experiences about the mobility of the patients. This group discussion involves the following questions:

- What are your experiences concerning patients going outside?
- What are the positive and negative aspects about this?
- How does the patient experience mobility?
- How do informal caregivers experience mobility according to you?
- What is your role in the mobility of the patient?

Part B. Each participant again makes a cognitive map about how they can stimulate or lower the mobility of seniors.

Part C. Each participant makes an ideal “device” to support the patients in going outside and explains what their device does to the rest of the group.

Note: these explanations help the researcher to filter the most important criteria. We do not aim to use these exact solutions in the development of MyGuardian.

3.2. Data Preparation/Translation

The collected data will be prepared for joint interpretation by making an initial rough selection of statements and observations and translating them into English.

3.3. Transferability

Each end user organization has described exactly how many people took part in each focus group and individual interviews, what where the responses for all the work, not only themselves point of view, but all the results from the focus.

Each organization has made pictures or videos that shown the interviews, to do the conclusions and the deliverable.

4. Results by Country

Being three the end users organizations involved in the project, first individual conclusions per country will be analyzed, finalizing with the final conclusions including the summary of the final set of requirements obtained.

4.1. Spain Results

4.1.1. Seniors

The Seniors interviewed belong all to the population of Zafra and Los Santos de Maimona, which also means that they come from a rural environment, that’s significant because they are used to stay long times out of their houses, going to buy bread each day, to visit their relatives, and etc.

Collaborating institution in Spain was “*Fundación Asmi*” which is a day Center where Seniors go daily during the morning to perform various activities to improve their memory. On one of the informal caregivers meeting, MyGuardian study goals were explained, as well as the procedure for the interviews and the participants were asked to subscribe to the study.

In our cases the people who have been part of the study were 2 women and 2 men, in between 60 and 75 years old. Although it was made a presentation of the project and it was explained which would be their role in the interviews participation, the informal caregivers didn't wanted to participate themselves and neither their relatives, as they have some popular costumes established, and do not feel comfortable with something they do not properly know, although seniors itself agreed in collaborating with the study, but as they cannot decide by themselves most of them rejected the offer. Finally it was possible to do 4 interviews with seniors with a low dementia level, their caregivers agreed as they understood that it was for their own benefit.

Image 1. Senior Interview

Image 2. Senior Interview

The interviews were conducted by the MyGuardian researcher who was questioning them along the methodological approach described above, while they were answering to the topics of the probes (Annex 1), the interviews were recorded in video in order to analyze later the answers given, and to be able to be completely involved in the conversation. Interviews lasted between an hour and hour and a half; they were at the seniors' house, and with the collaboration of the informal caregivers.

The responses obtained where:

Daily life

- In their daily life they are helped by their informal caregivers: partners and possibly children.
- Normally during the week they go every morning to the day care center, by a bus property of the center or carried on by their informal caregiver.
- They do activities in the day care center, to increase their memory, and also to understand computers.

Going out

- The 80% of the patients stay at home by their own, while the caregiver is doing some other tasks outside, but they are usually in a feeling of fear, as they know they can forget something suddenly and go out.
- Those who go out alone, the 80%, go as much to have a quick walk round the house, although sometimes they go to buy something to the market, just the days they feel more confident.

Health status

- All the patients have some sight problems.
- Although they have Alzheimer, which is a most burdensome disease, they have not many other health problems.

Emotional

- All of them are conscious of their disease, and know that they have to learn to keep on with it for the rest of their life.
- Those who have children are more accompanied than the one who aren’t.
- Tree of them have lived along their life in many towns because of their profession, and because of that they’re more afraid when they go out, due to the problem of remembering the different streets.
- They all have a dream of travelling abroad, although they admit that when they were young, they didn’t like it too much.
- All of the women would like to go to the church alone; currently they have to wait for their caregiver.
- Most of them ask themselves while they are talking what where they talking about, suddenly they forgot what was the conversation about, or what they were going to do.

Technological Knowledge

- They know how to use a mobile phone, all of them have one, caregivers feel more confident..
- They have no knowledge regarding computers, or internet, that’s why they work on it in the day care center..

4.1.2. Informal Caregivers

These stakeholders are all relatives from the patients, in this case, they are the partners, there are 3 women and one man, and all of them are from Zafra and Los Santos de Maimona. They have no professional knowledge about sanitary cares, but they are in contact with professionals for any further assistance.

Caregivers were present in semi-structured interviews with the senior, so they knew the questions were going to perform, they were active and answered all questions openly. Focus duration was one hour, and was implemented at the premises of Cetiex.

Image 3. Informal Caregivers Focus Group

Based on the answers we could achieve:

Daily life

- The informal caregivers who participate in the Focus Group live with the Seniors interviewed, they spent their days with them, and are helped by their children and possibly the neighbors.

- Only the man being informal caregiver still works, but only during the morning; he is a teacher along the time where the senior is in the day center, if there is no possible to have the Senior occupied in the morning, the a relative or a neighbor takes care of the senior during his work time.

- The other caregivers had to stop working, as they couldn't afford taking care of his relative with their jobs; it was too expensive to have an adidtional person talking care of them.

Going out

- Tree of them leave the senior alone for a short period of time, an hour or hour and a half, while they are doing housework, they don't feel confident when that happens.

- They don't want to close the doors of the house and leave the patient locked, as they think always that if something occurs inside, like a fire, the patient is not going to be able to escape of it. But if doors are not locked, the seniors can maybe go out by their own.

Emotional

- They are much happy that researchers think of them and their needs with their relatives.

- They don't feel confident when his relative goes outside alone, they would be pleased if they had some help, doesn't mean a person, but maybe some application would be good.

- Although they take care of their relatives, they don't have experience with it, making them having more fears than they should, they became hyper frequent.

Technological Knowledge

- All of them have their own smartphones.
- The 50% have computers and have knowledge regarding internet, mail and social networks.

Care activities

- Although they tried to have routines, it's not always easy to keep them all the time, which makes difficult the care for the patient.
- To not get angry or impatient is difficult for the caregiver.
- They tried to keep the patient secure, but they can't do it always.

4.1.3. Formal Caregivers

The data collection was carried out in the private residence "*Puente Real*", which has 140 residents. The first thing you do when arriving at his new senior center is to classify him as Barthel Scale in physically valid, semi - valid, semi - physically assisted, semi - aided, assisted total, thereby attempting to assess the dependency and assistance.

Respondents are 100% women, whose profession is represented by 20% of psychologists, 60% of nurse's aides, and 20% for nurses. 40% of respondents care for the 140 patients and 60% of the 35 people who are part of the residence.

Image 4.Formal Caregivers Focus Group

The 100% match surveys agree that according to the Barthel scale, the level of dependency of the patients ranges from low to high depending on this level: physically valid, semi - valid, semi -

physically assisted, semi - aided, total assisted, thereby they consider their dependency and the needed of assistance. Therefore care is higher depending on which level rises.

Day Life

100% of respondents stated that the physically valid patient needs help for eating and taking his pills, the semi valid patient need help for shower and toilet, The physically semi-assisted needs help for having a shower, dressing and to be guided through places, the semi-assisted need to be helped for their disorientation, grooming, meals and need to be accompanied those who are physically assisted in all activities, need total aid.

Going out

All respondents say that when they become disoriented senior are too embarrassed to ask about where they wanted to go or what to do, they prefer to take other alternatives before asking for help.

Health status

It is also important that when patients are busy doing outdoor activities feel much better, physically and emotionally, and go less to the nursery looking for pills or saying they have pain.

Emotional

The 40% of respondents say that seniors are not so often dependent, is more to have sure they have attention.

100% of respondents say that at the end of the day, the feeling in their workday is satisfaction, utility and affection to their patients.

Technological Knowledge

100% of respondents agree that mobile device is helpful for valid patient's, semi valid, semi - assisted physically, if they had this device the caregivers would feel safer and will give them less hesitance to going out, because they will lose the fear.

4.1.4. Conclusions

The user study in Spain provided insight in the user needs for the MyGuardian service. In chapter 5, these needs will be interpreted to derive the user requirements.

User needs from the perspective of the senior:

- Ideally, for any equipment is carried, there must be no need to press any button; consider using voice control with auditory feedback.
- A smart assistant could help the seniors remembering what they are doing by stating their current activity every 5 or 10 minutes.
- A smart assistant could help the senior find their way back home. It might help if the senior sees someone familiar explaining the route.
- The system might be linked to a call center for taxis; the system could automatically communicate the location of the senior so the taxi can pick them up.
- Reminder for the pills, alarms to the caregivers.

- Big letters, capitals on any interface
- High and clear voices.
- The possibilities of collect the voices of the caregivers, so it would be sound familiar to the patient.

Regarding the device in Spain they were no useful conclusions obtained

User needs from the perspective of the formal? Informal? caregiver:

- Need to spend more time by themselves
- Need to feel confident to close their houses when they leave home.
- A smart assistant, which indicates the localization of the senior.
- For the informal caregiver filter the alarms in order not to have many.
- The system should be affordable
- For the informal caregivers, a smart assistant which help them not to be as hyper frequent.

4.2. Netherlands Results

The user research in The Netherlands was conducted with professionals from Careyn (home care service provider), with clients with dementia from Careyn, and with their family caregivers.

Over a period of 2 months we talked to 6 elderly with different forms of dementia, 8 informal caregivers, we conducted group sessions with 8 formal caregivers and an evaluation session with again 6 formal caregivers. We observed at the elderly- day care and the care-call center.

4.2.1. Seniors

The seniors were recruited through the dementia case managers of Careyn. They live in villages in the Rotterdam-The Hague area of The Netherlands. The seniors (3 male, 3 female) were between 60 and 83 years old. All participants live in their own house, with help from professional caregivers (Careyn) and family caregivers. 3 participants visit the “Day care Center” regularly, where they participate in various activities including physical activity and brain training.

The professional caregivers motivated the participants to take part in the user study. It was therefore no problem to recruit the required number of participants.

Image 5.Senior Interviews Netherland

The findings from the user study in The Netherlands are summarized in Appendix 3. The key findings regarding the seniors are:

Day life

- All the patients still lived at home; half of the patients visited the elderly day care. Depending on the situation they went there 4-1 day(s) a week.
- The senior participants all want to stay in their own house, together with their partners for as long as possible.
- All of the patients live an easy life together with their partner and/or children. They all live in a quiet neighborhood, within a small community.
- All the seniors get support from family members. But they also get professional help to provide the care that is required, or to assist with household tasks.
- None of the patients liked to be left alone by their partner; they feel insecure when this happens.
- Most of the patients had difficulties to orientate on date and time. They forget which day it is, but also which part of the day it is. One senior we visited regularly went out to do groceries in the middle of the night.

Going out

- Most of the patients are still going out to go for a walk or do some groceries, either alone or together with somebody else. One patient still made one-hour bike rides on her own. Only one patient almost never left the house anymore.
- Although the patients are still going out on their own, they do sometimes fail to find their way or remember what they were up to. 2 patients that still drive the car (only locally) experienced difficulties in finding the car back.

- Because of both age and the dementia, seniors live in a world that becomes smaller and smaller. Whereas in their younger days they might have travelled around the world, they now only move around locally.

- All of the patients were having difficulties to navigate on their own, and to remember the way and where they were headed.

- Multiple patients we interviewed had to give up driving (car, bike, scoot mobile) after a professional advice from a doctor or instructor.

- The seniors are really attached to local trips, such as going to the market or do groceries. These “normal” trips are also hard to give up.

Health Status

- Besides dementia some of the patients had some light health problems. Such as varicose veins and bruises from falling. Three of the patients had to use a walker when walking outside the house.

- For medical care, all of the patients were visited by district nurses. Or they went out to visit the general practitioner or the neurologist.

Emotional

- All of the patients acknowledge the fact that they have Alzheimer but did sometimes under-estimate the illness and don’t take the effects very seriously.

- Some of the seniors already lost the ability to empathize, which is a known, serious effect of the illness. It results in misunderstandings and a carefree mindset, whereas the caregiver worries a lot.

- The seniors are depending on others, where they used to be self-supportive.

- All of the seniors with dementia experience a multitude of emotions, including worries (‘what if I don’t recognize my children no more’), anger, sadness, insecurity and shame.

- Some seniors mentioned that their decreased mobility made them feel as they would be handicapped.

Technological knowledge/ product use

- Because of memory-loss, agnosia (the loss of the ability to recognize objects, people etc), and apraxia (the loss of the ability to execute or carry out learned purposeful movements), the seniors have difficulties using new products. They even forget how to use ‘everyday’ products such as a television.

- Some patients had in particularly problems with language. For them it was hard to understand the meaning of a word and to use words. This also reflected on their disability to use email, phone, text messages or other written language.

- Because of dementia, seniors lose track of time. Time does not make any sense no more. Which makes it hard to use a calendar and clock.

- Most of the patients took a mobile phone with them when they were going out. But none of them was able to show us how to use (or at least unlock!) the product.

- One patient (with strong afasia) had a speak-computer to be able to communicate. She was now being trained at the day-care how to use the product.

- Products such as mobile phones or for example a speak computer are forgotten when the seniors are going out.

- It’s a challenge for both informal and formal caregivers to bring new products and operations into a system that is slowly falling apart.

- Because patients with dementia have a weak short-term memory but a very stable long term memory, they are not able to learn how to use new product but do still know how to operate product from the past.

4.2.2. Informal caregivers

The primary informal caregivers are generally the spouse and/or children.

In interviews with 8 informal caregivers (4 children, which are in between 50-60 years old, as the patients are in between 60-83 and , 4 spouses), we found that:

Day Life

- For a spouse of a senior with dementia, providing care becomes a 24/7 responsibility that requires full commitment.

- Even when another caregiver is in control, the direct informal caregivers do feel worried. They tend to check regularly (e.g., by phone) if everything is fine.

All the caregivers try to:

- Be creative in overcoming the effects of the illness and make the best out of it.

- Keep stimulating the person with dementia in order to delay the illness and to improve quality of life.

- Accept the illness, and learn about the effect to be able to cope with their situation.

- Respect the dignity of the patients, by not correcting them or become angry with them. This is hard because patients sometimes bring themselves in really dangerous and stupid situations.

Going out

- Most of the informal caregivers take the patients out for trips.

- Remarkable was, that most of the caregivers hardly go out alone anymore because they don’t want, or simply cannot leave the patient alone. Patients become really insecure and scared when they are being left alone.

Emotional

- Being an informal caregiver is something you become, it is not something you choose to be. All the informal caregivers explained this to us, they don’t have a choice so they don’t want to discuss the “what if” scenario’s. It is like it is.

- Informal caregivers worry when they leave the patient alone at home, because they might do something unwanted (e.g. cook, answer the phone, open the door for strangers), or might panic.

- The informal caregivers feel at rest when the senior with dementia is at day care, or when another (informal or professional) caregiver takes over the care for the patient.

- The relationship between the caretaker and caregiver changes from being a partner or child to being a caregiver. This is a heavy emotional process.
- According to the informal caregivers, caregiving requires respect, acceptance, thoughtfulness, creativity, patience and perseverance.
- The informal caregivers tend to feel they have to give a lot, but they get little in return.
- In terms of emotions, the informal caregivers tend to experience worries, anger ('she keeps doing this…!'), sadness, annoyance and frustration.

Technological knowledge/ product use

- Senior caregivers were not using any technical products. Accept for the more "standard" product such as television and phones.
- Most of the seniors had a mobile phone, but most of them because their children want them to have one. They often weren't able to operate the product.

Care activities

- Many caregivers are involved in taking care of the senior with MCI.
- Communication and coordination between caregivers is a challenge.
- It can be difficult to assess the current situation of the senior from a distance.
- They feel they are not always updated with the care activities that other people do.

4.2.3. Formal caregivers

For the formal caregivers they were conducted two groups of four formal caregivers in the generative session. These formal caregivers are all employees of Careyn and work as district nurses and case managers. The case managers only work with dementia cases whilst the nurses have a broader range of patients.

All of the participants were women.

The formal caregivers have different tasks:

- District nurses carry out the standard medical care the patients' needs by routine, such as wound care, injections medicine etc.
- Case managers, manage multiple cases of dementia. They check the psychological and physical health of the patient and give advice on wellbeing, living and care. A case manager visits a household once a month average. This can increase or decrease depending on the situation.
- Daycare: at the day care center, patients conduct in different activities such as: brain training, social activities and creative activities. Here they try to stimulate the damage brain of the dementia patients.

Besides these formal “care” tasks caregivers do much more for a household with a case of dementia:

- They give mental support to both patient and informal caregivers.
- They advise on daily life issues, such as mobility (whether to stop driving), activities (the elderly day care) and possible assisting products (emergency button, or GPS tracking system).
- They maintain the communication around the case, between family members or even between the patient and the partner.
- They assist in household tasks
- They give lectures and courses for informal caregivers about dementia, and how to cope with the effects of the illness.
- They not only keep track of the status of the patient but also the status of the informal caregiver and try to offer these caregivers some time on their own.

When we asked the formal caregivers what they would like to chance the following came up:

- They would like to create more freedom for both the informal caregiver and the patient with the use of care-products such as: GPS tracking system, the Zorgriem (“care belt”) and Geofence. Zorgriem is a small device that people can carry with them; it includes a GPS sender for tracking and localization. Geofence allows people to set virtual perimeters around geographic areas; GPS-based alerts are triggerd when the designated areas are breached. At this point the formal caregivers don’t have a clear overview on what technological solutions are available, and what solutions best meet their individual needs.
- They would like to see more products designed with a focus on dementia. There are many product designed for elderly but these don’t fit with the requirements of a user with dementia (i.e., with respect to cognitive capabilities).
- They would like to offer the patients who don’t want to go to elderly care center the opportunity to have brain training at premises of own home. And a customized day program, to spend their day.
- They would like to improve the communication between all the different caregivers of a dementia case. Nowadays the formal caregiver is often the link between all these stakeholders but an online “care-file” where all the stakeholders have access could solve this.
- They would like to divide tasks and responsibilities more efficiently among all the caregivers.
- They would like to be able to respond quickly in critical situations.
- They would like family caregivers to be the first contact when help is needed, e.g., when the senior needs help getting back home, ideally, the family caregivers would step in.
- The formal caregivers would like to improve communication between the group of both informal and formal caregivers

4.2.4. Conclusions

In The Netherlands, people with dementia tend to stay at home as long as possible. Formal caregivers support the informal caregivers, and together they provide the care needed by the senior with dementia for as long as possible. Dignity and respect are considered key constructs.

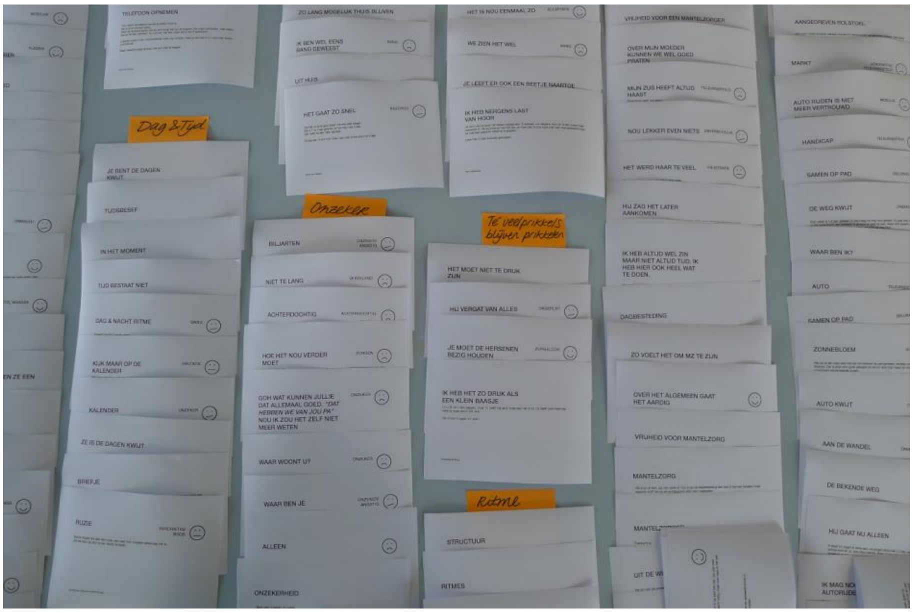


Image 6.Senior Interviews Netherland

The eight clusters below summarize the findings from the interviews and focus group sessions in The Netherlands:

1. Dementia; to be able to design a product for dementia patients the symptoms of the illness should be understood. Today there are many products designed for elderly but these products don't match the needs of a dementia patient. In order to design a successful product, designers should be completely aware of the dementia context, symptoms and effects on emotions, relationships and everyday life.

2. Emotions;

Dementia patients often experience the following emotions: they are afraid, ashamed, insecure, sad, angry, and in a later stadium – they become carefree.

Informal caregivers often experience the following emotions: they are sad, afraid, annoyed, frustrated and angry.

3. Mobility; Because of the brain damage people with dementia loose some functionalities, which often affects their mobility.

- They lose the ability to orientate
- They lose the ability to anticipate
- They suffer from short term memory loss
- The seniors lose track of time
- The seniors forget, for example what they are doing

- The seniors have difficulties using products, and have difficulties learning to use new products
- The seniors experience many emotions including worries, anger and shame.

4. Freedom

Freedom for the caregiver

An informal caregiver is something you become, not something you have chosen to be. This is often a partner or a child of the person with dementia. Because you love the person, it becomes a 24 hours a day, 7 days a week job to which you need to have full commitment to. This means that caregivers give up a big part of their freedom in order to give care.

When a person with dementia stays at home, while the caretaker is going out, there are 2 sorts of problems that do often occur:

- The patient has to function on his own, while he is not able to do so.
  The patient panics; because of the loss of the ability to sense time and the short term memory loss patients easily panic when the person that is taking care of them is gone for a moment.

Caregivers are able to have a moment for themselves when:

- The patient gets professional care
- Your role is taken over by another informal caregiver
- The patient is away for elderly-day care

Freedom of the patient

The freedom of person with dementia decreases, because this comes as part of a process, most of the people seem the accept this.

5. Product use of the patient

Some effects of the illness influences the interaction with products.

- Apraxia, the loss of the ability to execute or carry out learned purposeful movements.
- Aphasia, having difficulty remembering words, resulting in being completely unable to speak, read or to write.
- Agnosia, the loss of the ability to recognize objects, persons, sounds, shapes, or smells.
- Short term memory loss
- Intuitive use, because a damaged brain, the use of non-familiar products is very intuitive.

6. Relationship between the patient and the informal caregiver changes

The informal caregivers expressed that:

- they do feel worried and tend to check regularly if everything is fine
- they want to keep stimulating the senior in order to delay the illness
- they would like to improve the communication and coordination between caregivers

7. Communication between patient and caregiver changes

8. Formal caregivers would like to improve

- The way dementia spend their days
- The availability of suitable products for dementia
- The communication between different caregivers and family members of a dementia patient.

4.3. France Results

Conducting user studies in France relies on a two steps approval process. This legal framework was introduced to guarantee that the rights of the stakeholders were respected.

4.3.1. Step #1: "Comité de Protection des Personnes" (Committee for People's Protection)

The committee for People's protection performs a deep analysis of the study's protocol, including the notice of information and the informed consent. The protocol has to explain the objectives of the study, the assumptions, the procedure (number and nature of the meetings), the inclusion and the exclusion criteria, the risks and advantages for the people to participate.

In particular, this committee checks if the objectives of the study are respectful of the people and the research protocol is coherent with the objectives. Also notice and information and consent form have to explain clearly the nature and the study and what investigators expect from the participants. Furthermore, these two documents have to explain how the rights of the stakeholders are guarantee, in particular regarding their possibility to quit the study with no consequences.

4.3.2. Step #2: "Commission Nationale Informatique et Libertés CNIL" (Information commissioners's office)

In a second step the CNIL committee checks how personal data will be processed for the project. The processing has to be respectful of the People's liberties, which is particularly true for health data.

The nature of the data, the reason for their processing, the way the processing is done, the processing place and the data storage are checked. The CNIL committee also has a look at the notice of information and the consent form, as they have to mention that stakeholders can inspect the data they are concerned with.

These two steps were conducted between October 2012 and January 2013.

4.3.3. French user studies

The French user studies will follow the following schedule:

1. Recruitment phase [January to March 2013]: done in cooperation with professional caregivers from local memory clinics.

2. Design phase [February to May 2013]: individual and group meetings dedicated to the end-user requirements analysis

3. Evaluation phase [June to December 2013]: individual and group meetings dedicated to the evaluation of:

- Ergonomics of the device
- Ergonomics of the graphical user interfaces
- Ergonomics of the person device interactions
- Reliability of the technological blocks in a real environment

These evaluation workshops will provide an initial feedback regarding MyGuardian functionalities relevance, reliability, usability and usefulness.

Considering the gap between the French investigations and the Spanish and Dutch ones, the objective is not to define one more time the user needs but to make deeper the current results in parallel with the technological developments. As a result, the French cohort will participate to the design and the evaluation of the first technological components being developed in the meantime. Their role is really to guarantee that the development choices are coherent with the end-users needs.

5. User Requirements

After the interviews where ended in Span and the Netherlands, the Dutch team organized a workshop in their facilities during the MyGuardian project meeting in November 2012, where all the partners could have a look at what the conclusions of the Focus group were and which requirements for the three actors would be needed.

Image 7.-Analysis of the findings from the user studies

The requirements obtained are the ones the partners talked about, (not all of them should be included, and some of them could be optional). The MyGuardian participants have evaluated the findings from the user studies, defined the user requirements, selected the final requirements, and prioritized the requirements.

Image 9.-Clustering of the findings from the user studies

Image 8.-Sketch of 'the ideal MyGuardian service' based on the findings from the user study.

According to the results of the workshop the requirements obtained were:

5.1. Product/ Device

- *For the patients:*
    - The device is allows the senior to be mobile.
    - The device is easy-to-use and recognizable for the patients. No need to learn new interactions.
- *For the caregivers:*
    - When caregivers don't have smartphones there needs to be another option to access the service, i.e., access on a desktop computer in combination with text messages on a mobile phone
- Each device can be adjusted to the needs and preferences of the individual user.
- Battery
    - Battery power is optimal, possible use of advanced battery-efficient algorithm or even of solar panels (optional)
    - The caregiver is warned when the battery of the device of the patients, is low, alarms for them if necessary to charge.
    - A battery indicator to show that the device is charged and ready for use

- Affordable
    - Cheap enough to be taken around with senior, not worried that can be lost

5.2. Type of information about the senior

- Location
    - Real time localization of the patient and the caregiver(s).
    - Recognize semantics of the locations the patient is
- Senior state
    - Awareness of the potential to be lost (e.g., walking around in circles, running)
    - Awareness of the emotional state of the patient (including confusion)
- User state
    - Fall detection Body *temperature*
- Contextual information (together with the neighbor, because are the people who also take care of the patient)
    - Weather Functions

- Defining **safe areas**
    - Caregivers are able to set an area where the patient is free and safe to move around, as well as areas which are not safe by default (e.g., lake)
    - These areas don't have one fixed shape, but can be adjusted by the user.
    - When the patient moves out of the safe area, the patient will receive a warning; multiple types of warnings, escalating to the caregiver.
- The system can analyze location-time trends and changes from routine, i.e., the patients are in the supermarket for more than 3 hours, this usually takes her no longer than 1 hour. Or: you visit the hospital often, would you like to add this as new location to the system? (optional)
- Take away the worries of the patients, when the caregiver is gone, by inform about the whereabouts of the caregiver. This will reduce the patients' stress. Reminders.
- Minimize probability of false notifications.
- All the historical information about alarms, resolutions and status is stored in MyGuardian, giving the possibility to the practitioners to accessing this information that may help them to make a better diagnosis or even more suited treatments.
- Notifications
    - Notifications from the system to the informal caregiver about the status of the alarms, or help requested.

  - Notifications from the system to the formal caregiver when help is requested.

- Caregivers update the status of the alarm when finished and include useful information for the relatives about the action.

5.3. Responsibility and coordination

- Caregivers can set their availability for help
- A shared agenda is used for coordinating care around the patient
- Users are able to share agendas (optional)
- Group coordination of tasks
- There is a possibility of dispatching care activities to professional care givers.
  - Mechanism to link to a 24/7 care desk (‘zorgcentrale’) and to link to nurses, in such a way that the system fits the needs of the care organization.
  - There is a possibility to assign tasks to formal caregivers based in their proximity to the patient.
- People can set their preferences for information filtering (people don't want to receive all the available information, because people will just switch of their phones)
- Responsibility and roles can by dynamically set and alarms are automatically escalated accordingly.
  - The person who is first contacted in case of an emergency can be defined.

5.4. Patient

- The device can send out assistive reminders to seniors who are going out. "*You are going to the bakery to buy bread*"
- Patients can also use the device to let caregivers know what they are up to.
- Help patients not to forget the device.
- Reassurance mechanism for the patient (to know the service is working and that he/she has somebody looking for him/her)

5.5. Communication

- All the information and communication is stored in a central location, where every user has access to (in view of the access rights per user).
- Access rights per user.
- Set notifications to close the “help task” process when it’s accomplished.
- For the patient: use images instead of words when possible/preferred
- Possibility of video communication between caregivers

- Possibility of recording voices of the caregivers to use in, for example, navigation
- Assist the patients in understanding the concept of time.

5.6. *Customization*

- The possibility to set profiles to adjust each device to its user:
  - Service preferences
  - Look and feel
  - Typical activities
  - Network of caregivers, contact information and preferred mode of contact
  - Points of interest

5.7. *Trust/ reliability*

- Reassure the users that the patients are doing fine.
- Reassure the users regularly that MyGuardian is working
- Reduce stress level for caregivers, knowing where is the senior
- Reassure of the state of the patient

5.8. Table requirements

REQUIREMENTS			
PRODUCT/DEVICE		**ESSENTIAL**	**OPTIONAL**
Patients	Mobile device	🟩	
	Easy to use	🟩	
Caregivers	Alternative Access service	🟩	
Battery	Use of solar panels		🟥
	Alarms if need to charge	🟩	
	Indicator to show device is ready	🟩	
Affordable		🟩	
Adjustable preference of the device for each profile		🟩	
TYPE OF INFORMATION ABOUT THE SENIOR			
Location	Real time localization	🟩	
	Recognize locations		🟥
Senior State	Potential to be lost	🟩	
	Awareness of the confusion state		🟥
User state	Fall Detection		🟥
	Body temperature		🟥
Contextual Information (together with the neighbor)		🟩	
Weather			🟥
FUNCTIONS			
Safe areas	Set areas for the movement of the patient	🟩	
	They aren't fixed, can be adjusted by the user	🟩	
	A warning is send to the patient if he moves out	🟩	
	Multiple types of warnings		🟥
Analyze trends and changes		🟩	
Difference between false positives, false alarms.			🟥
Inform about the whereabouts of the caregiver.		🟩	

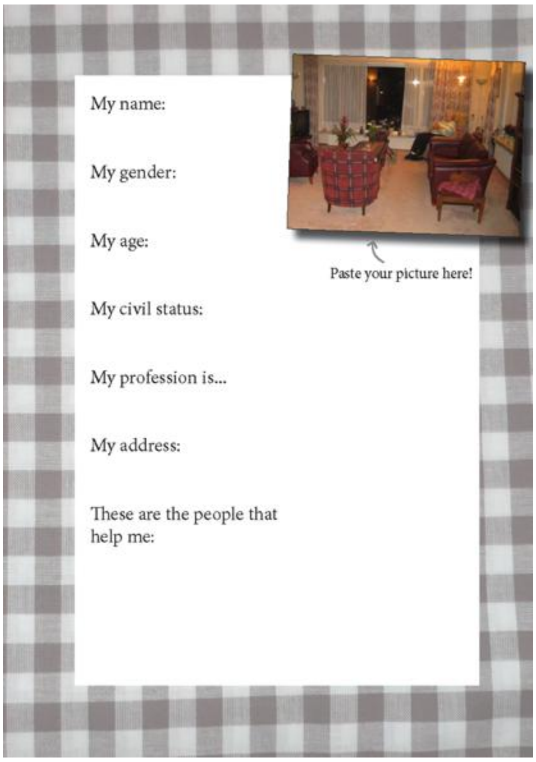
Reminders			🟥
Information is stored with access for the users		🟩	
Notifications to the informal caregiver about the status or help requested.		🟩	
Notifications to the formal caregiver when help requested		🟩	
RESPONSIBILITY AND COORDINATION			
Define your availability as a caregiver		🟩	
Group coordination of tasks		🟩	
Shared agenda used for coordinating care around the patient			🟥
Dividing tasks among users		🟩	
Dispatching care activities	Mechanism to link to a 24/7 care desk and to link to nurses.	🟩	
	Assign tasks based in their proximity to the patient.		🟥
Preference for Filtering information		🟩	
Responsibility and roles are automatically escalated		🟩	
PATIENT			
Device send reminders to them			🟥
Use the device to let caregivers know where they are up to		🟩	
Help not to forget the device.		🟩	
Reassurance mechanism		🟩	
COMMUNICATION			
All the information and communication is stored in a central location, where every user has access to		🟩	
Access rights per user		🟩	
Set alarms to close the process		🟩	
Use images instead of words when possible			🟥
Video communication between caregivers			🟥
Recording voices of the caregivers to use in navigation			🟥
CUSTOMIZATION			
Service preferences		🟩	

Look and feel	🟩	
Typical activities	🟩	
Network of caregivers	🟩	
Points of interest	🟩	
TRUST/ RELIABILITY		
Reassure the users that the patients are doing fine.	🟩	
Reassure the users regularly that MG is working	🟩	
Reduce stress level		🟥
Reassure the state of the patient		🟥

Table 1 MyGuardian table

6. Annexes

6.1. Appendix 1: Probe for seniors



My name:

My gender:

My age:

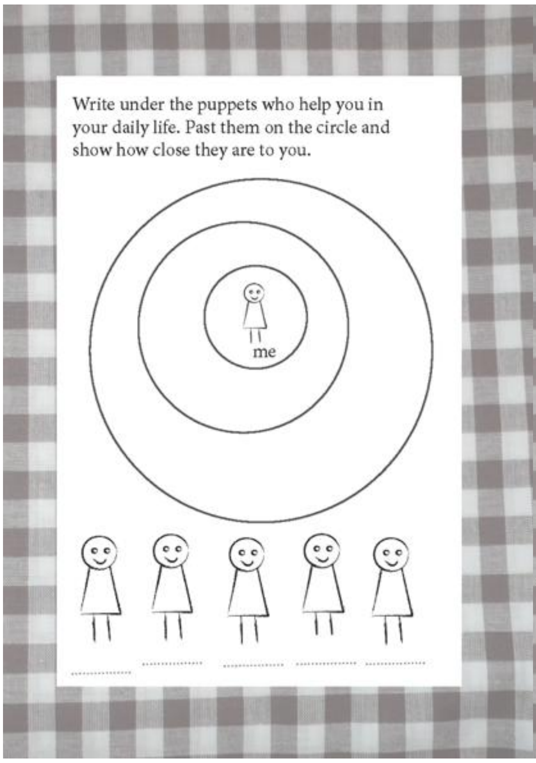
My civil status:

My profession is...

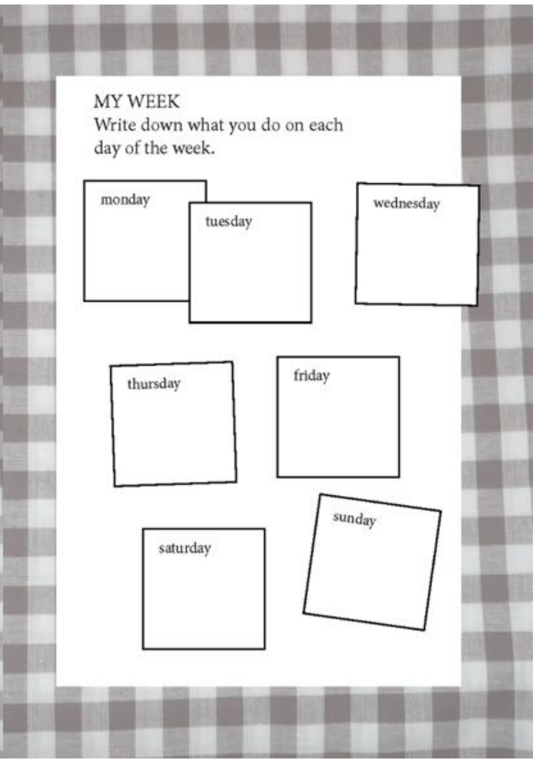
My address:

These are the people that help me:

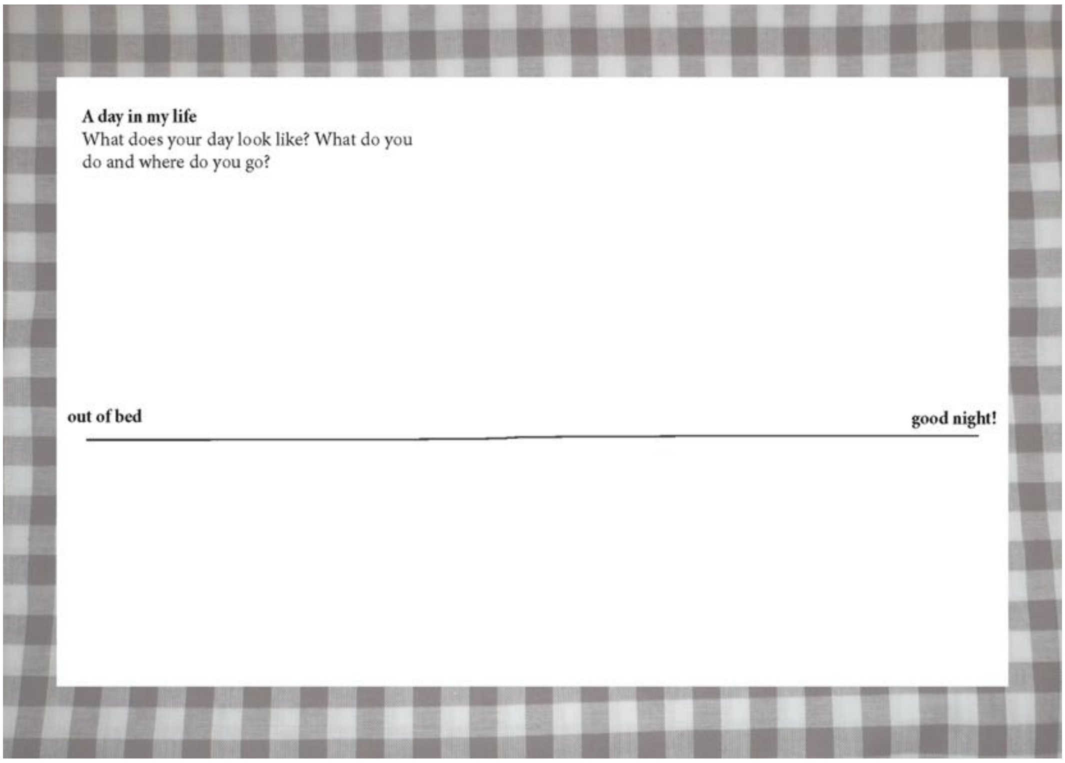
Paste your picture here!



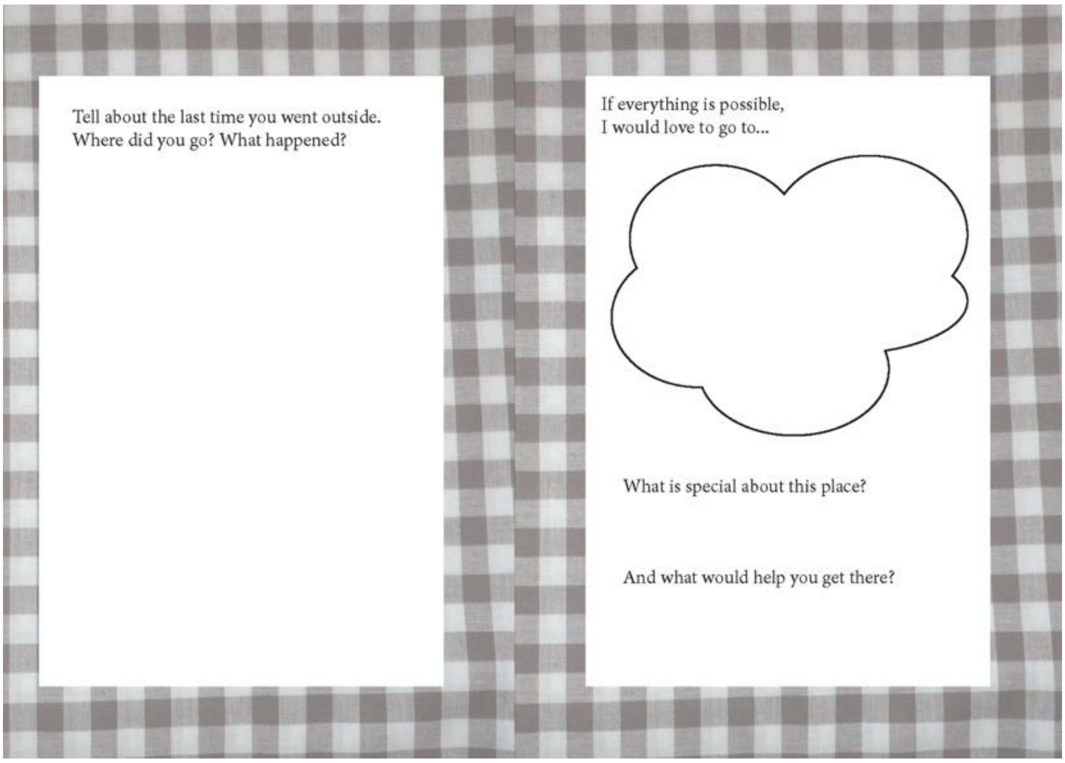
Write under the puppets who help you in your daily life. Past them on the circle and show how close they are to you.



MY WEEK
Write down what you do on each day of the week.



A day in my life
What does your day look like? What do you do and where do you go?

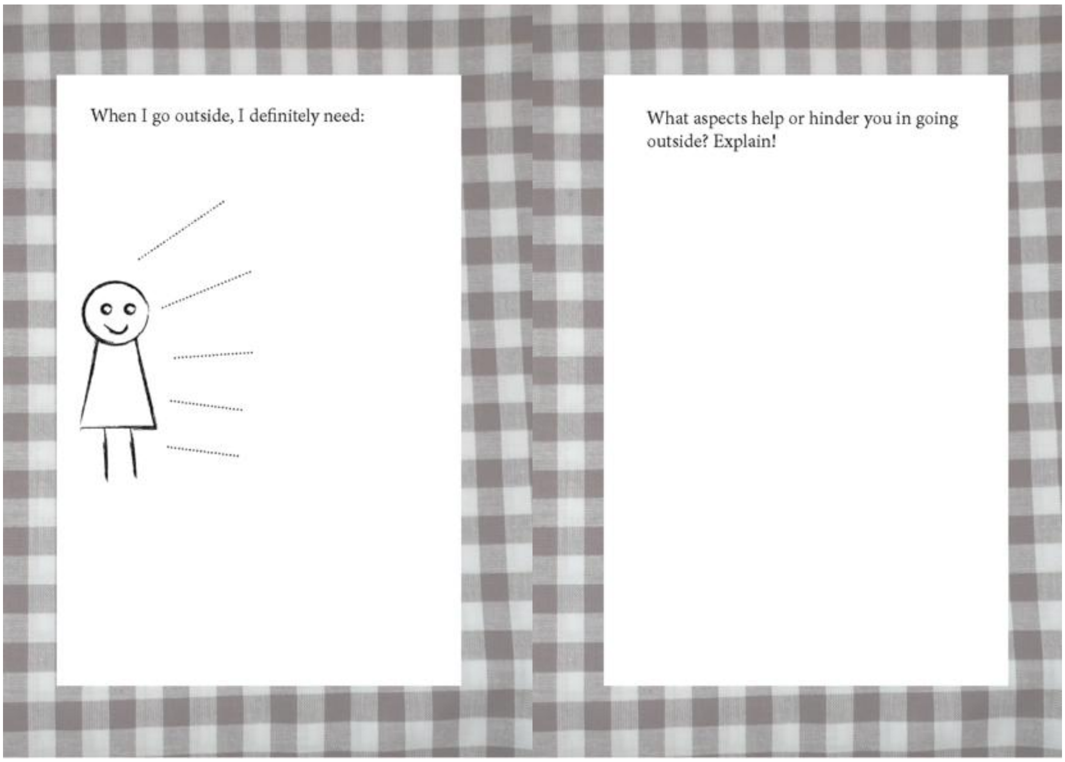


Tell about the last time you went outside.
Where did you go? What happened?

If everything is possible,
I would love to go to...

What is special about this place?

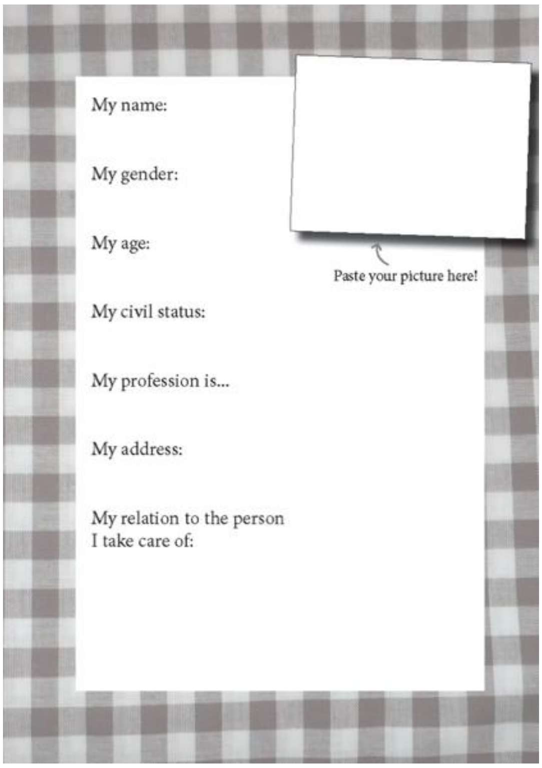
And what would help you get there?



When I go outside, I definitely need:

What aspects help or hinder you in going outside? Explain!

6.2. Appendix 2: Probe for Informal Caregivers



My name:

My gender:

My age:

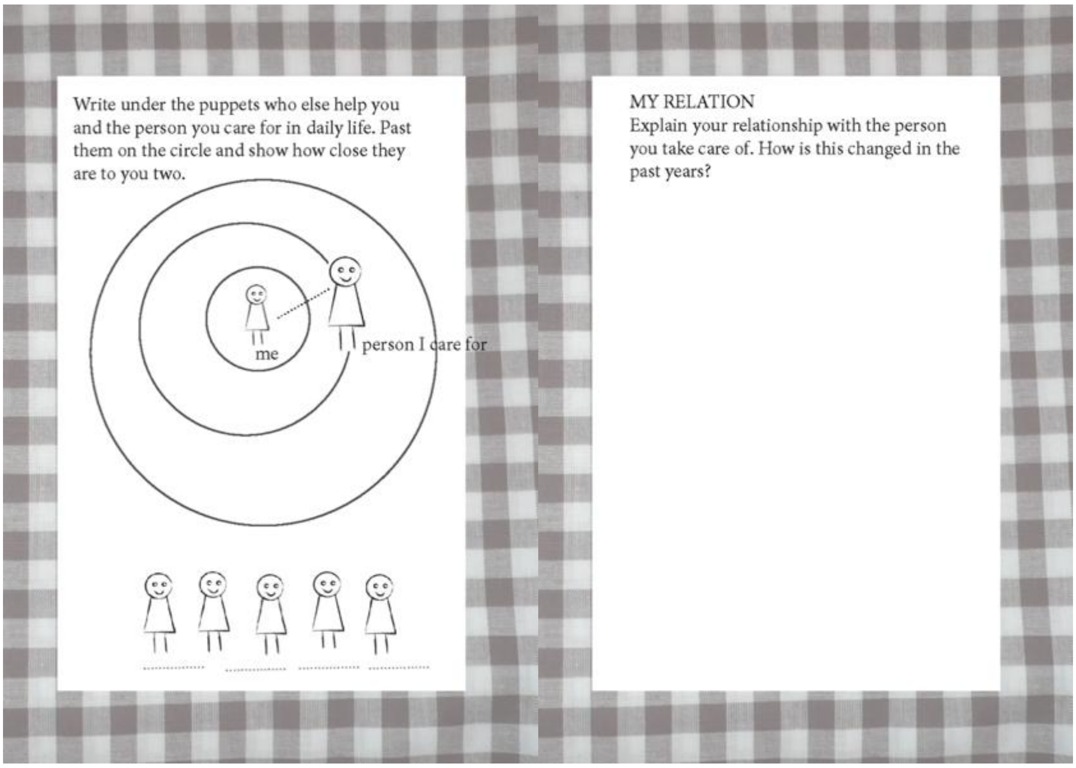
My civil status:

My profession is...

My address:

My relation to the person
I take care of:

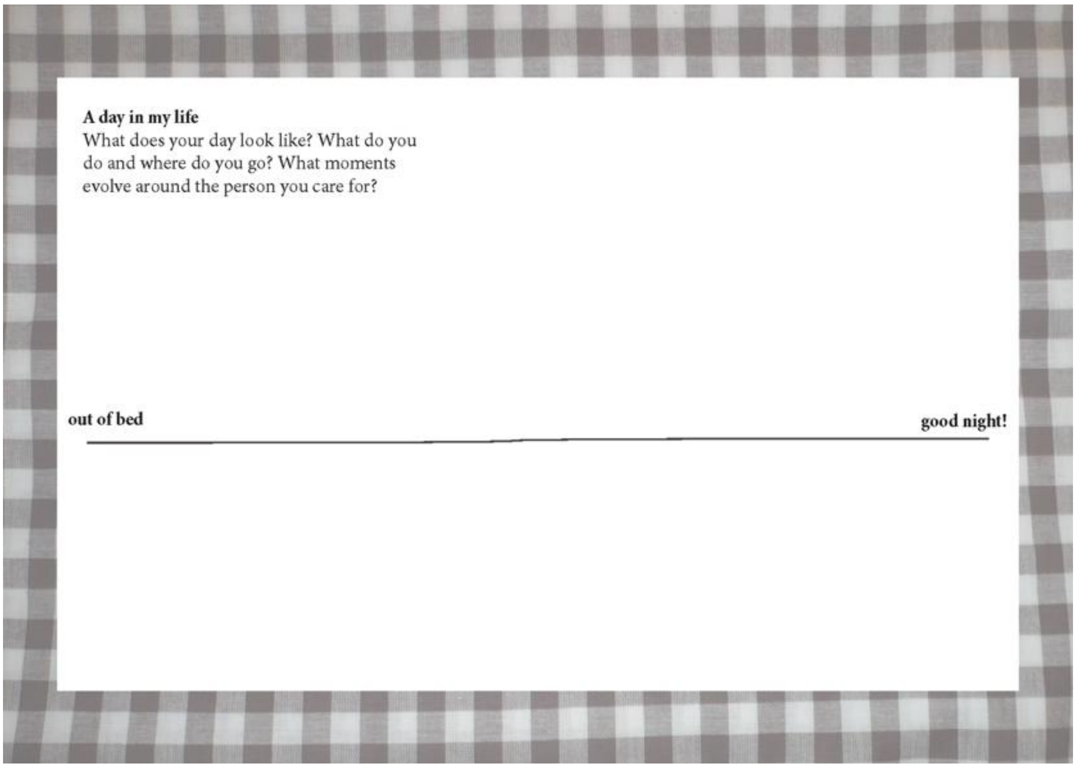
Paste your picture here!



Write under the puppets who else help you and the person you care for in daily life. Past them on the circle and show how close they are to you two.

MY RELATION

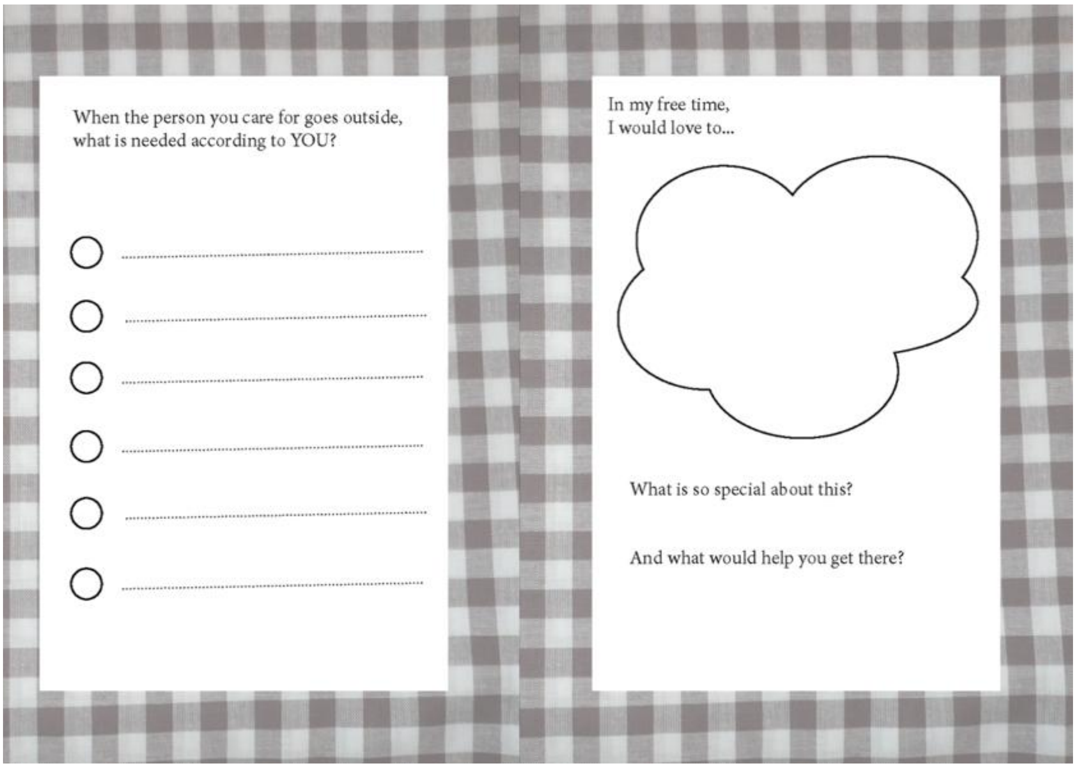
Explain your relationship with the person you take care of. How is this changed in the past years?



A day in my life

What does your day look like? What do you do and where do you go? What moments evolve around the person you care for?

out of bed **good night!**



When the person you care for goes outside, what is needed according to YOU?

○ ....

○ ....

○ ....

○ ....

○ ....

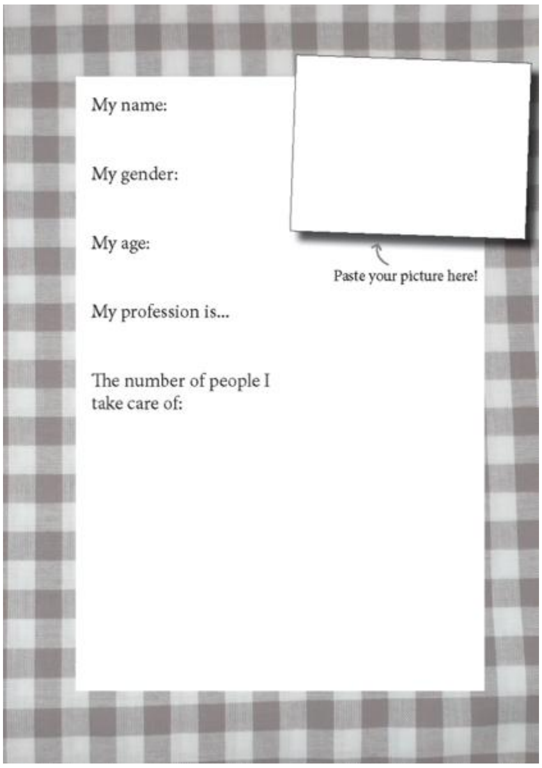
○ ....

In my free time,
I would love to...

What is so special about this?

And what would help you get there?

6.3. Appendix 3: Probe for Formal Caregivers



My name:

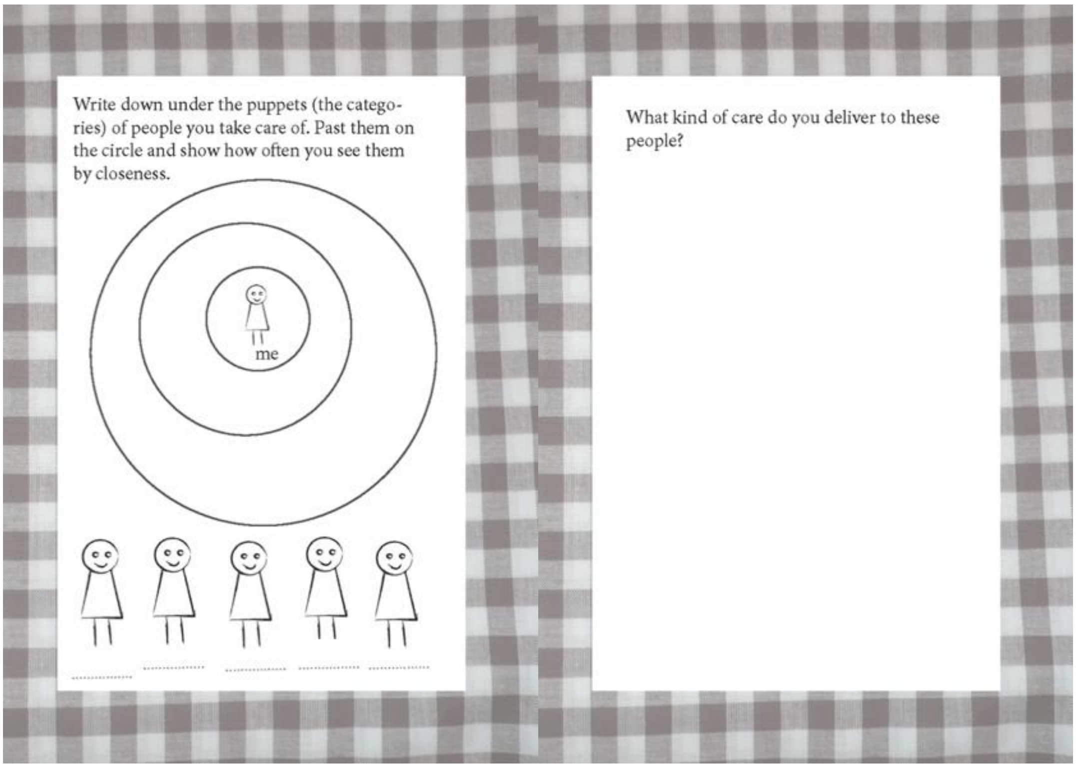
My gender:

My age:

My profession is...

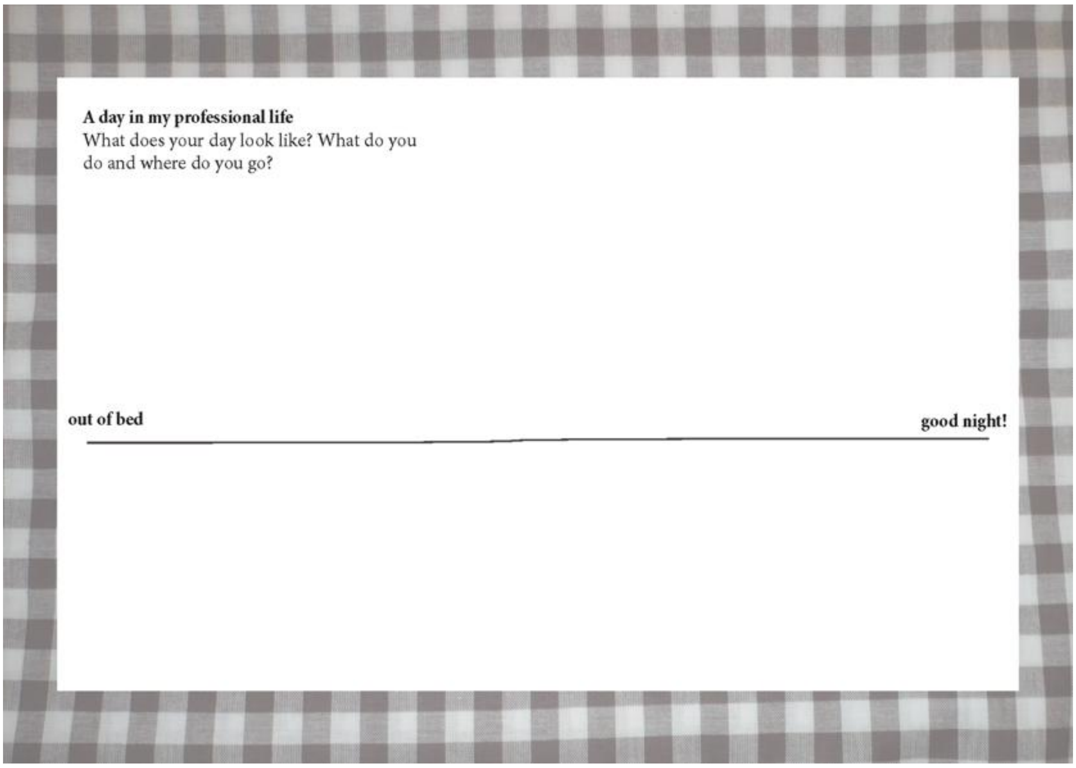
The number of people I take care of:

Paste your picture here!



Write down under the puppets (the categories) of people you take care of. Past them on the circle and show how often you see them by closeness.

What kind of care do you deliver to these people?



A day in my professional life
What does your day look like? What do you
do and where do you go?

out of bed **good night!**

6.4. Appendix 4: Netherlands findings

Patient

Wim de Bruijn

- **→ 78 years old**
- **→ lives together with his wife**
- **→ they have 2 daughters who visit them monthly**
- **→ visits the elderly day care centre 2 times a week**
- **→ 4 years ago diagnosed with Alzheimer**

Already 4 years ago I was diagnosed with Alzheimer. I had a hard time remembering things for a period of time. I never suffered from it, but the people around me started to worry about me. Together with my wife I visited the doctor, from then on I started to take medicine to slow down the process.
I'm doing ok, it's only my short-term memory that is going bad, but there is also a lot of stuff I still remember.
Sometimes I worry about the future, I'm afraid that there will be a moment that I will not be able to recognize my own family anymore, luckily that is still far away.

Brain

My short-term memory is really bad. I can walk out of the door to do a grocery but the moment I am at the end of the street I have already forgotten what I was going to do. Sometimes I'm ashamed, especially when I don't recognize people or their names.

Time doesn't make any sense anymore. I don't know which day it is when I wake up in the morning. And I often forget if it's morning or evening. My wife helps me with small notes telling me the day and what we will do. Without her I have no day-rhythm.

At the elderly day care we do a lot of brain training, that's nice because we talk about the things from the past. The things I still know.

Emotions

The illness makes me insecure, I question my own memory, because I know I can easily be wrong. I never felt like this before.
I'm often ashamed because of my memory problems. I'm being corrected a lot, and I have to ask the same question over and over again. I prefer talking about the past, because then all the information becomes really clear.

The doctor and case manager informed me about Alzheimer, and what will happen over the year. This scares me, I'm afraid for the moment I won't recognize my own family anymore and being completely dependent on others.

Relationship

More and more I'm depending on my wife. That is a clear shift in our relationship. I really need her, to get through the days and I hate it when she is gone. I can see that my illness makes her sad and very tired. She can become very angry with me, and I never understand why.

We always lived a very social life, and our children and grand children still visit us regularly. These social events became hard for me, it's always very crowded and this makes me tired. Although my wife keeps saying it is important for me to have these moments I tend to withdraw myself from them.

Freedom

I have less freedom, since my short-term memory became so bad. Because I depend on my wife and others there are much more people involved, like for example the case manager and the doctor. These people discuss a lot about me without me, sometimes I'm a bit annoyed by that.

My wife set some basic rules for me, for example: I'm not allowed to cook when I'm alone and when I leave the house I always have to take my mobile phone with me. Also she doesn't want me to open the mail.

I don't like to do things on my own so much because of all these rules; I'd rather stay home, read the newspaper, help my wife and maybe walk around the block.

"It feels like being handicapped, there is so much I have to give up in the sense of mobility"

Mobility

It feels like being handicapped, there is so much I have to give up in the sense of mobility. I am not allowed to drive no more, I had to take a test and I didn't pass it. The guy told me that I wasn't able to anticipate.
I still walk and cycle sometimes, but I get lost so easily these days. Somehow I'm not able to orientate myself as I used to do.

And also my memory-loss doesn't help. It happened to me multiple times that I stepped out of the door to do a grocery and by the end of our street forgot what I was going to do, fortunately my wife puts little notes in my pocket to remember me about these things.

Product use

I have to take my mobile phone with me, when I leave. I do so, but I have no idea how this thing works. My daughter gave it to me. We practice together but somehow I don't store the information.

We always use a microwave to heat up our soup together, which I could perfectly understand and use. Last week it broke and my wife and daughter bought a new one. The new one is very hard to understand, and I'm still not able to use it.

Communication

Communicating became hard the last couple of years. I have to remember a lot of information when I'm talking to somebody and I get easily distracted. People also tend to ask a lot of questions, which is hard for me. I noticed that if I can't see the options, it's very hard for me to choose between multiple options.

Informal caregiver

Riet de Bruijn

→ 74 years old
→ lives together with her husband
→ they have 2 daughters who visit them monthly
→ loves to read and play cards

4 Years ago my husband was diagnosed with Alzheimer. Because I had the sense that there was something wrong with him for a long time, I felt a relief when the word was finally out. Since then our life changed a lot. My husband changed, and also our relationship became different from what we were used to. I get a lot of support from our daughters but still it is a very heavy job, Alzheimer.

Brain
At first glance you might not even notice that there is anything wrong with my husband. Even when you talk to him, you might think there is no problem. But after a while you will notice. He asks questions twice, repeats something what he explained earlier and is easily distracted.

Because I live with him I notice every detail of the Alzheimer: he stands up to get the mail and returns with a cup of tea. He doesn't seem to remember our neighbour's names and he doesn't recognize the nurse that visits us every week. With everything he depends on me, he uses my brains to think and make decisions.

Emotions
It's really sad to see that the one I love the most, turns into someone else, someone different.
I can also get very frustrated or angry by his behaviour. It's just unbelievable how much he forgets. And he just doesn't seem to mind. "What does it matter that I forgot to get the mail? I can still get it right?"
He also does a lot of stupid things: het starts cooking, and then completely forgets what he is doing. Which means that he leaves the stove on and walks away to read the newspaper. Luckily I notice these things on time, but these things make me really mad.
I'm afraid of what is lying ahead of us, I have this image in my mind of spending my last days with Wim, and I wish that I will be able to. I just want to stay together.

Relationship
It's strange to notice that your partner slowly changes and becomes a child again.
Our relationship changed, and will continue to change. That's hard, because this is not how we both imagined our time together. Although I get a lot of support I can feel very lonely sometimes. I do get support also from professionals like the case manager and the doctor.
I do take Wim to birthdays and invite our family, I learned that I have to keep stimulate his brain, challenge it, although sometimes it seems a bit too much for him.

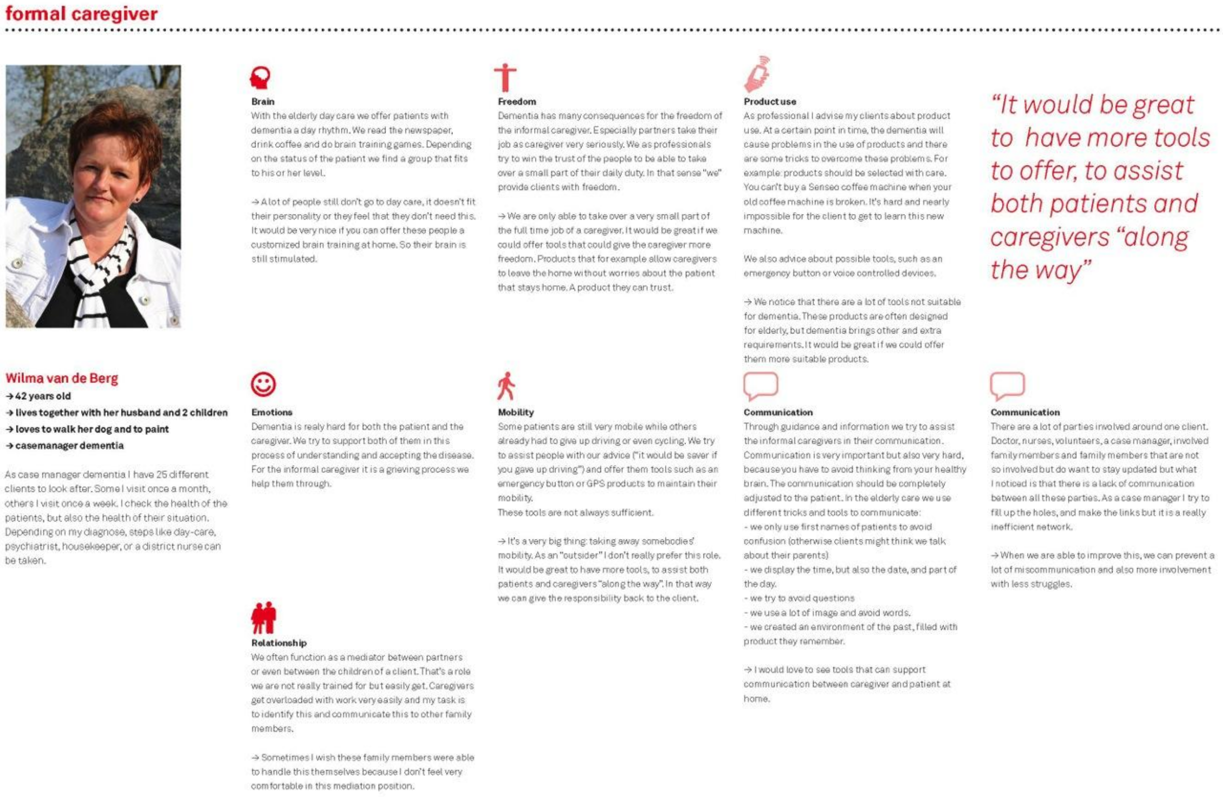
Freedom
I have less freedom then I used to have. My husband needs me, and doesn't like to see me leaving. It does happen that I go to a shop or the hairdresser really quickly, and when I return he always seems nervous and asks me why it took me so long.
Besides that I'm also a bit worried when I leave him, you never know what you will find when you return back home. I have to trust him and give him some freedom, but I'm so scared he will do something stupid.
It might sound a bit cruel but I love the moments when he isn't around. When he goes to the day care centre I feel so relieved and free to do whatever I want. I often take the bike to do some shopping and visit a friend and sometimes my daughter takes me on day trips, which I enjoy very much.

"It might sound a bit cruel but I love the moments when he isn't around. When he goes to the day care centre I feel so relieved and free to do whatever I want."

Mobility
We are less flexible since Wim had to give up his driving. That's hard because you give up a big part of your freedom. On the other hand it is much saver like this.
Wim still loves to go for a walk or to cycle, but the Alzheimer also influenced his ability to orientate and anticipate. He gets lost very easily. I feel relieved when he is back home again.

Product use
Wim doesn't seem to understand certain products anymore. He has a mobile phone, which he has got to take with him when he leaves. But when I try to call him he isn't even able to pick up.
We had a microwave for years and last week it didn't work anymore. I bought a new one together with my daughter and this one doesn't seem to be that different compared to what we used to have but still he doesn't understand how it works.
Last month I saw him searching for the phone when the doorbell rang. He is able to correct himself very easily but these details do stand out to me.

Communication
I notice that he has difficulties with deciding for the last couple of months. When I ask him would you like a piece of cake or a cookie, he doesn't really answer. When he stands next to me and sees both of the options he says: "ah nice a cookie!".
He also lost track of time, he never knows which day it is. Once, when I asked him to set the table because we were almost ready for supper he set the table for breakfast.



formal caregiver

Wilma van de Berg

- → **42 years old**
- → **lives together with her husband and 2 children**
- → **loves to walk her dog and to paint**
- → **casemanager dementia**

As case manager dementia I have 25 different clients to look after. Some I visit once a month, others I visit once a week. I check the health of the patients, but also the health of their situation. Depending on my diagnose, steps like day-care, psychiatrist, housekeeper, or a district nurse can be taken.

Brain

With the elderly day care we offer patients with dementia a day rhythm. We read the newspaper, drink coffee and do brain training games. Depending on the status of the patient we find a group that fits to his or her level.

→ A lot of people still don't go to day care, it doesn't fit their personality or they feel that they don't need this. It would be very nice if you can offer these people a customized brain training at home. So their brain is still stimulated.

Emotions

Dementia is realy hard for both the patient and the caregiver. We try to support both of them in this process of understanding and accepting the disease. For the informal caregiver it is a grieving process we help them through.

Relationship

We often function as a mediator between partners or even between the children of a client. That's a role we are not really trained for but easily get. Caregivers get overloaded with work very easily and my task is to identify this and communicate this to other family members.

→ Sometimes I wish these family members were able to handle this themselves because I don't feel very comfortable in this mediation position.

Freedom

Dementia has many consequences for the freedom of the informal caregiver. Especially partners take their job as caregiver very seriously. We as professionals try to win the trust of the people to be able to take over a small part of their daily duty. In that sense "we" provide clients with freedom.

→ We are only able to take over a very small part of the full time job of a caregiver. It would be great if we could offer tools that could give the caregiver more freedom. Products that for example allow caregivers to leave the home without worries about the patient that stays home. A product they can trust.

Mobility

Some patients are still very mobile while others already had to give up driving or even cycling. We try to assist people with our advice ("it would be saver if you gave up driving") and offer them tools such as an emergency button or GPS products to maintain their mobility.
These tools are not always sufficient.

→ It's a very big thing: taking away somebodies' mobility. As an "outsider" I don't really prefer this role. It would be great to have more tools, to assist both patients and caregivers "along the way". In that way we can give the responsibility back to the client.

Product use

As professional I advise my clients about product use. At a certain point in time, the dementia will cause problems in the use of products and there are some tricks to overcome these problems. For example: products should be selected with care. You can't buy a Senseo coffee machine when your old coffee machine is broken. It's hard and nearly impossible for the client to get to learn this new machine.

We also advice about possible tools, such as an emergency button or voice controlled devices.

→ We notice that there are a lot of tools not suitable for dementia. These products are often designed for elderly, but dementia brings other and extra requirements. It would be great if we could offer them more suitable products.

Communication

Through guidance and information we try to assist the informal caregivers in their communication. Communication is very important but also very hard, because you have to avoid thinking from your healthy brain. The communication should be completely adjusted to the patient. In the elderly care we use different tricks and tools to communicate:
- we only use first names of patients to avoid confusion (otherwise clients might think we talk about their parents)
- we display the time, but also the date, and part of the day.
- we try to avoid questions
- we use a lot of image and avoid words.
- we created an environment of the past, filled with product they remember.

→ I would love to see tools that can support communication between caregiver and patient at home.

"It would be great to have more tools to offer, to assist both patients and caregivers "along the way"

Communication

There are a lot of parties involved around one client. Doctor, nurses, volunteers, a case manager, involved family members and family members that are not so involved but do want to stay updated but what I noticed is that there is a lack of communication between all these parties. As a case manager I try to fill up the holes, and make the links but it is a really inefficient network.

→ When we are able to improve this, we can prevent a lot of miscommunication and also more involvement with less struggles.

6.4.1. Meeting #2: discussion (draft)

6.4.1.1. *Caregiver influence*

Answers that are mentioned in this document are the senior's ones. The caregiver sometimes gives his own opinion, and some of them are recalled in the verbatim. Nevertheless some questions were discussed between the senior and the caregiver. Here is the interviewer's point of view regarding the relation between the senior and the caregiver during the interview, with a possible impact on the senior's answers. To interview separately seniors and caregivers is a complex issue (from an ethical point of view to an organisational one), but it does not seem to be necessary at this stage of the process.

Interview "Ann": The senior (wife) freely gives her opinion. The caregiver (husband) gives his own opinion for each question, in general after his wife, and does not try to influence her. The caregiver's opinion is more like a thought about what could be done for elders and elders with cognitive impairments, not necessarily for his wife (deny of the impairments). It is important for him to participate and to try to give helpful ideas. The senior is more passive, giving her opinion with no more debate.

Interview "Arg": The senior (husband) freely gives his opinion but the caregiver (wife) react many times, considering that her husband is minimizing the troubles and the way they have an impact on their lives. At the end, the senior's answers are sometimes influenced by the caregiver's reactions.

Interview "Cham": The senior (mother) freely gives her opinion, in particular regarding the technology ("*Would you use a Smartphone for […]? Senior: I don't think so. I say it straight").*

Nevertheless, the senior considers the caregiver (her son) reactions, which may at the end influence her answers (she is less categorical). The caregiver is absolutely not saying that his mother is minimizing the situations; he is just trying to open his mother’s eyes regarding the technology and how it could impact positively her life. Sometimes the senior asks her son which answer she should give; at this time she clearly wantes to please her son, who reacts cleverly and tries not to influence his mother.

6.4.1.2. *Key concepts*

- **Reassurance.** Reassuring is a key concept for MyGuardian, certainly one of the main technological opportunities resulting from this fieldwork. Even the senior that is the less interested by the technology considers this opportunities as useful. Senior and caregiver are concerned.
- **Training.** The seniors and caregivers explicitly express the training of the future device as a need. Using this kind of technology is a challenge for them, and training is one of the key approaches to take up this challenge.

6.4.2. Final scenario illustrating MyGuardian functionalities

Here is a draft for a scenario illustrating MyGuardian functionalities, based on the fieldwork that was conducted by AGIM.

“Today Mary has to go to the shopping centre. She has to go to the shoemaker and then to the drugstore. Mary drives, and when she parks her car at the shopping centre, she first writes down the place where the car is parked. She knows that she may forget this information. As a landmark, she uses the car park’s landmarks or sometimes she parks her car close to a noteworthy place, like the gas station. All the process is facilitated by her **MyGuardian’s NoteMe** application.

She also uses the application to write down that she has to go to the shoemaker and the drugstore. Sometimes she forgets the reason why she went to a place.

During her shopping, she walks past a bookstore and has the idea to go the library. It could be a good idea to borrow one or two books; she has nothing special to do for the next week. But the library accessibility is limited by car; it is very complicate to park there. So Mary decides to take the bus, it is very simple to go there by bus, using **MyGuardian’s GuideMe** application. As MyGuardian knows she is at the shopping centre, she just has to select the point of interest – the library – to know which bus line to take and where to get off.

At the library, Mary borrows two books and writes down the date she has to take the books back. **MyGuardian’s RemindMe** Application is designed for that.

During this time, her husband, Georges, is at home. As the time goes and Mary is not back, Georges checks where Mary is. Thanks to **MyGuardian’s ReassureMe** application, Georges sees that Mary is not at the shopping centre but at the library. That’s a good idea thinks Georges.

When Mary leaves the library, someone tells her that the busses stopped running, because of an accident. As the shopping centre is not so far, Mary decides to go back to her car on foot. After few minutes walking she realises that she may have take the wrong direction, and she feels anxious. She uses **MyGuardian’s ReassureMe** application to call her husband. Georges is still at home, but he decided to mow the grass and cannot hear the phone ringing. MyGuardian then transfers the phone call to Mary’s daughter, Natalie, who is at her office. Natalie takes her mother’s call, and reassure her by explaining how to join the shopping centre: Mary has to go in the church direction, a landmark that Mary knows well.

At 3 in the afternoon, Georges has to go to the garage, for the car maintenance. Mary stays at home. At 3:30, Mary starts feeling anxious. She has a look at **MyGuardian’s ReassureMe** application and sees that her husband is “on line”, meaning that she can easily join him if necessary. This is reassuring.

In the evening, Mary and Georges take a walk to Natalie’s home. There they speak about Sarah’s dance exhibition. Sarah is 10; she is Natalie’s daughter, and takes dance courses with her friends. Her grand mother promised her to cook a beautiful cake for the dance exhibition party that will celebrate the end of the year. For her mother not to forget, Natalie uses **MyGuardian’s RemindMe** application, on her own phone, to write down this cooking task.”