MONUMENT

MOre NUrturing and More Empowerment Nested in Technology

With the support of the European Regional Development Fund

O6.1 Tests co-creating remote monitoring technologies (TRL7) - *Summarizing D2.2.1 - D2.2.4*

WITH THE SUPPORT OF THE EUROPEAN REGIONAL DEVELOPMENT FUND

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Preface

The informal caregiver is a key actor of an effective and integrated service to people living with dementia (PLWD), but support is often lacking. The overall goal of the project is to diminish the burden of informal caregivers of PLWD by providing professional and structural assistance, and tailor-made technological solutions. In this work package, the different (informal) caregivers were iteratively involved to help create a remote monitoring prototype with technology readiness level 7 (TRL7). The prototype combines existing technology platform solutions, and ad-hoc developed modules to adapt the technology to the needs of the end user. Imec (pilot partner 3 or PP3) enabled the ad-hoc module development and generated a list of available and suitable technologies. Taken together, the aim is to strengthen the resilience and perseverance of the informal caregivers allowing people with dementia to continue to live at home. This chapter describes the process, outcomes, and future perspectives for a customised remote monitoring application for PLWD. See Deliverable D2.2.3 Iterative testing, evaluating and design of a remote monitoring prototype for a detailed overview of the iteration process.

During this deliverable when we mention informal caregivers, we define them as follows:

> *People who provide care to an ill person because of their relationship with them, but without training and salary. Informal care is mainly provided by family members or others who are close to the PLWD, such as neighbours and friends.*

Gap analysis and opportunity identification

The goal of this work package is to develop professional and structural support for informal caregivers of PLWD using technological solutions tailored to their needs. To get a comprehensive view on these needs we conducted a state of the art. We gathered information from literature and other dementia-related resources such as the Alzheimer's Society[1] and verified our findings through expert interviews including informal caregivers. The identified needs were categorized in agreement with the existing problem classification published by the Alzheimer's Society. Next, we mapped available technologies that might accommodate the identified needs. Although present technologies could help informal caregivers with certain activities, the state of the art indicated these technologies are currently underused. This is due to a lack of awareness on the one hand and a mismatch between the technology and the constantly evolving needs of the caregiver – depending on the symptoms and stage of dementia – on the other.

Increasing awareness among caregivers could be facilitated by the Odense house in Mechelen by making demonstrators available. To meet the changing needs of the caregiver, we decided to develop a centralized platform that **integrates multiple applications with a modular character.** In the next paragraph we elaborate on the identified needs and possible solutions.

Problem identification – the needs of the informal caregiver

The state of the art highlighted that the most common problems correspond to four categories listed by the Alzheimer's Society: daily activities, safety, communication, and social and leisure activities. Resilience of the informal caregiver was added as an additional category in line with the overall scope of the project. Here were provide a summary of the identified problem categories and the assistive technologies that might offer a solution.

- **Caregiver resilience – health & wellbeing**: Informal caregivers are a very important element in the care system. But increasing tasks and responsibilities often decreases their resilience. This in turn determines whether a PLWD can continue living at home or needs to shift to assisted living conditions. To strengthen the caregiver's resilience, several digital solutions exist, mainly **platforms and online communities**, providing them with information and access to support groups.
- **Daily activities:** As the stage of dementia progresses over time, the informal caregiver becomes more responsible for the various daily activities of PLWD and this can put a high strain on the informal caregiver. Tasks like cooking, washing, and medication adherence rely on memory, orientation, or communication. Assisted technologies **guiding PLWD in their daily tasks**, help the informal caregiver to reduce the workload and increase quality time.
- **Safety:** It is important that informal caregivers of people with dementia know they are safe, especially when they live alone or are left alone for a couple of hours. Technology that **supports and monitors the safety of PLWD** can help them to live at home longer and improves the mental health of the caregiver. Safety devices like fall detection mechanisms can additionally be **linked to telecare systems** to ensure continuous follow-up.

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[1] Source: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/factsheet_assistive_technology_%25E2%2580%2593_devices_to_help_with_everyday_living.pdf

- **Communication:** Telecare usually refers to a system or devices that **remotely monitors** people living in their home, enabling them to **access support or responder** services when necessary. The various pieces of technology are **connected via a telephone line or over the internet**. Telecare systems mostly include community alarms, sensors and movement detectors, and video conferencing, monitoring a person's activities. When a problem occurs or someone presses the alarm button, an alarm is triggered which notifies the caregiver or alarm center.
- **Social and leisure activities:** With the increasing availability of tablets, smartphones and apps, there are many new options to help people **stay in touch** and **engage** with friends and family. They also offer opportunities for creative activities such as playing music or life story work, which is important for the **wellbeing** of a person with dementia.

During the one-on-one interviews we asked the informal caregivers (n=7) to exemplify how the identified problems interfere with their caring activities and plot the problem on a graph according to the frequency and impact on their lives (see figure 1). The mapping exercise allows us to estimate which solutions would improve the lives of the informal caregiver the most and is worth investing is (need-solution fit).

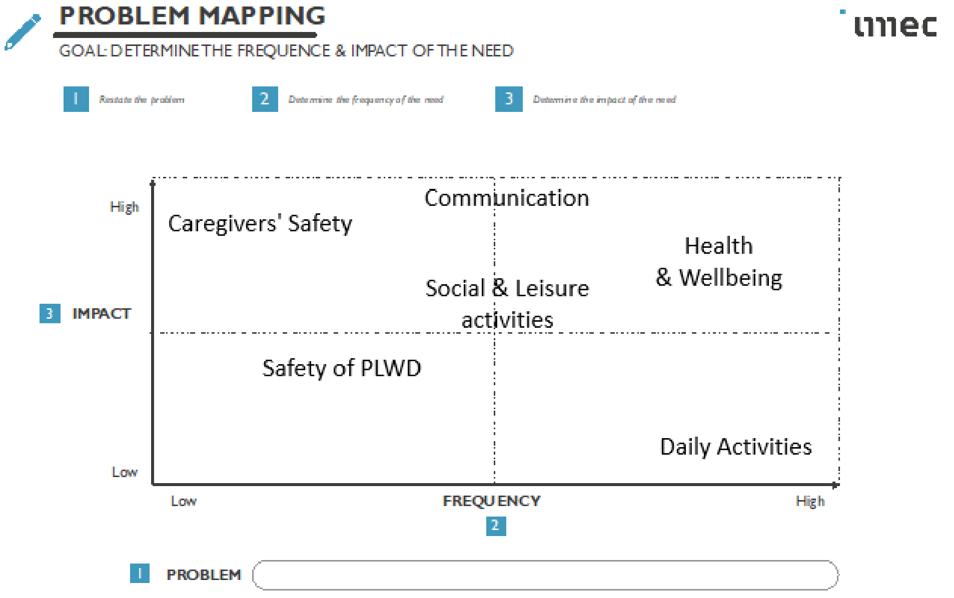
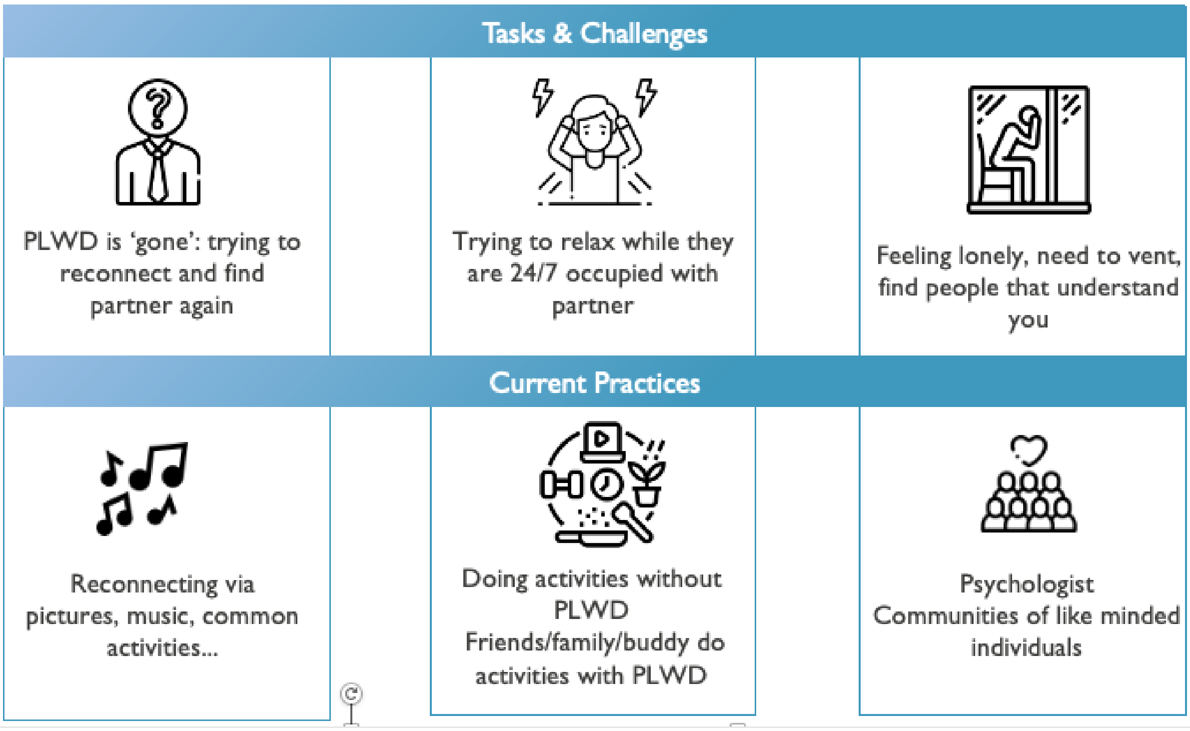


Figure 1: Graph representing how informal caregivers plot the problems they encounter in terms of frequency and impact.

Overall, informal caregivers master daily tasks and challenging situations related to safety (see appendix A), but they experience difficulties with health and wellbeing, communication, and social and leisure activities, in that order of importance. The caregivers however indicated that communication solutions should focus on communication with the PLWD instead of telecare systems that rather aim at supporting safety. The interview also pointed out that both the safety of the PLWD and the informal caregiver should be taken into consideration.

Health and wellbeing of the informal caregiver seemed the most impactful for three reasons (see figure 2): (1) they feel like they are slowly losing their partner and the (intimate) connection they used to have. The grief of losing someone that is mentally gone but physically still there makes them search for different ways in which they can still hold on to the past. Informal caregivers search for alternative ways to revive the connection via songs they both like, showing pictures of the past, or finding new activities. While the grief evolves, (2) the loneliness increases. Informal caregivers are often withdrawn from previous habits and lifestyles, and their social circle cannot provide the (emotional) support they need. They start feeling lonely and want to connect with likeminded individuals that truly understand what they are going through (e.g., the loss, the frustration, the challenges and how to cope) and want to be able to express their feelings (e.g., ability to vent without feeling guilty). Informal caregivers that regularly visit their psychologist or belong to a community of other caregivers report more positive on their wellbeing. As taking care of a person living with dementia becomes a fulltime job, (3) it also becomes harder to relax and take some time for themselves. They feel like they are continuously occupied with the PLWD and struggle to switch off in their own free time.



Tasks & Challenges

PLWD is 'gone': trying to reconnect and find partner again

Trying to relax while they are 24/7 occupied with partner

Feeling lonely, need to vent, find people that understand you

Current Practices

Reconnecting via pictures, music, common activities...

Doing activities without PLWD
Friends/family/buddy do activities with PLWD

Psychologist
Communities of like minded individuals

Figure 2: Overview of health and wellbeing challenges and current practices that are implemented to improve the problem.

Communication is directly linked to the wellbeing of the informal caregiver. As the disease evolves over time, it becomes very challenging to interact with PLWD. Dementia affects the brain's temporal lobe which influences the ability to process language. Even in early-stage dementia, caregivers may notice a decline in formal language (vocabulary, comprehension, and speech production), something all humans rely on to communicate verbally[2]. By asking questions and trying to understand context by making PLWD to point out important elements, together with lots of patience, the informal caregivers uncover what the PLWD is trying to say.

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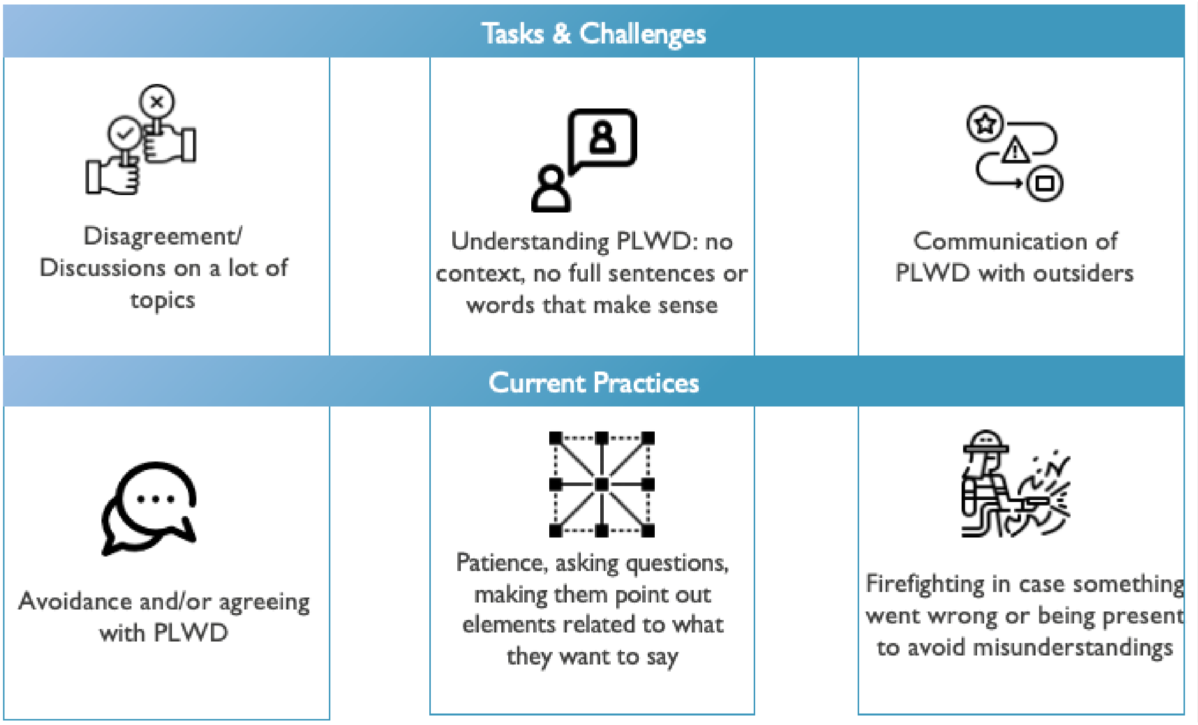
[2] https://hopehospice.com/blog/how-alzheimers-disease-affects-communication/

Dementia also changes a person’s ability to use reason and logic, which may lead to arguments. Because you cannot win an argument from someone whose brain is incapable of processing logic, caregivers often simply acquiesce or avoid discussion with PLWD (see figure 3 for an overview).



Tasks & Challenges

Disagreement/ Discussions on a lot of topics

Understanding PLWD: no context, no full sentences or words that make sense

Communication of PLWD with outsiders

Current Practices

Avoidance and/or agreeing with PLWD

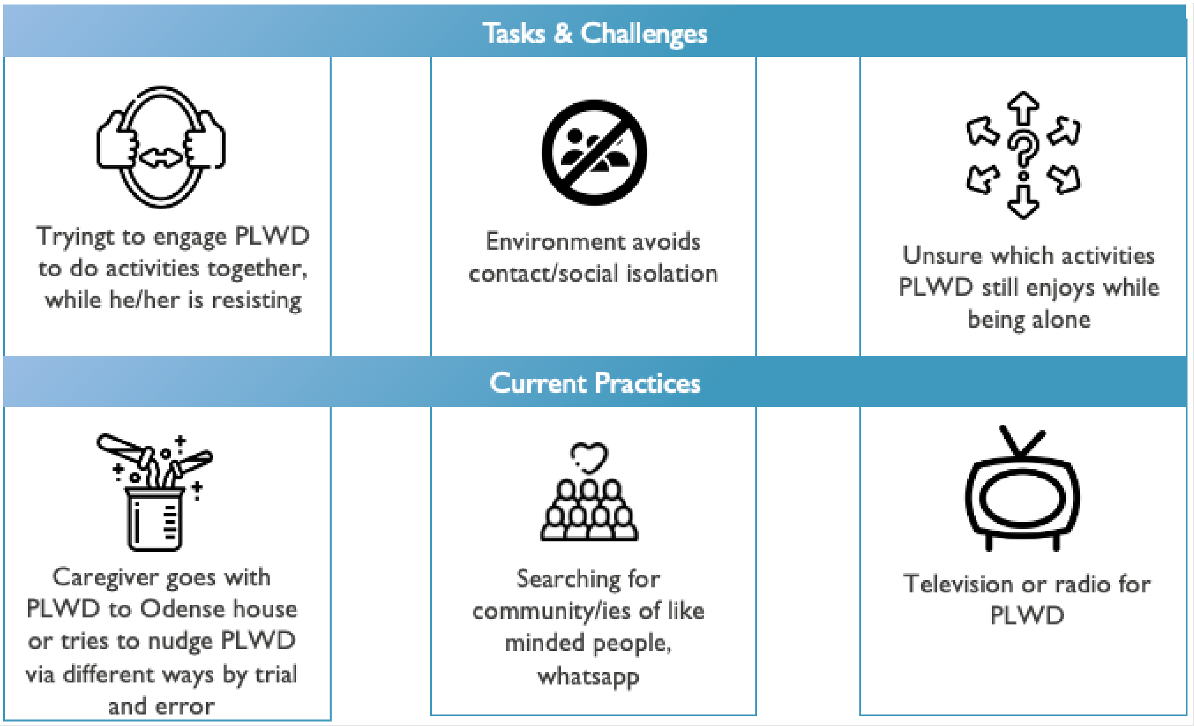
Patience, asking questions, making them point out elements related to what they want to say

Firefighting in case something went wrong or being present to avoid misunderstandings

Figure 3: Overview of tasks and challenges related to communication and current practices that are implemented to improve the problem.

Social and leisure activities are closely related to the wellbeing of the informal caregiver. Finding appropriate social and leisure activities for PLWD is challenging. The disease impacts the ability to execute certain activities so informal caregivers search for new activities to do together or that give PLWD a feeling of pleasure and purpose. Moreover, as the disease evolves, the social network of PLWD might fade away as people often don’t know how to cope with the changing situation (see figure 4 for an overview).

Although supporting the PLWD in their **daily activities** takes up a lot of time of the informal caregiver and daily problems occur (e.g., resistance to wash themselves), the impact on the informal caregiver remains limited (see appendix A, figure A1). The same applies to the PLWD’s **safety** (see appendix A, figure A2), although anticipating to unsafe situations is very difficult because it is not based on a habit or recurring behavior. Once the endangering behavior starts to repeat itself (e.g., repeated falling), PLWD have reached the tipping point where they can no longer live at home. In certain cases, the safety of the informal caregiver may also be compromised. This often occurs when the PLWD is suffering from psychotic attacks and becomes aggressive towards the caregiver.



Tasks & Challenges		
Tryingt to engage PLWD to do activities together, while he/her is resisting	Environment avoids contact/social isolation	Unsure which activities PLWD still enjoys while being alone
Current Practices		
Caregiver goes with PLWD to Odense house or tries to nudge PLWD via different ways by trial and error	Searching for community/ies of like minded people, whatsapp	Television or radio for PLWD

Figure 4: Overview of tasks and challenges of caregivers' social and leisure activities and current practices that are implemented to improve the problem.

Conceptual solutions

To start, we drew four conceptual solutions that potentially contribute to the health and wellbeing, communication, and social and leisure activities of the informal caregiver and PLWD.
To verify whether these concepts could increase resilience, informal caregivers were asked via one-on-one interviews (n=7) to examine the concept and share their initial thoughts. Afterwards we explained the concept, asked for feedback and a ranking of all concepts in relevance for informal caregivers. We focussed on solution for sleep, safety, stress/agitation and executing tasks.

Conceptual solution 1: Sleep & night wandering monitor

Night wandering is a common trade for the person living with dementia. They lose their ability to distinguish day and night which can result in (multiple) visits to the bathroom or casual wanders around the house during the night[3]. Moreover, dementia is known to impact eyesight, which can cause for instance falling or bumping into things. Changes in eyesight is caused by alterations in the brain, including basic eye functions like perception, and how the brain processes the information received by the eyes[4] . There are three common changes and behaviors associated:

1. the field of vision narrows as they would be wearing binoculars,
2. the brain shuts down information making it harder to distinguish between 2 or 3-dimensional objects
3. the changes in their vision, impact their motor skills.

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[3] https://www.alz.org/help-support/caregiving/stages-behaviors/sleep-issues-sundowning
[4] https://dailycaring.com/dementia-and-eyesight-an-expert-explains-common-changes-and-behaviors-video/

Altogether, this behavior has a high impact on informal caregivers living together with PLWD. They often remain alert during sleep to ensure PLWD do not endanger themselves during the night.
To avoid incidents, the informal caregiver removes certain objects to prevent bumping into them or extra barriers are installed for the safety of the PLWD (e.g., stairs safety gate).
Besides these mechanical solutions, digital alternatives also support PLWD at night:

- Lighting up certain areas for visibility and guidance
    - Leave on the bathroom lights
    - Motion sensors with lights
    - Mobile lights placed in such a way they light up the direction towards the bathroom for example
- Special alarm clocks projecting and indicating time of day, trying to orient PLWD in time and space

Despite these preventive actions, informal caregivers indicate they remain in a sort of 'wake' mode at night in case intervention should be required. Also, when the PLWD suffers from occasional psychotic attacks, the caregiver stays alert during the night, to safeguard both the safety of the PLWD and themselves.

Inadequate sleep has an impact on **mood and behavior** of the PLWD and informal caregiver. As such providing a solution that contributes to better sleep, could increase the health and wellbeing of the informal caregiver. The first conceptual solution monitors whether a person with dementia is getting up at night (see figure 5). When this happens, the lights in the room towards the bathroom automatically switch on. The caregiver also receives an alarm so they can help the PLWD. In the bedroom a special alarm clock is present to indicate the right time of day and orient the PLWD in time and space.

Figure 5: Conceptual solution to monitor sleep and night wandering of PLWD.

To adjust the monitoring to the caregiver's needs, a flexible alarm system can be linked.
For example, having the ability to receive notifications when they deviate from their regular route (e.g., the way to the bathroom). Therefore, the solution requires a geofencing mechanism. Informal caregivers also prefer personalized light settings: bright for the elderly, but soft for people with young dementia. The solution should also turn off the lights automatically when the PLWD is back in bed.
A nice add on could be that the system nudges the PLWD to behave a certain way: guide them in the toileting process, remember to hold the handle to prevent falling, or help them back to bed. This could be done through pre-recorded speech of the informal caregiver.
To improve overall care, incorporated automatic alerts could help identify if the PLWD has experienced multiple consecutive nights of poor sleep. Together with planned activities and tracked symptoms of that period, the caregiver can explore the triggers of poor sleep quality.

Conceptual solution 2: Safety system

In general, informal caregivers try to avoid unsafe situations by taking precautions, going from hiding the car keys to installing sensor-based systems such as door locks or a camera system to monitor the person living with dementia. Safety may be affected by changes in the environment but also by dementia-related symptoms like confusion, memory loss and disorientation, limited mobility and coordination[5]. Many technological solutions exist to help prevent dangerous situations (e.g., smart button for cooking top) or warn the care circle in case a dangerous event takes place (e.g., fall monitor system). But unsafe events are unpredictable and inconsistent so there is no one-size-fit-all solution, which creates concern and puts a brake on the caregiver's personal activities.

Figure 6: Conceptual solution to increase the safety of PLWD.

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[5] https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/dementia-safety-issues#safety-inside-the-home-for-people-with-dementia

The concept for safety (see figure 6) was built to increase the caregiver's health and safety as well as their social and leisure activities. Imagine a modular solution that uses sensors to monitor whether a dangerous situation occurs – the tap water keeps running, the cooking stove is on for too long, etc. After detection of a potentially dangerous situation, the system sends a warning to your smartphone. In turn you can start a video call (one way) with the PLWD to nudge them towards the right behavior.

Several informal caregivers indicated this solution as the least attractive and suggested a more flexible approach in which different sensors could be added. Moreover, the informal caregiver would need contextual information upon a notification to assess the danger. This could be done with cameras, but they feel uncomfortable with the 'Big Brother' aspect. The (un)predictive nature makes the return on investment questionable. Nevertheless, the unidirectional and automatic opening of a communication channel by the caregiver while no interaction is required from the PLWD sparked interest among caregivers.

Conceptual solution 3: Guiding task execution

Participating in suitable activities can help a person with dementia to achieve purpose and pleasure. It can also play a role in in dealing with challenging behaviors[6]. Exercise for example has a positive impact on their mood, sleep, maintenance of motor skills and social skills. Considering the positive impact, informal caregivers try to stimulate activities and task performance in the person living with dementia. Yet, dementia is also known to make everyday tasks difficult, especially as the disease evolves over time[7]. There are several actions the informal caregivers already take to make task execution easier for PLWD. This can go from reminders (e.g., a note on the table or day calendar), to a step-by-step guide for simple tasks or even a demonstration for more complex actions allowing the PLWD to mirror the behavior (e.g., gardening). A solution that supports PLWD to execute tasks independently can contribute to the health and wellbeing of PLWD and expand their social and leisure

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[6] https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/dementia-activities-and-exercise
[7] https://www.alzheimers.org.uk/get-support/staying-independent/everyday-tasks-dementia

activities.

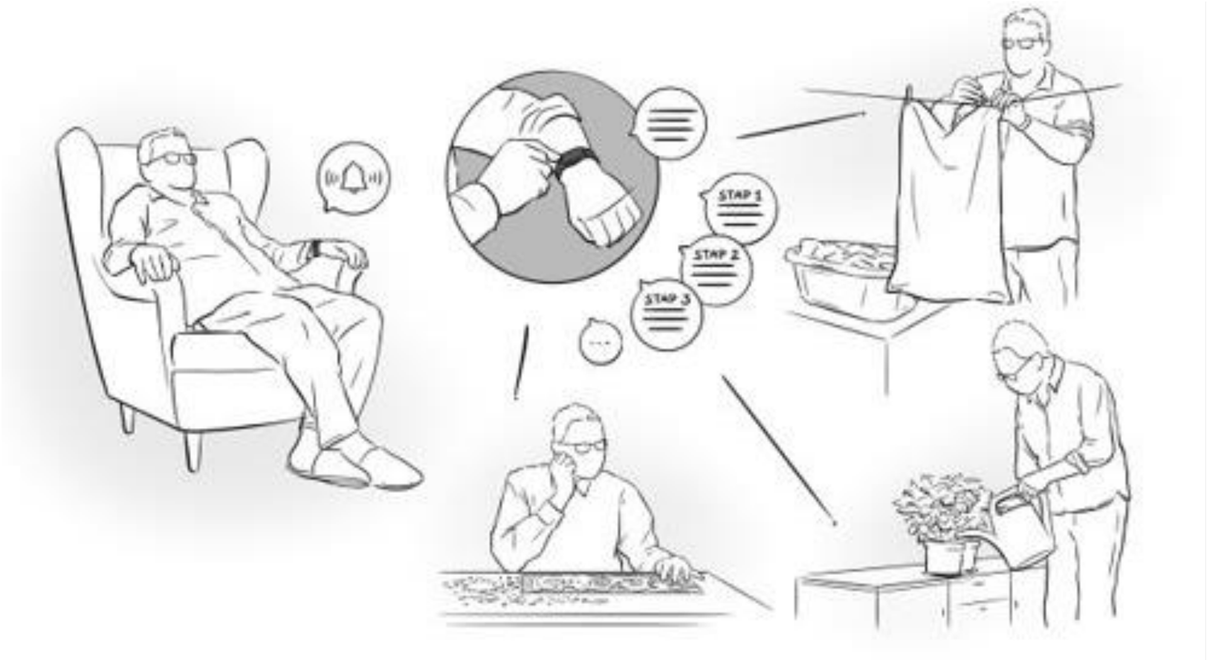

Figure 7: Conceptual solution to guide PLWD in performing daily tasks and social activities.

The concept was presented as a step-by-step guide tailored to the needs of PLWD (see figure 7). The PLWD wears a watch that guides them via speech to execute the tasks. The informal caregiver can schedule tasks and the PLWD are notified when the task starts. PLWD subsequently receive a spoken message from the caregiver that helps them perform the task. Like this, the informal caregiver can split complex tasks into multiple small tasks and support PLWD step-by-step through voice recording.

Caregivers confirm that PLWD can no longer perform complex tasks which leads to additional responsibilities for the caregiver – either to perform the task for PLWD or via step-by-step guidance. They feel the concept can help them in having PLWD to perform activities such as personal hygiene that otherwise would lead to resistance/anger. Ideally, the solution does not require any interaction from the PLWD, and it should focus on very simple tasks. According to the informal caregivers the conceptual idea can also be linked to activities related to the sleep and safety solutions (e.g., hold on to the bar before sitting down on the toilet). Also, the caregivers suggested to integrate a motivational component for PLWD into this concept (e.g., good job, you are doing well).

Conceptual solution 4: Stress/Agitation Monitor

Restlessness and agitation are common behaviors in people living with dementia and understanding the root cause supports appropriate care. For example, when a strange noise causes agitation the caregiver knows how to reassure the PLWD[8]. Recognizing what is going on with PLWD can contribute to health and wellbeing, and communication between informal carers and PLWD.

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[8] https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/restlessness

Figure 8: Conceptual solution that allows the informal caregiver to monitor the stress level of PLWD

The solution was presented as a watch measuring heart rate and galvanic skin response as an indication of agitation. The output can be seen on a smartwatch or online platform. Caregivers acknowledge it would be useful to have insights in situations where PLWD are experiencing increased stress levels so they can act accordingly:

- Indication of psychosis attack
- Indication of panic mode
- Indication of boredom

The informal caregivers would like to receive a notification (rule based) via a smartphone application or online platform when stress levels of the patient are elevated, together with suggestions on how to react (e.g., change activity). In case of psychosis, these notifications should alert the carer to take precautions for self-protection. Additionally, they see benefits for usage in care centres as employees have to follow up multiple individuals and it would provide them with insights into prioritization.

The possibility to measure more parameters like blood pressure and heartrate, would make it easier to follow up on the general health of PLWD and an easy-to-read time indication would help PLWD to orient themselves. Ideally this solution also operates with a cascading system indicating who to contact in case the primary caregiver cannot (re)act in time. Linking the concept to an alarm center ensures the safety of PLWD (when no caregiver is available) and the caregiver (for example in the case of psychosis).

Conclusions of the prior study

The interviewed informal caregivers were all primary caregivers living with PLWD. Among the caregivers there was no consensus when ranking the conceptual solutions. This is due to the differences in the stage of dementia as well as the affected brain area. Each situation is unique and evolves over time meaning there is no one solution to support all informal caregivers equally. Instead, a modular tool to adjust the type of sensors depending on the caregiver's need would contribute to their health, wellbeing, and overall resilience. This led to a new remote monitoring prototype design including personas and a scenario.

MONUMENT remote monitoring prototype design

The primary informal caregiver, often the life partner, has the main responsibility and takes on most of the caring tasks. As the disease evolves more activities are added, but also the type of care depends on the disabilities of PLWD. The intensity of the different tasks grows over time, as well as their concerns for PLWD. Primary caregiver experiences a lot of distress trying to fulfil several roles simultaneously – studying or working, household, and caring.

The remote monitoring concept deploys technology to assist and track PLWD from a distance, follow up on the situation and gather relevant data using an online platform (see appendix A, figure A3). Through the platform, information can be easily exchanged between the primary and other informal caregivers like friends and family. This approach should reduce the number of tasks for the primary caregiver, leaving room to focus on work or studies and pursue private activities. Increasing resilience of the primary caregiver ensures that PLWD can continue living at home.

Based on the state of the art and the interview, the prototype aims for (primary) informal caregivers living with a person with young onset dementia who are open to use technology to cover (part of) their tasks. The older informal caregivers are more resistant because they fear technology might replace human contact and are more protective of their caring experience. The wireframes developed for this concept were evaluated with the informal caregivers in multiple iterations to improve the application.

First iteration – prototype with sensory monitor and diary

The solution monitors several parameters of PLWD: number of steps, sleep, heart rate and mood. The first three parameters can be measured using wearables, whereas the mood is determined by the informal caregiver with a scoring mechanism. To detect disease evolutions over time, notes can be added in the system and linked with an activity or event. Figure 9 and figures A4 - A5 display the mobile application wireframes developed for this concept.

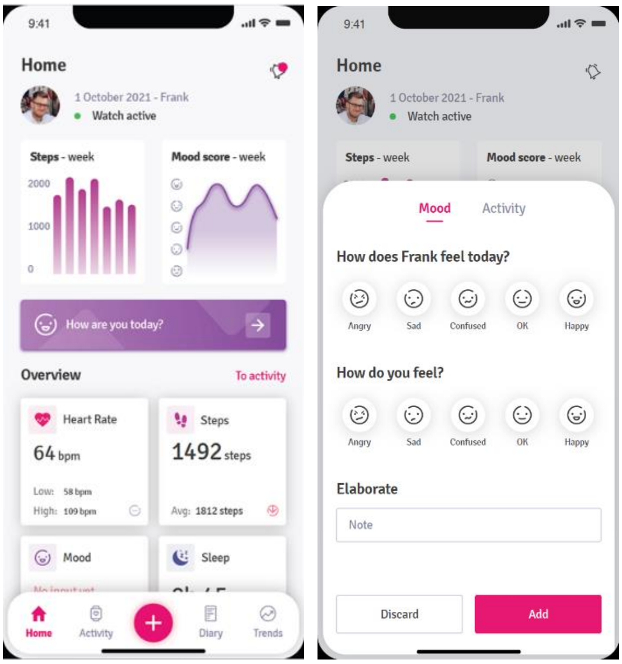

Figure 9: Wireframes developed for the initial concept displayed on a smartphone. The wireframe on the left shows the home page with an overview of the measured parameters, the wireframe on the right indicates the mood scoring page.

According to the Global Deterioration Scale (CGS) there are 7 stages of dementia[9]:

1. No cognitive decline
2. Very mild cognitive decline
3. Mild cognitive decline
4. Moderate cognitive decline
5. Moderately severe cognitive decline
6. Severe cognitive decline
7. Very severe cognitive decline

In line with the goal of the project, the prototype will mainly focus on early and mid-stages (stages 4, 5 and 6) as these are the stages for which the person has received a diagnosis but still functions independent and/or lives at home. During the interviews we've noticed that depending on the stages, the primary informal caregiver of a person living with young onset dementia will be interested in different features. Therefore, we've decided to develop a modular prototype that can be adjusted to the caregiver's needs instead of the stage of dementia. To estimate which functionalities are most interesting to include, we summarize the most common symptoms for PLWD stage 4-6 below.

In **stage 4**, PLWD have a moderate cognitive decline which can lead to the following symptoms:

- Difficulty concentrating
- Forgets recent events
- Cannot manage finances
- Cannot travel alone to new places
- Difficulty completing tasks
- In denial about symptoms
- Socialization problems, resulting in withdrawal from friends or family
- Physician detects cognitive problems

Stage 4 lasts approximately 2 years and PLWD in this stage still try to perform their activities independently.

In **stage 5**, the mid-stage with moderately severe cognitive decline which lasts on average 1,5 years, we witness following signs and symptoms:

- Major memory deficiencies
- Need assistance with activities of daily living (ADL) like dressing, bathing, etc.
- Forgets details like address or phone number
- Doesn't know time or date
- Doesn't know where they are

The caring responsibility of the primary informal caregiver slowly grows during this stage, as well as anxiety when not around.

Stage 6 lasts 2,5 years and is characterized by severe cognitive decline and displays following symptoms:

- Cannot carry out ADL without help
- Forgets names of family members
- Forgets recent events
- Forgets major events in past
- Difficulty counting down from 10
- Incontinence (loss of bladder control)
- Difficulty speaking
- Personality and emotional changes
- Delusions
- Compulsions
- Anxiety

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[9] https://www.dementiacarecentral.com/aboutdementia/facts/stages/

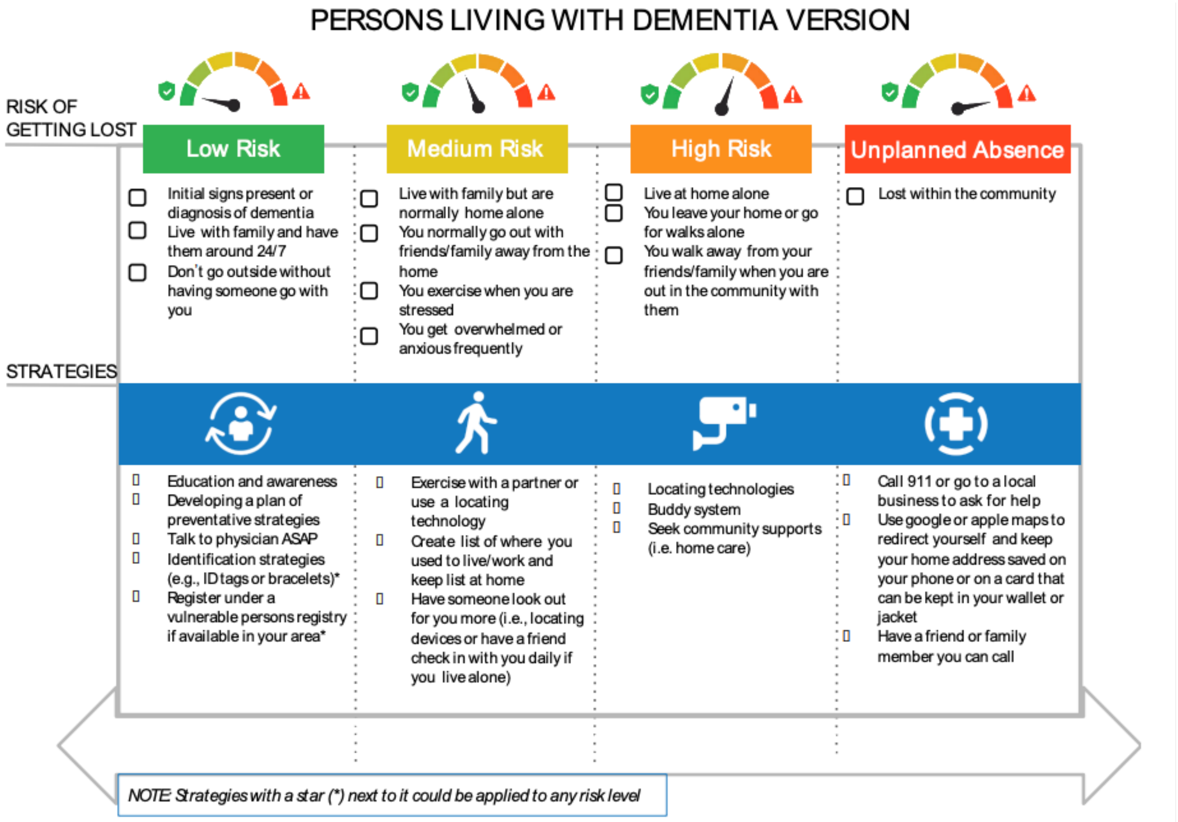
At stage 6 it becomes nearly impossible for PLWD to stay home alone. Therefore, the primary informal caregiver must either stay at home or rely on other caregivers like friends and family or professional caregivers such as volunteers, nurses, or day-care to support in the caring activities.

The primary informal caregivers found **sensory monitoring** important especially for stage 4 and 5. The secondary informal caregivers on the other hand showed more interest in the journaling possibility of the concept - they only get part-time involved in a later stage (5-6) and could use this tool to inform and be informed. Because the primary informal caregiver, our main target, is not yet convinced about the added value of the journaling aspect (see appendix A, figures A6-A7) we decided to focus on the sensory part of the prototype.

Second iteration – location tracker prototype

The primary informal caregivers are mainly interested to monitor location, activity, sleep, and hygiene, without acting as 'Big Brother'. Monitoring reassures the caregiver that the PLWD is self-reliant when home alone, which contributes to the (mental) health and wellbeing of the caregiver.

Knowing the exact whereabouts of PLWD via location tracking is desirable at different stages of the disease (see figure 10). Insight into the daily activities of PLWD such as sleeping and showering are informative for the caregiver but are not perceived as a must. To safeguard the patient's privacy, the prototype will focus on location tracking.



PERSONS LIVING WITH DEMENTIA VERSION

	Low Risk	Medium Risk	High Risk	Unplanned Absence
RISK OF GETTING LOST	☐ Initial signs present or diagnosis of dementia ☐ Live with family and have them around 24/7 ☐ Don't go outside without having someone go with you	☐ Live with family but are normally home alone ☐ You normally go out with friends/family away from the home ☐ You exercise when you are stressed ☐ You get overwhelmed or anxious frequently	☐ Live at home alone ☐ You leave your home or go for walks alone ☐ You walk away from your friends/family when you are out in the community with them	☐ Lost within the community
STRATEGIES	☐ Education and awareness ☐ Developing a plan of preventative strategies ☐ Talk to physician ASAP ☐ Identification strategies (e.g., ID tags or bracelets)* ☐ Register under a vulnerable persons registry if available in your area*	☐ Exercise with a partner or use a locating technology ☐ Create list of where you used to live/work and keep list at home ☐ Have someone look out for you more (i.e., locating devices or have a friend check in with you daily if you live alone)	☐ Locating technologies ☐ Buddy system ☐ Seek community supports (i.e. home care)	☐ Call 911 or go to a local business to ask for help ☐ Use google or apple maps to redirect yourself and keep your home address saved on your phone or on a card that can be kept in your wallet or jacket ☐ Have a friend or family member you can call

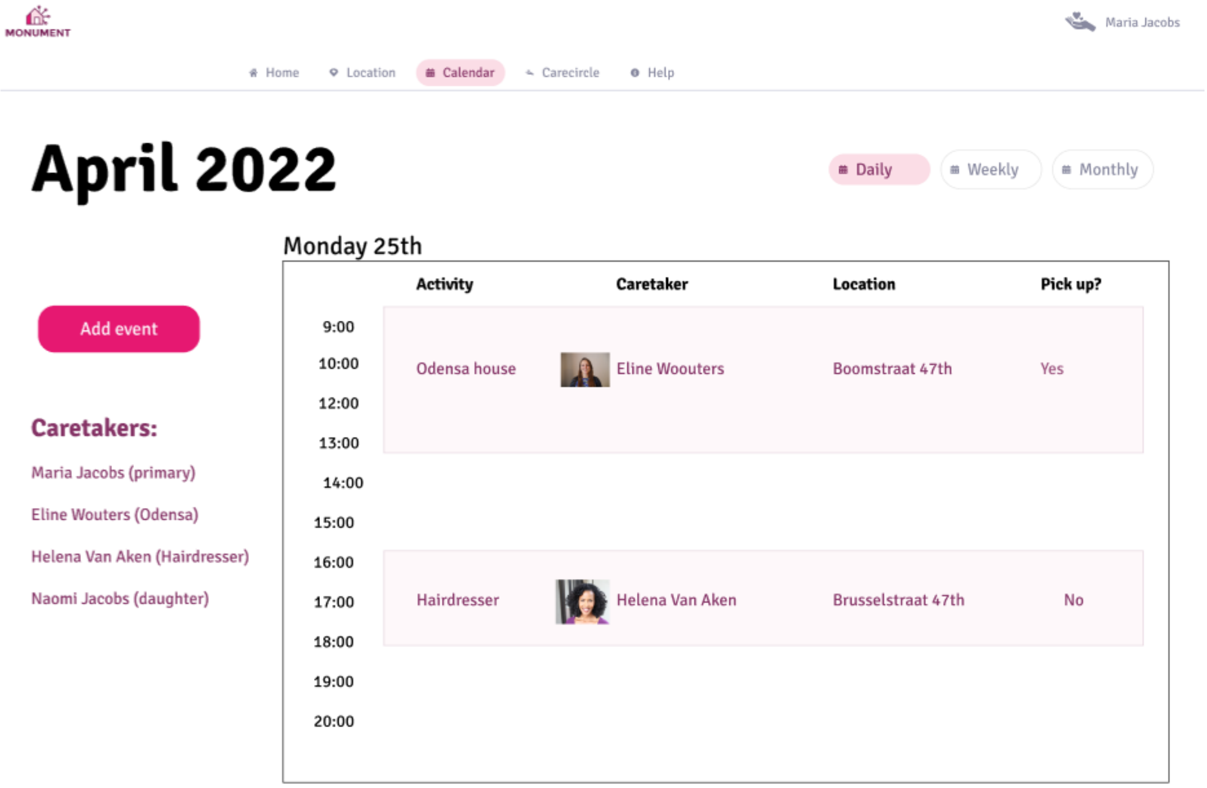
NOTE: Strategies with a star (*) next to it could be applied to any risk level

Figure 10: Picture demonstrating the risk of getting lost at the different stages of dementia. When you live at home with family, which is a typical situation during the early stages of young onset dementia, the risk is medium level. To reduce the risk, PLWD should be accompanied or tracked using location technology. (Source: https://brainxchange.ca/Public/Files/Safety/PLWD-who-go-missing.aspx)

Especially in the early stages informal caregivers motivate PLWD to remain active throughout the day as this contributes to slower cognitive decline, greater social interactions, independence, improved self-esteem, and a better mood[10]. PLWD are stimulated to leave the house to go to the bakery, ride the bike, visit friends, and more. To ensure PLWD remember the way back home, the informal caregiver works out fixed routes and routines with them.

Currently, common **GPS locators** incorporated in smartphones are being used, but these tracking devices do not fulfil the needs of PLWD and the informal caregiver. These applications require the carer to log in if they wish to access the location data, implying that unexpected situations will most likely remain unnoticed. PLWD on the other hand want to maintain their independence but existing applications need action from their side – push an alarm button – to notify the informal caregiver when they get lost.

Feedback provided by the primary informal caregivers point towards a system that generates notifications when PLWD deviate from their usual pattern, potentially indicating PLWD are lost or wandering. Adding other caregivers involved to the prototype is also specified as a desirable feature so location data can be shared (see figure 11-12).



April 2022

Caretakers:
Maria Jacobs (primary)
Eline Wouters (Odensa)
Helena Van Aken (Hairdresser)
Naomi Jacobs (daughter)

Monday 25th

	Activity	Caretaker	Location	Pick up?
9:00				
10:00	Odensa house	Eline Woouters	Boomstraat 47th	Yes
12:00				
13:00				
14:00				
15:00				
16:00				
17:00	Hairdresser	Helena Van Aken	Brusselstraat 47th	No
18:00				
19:00				
20:00				

Figure 11: Example of the caregiver wireframe. The primary informal caregiver can add other informal caregivers to the prototype and indicate if they should be able to track and share location data of the PLWD.

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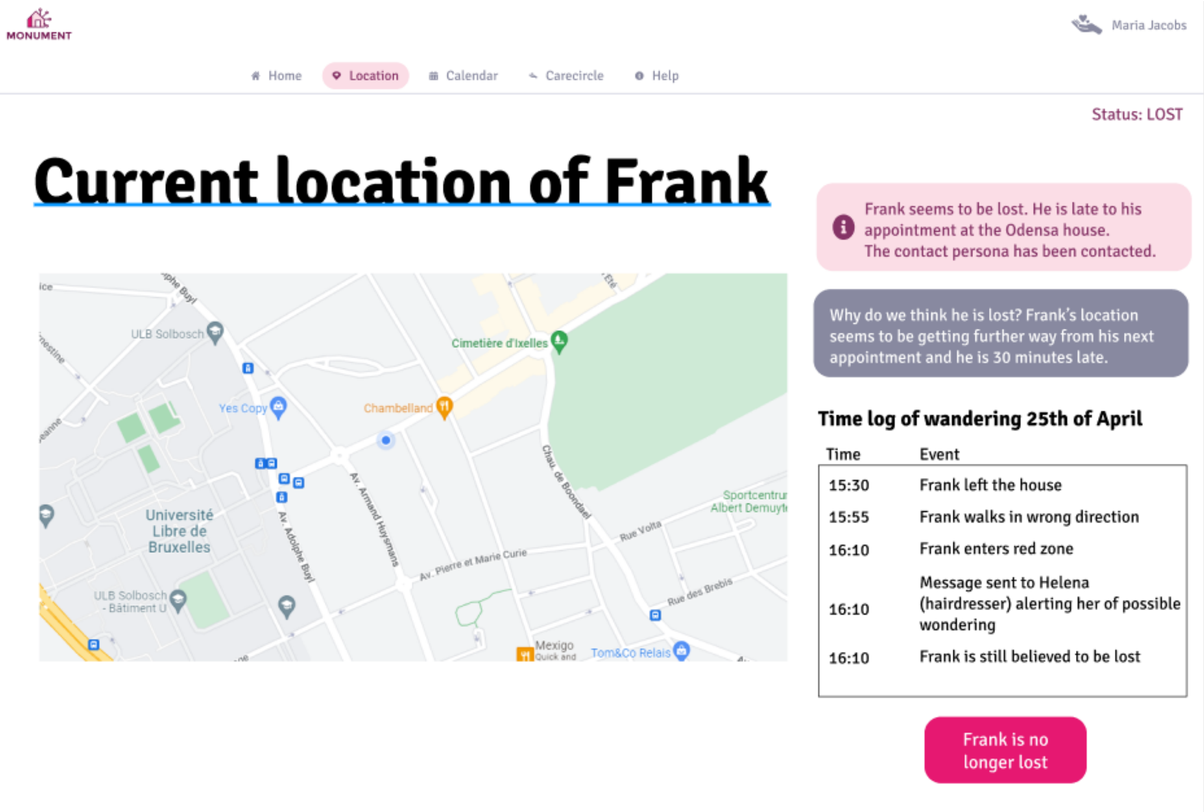
[10] https://www.alzheimers.org.uk/get-support/daily-living/exercise



Status: LOST

Current location of Frank

Frank seems to be lost. He is late to his appointment at the Odensa house.
The contact persona has been contacted.

Why do we think he is lost? Frank's location seems to be getting further way from his next appointment and he is 30 minutes late.

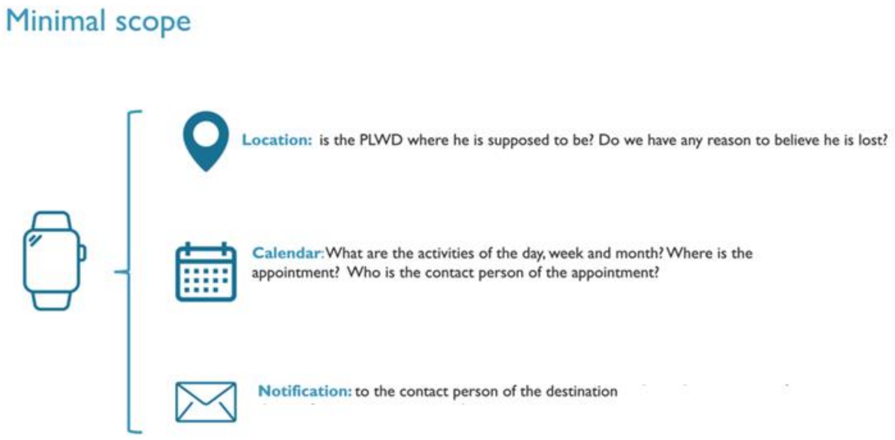
Time log of wandering 25th of April

Time	Event
15:30	Frank left the house
15:55	Frank walks in wrong direction
16:10	Frank enters red zone
16:10	Message sent to Helena (hairdresser) alerting her of possible wondering
16:10	Frank is still believed to be lost

Figure 12: Example of the wireframe to track the location of Frank, a person diagnosed with dementia. The activity log is available for review and notifications are sent to the responsible informal caregiver when Frank deviates from the predicted route.

Informal caregivers had an overall preference for a smartwatch to monitor location. An elegant and discrete design, and an easy-to-read clock to help PLWD orient in time, could motivate them to wear the tracker continuously. The insights gathered so far made it possible to determine the minimal scope for prototype development (see figure 13):

- The prototype will make use of a smartwatch
- The application is used to track the location of PLWD
- Calendar events can be added in the application
- Other caregivers can be added in the application
- The application sends a notification to the indicated contact person when the PLWD deviates from their normal/expected behavior


Minimal scope

Location: is the PLWD where he is supposed to be? Do we have any reason to believe he is lost?

Calendar: What are the activities of the day, week and month? Where is the appointment? Who is the contact person of the appointment?

Notification: to the contact person of the destination

Figure 13: Visual representation of the minimal scope to develop the remote monitoring prototype.

Third iteration – remote tracking devices

According to the state of the art, several off the shelf devices are available that allow location tracking of PLWD. Some of these tracking devices include an alarm button as a safety mechanism for PLWD to press when they are lost. Others enable two-way voice communication, which allows to make a connection and the ability to help the PLWD from a distance. These devices come in different forms and shapes like watches, necklace or inserts in the shoe.

Devices as described above often have a stigmatizing effect and don't fit in everyday life. As a pragmatic solution, PLWD use smartphone applications such as WhatsApp location tracking. This however implies PLWD should carry their smartphone with them all the time. The informal caregivers indicated during earlier iterations that some PLWD, especially in early-stage young dementia, would prefer a regular smartwatch without alarm button as a location tracker. Having a smartwatch including a tracker and SIM card has the advantage to monitor location even when a smartphone is not in the vicinity. When the device can integrate other systems, extra functionalities could be added with a user-friendly interface.

We added an addendum to the state-of-the-art study and created a new search for smartwatches that have these functionalities. Table 1 provides an overview of the most relevant features of the currently available smartwatches that meet our requirements.

Table 1: Overview of smartwatches that can be used as independent location tracker and their functionalities.

WEAR OS smartwatches	Price (euro)	SIM card	Activity	Battery in smart mode (days)	Sleep tracking	Heart rate monitoring	Google assistance	GPS	Waterproof (minutes)
Fossil Gen 5LTE	300	yes	yes	1.5	yes	yes	yes	yes	Yes
Galaxy watch4	200	yes	yes	2	yes	yes	yes	yes	yes (30')
Galaxy watch4 classic LTE	300	yes	yes	2	yes	yes	yes	yes	yes (30')
Mobvoi TicWatch Pro LTE	300	yes	yes	3 (or 2)	yes	yes	yes	yes	yes
Montblanc Summit 2	1200	yes	yes	1	yes	yes	yes	yes	yes
Montblanc Summit Lite	800	yes	yes	1	yes	yes	yes	yes	yes

During one of the study visits presented by HZ University of Applied Sciences in February 2022 an additional system was introduced to the MONUMENT partners, namely FreeWalker – Moving Safely, Living Independently – AAL Programme (freewalker-aal.eu). FreeWalker remains in a research stage, but some elements were made commercially available by SafetyTracer (https://www.safetytracer.eu/). SafetyTracer has several devices – kompy devices (see figure 14) – with similar functionalities and different formfactors which complies with the personalised preferences of PLWD.

Figure 14: Overview of available kompy devices and applications. (Source: https://www.safetytracer.eu/de-kompy)

The functionalities of the SafetyTracer platform were very similar to the requirements identified during the iterations. Therefore, we decided to initially create and test the prototype with the kompy watch. Through minimal changes we could add features such as linking the location to certain calendar events and allowing multiple (temporary) caregivers to receive a notification and (temporary) link to the location of the PLWD. Eventually, integration of any type of device with an open API should allow the informal caregiver and PLWD to use it with a tracking device of their choice. Therefore, the codebase will be made available as open source.

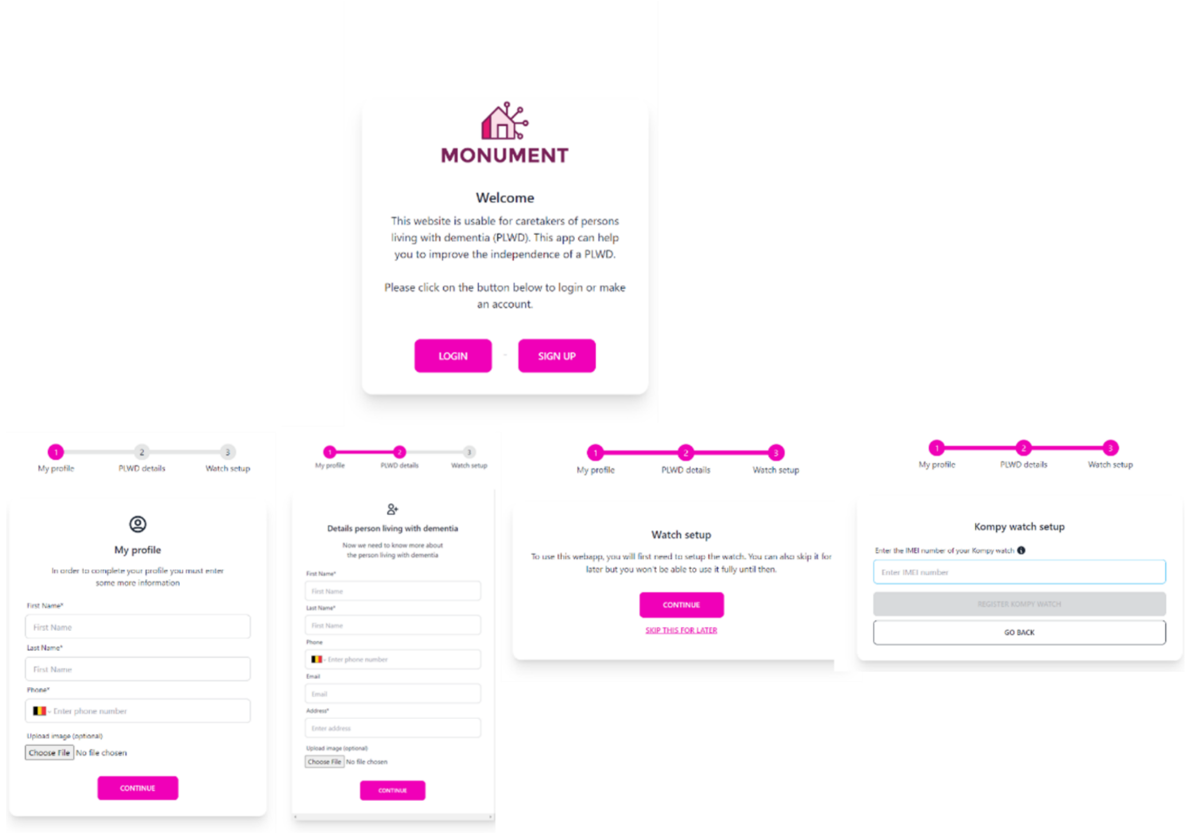
Fourth iteration – minimal scope prototype

For the minimal scope prototype, we developed a web application integrating the kompy watch. The web application is available on both a computer and a smartphone. The functioning prototype is based on the wireframes mentioned above and has the following features:

1. Login/sign-up page
2. Homepage
3. Map with the last known location
4. Overview of the care circle
5. Calendar
6. Notification system via email and text message
7. User interactions

1. Login/sign-up page

The login/sign-up page indicates what the website can be used for. To use the application, the informal caregiver must first create an account in three steps: add personal information, information about the PLWD, and the setup of the kompy watch (can be skipped) (see figure 15).



MONUMENT

Welcome

This website is usable for caretakers of persons living with dementia (PLWD). This app can help you to improve the independence of a PLWD.

Please click on the button below to login or make an account.

My profile

In order to complete your profile you must enter some more information

First Name*: First Name
Last Name*: First Name
Phone*: Enter phone number
Upload image (optional): Choose File No file chosen

Details person living with dementia

Now we need to know more about the person living with dementia

First Name*: First Name
Last Name*: First Name
Phone: Enter phone number
Email: Email
Address*: Enter address
Upload image (optional): Choose File No file chosen

Watch setup

To use this webapp, you will first need to setup the watch. You can also skip it for later but you won't be able to use it fully until then.

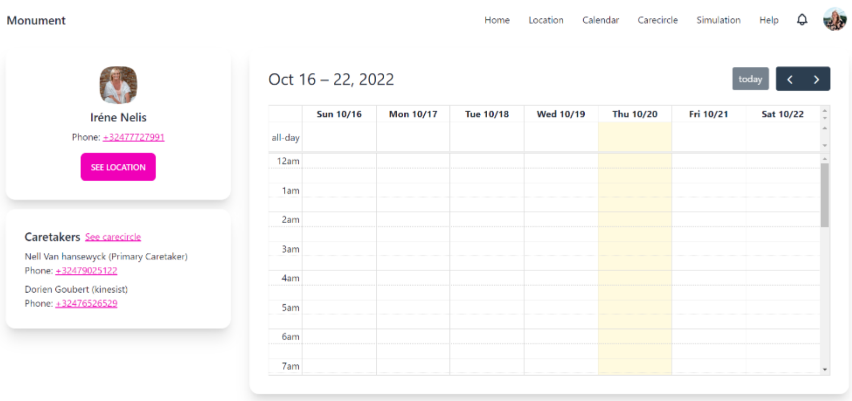
Kompy watch setup

Enter the IMEI number of your Kompy watch: Enter IMEI number

Figure 15: Screenshots from the web application developed for the remote monitoring prototype. After entering the welcoming page (upper image), the informal caregiver must sign up and create an account through 4 consecutive steps (lower images, from left to right)

2. Homepage

Once the informal caregiver has logged in, they arrive at the homepage. This page gives an overview of the calendar and the care circle. The menu bar at the top, allows the user to navigate between the different features (see figure 16).



Iréne Nelis
Phone: +32477727991

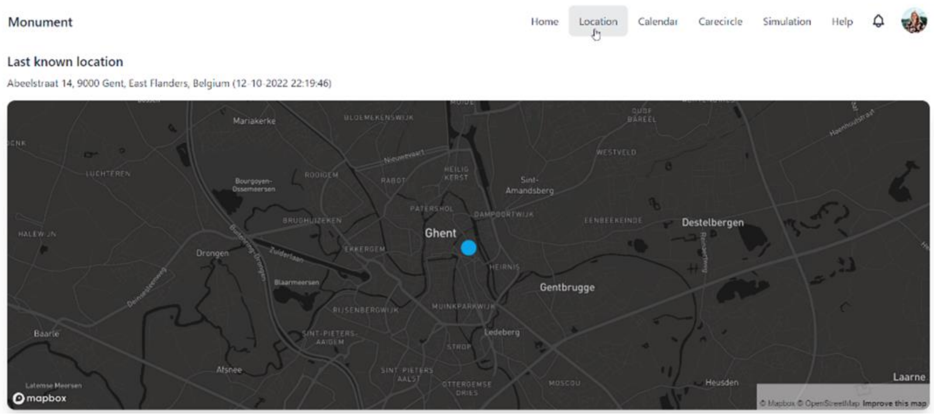
Caretakers See carecircle
Nell Van hansewyck (Primary Caretaker)
Phone: +32479025122
Dorien Goubert (kinesist)
Phone: +32476526529

Oct 16 – 22, 2022

Figure 16: Screenshot from the web application's homepage, providing an overview of the care circle and the calendar.

3. Location

The location page indicates the current position of the kompy watch using an address stamp. If the location cannot be found, the last known position is displayed with a timestamp (see figure 17).It is important to note that the kompy watch uses a GPS signal, making it more difficult to track locations inside a building, and it can take up to five minutes to detect a GPS signal when going outside.



Last known location

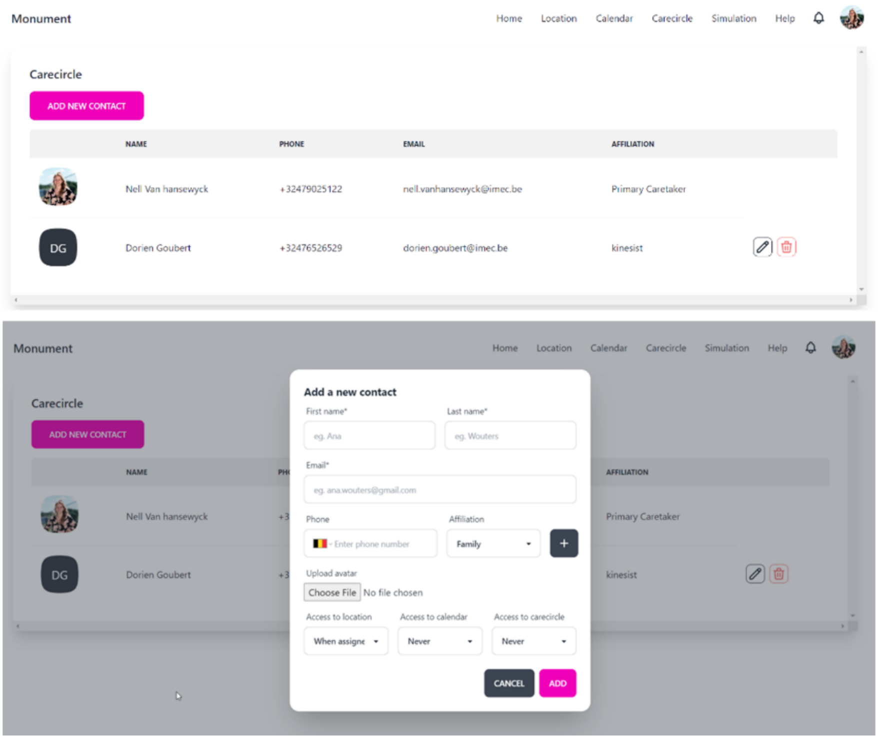
Abeelstraat 14, 9000 Gent, East Flanders, Belgium (12-10-2022 22:19:46)

Figure 17: Screenshot from the location page of the web application. The last known position of the PLWD is indicated with a blue dot on a map.

4. Care circle

The informal caregiver can create a care circle, containing a group of people involved in the care of PLWD (e.g., family members, friends, neighbours) (see figure 18). When someone has been added to the care circle, this person will get an invite to create an account for the web application to get access to the page of the PLWD. The informal caregiver can assign the appropriate access rights for each caregiver, being:

- Access to location: always/when assigned as a contact person
- Access to calendar: never/read/read and edit
- Access to care circle: never/read/read and edit



Carecircle

NAME	PHONE	EMAIL	AFFILIATION
Nell Van hansewyck	+32479025122	nell.vanhansewyck@imec.be	Primary Caretaker
Dorien Goubert	+32476526529	dorien.goubert@imec.be	kinesist

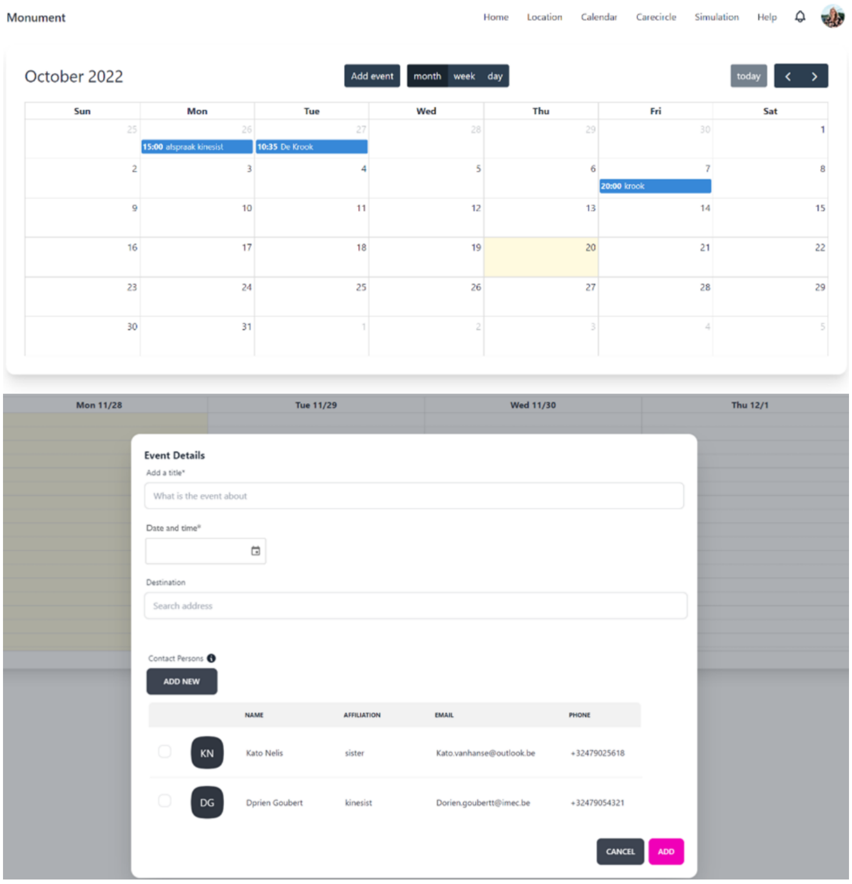
Add a new contact

First name*: eg. Ana
Last name*: eg. Wouters
Email*: eg. ana.wouters@gmail.com
Phone: Enter phone number
Affiliation: Family
Upload avatar: Choose File No file chosen
Access to location: When assigne
Access to calendar: Never
Access to carecircle: Never

Figure 18: Screenshot from the web application providing information about the PLWD's care circle (top) and showing the option to add other informal caregivers or contact persons (bottom).

5. Calendar

The calendar feature allows the informal caregiver to schedule an event or an appointment for PLWD (see figure 19). When adding a new appointment, a contact person has to be assigned so a notification can be sent in case the PLWD is late. Contact persons can be part of the care circle but also external people like a hairdresser or physiotherapist.



Event Details

Add a title*: What is the event about

Date and time*:

Destination: Search address

Contact Persons

ADD NEW

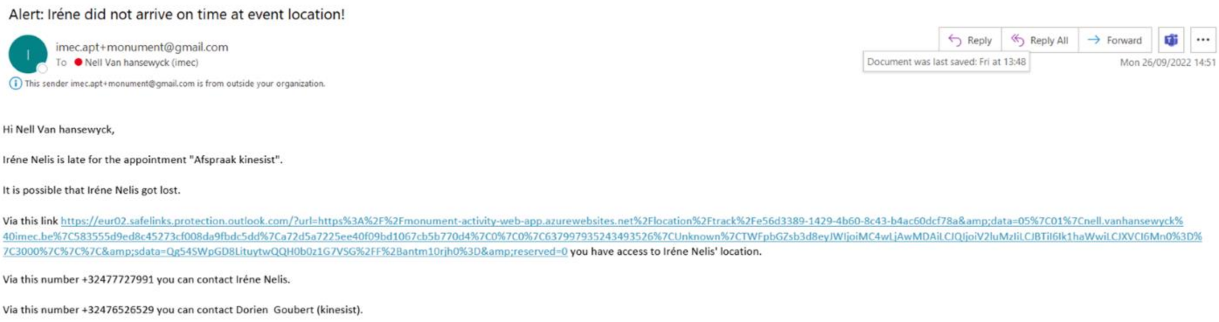
		NAME	AFFILIATION	EMAIL	PHONE
☐	KN	Kato Nelis	sister	Kato.vanhanse@outlook.be	+32479025618
☐	DG	Dprien Goubert	kinesist	Dorien.goubertt@imec.be	+32479054321

CANCEL ADD

Figure 19: Screenshot from the calendar page providing an overview of the PLWD's planned events (top), and the option to add an event (bottom).

6. Notification system

When the PLWD is 10 minutes late for a registered appointment, the informal caregiver and the assigned contact persons receive a text message and an email (see figure 20). The message contains a link to the location page of the web app to check the actual position of the PLWD, the phone number of the PLWD (if available) and the phone numbers of the other contact persons. The web link remains valid until 20 minutes after the end of the appointment.



Alert: Iréne did not arrive on time at event location!

imec.apt+monument@gmail.com
To Nell Van hansewyck (imec)

This sender imec.apt+monument@gmail.com is from outside your organization.

Document was last saved: Fri at 13:48

Mon 26/09/2022 14:51

Hi Nell Van hansewyck,

Iréne Nelis is late for the appointment "Afspraak kinesist".

It is possible that Iréne Nelis got lost.

Via this link https://eur02.safelinks.protection.outlook.com/?url=https%3A%2F%2Fmonument-activity-web-app.azurewebsites.net%2Flocation%2Ftrack%2Fe56d3389-1429-4b60-8c43-b4ac60dcf78a&data=05%7C01%7Cnell.vanhansewyck%40imec.be%7C583555d9ed8c45273cf008da9fbdc5dd%7Ca72d5a7225ee40f09bd1067cb5b770d4%7C0%7C0%7C637997935243493526%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=Qg54SWpGD8LituytwQQH0b0z1G7VSG%2FF%2Bantm10rjh0%3D&reserved=0 you have access to Iréne Nelis' location.

Via this number +32477727991 you can contact Iréne Nelis.

Via this number +32476526529 you can contact Dorien Goubert (kinesist).

Figure 20: Example of an email notification generated by the web application when the PLWD is late for a scheduled appointment.

7. User interactions

We organised several user experience (UX) tests with informal carers to validate the requirements and collect input for further improvements. Throughout the UX test we asked the end users to create an account, add someone to the care circle and add a relevant calendar event. During the first round of user testing, the integration with the kompy watch seemed unsuccessful. Therefore, we've included a feature to simulate that a PLWD is late for a calendar event to be able to trigger notifications (see figure 21). The figure below (figure 21) shows a visual presentation of this simulation feature.

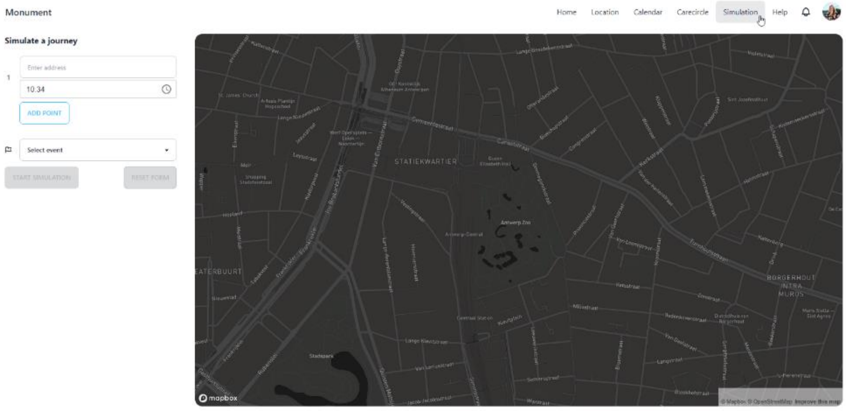


Figure 21: Screenshot from the web application showing the simulation feature to test the notification system.

Based on the end users' feedback we made the following changes to improve the user interface:

- A calendar week overview instead of a day overview on the homepage.
- Possibility to add events without a contact person and location for a complete overview of the week planning, including in-house visits or other recurring events such as a doctor visit at home or cleaning aid.
- Feature to add the current location to google maps and start navigation.
- Possibility to choose whether the primary caregiver receives a notification or not.

After implementation of these requirements, we demonstrated our prototype at the Dementia XL Day at the Odense House in Mechelen to a group of seven informal caregivers. In general, they were enthusiastic about the prototype and indicated that the simplicity of the prototype makes it low-key and accessible for many (elderly) end users. Also, the possibility to add a contact person on site of the appointment is perceived as an advantage towards anticipation. They believe this innovation can save time for the informal caregiver and give the PLWD a better sense of independence.

Beside those positive aspects there were also some remarks. First, the informal caregivers are worried that PLWD will not wear the watch because of possible shame, stigmatization, and the feeling of being controlled. To accommodate this, they suggest PLWD could receive messages through the watch (e.g., “it's time to leave for your appointment at the Odense house”). Informal caregivers also indicated that adding events to the calendar feels as another task, although they believe this innovation can save time. Lastly, the informal caregivers made us aware that the prototype will be most useful for PLWD stage 4, when the patient has only a moderate cognitive decline. For PLWD with a more advanced stage of dementia, more precautions are often needed to prevent them to go out alone.

Fifth iteration – prototype testing

Once the integration with the kompy watch was successful, we organized two additional user tests. To test the complete user flow, we conducted a role play simulating an appointment at the Odense house (see blue box for scenario).

Scenario prototype testing

Josephine is 58 years old and was diagnosed with Young Onset Dementia two years ago. Her husband Dany (59) and their daughter Sophy (25) take on the caregiving tasks, but Dany is the primary caregiver.
Since last year, Josephine has a hard time going out by herself as she got lost the last time she went to the Odense house on her own. Because Dany doesn't have a lot of time for himself, and needs to join Josephine to every appointment, he feels tired and emotional. Therefore, he decides to use a web application including a calendar, coupled to a smartwatch that can track Francine's location.
Dany creates an account on the web application and adds their daughter to the care circle. Thereafter, he adds an appointment at the Odense house at 16:00 to the calendar and adds Justine – an employee of the Odense house – as a contact person. He makes Josephine wear the watch and she leaves the house to go to the Odense house. Along the way she starts wandering without realizing she is heading the wrong direction. At 16:10 Dany and Justine get a text message telling them that Josephine is late for the appointment and they can acces her live location via the link they received with the notification. Dany and Justine call each other and discuss who will look for Josphine.

The primary caregiver took the role as caregiver. The Odense house contact and the PLWD were played by two employees of the Odense House in Mechelen. We decided not to include the PLWD at this stage of the testing for safety reasons and to avoid panic or confusion the role play might cause.

Figure 22: Picture taken during the role play testing the remote monitoring prototype

The role play (see figure 22) revealed that the user experience of the application could be improved, especially for elderly people. The detected flaws are categorized and explained below.

Information and communication

Labels in the applications should be more intuitive with a clear call to action.
For example:

- When adding an event to the calendar, it was not clear that the “start time” and “end time” referred to the start and end of the appointment and not the departure and arrival time.
- When adding another contact persons to the event they have to add themselves as a contact person if they would like to receive a notification.
- End users interpreted the term “care circle” as a team of professional health care workers like the nurse, general practitioner, or physio therapist.

User flow and actions

The required actions are not always applicable or relevant.
For example:

- An e-mail address is mandatory for the contact person, but the primary informal carers do not know all the email addresses.
- When adding an appointment, the application requires extra information such as the address. To reduce the number of steps in the application, it would be convenient to have an auto-fill feature for recurring appointments.
- When you go to the Odense house, there is often no specific start or end time. Therefore, it would be more relevant to use “time of departure” and “time of arrival” instead.
- To anticipate that PLWD forget their appointment, the end users recommended they should receive a notification on the watch as a reminder.

The daily life context

- Smartphones generate notifications all the time, risking the informal caregiver misses an important notification about the PLWD. Therefore, the messages sent by the application should raise a sense of urgency (for example through repetitive messaging).
- Linked to that, a contact person isn’t informed when they are added to a certain calendar event, making them unaware of a potential (urgent) notification. Moreover, chances are that the contact person is not available due to work which implies they would not be able to act upon the message. Therefore, the informal carer and contact person should have a clear set of rules amongst each other on how to use the application.
- Confusion arose when the PLWD got lost: the informal caregiver thought it was obvious that the contact person in the Odense house would search for the PLWD, whereas the contact person in the Odense house indicated that it is not always possible for them to leave their job. The contact person at the Odense house stressed out that expectation management to the informal caregiver is crucial.
- Some end users have doubts about the willingness or practical barriers to contribute to this initiative by a doctor, dentist, physio therapist, hairdresser, or butcher. Only the Odense house, visiting family and friends, and maybe a physio therapist were considered most useful.
- Finding the PLWD appeared challenging as the exact position constantly changes when wandering. The notification included two links: one link to the current position and another link to google maps to navigate to the PLWD’s location. The contact person preferred the link to google maps including the navigation but google maps did not synchronize with the actual position. It would also be useful for the contact person to know how the PLWD moving (by bicycle or on foot) to anticipate how fast the location changes.
- The text in the notification was too long to read.

- The link to the current location in the notification is only accessible for 20 minutes after the end of the event. In reality, it can take up to 4 hours before a PLWD is found.
- The geofence is too large (150m). A PLWD can still get lost within those 150m.

Based on the above feedback we implemented the following quick wins as an iteration for the next user test:

- Change the colour of the “add event” button so it is easily noticed
- Adding an event by clicking the calendar frame
- Rename “start time” and “end time” to “start of the appointment” and “end of the appointment” respectively
- Person who adds an event is by default selected as a contact person
- Only one link in the notification: link to the current location
- Remove last names in notification to make text shorter
- Rename “see on google maps” button on the location page of the application to “navigate to this location via google maps”
- Extend access to location link from 20 minutes to 4 hours after the start of the calendar event
- Decrease the geofence from 150m to 50m

Sixth iteration – prototype testing 2.0

After implementing the above-mentioned improvements, we performed a second role play with another informal caregiver, using the same scenario. The following additional feedback was gathered:

Information and communication

Labels in the applications should be more intuitive with a clear call to action.
For example:

- The informal caregiver forgot to add an address when adding the event to the Odense house. He assumed that filling in the field “title” would be enough to trigger notifications in case the PLWD is late for the appointment.
- It was not clear for the informal caregiver who should be added as a contact person to an event because he did not see the tooltip with the explanation what a contact person is.
- The informal caregiver was not sure whether the other contact person had also received a message, and therefore didn’t know whether the contact person could actually find the the PLWD
- Both the informal caregiver and the contact person didn’t realize that the phone number of each of them was mentioned in the notification. They looked up the phone number of each other in their phone.
- It’s confusing for end users that you can navigate to the location via google maps, but that you have to keep going back to the location page and use the new updated location to navigate to the updated location.

This time a female PLWD was included to test the kompy watch for an hour. The kompy watch felt very comfortable to wear and the feature that monitors the number of steps is a motivator to wear the watch throughout the day. But in her opinion, women would prefer to wear their own, more elegant watch and carry the kompy watch in their handbag instead.

Based on the two scenario tests we decided to implement additional improvements:

- An autocomplete input to reuse previously added appointments
- Immediately ask for the destination address when a calendar event is added
- Rename “contact person” field as “Who should get a notification when (*name PLWD)* is late for the appointment?”
- Send a text message and email to contact persons to inform them they were added to a calendar event, and to notify the creator of the event if they are not available.

Conclusions MONUMENT remote monitoring prototype

Informal caregivers are pivotal figures in the primary care of people with dementia. They do the housekeeping, guide PLWD with their daily actions, take precautions to ensure safety, but support is lacking which reduces their resilience. Although technological innovations exist to assist caregivers in their work, one technology does not fit all needs. Moreover, as the dementia evolves over time, so do the responsibilities of the caregiver. From our user research we identified **the need to integrate multiple applications** on a central platform. We've started from existing technology to track the location of PLWD and coupled other functions found useful for caregivers, like a calendar feature and the option to share information with the care circle. A partnership was established with SafetyTracer to integrate their tracking service (open API) with an agenda and information sharing system. Throughout this project, the concept and prototype were modified multiple times based on iterative feedback from the informal caregivers. As a result, the remote monitoring prototype provides insight in the PLWD's whereabouts, adapted to the caregivers' needs, which leads to increased (mental) health and resilience of the caregiver.

Compared to currently available technologies, our prototype tracks the location of PLWD taking into their independence and privacy. Only when the location deviates from what was expected based on calendar events, a notification is sent to a contact person who can subsequently access the localisation data of the patient. Being able to share this information with multiple caregivers and involved medical personnel, relieves the primary caregiver from some of his responsibilities. The modular nature of the application enables caregivers to adjust the system to their evolving needs and incorporate additional sensory features to monitor progression of the disease (see figure 23).

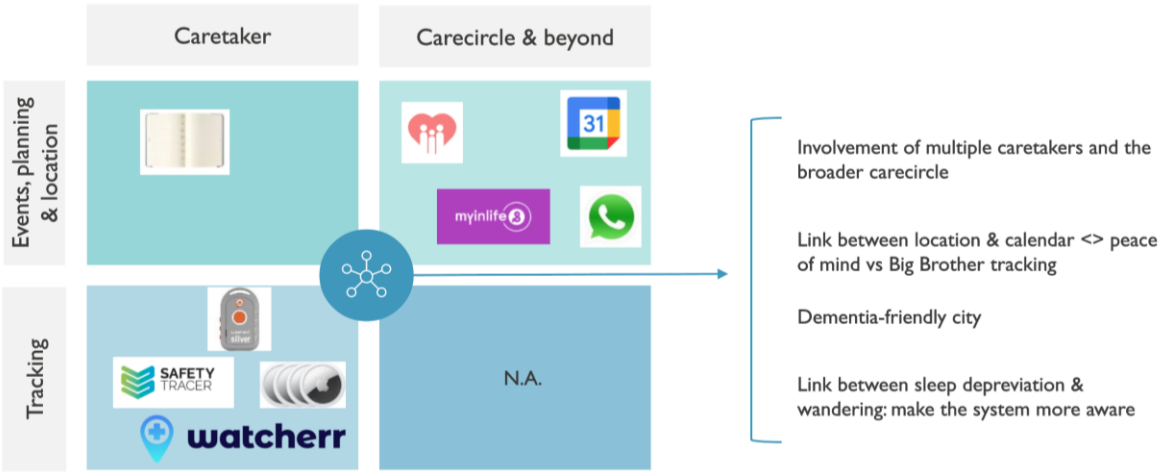


Figure 23: Visual representation of the added values of the MONUMENT remote monitoring prototype compared to existing technology. Integrating multiple functions like location tracking linked with a calendar notification system, involving a broad care circle, and the modular nature, make this prototype unique in its kind.

The prototype is available online (https://monument-activity-web-app.azurewebsites.net). Due to project limitations, we were not able to implement all suggestions gathered from the informal caregivers. Nevertheless, this information might be of particular interest for existing technology providers to improve their services or expand our prototype. To enable that, the code developed during this project using a Kompy Watch can be retrieved on the github open source repository (https://github.com/imec-int/monument-plwd).

List of additional requirements

The additional feedback received from informal caregivers is summarized here as a list of requirements that could improve the existing remote monitoring prototype.

Instructions

- Add an explanation on the care circle page that explains what is meant by care circle
- Add an instruction on the location page that you need to update the live location in google maps every time you want to navigate to the last known location.
- Add a picture of the kompy watch and where to find IMEI nr during the setup of the Kompy watch

User Flow

- Make filling in an email address of a contact person not mandatory
- Show the telephone number of the other contact persons before the telephone number of the PLWD in the notification.
- Add a repeat feature to repeat a calendar event every day/week/month
- Use “time of departure” and “time of arrival” instead of “start of appointment” and “end of appointment”. Let “time of departure” trigger a notification on the smartwatch to remind the PLWD that they should leave for the appointment.
- As a contact person, I want to receive an invitation to be a contact person for a certain calendar event, and be able to reject this invitation

User experience

- Replace "add new contact person" button to bottom of table of contact persons when adding a calendar event.
- Make the icon for adding a new affiliation while adding a contact person/care circle member more visible.
- Improve the UI to make it more user friendly for people who are not used using technology:
    - simplifying terms as “sign up” to “create an account” and “add an avatar” to “upload a profile picture”
    - adding a zoom in and zoom out button to the location map so you don’t have to use the trackpad
    - avoid using tooltips but explain terms like “contact person” and “care circle member” immediately in the screen

Future perspectives - extended remote monitoring prototype

In this project, a prototype was designed based on the minimal scope to track the location of PLWD, linked with a calendar feature and the ability to add other informal caregivers as contact persons when the PLDW shows abnormal behaviour. Because of the modular nature of the application, the scope can easily be extended with additional functionalities.

Sleep tracking
Sundowning – increased confusion and restlessness occurring in the late afternoon or evening – mostly affects people in the mid to later stages of dementia and is closely linked with sleep deprivation. It is uncertain whether a lack of sleep is a result of dementia, or it leads to worsened dementia symptoms, but it can be an indication of potential wandering[11]. As such, tracking sleep combined with integrated algorithms (e.g., predicting wandering, falling or even hallucinations) might prevent PLWD from wandering and getting lost.

Journaling for an adaptive care circle
As the disease evolves, the informal caregiver becomes more reliant on secondary caregivers such as friends, family, or professionals to share the caring responsibilities. Different caregivers execute the tasks intermittently, which requires efficient transfer of information and communication within the care circle. Passing relevant information can happen in person (when appropriate) or using digital communication channels like a WhatsApp (group) chat. Especially for quick updates on daily activities, medication intake, evolutions or doctors' visits, a communication platform plays a crucial role. Secondary caregivers are in demand to receive more information because they are only involved a limited amount of time and lack the overview. Sharing all information however can overload the primary caregiver with documenting duty. Most informal caregivers indicate they keep mental notes or use pen and paper and post-it notes for planning care tasks, writing down concerns and symptoms. Communication with other caregivers is therefore often limited and inefficient. Some use a WhatsApp group, but better digital tools exist to support the care circle with journaling and tasks allocation. Digital journaling tools keep track of everyday caregiving routines and tasks can easily be redefined and shared with the care circle, lowering the workload of the primary caregiver, and providing daily structure. These tools could help to reduce the stress of (primary) caregivers and improve accuracy of important health information (e.g., detailed symptom tracking, changing patterns).

Caregivers feel more dedicated to report if an appropriate tool is available. Here we provide a non-exhaustive list of some journaling tools existing today:

- Mantelzorger app: https://mantelzorger.app/?gclid=Cj0KCQiAm5ycBhCXARIsAPldzoXFolORcxHHACjIpUVx-Er6j9nX04MpCu1t7aQF7YzGZftbsignSEQaAj1-EALw_wcB
- ShareCare: https://www.sharecare.com/
- Caren: https://www.carenzorgt.nl/
- Quli: https://www.quli.nl/
- Nettie regel app: https://nettie.nu/

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[11] https://www.alz.org/help-support/caregiving/stages-behaviors/sleep-issues-sundowning#:~:text=People%20living%20with%20Alzheimer's%20and,(referred%20to%20as%20sundowning)

From the interviews with the informal caregivers, it became clear journaling tools should focus on information sharing regarding routines. For someone with an impaired memory, routines are vital to prevent PLWD from getting lost. Therefore, a calendar open to the whole care circle should acts as a core element in journaling. Features like a shared reminder and a scheduling assistant to log daily activities, appointments, or the week menu, will contribute to daily structure and communication. A structured support grants primary caregivers remote control and it helps PLWD to remember the daily schedule. Below we discuss the possible features of a journaling platform based on the interviews with different types of caregivers.

Family caregiver

Children of PLWD often have to juggle between work, the household and care for their parent with dementia. A journaling platform would give them with a quick overview their parent is doing well and could inspire them to choose appropriate activities in their caring time. Family caregivers indicated that access to a weekly calendar is a crucial requirement when scheduling their care activities. Table 2 provides a summary of desired features for family carers and their concerns about a journaling app (see appendix A, figure A7 for the mock-up design).

Table 2: Overview of desired features and barriers coupled to a journaling application for family caregivers.

Features	Barriers
• Calendar is key (weekly overview) • Routine tracking – when routine is not followed (e.g., indication of mood or confusion) • Insights in parameters like sleep, activity, stress, and frustrations • Personal information on profile page PLWD • Contact details of care circle and medical personnel like the general practitioner • Follow-up on important daily tasks like medication intake • Inspiration for activities • Sharing pictures of activities (e.g., at day-care)	• Too much detail on sensor data • Motivating PLWD to be active in case they have some problems e.g., knee problems, risk of falling, … • Reducing personal contact • Only works with caregivers that are not family

Voluntary caregiver

Volunteers are people without professional occupation (anymore) that like to take on voluntary tasks that benefit society. Official organizations arrange and assign the tasks to the available volunteers who are paid a minimal fee for their engagement. The time that volunteers spend with PLWD is very ad hoc, making information sharing and a clear task distribution essential. Table 3 provides a summary of desired features for voluntary carers and their concerns about a journaling app (see appendix A, figure A8 for the mock-up design).

Table 3: Overview of desired features and barriers coupled to a journaling application for voluntary caregivers.

Features	Barriers
• Reminder of the expected tasks • Sharing notes between caregivers and communicating to the next caregiver • Information on activities: preferred and disliked activities • Sharing pictures of activities • Calendar so they can communicate to PLWD what will happen next • Instant messaging via platform (e.g., quick update from informal caregiver to volunteer) • Ticking the box when tasks are finished • Interesting information: inspiration for activities and food preferences	• Digital illiterate (older or lower educated individuals) • Lack of communication skills (using icons instead) • No smartphone from the official organization, and not allowed to have access to patient data on a private device

Professional caregiver

Professional caregivers are self-employed or linked to a specific organisation that provides them with the tools to care for the PLWD at the house of the PLWD. They often help the PLWD in their daily tasks such as toileting or eating. The professional carers are often responsible for multiple patients and work intermittently with other professional carers to provide continuous care throughout the day. Therefore, the journaling application should provide them easy access to personal information, contact details care circle and calendar events (see figure 24). Table 4 provides a more elaborate summary of desired features for professional carers and their concerns about a journaling app.

Table 4: Overview of desired features and barriers coupled to a journaling application for professional caregivers.

Features	Barriers
• Link with personal goals of informal caregiver and PLWD are important (goal-oriented care) • Only share relevant information (avoid data dump) • Sharing information per role/type of informal caregiver • Notification when things change • Information on routines, food, tasks and task allocation • Mood board PLWD (personal information, preferences, and triggers) • Overview of last week: sleep, activity, mood, meals • Message from previous caregiver	• If one person in ecosystem is not online, it will no longer work • Shy to ask for help • Old habits are hard to exchange (e.g., WhatsApp group chat) • No integration: interoperability with existing system is needed • Unstructured information (e.g., free text) • Have their own system for communication amongst professionals • Digital illiterates (learn new programs and tools) • No added value when information sharing is amongst professional caregivers

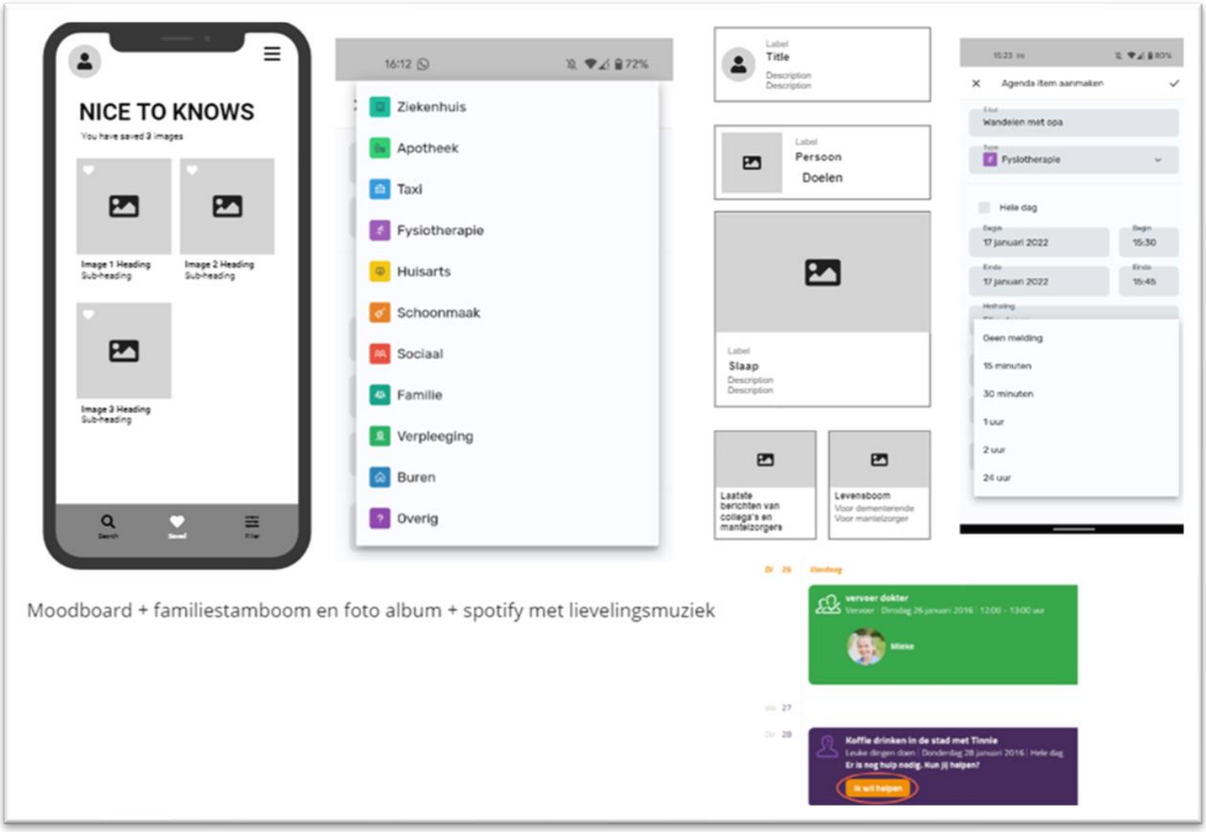


Figure 24: Example of mock-up made by professional caregivers

Day care caregivers

When PLWD require (constant) support for their daily tasks or can no longer stay at home alone, usually in the later stages of dementia, they can go to day care. Day care employs a mix of volunteers and personnel to entertain and care for multiple PLWD. For that reason, structural support is the most important for efficient organization of day care. Table 5 provides a summary of desired features for day care caregivers and their concerns about a journaling app.

Table 5: Overview of desired features and barriers coupled to a journaling application for day care caregivers.

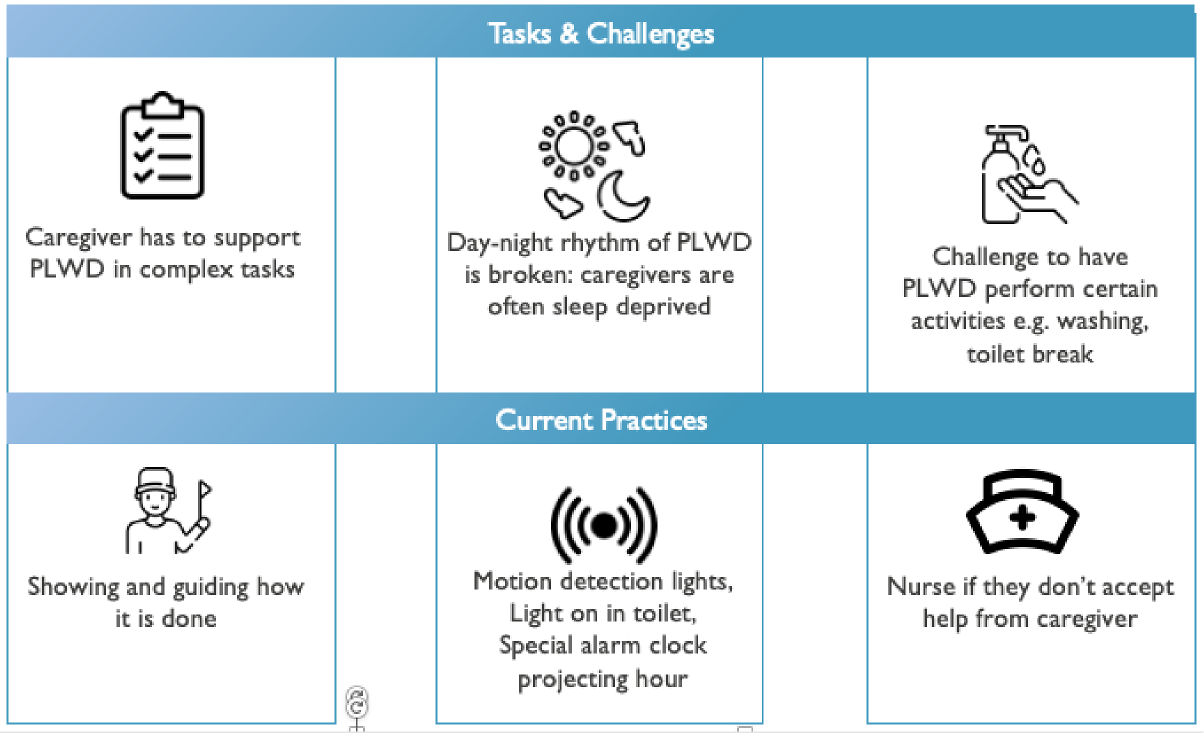
Features	**Barriers**
• Structure is number one priority • Need a quick patient update: returned from hospital, has fever, problems swallowing, etc. • Sharing information with the family: good day, activities, what went wrong, etc. • Show that we improve quality of life for PLWD • Involvement of PLWD • Insights in sleep (determining factor)	• Old habits are hard to exchange (e.g., paper files)

• Follow-up on tasks and whether they are performed (e.g., medication intake, toileting) or need a redo	

In summary, the prototype developed in this work package provides structural and professional support for informal caregivers of people living with dementia. The modular nature of the application permits the caregivers to integrate suitable technology fitting their needs and adjusted to the disabilities of the PLWD. The prototype can evolve along with the disease progression, making it a sustainable support solution for informal caregivers. With this prototype, we hope to increase the resilience of the informal caregivers, allowing PLWD to live at home longer.

ADDENDUM

Appendix A



Tasks & Challenges

Caregiver has to support PLWD in complex tasks

Day-night rhythm of PLWD is broken: caregivers are often sleep deprived

Challenge to have PLWD perform certain activities e.g. washing, toilet break

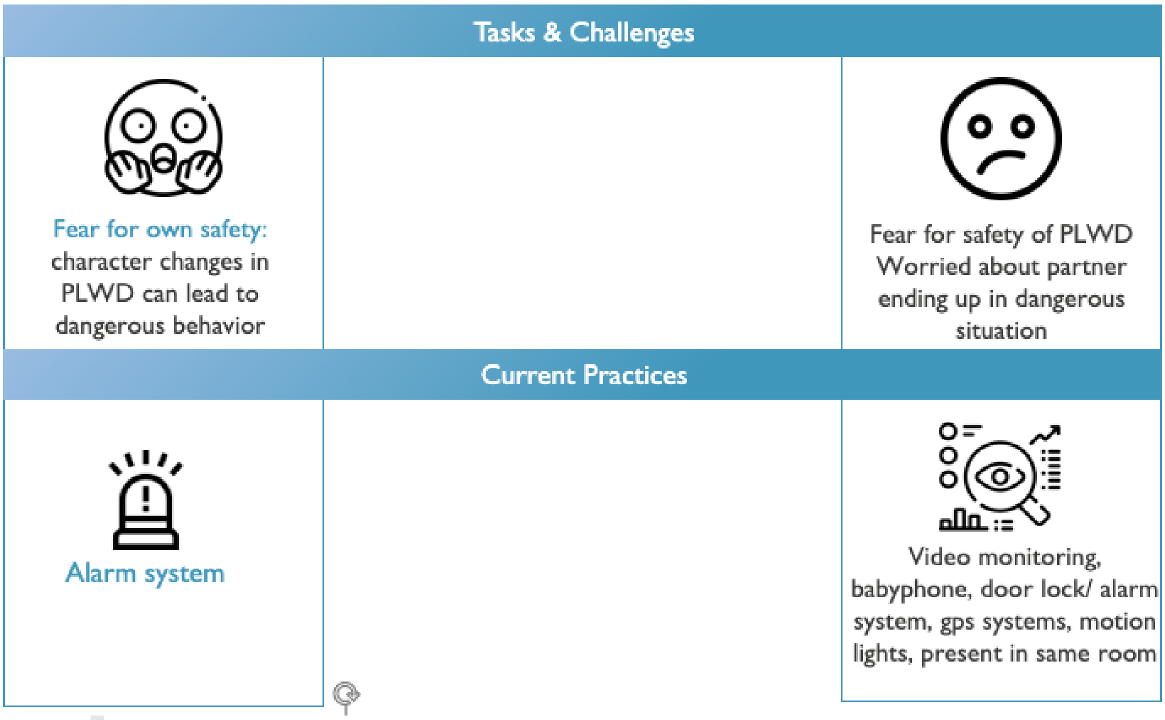
Current Practices

Showing and guiding how it is done

Motion detection lights, Light on in toilet, Special alarm clock projecting hour

Nurse if they don't accept help from caregiver

Figure A1: Overview of tasks and challenges of how caregivers support daily activities.



Tasks & Challenges

Fear for own safety: character changes in PLWD can lead to dangerous behavior

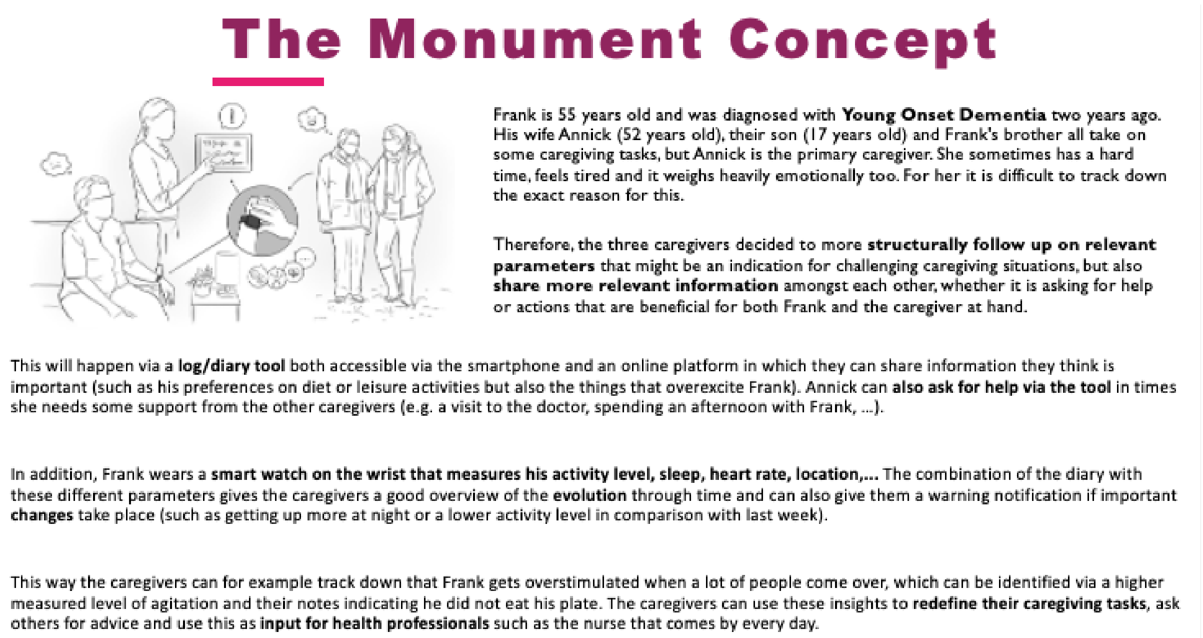
Fear for safety of PLWD Worried about partner ending up in dangerous situation

Current Practices

Alarm system

Video monitoring, babyphone, door lock/ alarm system, gps systems, motion lights, present in same room

Figure A2: Overview of tasks and challenges related to the protection of caregivers' and PLWD's safety.



The Monument Concept

Frank is 55 years old and was diagnosed with **Young Onset Dementia** two years ago. His wife Annick (52 years old), their son (17 years old) and Frank's brother all take on some caregiving tasks, but Annick is the primary caregiver. She sometimes has a hard time, feels tired and it weighs heavily emotionally too. For her it is difficult to track down the exact reason for this.

Therefore, the three caregivers decided to more **structurally follow up on relevant parameters** that might be an indication for challenging caregiving situations, but also **share more relevant information** amongst each other, whether it is asking for help or actions that are beneficial for both Frank and the caregiver at hand.

This will happen via a **log/diary tool** both accessible via the smartphone and an online platform in which they can share information they think is important (such as his preferences on diet or leisure activities but also the things that overexcite Frank). Annick can **also ask for help via the tool** in times she needs some support from the other caregivers (e.g. a visit to the doctor, spending an afternoon with Frank, ...).

In addition, Frank wears a **smart watch on the wrist that measures his activity level, sleep, heart rate, location,...** The combination of the diary with these different parameters gives the caregivers a good overview of the **evolution** through time and can also give them a warning notification if important **changes** take place (such as getting up more at night or a lower activity level in comparison with last week).

This way the caregivers can for example track down that Frank gets overstimulated when a lot of people come over, which can be identified via a higher measured level of agitation and their notes indicating he did not eat his plate. The caregivers can use these insights to **redefine their caregiving tasks**, ask others for advice and use this as **input for health professionals** such as the nurse that comes by every day.

Figure A3: Scenario illustrating the initial remote monitoring concept.

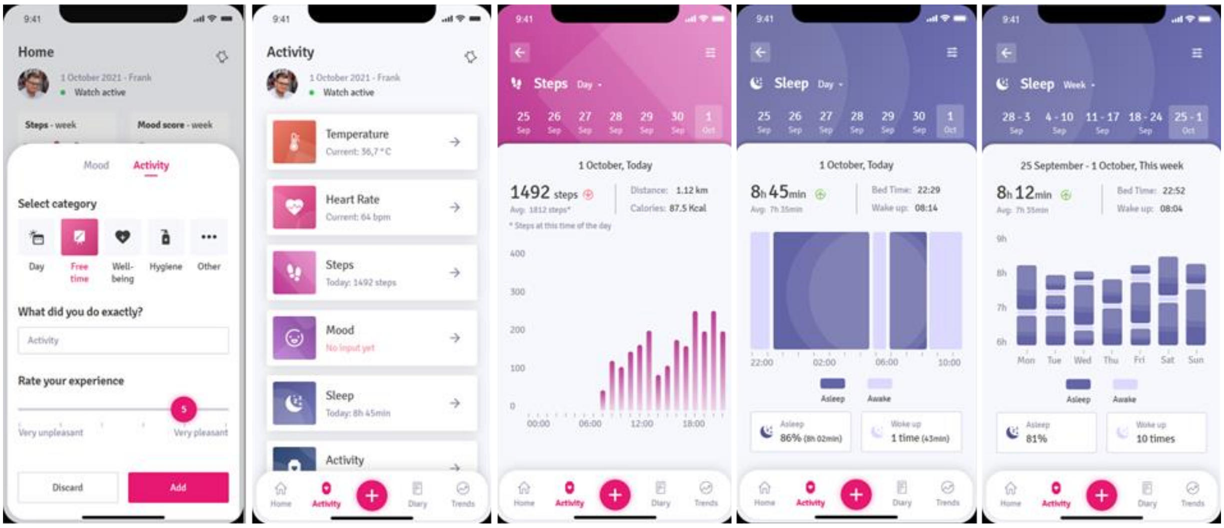
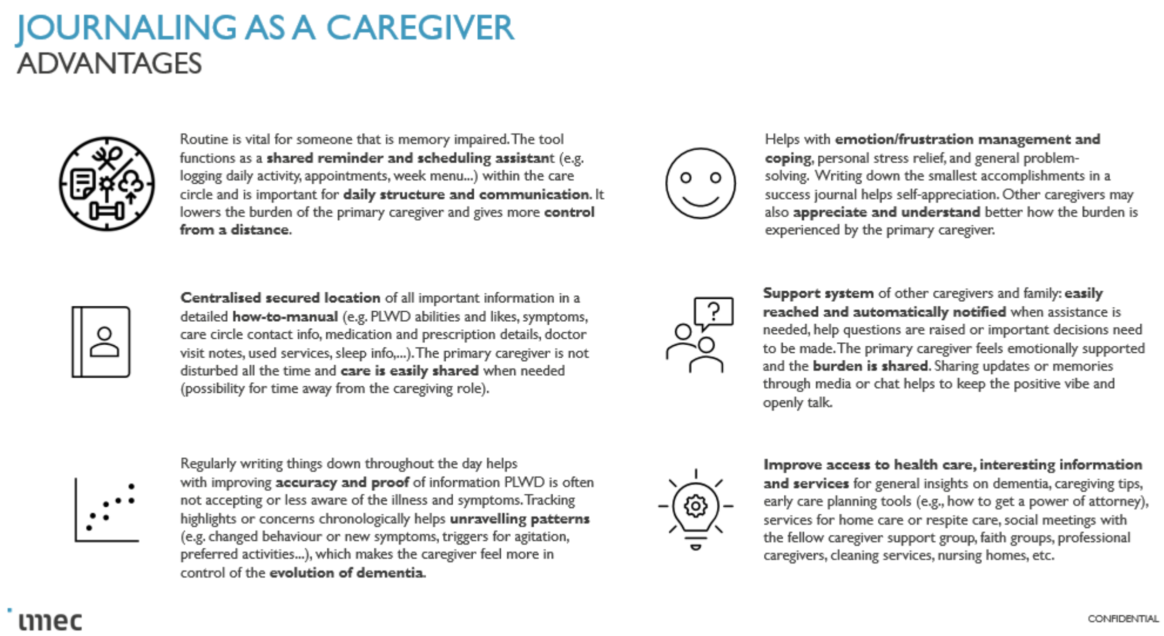


Figure A4: Wireframes illustrating the activity tracker of the initial concept.

Figure A5: Wireframes illustrating the diary feature an trends page of the initial concept.



JOURNALING AS A CAREGIVER
ADVANTAGES

Routine is vital for someone that is memory impaired. The tool functions as a **shared reminder and scheduling assistant** (e.g. logging daily activity, appointments, week menu...) within the care circle and is important for **daily structure and communication.** It lowers the burden of the primary caregiver and gives more **control from a distance.**

Helps with **emotion/frustration management and coping**, personal stress relief, and general problem-solving. Writing down the smallest accomplishments in a success journal helps self-appreciation. Other caregivers may also **appreciate and understand** better how the burden is experienced by the primary caregiver.

Centralised secured location of all important information in a detailed **how-to-manual** (e.g. PLWD abilities and likes, symptoms, care circle contact info, medication and prescription details, doctor visit notes, used services, sleep info,...). The primary caregiver is not disturbed all the time and **care is easily shared** when needed (possibility for time away from the caregiving role).

Support system of other caregivers and family: **easily reached and automatically notified** when assistance is needed, help questions are raised or important decisions need to be made. The primary caregiver feels emotionally supported and the **burden is shared.** Sharing updates or memories through media or chat helps to keep the positive vibe and openly talk.

Regularly writing things down throughout the day helps with improving **accuracy and proof** of information PLWD is often not accepting or less aware of the illness and symptoms. Tracking highlights or concerns chronologically helps **unravelling patterns** (e.g. changed behaviour or new symptoms, triggers for agitation, preferred activities...), which makes the caregiver feel more in control of the **evolution of dementia.**

Improve access to health care, interesting information and services for general insights on dementia, caregiving tips, early care planning tools (e.g., how to get a power of attorney), services for home care or respite care, social meetings with the fellow caregiver support group, faith groups, professional caregivers, cleaning services, nursing homes, etc.

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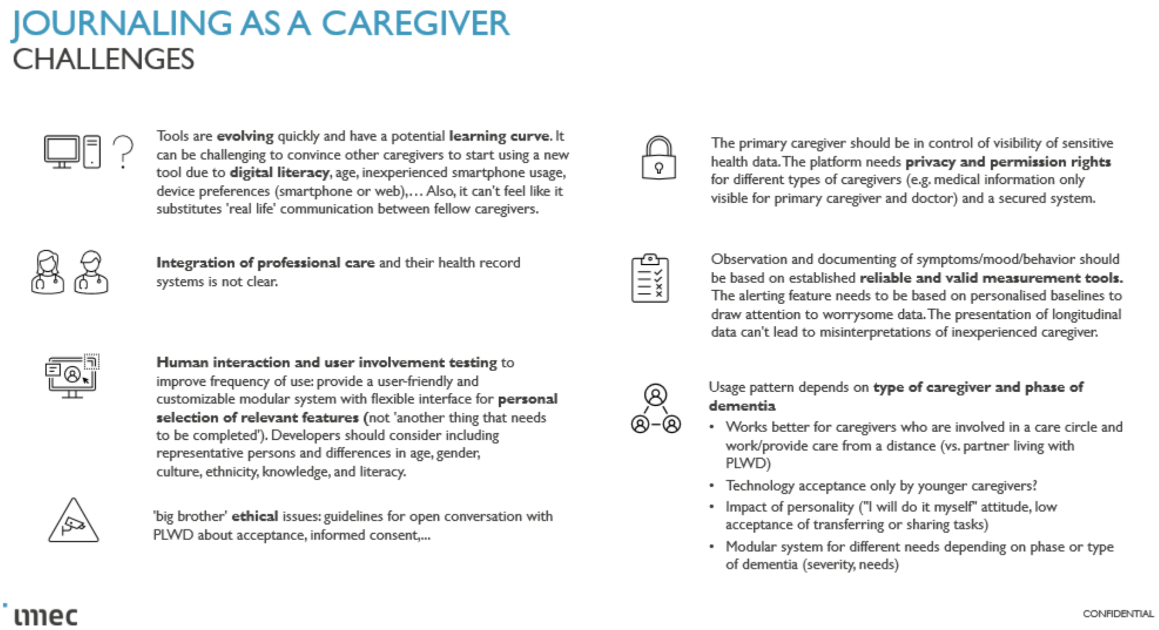
Figure A6: Figure summarizing the main advantages of journaling indicated by informal caregivers.



JOURNALING AS A CAREGIVER
CHALLENGES

Tools are **evolving** quickly and have a potential **learning curve.** It can be challenging to convince other caregivers to start using a new tool due to **digital literacy**, age, inexperienced smartphone usage, device preferences (smartphone or web),… Also, it can't feel like it substitutes 'real life' communication between fellow caregivers.

Integration of professional care and their health record systems is not clear.

Human interaction and user involvement testing to improve frequency of use: provide a user-friendly and customizable modular system with flexible interface for **personal selection of relevant features** (not 'another thing that needs to be completed'). Developers should consider including representative persons and differences in age, gender, culture, ethnicity, knowledge, and literacy.

'big brother' **ethical** issues: guidelines for open conversation with PLWD about acceptance, informed consent,...

The primary caregiver should be in control of visibility of sensitive health data. The platform needs **privacy and permission rights** for different types of caregivers (e.g. medical information only visible for primary caregiver and doctor) and a secured system.

Observation and documenting of symptoms/mood/behavior should be based on established **reliable and valid measurement tools.** The alerting feature needs to be based on personalised baselines to draw attention to worrysome data. The presentation of longitudinal data can't lead to misinterpretations of inexperienced caregiver.

Usage pattern depends on **type of caregiver and phase of dementia**
- Works better for caregivers who are involved in a care circle and work/provide care from a distance (vs. partner living with PLWD)
- Technology acceptance only by younger caregivers?
- Impact of personality ("I will do it myself" attitude, low acceptance of transferring or sharing tasks)
- Modular system for different needs depending on phase or type of dementia (severity, needs)

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Figure A7: Figure summarizing the challenges associated with a journaling task as perceived by informal caregivers.

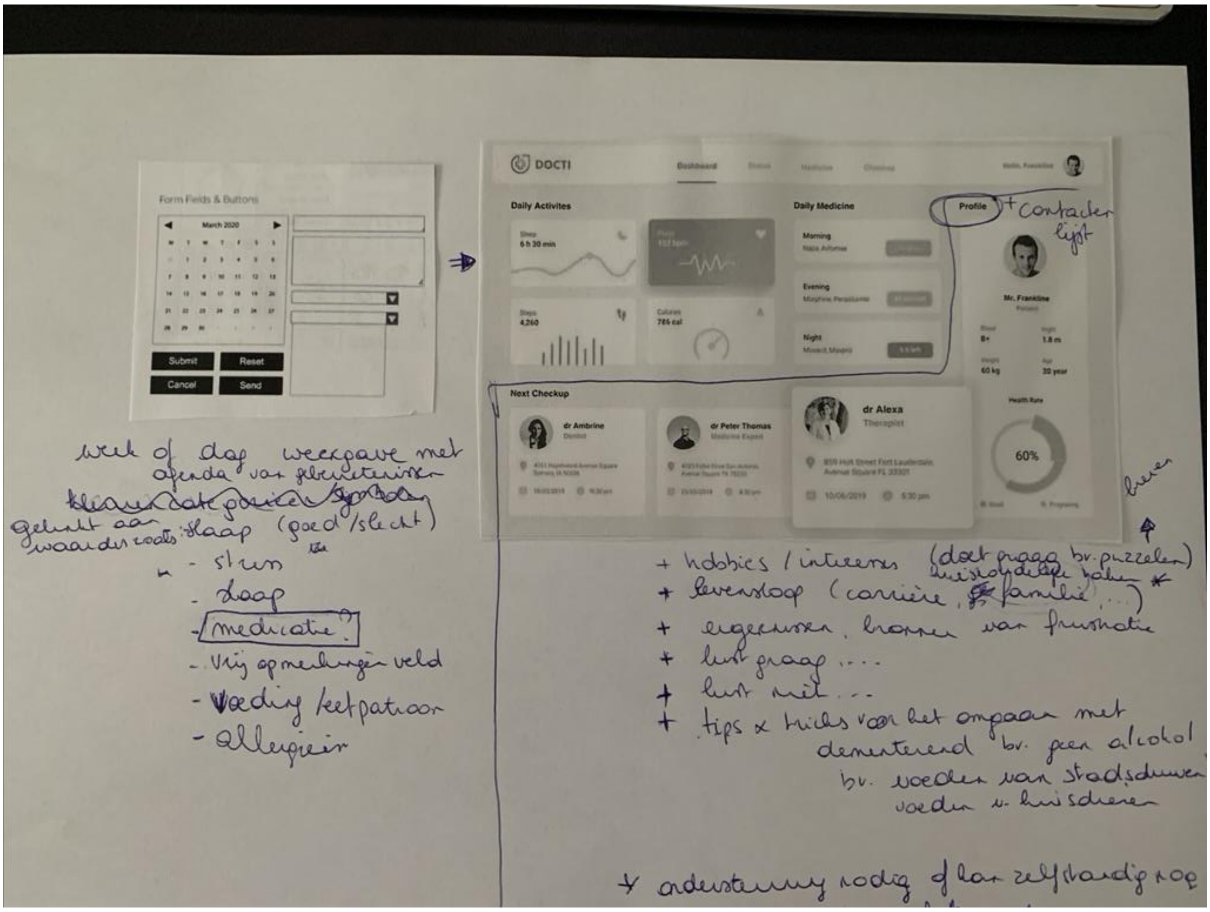
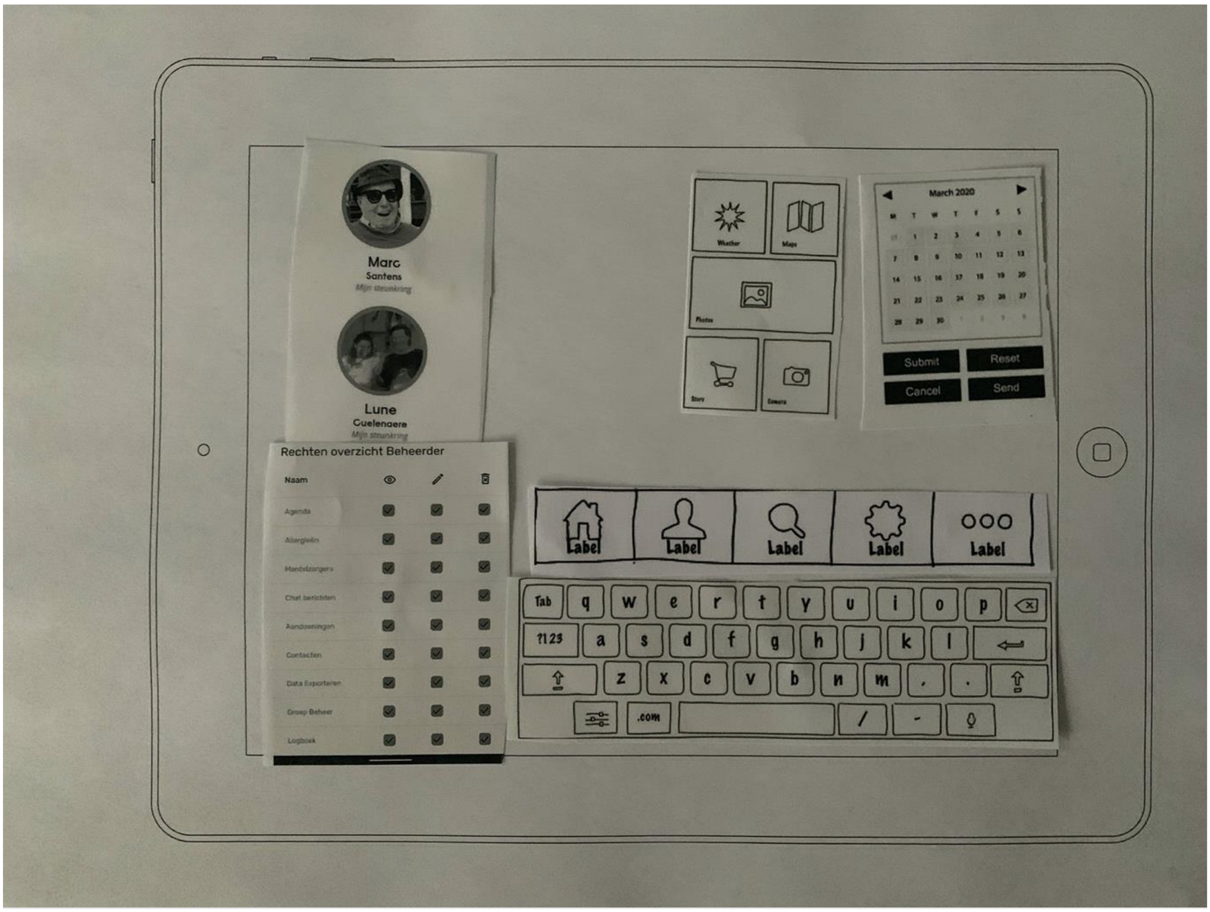


Figure A8: Mock-up of a remote monitoring platform created by family caregivers.



Rechten overzicht Beheerder

Naam	👁	✎	🗑
Agenda	☑	☑	☑
Allergieën	☑	☑	☑
Mantelzorgers	☑	☑	☑
Chat berichten	☑	☑	☑
Aandoeningen	☑	☑	☑
Contacten	☑	☑	☑
Data Exporteren	☑	☑	☑
Groep Beheer	☑	☑	☑
Logboek	☑	☑	☑

Figure A9: Mock-up of a remote monitoring platform created by voluntary caregivers.