Report
Building Block Policy Level
Led by PP2 and PP8

Contents

1. Executive summary

The overall goal of the Odense house project is to diminish the burden of informal carers of people living with dementia (PLWD) through professional and structural support of the informal carers and the use of tailor-made technological solutions. The project aims to strengthen the resilience and perseverance of the informal carers so that PLWD can stay at home longer. Within the project, the informal carer is an acknowledged main actor of effective and integrated service to PLWD.

The Odense house is continuously tailored to the needs of PLWD and their informal carers. To facilitate the adjustment to needs, the Odense house Mechelen used a combination of research, co-creation and iteration to develop a service centre adapted to the needs of PLWD and their informal carers.

Overall, five criteria need to be matched to implement the Odense house concept within your own organization. These five criteria can be found in *figure 3*. A program that consolidates and structures early information, support and recreation is needed to support informal carers. The report showcases a few examples of activities that different partners used to provide information and recreation to support informal carers. Examples of recreation activities included wood crafting sessions, singing together and a was & bronze workshop. Examples of activities for providing information and support were discussion groups for informal carers on a specific topic or family group sessions.

Besides organising physical meetings, the project also created a digital platform. The MeMo by Monument website consolidates information on dementia-friendly services and enhances exchange with peers. It has five main building blocks.
1. Information, including articles, books, videos etc.
2. Tips & Advice; including blogposts by and for informal carers
3. Technology; including blogposts about useful technology
4. Events & places; search for nearby events and interesting places for PLWD
5. Monument project; dissemination of information regarding the Monument project

In order to strengthen the resilience and perseverance of informal carers, the project also used existing assistive technology accessible in an experimental manner by enabling timely introduction and adaptation to the needs of the informal carers. For this process, we've used the steps that can be found in figure 21.

The Odense house partners tested co-creating remote monitoring technologies in an operational environment adjusted to the specific needs of the informal carer. The timeline and iterations for this process can be found in figure 23.

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2. Introduction

Dementia is a growing social problem. The WHO considers dementia the first priority. The high cost of it will challenge health systems to cope with the predicted future increase of cases. A solution lies in the socialization of care. To make this possible, informal carers are a crucial factor. However, care for PLWD is a lot more challenging than care for people without dementia. The health of informal carers suffers from this. A strong network, more knowledge, insight and skills among informal carers could make a difference in their care burden. In addition, providing respite care for dementia caregivers to engage in leisure can be a promising coping strategy. Technological applications for the service of PLWD and their informal carers exist, but are often unknown, are not developed in collaboration with informal carers and therefore not geared to their needs. Assistive technologies on the market are insufficiently accessible, without opportunity to experiment and often not introduced on time.

2.1 Overall goal

The project wants to diminish the burden of informal carers of people living with dementia by professional and structural support of the informal carers and the use of tailor-made technological solutions. The project aims to strengthen the resilience and perseverance of the informal carers so that people living with dementia can stay at home longer. The informal carer will be acknowledged as main actor of an effective and integrated service to PLWD.

2.2 Cross-border approach

The project partners face common challenges in terms of socialization of care and improving support for informal carers of PLWD. By combining knowledge and good practices, we can achieve innovative solutions and improved services in the UK, FR, BE and NL. The countries involved in the 2Seas area have built up different expertise, which offers opportunities for mutual growth and co-creation.

- NL brings expertise and experience from their implemented Odense houses. They take a leading role in this.
- UK brings valuable expertise and experience in the field of dementia-friendly communities and of barriers and specific needs for PLWD and their informal carers when accessing outdoor activities.
- BE has experience with a walk-in home preliminary process. Imec brings a broad expertise in living labs and technological innovation.
- FR has a support and respite platform for caregivers in general.

3. Main outputs

Main outputs mentioned in the application form are following:

- Pilot offering support to informal carers of PLWD based on the Odense concept, consolidating and structuring early information, support and recreation
- Digital platform by and for informal carers of PLWD, consolidating information on dementia friendly services, and enhancing exchange with peers
- Service center adapted to the needs of PLWD and their informal carers (LP)
- Demos making existing assistive technology (TRL9) accessible in an experiential manner, enabling timely introduction and adaptation to the needs
- Tests co-creating remote monitoring technologies (TRL7) in operational environment tailored to the specific needs of the informal carer of PLWD
- Site adapted to improve the use by PLWD and their informal carers, including improvements to signage

3.1 Deliverable description

D 2.3.4 building block policy level consolidates all results from WP1, WP2 and WP3, increasing accessibility, transparency and visibility of the Odense activities and model. It is a major stepping-stone as referral between professional carers and informal carers. All case studies from the pilots will be available for policy makers on the platform, in the language of the Member state, with an executive summary in three languages. All partners involved. Led by PP8 and PP2.

4. Building block policy level

The concept of an Odense house (OH) is central in this report. An OH is an information-, advice- and meeting place for people with (early) dementia, informal caregivers and their families and friends. There is room for meetings, support, activities and advice. An OH offers a voice to people with dementia and informal caregivers. It is a safe place in the heart of their own local community where they can feel 'at home'. The Information service is intended for a broad range of interested target groups.

In the activities of work package 3, pilot partners namely Norfolk County Council (the UK), The National Trust for places of Historic Interest of Natural Beauty (the UK), City of Mechelen (BE) where learning from VWO Zorg (the Netherlands) what the OH concept means and how to implement it in their own regions. The MONUMENT project team gathered in the OH Walcheren (figure 1) and the values of the Odense house concept were explained (figures 2 and 3).

Figure 1: MONUMENT project learning from OH Walcheren
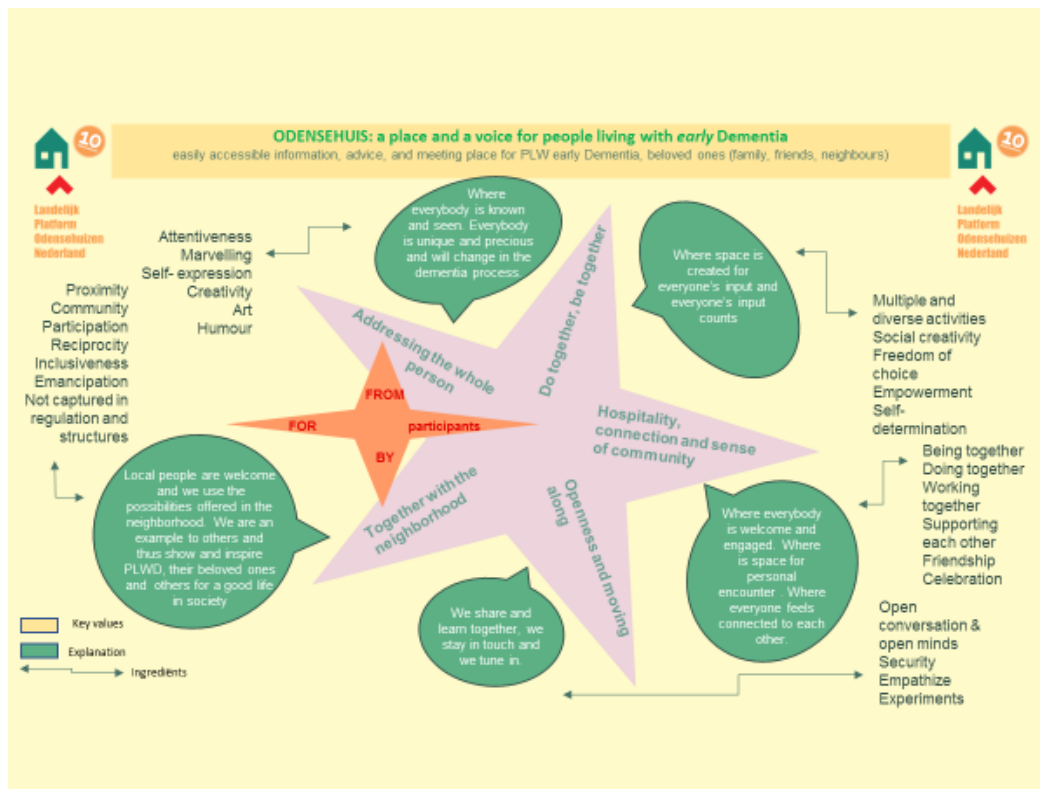
Figure 2: Values Odense house (1)
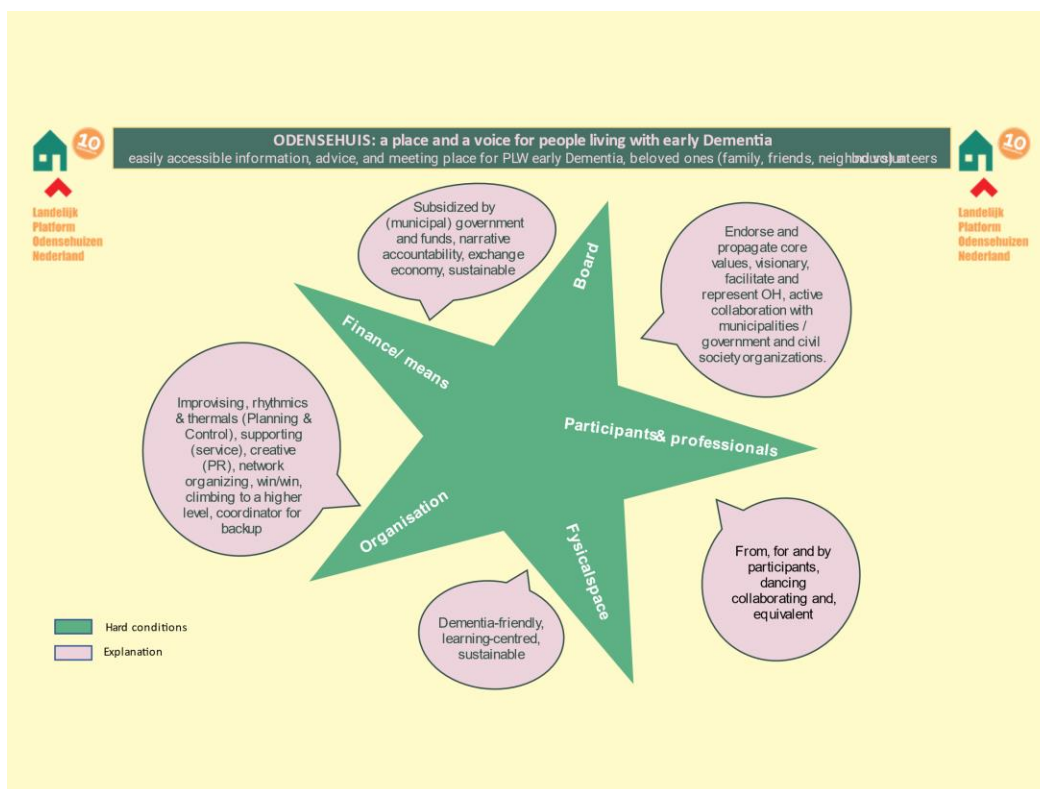
Figure 3: Values Odense house (2)

The Odense house Walcheren has two separate locations with different kinds of activities. The first location is located near the city center. Exercise activities, creative activities and cooking activities are organized at this location (figure 4, 5 and 6).

Figure 4: Exercise activities in the Odense house Walcheren

Figure 5: Creative activities in the Odense house Walcheren

Figure 6: Cooking activities in the Odense house Walcheren

The second location is located near a kitchen garden and is called "Het Tuinhuis" ("The Garden shed"). People living with dementia are encouraged to start their own kitchen garden. The project team also visited this location (figure 7, 8 &9).

Figure 7: "Tuinhuis Walcheren" (1)

Figure 8: "Tuinhuis Walcheren" (2)

Figure 9: "Tuinhuis Walcheren" (3)

5. Pilot offering support to informal carers

After pilot partners have learned about the concept of the OH, different kind of activities were introduced in pilot regions. In this chapter, a few examples of these activities will be discussed.

Story of City of Mechelen

With various activities, we ensure that caregivers and people with (young) dementia experience beautiful NOW moments.

Figure 10: OH Mechelen singing

We have organized moments for people living with dementia and their carers to sing together (figure 10). The project is called 'I will always hear you'. Because singing together connects. Singing together connects and makes people with dementia more active. It appeals to their abilities in a positive way. And you do not have to be a singing talent.

Figure 11: OH Mechelen Was & Bronze workshop

During the Was & Bronze workshop, our carers and people with dementia worked together with wax. We asked them to create moments that they enjoy. All these small scenes were immortalized in a bronze artwork (figure 11).

The Family Groups on Dementia and Young Dementia bring together family members and carers of people with dementia in a friendly atmosphere where they exchange information, experiences and support (figure 12).

Figure 12: OH Mechelen family groups

The discussion café is a meeting place for fellow sufferers where, through a variety of topics, you can learn to understand what dementia is and what it means for the person facing this condition. The discussion café is aimed at family members, carers and people living with dementia. It is a moment where information about dementia is shared with others. For more information click on the link.

www.mechelen.be/tmonument-inloophuis

Story of AFEJI

Our Odense House proposes one activity per week. A first meeting with the informal caregivers took place in March as a coffee moment. The aim of the activity was to present MONUMENT and the future Odense House. During the activities, we let the informal caregivers discuss about their needs: they used post-its and images to put on a screen that represented the Odense House. Activities, sharing, relaxing, a place to connect with people, moral and physical support, these are the activities of what the informal caregivers would like to find in the Odense House.

In May, a presentation to the Hypnosis project that is supported by the University of Lille took place for couples in which one of the partners has Alzheimer's disease. Some outdoor activities are organized too: in June, a visit of a beehive will be organized and nature walks to connect with the nature.

Cultural activities such as the Odense House decoration are planned, and karaoke time for the music festival.

Story of Norfolk County Council

Norfolk's pilot focuses on delivering the Odense Huis model to specifically help overcome barriers preventing people living with dementia and their carers from accessing quality outdoor activities. Informed by Focus Groups, our Outreach Officers worked with local

support groups such as Norfolk Museum Services' Community Culture Club and Libraries to trial activities and strengthen the local network. These indoor peer support sessions were ideal for the colder months.

Carers joined scoping visits to sites such as Shallowbrook lakes and geocaching in suburban green spaces (figure 13). The scoping visits increased our understanding of carer and PLWD priorities, from a need for a pan-disability perspective, fears of open water to the joy of hands-on activities. These initial outings with carers and PLWD informed the delivery of multiple half-day leisure activities at the Nancy Oldfield Trust on the waterways of Norfolk.

Carers and PLWD also tested the accessible self-drive tour at the wildlife park Watatunga across 170 acres of parkland on varied terrain. Two woodcraft sessions were also trialled at Strumpshaw Fen hosted by enablers from The Green Light Trust (figure 14). Prior to the leisure events, site staff attend NCC's formal training 'Pathways into Nature' to aid their preparation and awareness for how to support carers and those living with dementia.

Figure 13: Wildlife park Watatunga

Figure 14: Woodcraft session

Our aim has been to model equitable outdoors access and shared learning that promotes peer support and wellbeing for carers, which provided many reflective learning opportunities for all.

The culmination of this learning will be showcased and celebrated with our local MONUMENT friends and stakeholder at Family Day in June 2022. Our reflective practice will be applied into delivering enhanced accessibility and enrichment within the outdoor green spaces at Gressenhall Farm & Workhouse.

6. Digital platform by and for informal carers of PLWD

Within the Monument project, we had the ambition to extend the services of the Odense houses online, into a platform that should become the digital backbone of the Odense pilots. In the beginning of the project, the project partners discussed about the different building blocks of the platform and how they should look like. Based on these discussions, wireframes were sketched by a designer to communicate about the scope of the platform towards the project partners but also to receive some feedback from informal carers. After some iterations on the designs, the website was built.

The digital platform MeMo by Monument is a website made by and for informal caregivers of people living with dementia. For informal carers it is often hard to find reliable and up-to-date information on living with dementia in one place. That is why within the Monument project a multilingual digital platform for France, Flanders, the United Kingdom and the Netherlands was created.

The website structure

MeMo by Monument consolidates information on dementia friendly services and enhances exchange with peers. The platform brings together relevant information in five building blocks (figure 15):

- The 'Info, support & education' building block is a collection of links to interesting articles, books, videos, courses, organizations, etc. Hereby MeMo by Monument wants to gather existing information rather than creating new information. Based on the tag words used, informal carers can see other possible interesting links to the topic they were searching for.
- The 'Tips & advice' building block was designed to share (small) blogposts by and for informal carers. More concretely, by sharing advice to one another via blogposts, we aim to support informal carers on a variety of topics. In the first stage of the website, blogposts will be created together with the Odense houses to reduce the burden and threshold for informal carers.
- The 'Technology' building block was designed the same way as the 'Tips and advice' section with the main difference that all blogposts within the building block should focus on the use of technology tailored to informal carers.
- In the 'Events & places' building block, you can find a map on which you can search for nearby events and interesting places specifically tailored to informal carers and people living with dementia.
- Finally, the 'Monument' building block was built to disseminate information regarding the Monument project, its outcomes and the different Odense houses. Whereas the previous building block focus on informal caregiver, the first focus of this building block is towards local stakeholders and policymakers.
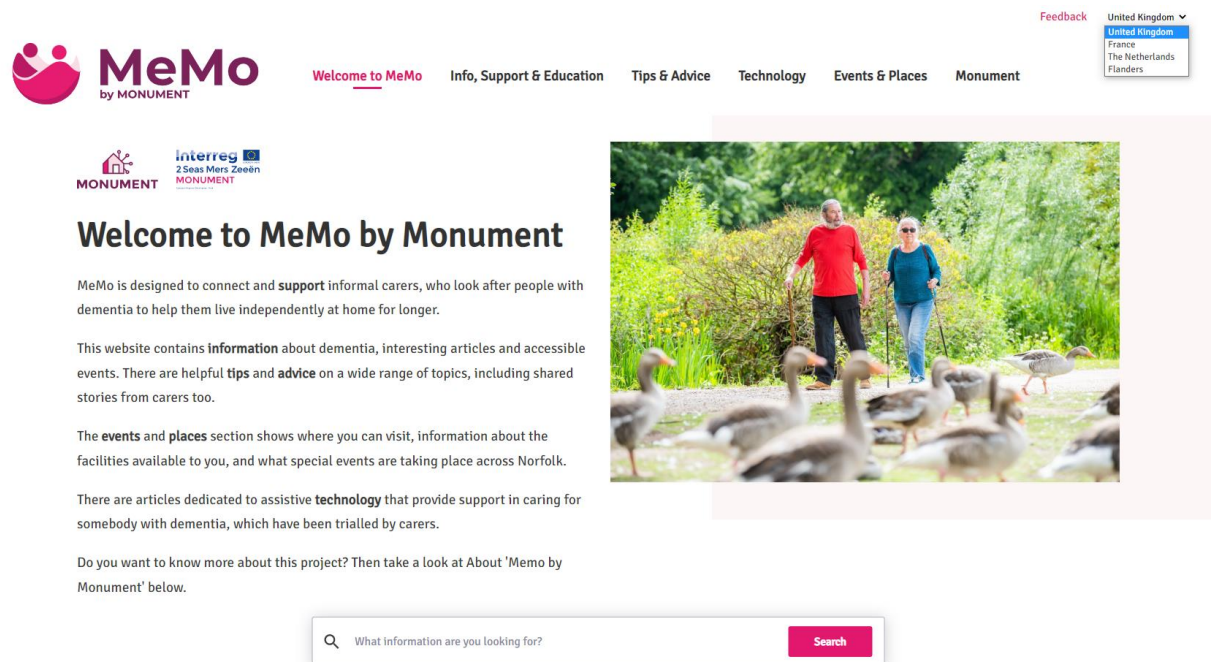
Figure 15: Web structure MEMO platform

In the 'Tips & advice' and 'Technology' sections the platform encourages caregivers to get in touch with their local pilot and to create blogposts in which they can give tips and advice on general topics and on technology in specific.

On the Home page of the platform, you can find a generic search bar. This search function can be used to search for content over the entire platform. It also allows you to search for content related to specific tag words.

Every region has its own URL, however, if you want to go on Holidays to France and want to see events or activities tailored to informal carers and persons with dementia, you can easily navigate and search the other regions websites as well.

Governance of the MeMo by Monument platform

The website is built in such a way that different organizations can add content to the website. Each region (or URL) has one administrator organization. This organization is responsible for adding general information to the website. Next to this, the administrator organization can add other organizations to their backend environment, so that they can add content related to 'info, support & education', 'Tips & advice', 'Technology' and 'Events & places'. Every organization with the right to add content on the platform can allocate roles to its users as 'super admin', 'editor' and 'user'. The 'Super admin' can invite new users, can edit content and can publish content. The 'Content editor' can edit content and publish content. The 'Authors' can write content but cannot publish it. This governance structure was set up to make the platform future proof if other Odense houses want to be involved on the website as well. Next to this, organizations can add super-users to help them write content, whilst the Odense houses still have a gatekeeping function to maintain quality and objectivity on the website.

URL:

- Flanders: www.memo-monument.be
- The Netherlands: www.memo-monument.nl
- France: www.memo-monument.fr
- The United Kingdom: www.memo-monument.co.uk

7. Service center adapted to the needs of PLWD and their informal carers (LP)

The city of Mechelen set up a collaboration with the PhD students Interior Design from Thomas More in order to fully adapt the Odense house to the needs of the PLWD and their informal carers.

Through various workshops and an iterative process of feedback from the informal carers and the PLWD, the PhD students created a design, followed up the tendering of various parties and did the follow up on-site.

Figure 16. Research

Figure 17. Co-creation

Figure 18. Iteration

One of the main insights was that the space should be as serene as possible, with not too many distractions, patterns, posters, etc. as the space is already full of people and activities.

These various activities are split up into two zones in the design: an active (white in figure 19) and a quieter zone (yellow in figure 19).
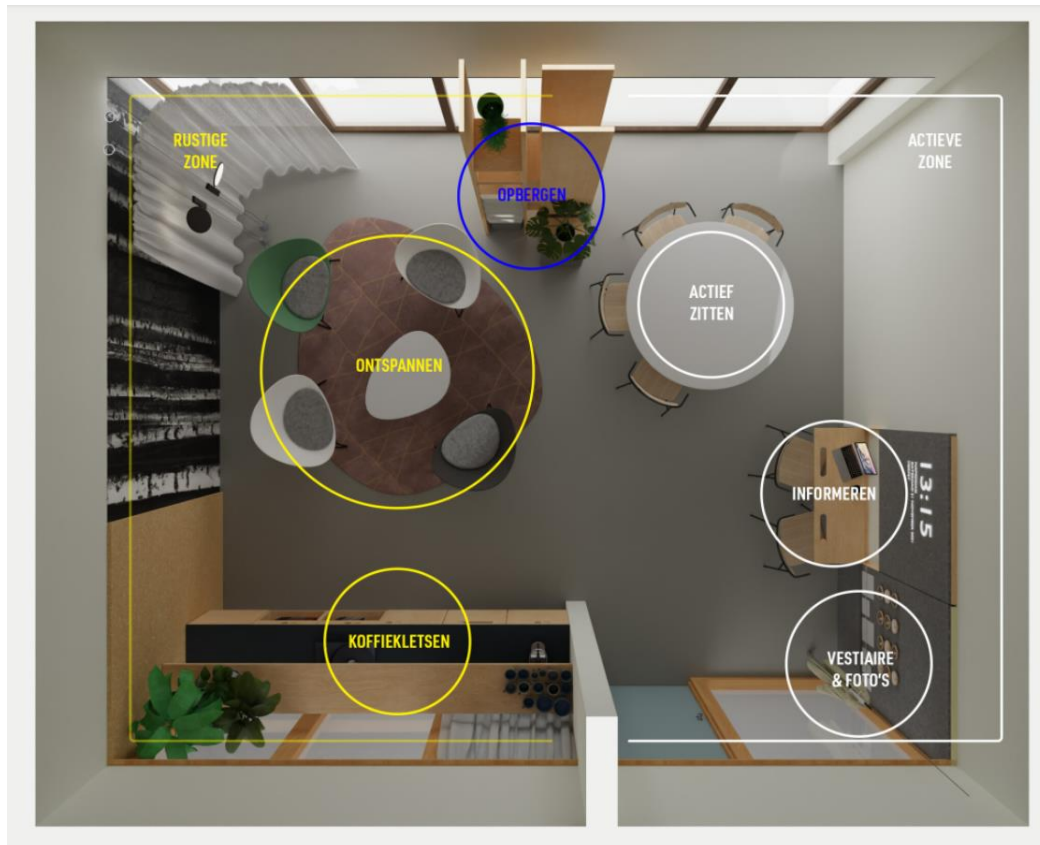
Figure 19: Layout OH Mechelen

The works carried out are the following:

1. Remove wall between two smaller rooms
2. Redo the flooring
3. Install photo wall
4. Install custom furniture in the room
5. Fix lighting, electricity and smart TV
6. Install curtains
7. Insert furniture.

The parts of the process where the PLWD and their informal carers have been most involved, is the initiation phase, expressing their needs and thus defining the design. Secondly, they have also been closely involved in the selection of the furniture, giving input on colors, feedback, design and sometimes even testing some of the pieces (figure 20). The link to the original 3D design video: https://youtu.be/lj8bo3Kvonk

Figure 20: Design OH Mechelen

8. Demos making existing assistive technology (TRL9) accessible in an experiential manner, enabling timely introduction and adaptation to the needs

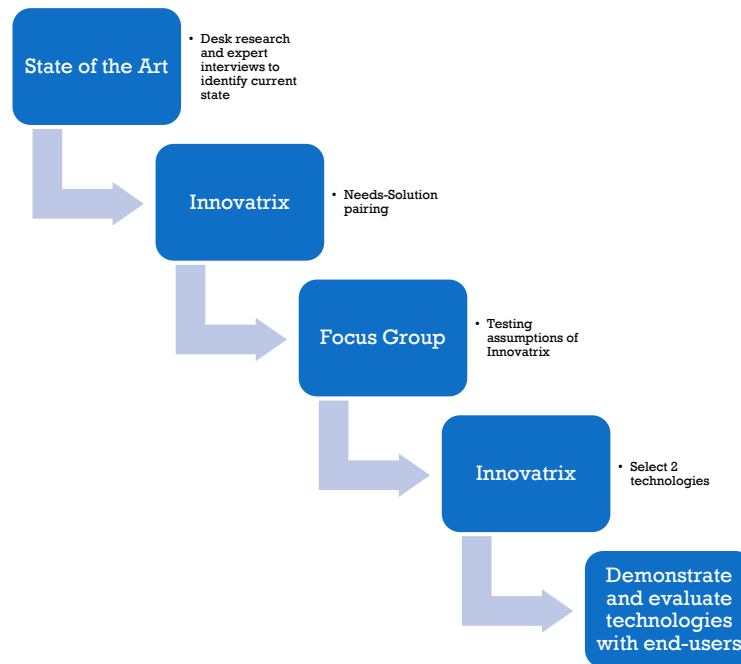The process we followed is outlined below in figure 21

Figure 21: Followed process for making existing assistive technology accessible

At the beginning stages of the Monument project, we performed a state of the art of existing assistive technologies for caregivers and people living with dementia. A state of the art is done by doing desk research. This means looking at existing outcomes of studies, literature, etc. You bundle the information you find so that you can leverage from existing data and you avoid reinventing the wheel. Expert interviews where then performed, meaning we asked experts in the domain of dementia and existing assistive technologies, to evaluate whether we were missing anything in our overview. Everything was bundled in a PowerPoint, referred to as state of the art.

According to our desk research and expert interviews 5 types of technologies were identified that can benefit both the informal caregiver and the PLWD, namely technologies focusing on (1) daily living, (2) safety, (3) telecare, (4) engagement, social participation & leisure as well as (5) resilience. For an overview, we refer to our State of the Art document as a deliverable. Assistive technologies are beneficial to informal carers as they lower the burden of the informal carer, allow them to 'let go' for a moment and/or connect with the PLWD. Overall, the attitudes towards the technologies from an informal carer perspective are positive, yet the uptake of these technologies is low. The main reasons for this can be a lack of awareness, the

fact that they do not cover the needs properly (the delivered value is too low) or the barriers to adopt the technologies are too high.

To identify the mismatch, we filled in the Innovatrix framework per pilot to map different technologies on the needs of the informal carers. This helped the pilots to on the one hand identify whom they wanted to demonstrate the technologies in their Odense house, which needs they were experiencing and how they are currently trying to solve those needs. Additionally they had to think about potential existing technologies (solutions) that could solve these needs and which value those technologies can bring to the users, compared to alternative ways of coping with their needs. Aside from the perspective of the end-users, the Odense pilots also had to think what goal they wanted to accomplish by providing these technologies to the end-users (value capture) and whom they want to collaborate with to be successful. An example of the Innovatrix framework is provided below (figure 22).

INNOVATRIX

GOAL: MAP YOUR ASSUMPTIONS & INDICATE YOUR 5 KEY ASSUMPTIONS

imec

CUSTOMER SEGMENT		What customer segments to focus on? What are key characteristics? What is the use-context?	
NEEDS		What are the needs of the customer segment? How do we prioritize these needs?	
CURRENT PRACTICES		Who or what are competitors, alternatives, customer behavior? What are the pains and gains of these current practices?	
VALUE PROPOSITION		What (measurable) impact will you create for this customer segment?	
SOLUTION		What are the components of your (digital) solution? How do these components differ for the different customer segments?	
KEY PARTNERS		Who are your key partners? How to interact with stakeholders?	
VALUE CAPTURE		What value (monetary and non-monetary) do I receive in return? What price should I set (and how)?	
BARRIERS		What are the barriers for adoption, usage and market entry?	

#1   Source: imec.livinglabs   IVTx Link INNOVATRIX

Figure 22: Example Innovatrix framework

The unknowns were marked as assumptions in the online Innovatrix tool (https://open.innovatrix.be/public/apply/Open%20Innovatrix) so the pilots could validate them with end-users. The assumptions served as input for the topic guide, a list of questions,

to be checked with the end-users. Each pilot organized a focus group with informal carers to validate whether they were on the right track to select their technologies. Based on the outcomes of the focus group, the board was updated; assumptions were validated, invalidated and iterated upon. The outcome was two selected technologies to be demonstrated in each pilot Odense House.

These technologies will then be tested with end-users and feedback will be provided to the supplier in order to further improve technologies so they meet the needs of users accordingly.

9. Tests co-creating remote monitoring technologies (TRL7) in operational environment tailored to the specific needs of the informal carer of PLWD

Involving users in the innovation process is nothing new. The earliest phase in which a user can be engaged is when generating innovative ideas in order to develop new concepts. This is to mainly get a first indication of the needs and wants of users and potential ideas for later use cases. In a first phase of developing a new prototype, we started from the state of art (as described in 6.5). What is currently known about the needs and wants of informal carers, and which technologies try to tackle these needs as well as where are there existing gaps. This was done by doing desk research complemented with expert interviews. We mainly looked at the current state of resilience reduction of informal carers of PLWD. Which carers are experiencing most issues with their resilience and which circumstances trigger the resilience being under pressure? Informal carers that live together with the PLWD are most stressed out. There are four situations leading to less resilience for which no solutions exist today.

1) A lack of sleep because the PLWD starts wandering at night, becomes aggressive, etc.
2) Constantly being worried about the safety of PLWD when not being around
3) Not being able to connect with the PLWD anymore
4) Constantly having to show PLWD how to perform (complex) tasks and 'entertain' them.

Based on these four categories, we created four concepts, which we evaluated with end-users, namely the informal carers during several interviews. Seven caregivers were involved in Flanders. This process was repeated in the different pilots to iterate gradually on the concept and define the requirements of the prototype. Nine iterations took place with end users. For an overview of the iterations, we refer to the picture below (figure 23).
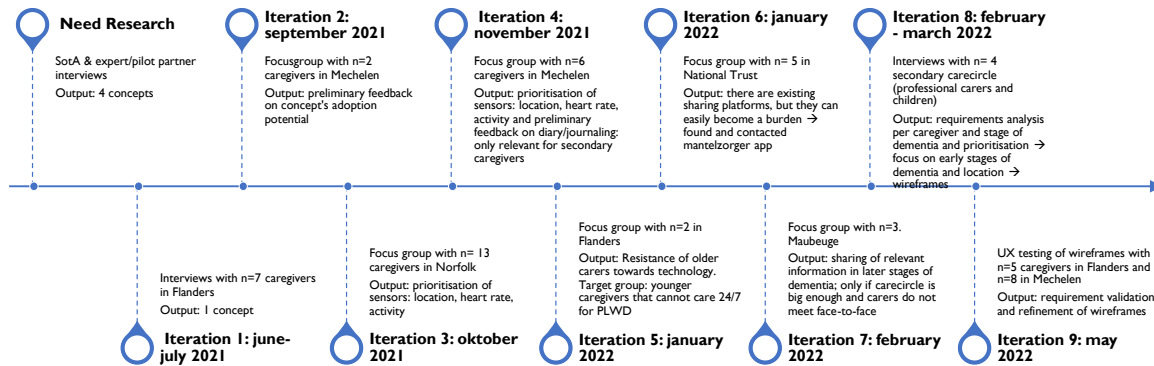
Timeline and iterations

Need Research

SotA & expert/pilot partner interviews

Output: 4 concepts

Iteration 2: september 2021

Focusgroup with n=2 caregivers in Mechelen

Output: preliminary feedback on concept's adoption potential

Iteration 4: november 2021

Focus group with n=6 caregivers in Mechelen

Output: prioritisation of sensors: location, heart rate, activity and preliminary feedback on diary/journaling: only relevant for secondary caregivers

Iteration 6: january 2022

Focus group with n= 5 in National Trust

Output: there are existing sharing platforms, but they can easily become a burden → found and contacted mantelzorger app

Iteration 8: february - march 2022

Interviews with n= 4 secondary carecircle (professional carers and children)

Output: requirements analysis per caregiver and stage of dementia and prioritisation → focus on early stages of dementia and location → wireframes

Interviews with n=7 caregivers in Flanders

Output: 1 concept

Iteration 1: june-july 2021

Focus group with n= 13 caregivers in Norfolk

Output: prioritisation of sensors: location, heart rate, activity

Iteration 3: oktober 2021

Focus group with n=2 in Flanders

Output: Resistance of older carers towards technology. Target group: younger caregivers that cannot care 24/7 for PLWD

Iteration 5: january 2022

Focus group with n=3. Maubeuge

Output: sharing of relevant information in later stages of dementia; only if carecircle is big enough and carers do not meet face-to-face

Iteration 7: february 2022

UX testing of wireframes with n=5 caregivers in Flanders and n=8 in Mechelen

Output: requirement validation and refinement of wireframes

Iteration 9: may 2022

Figure 23: Timeline and iterations

The evolution from concept to prototype with end-users is visualized below in figure 24

The Monument Concept

Frank is 55 years old and was diagnosed with **Young Onset Dementia** two years ago. His wife Annick (522 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.
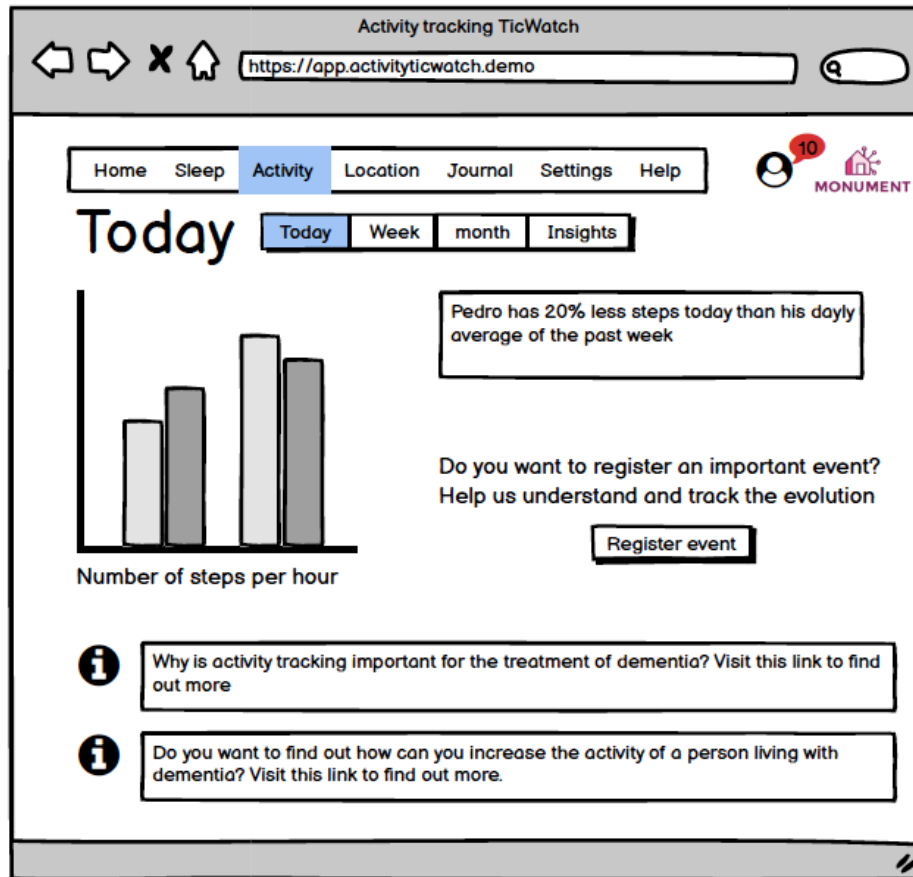
Figure 24: Concept, personas with storyline

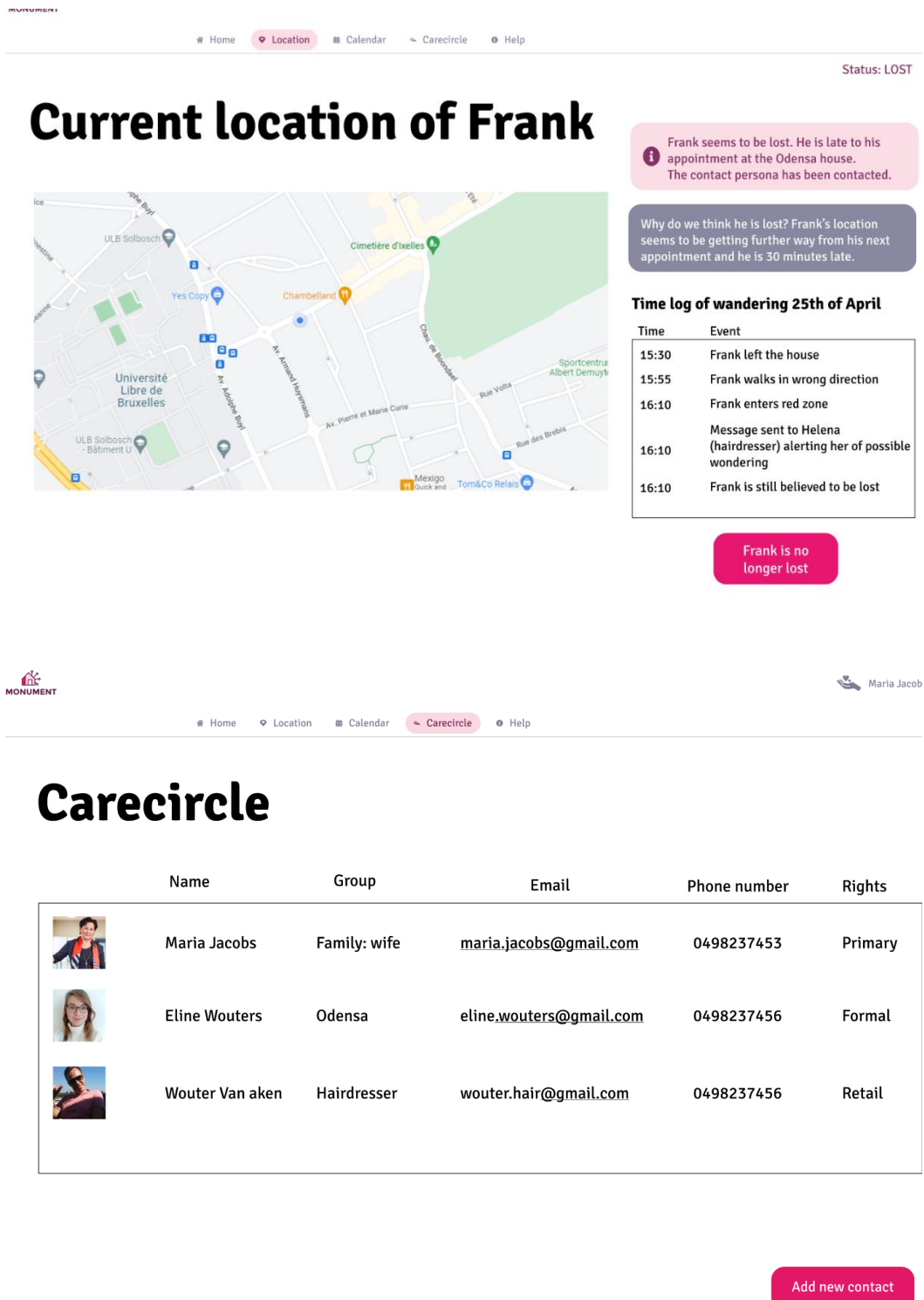*Figure 25: Digital wireframes*

Figure 26: Clickable wireframes

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<u>Challenges and tips for involving informal carers</u>

As caregivers are experiencing problems with their resilience as mentioned above, this made it challenging to involve them in the project. We collaborated with different organizations (Odense pilots, Alzheimer liga, Expertise centrum voor Dementie, local cities organizing support groups, etc.) and our own network to recruit caregivers. The best approach was to become part of already organized initiatives and use some of their time slots to evaluate and iterate on the prototype. During the first year of the project, this was not possible as everything was cancelled due to the Covid-19 pandemic. During the second year, we were able to benefit more from this approach. For future projects that want to involve informal caregivers, it will be important to have a good understanding and collaborative agreement with organizations that are immediately connected to these caregivers and organize activities.

10.   Site adapted to improve the use by PLWD and their informal carers, including improvements to signage

All of the adaptations to the Reed Barn have been completed based on a dementia audit we conducted in October 2021. New lighting has been added replacing the old which now provides dimmable natural imitation lighting which is a vast improvement to the previous lighting. The space has also been transformed with new furniture to give it a much more homely and comfortable feeling for its users. Pictures on the wall have given reminiscence resources for those attending the service. The toilets have been painted with paper towel dispensers added to help those who find the hand air dryers too loud and upsetting. Exit signs have also been placed on the toilet. Additional signage in the garden is being drawn up a supplier to ensure it meets requirement and will be placed throughout the journey and garden.
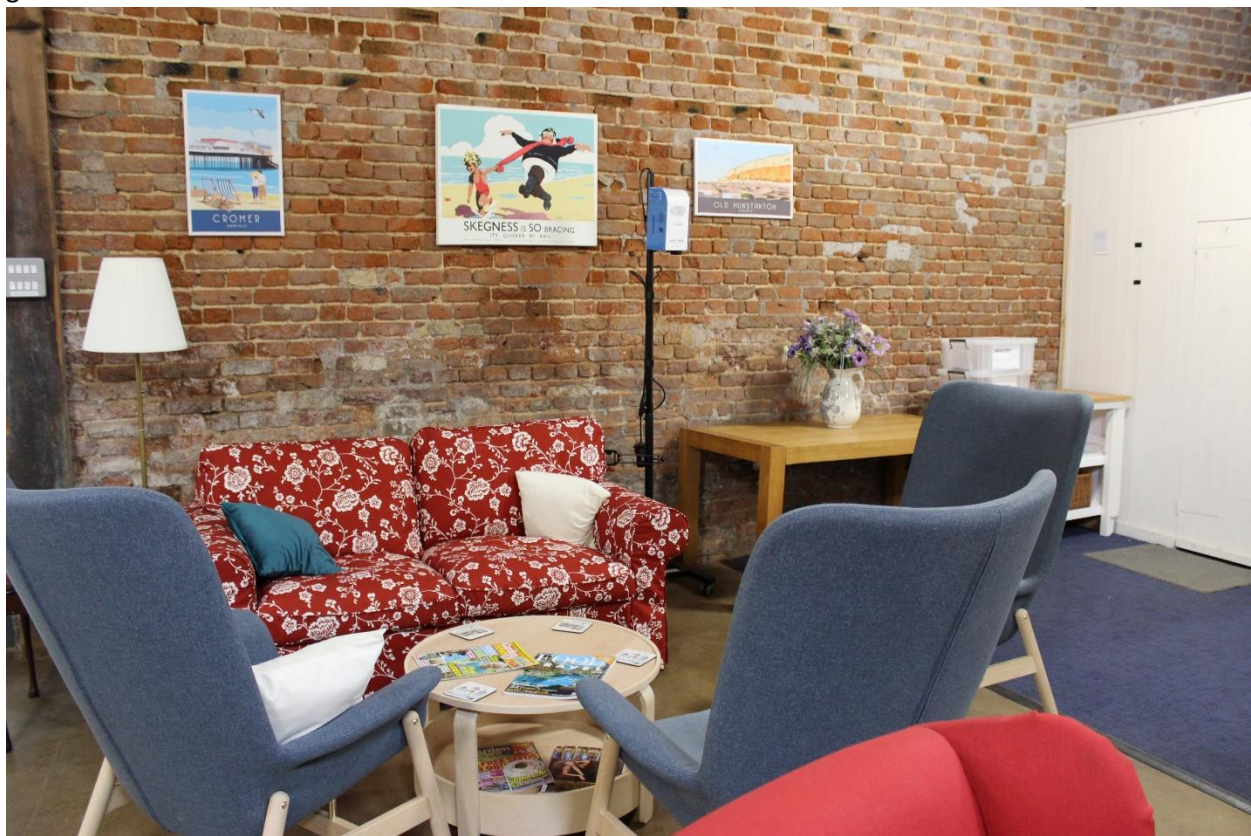

Figure 27: Odense house National Trust