

MONUMENT

*More NURturing and More Empowerment Nested in Technology
With the support of the European Regional Development Fund*

CONSOLIDATED REPORT OF 6 CROSS-BORDER LEARNING SESSIONS AND PILOT EVALUATION



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MORE Nurturing and More Empowerment Nested in Technology: A Consolidating Report of 5 Cross-border Learning Sessions

1. Pilot Sites: their context

The MONUMENT project is a cross-border project, that is active in 4 different countries: Belgium, the United Kingdom, the Netherlands and France. In each of these countries, one (or more) organizations were appointed to create and strengthen the Odense model in their region. In total, there were five organizations that worked on this Odense model: Afeji (France), Norfolk County Council (UK), The National Trust for Places of Historic Interest of Natural Beauty (UK), WVO Zorg (Netherlands) and Stad Mechelen (Belgium). The international character of the project provides a multi-layered form of information management and exchange of expertise. Each partner has their own set of skills and expertise, which they can exchange with one another to ensure that each has proper knowledge to fully develop the Odense house:

- NL (WVO Zorg) brings expertise and experience from the implemented Odense house in Walcheren.
- UK (Norfolk County Council; the National Trust) brings valuable expertise and experience in the field of dementia-friendly communities and of the specific needs and barriers of PLWD and their informal caregivers when accessing outdoor activities.
- BE (Stad Mechelen) has experience with a walk-in home preliminary process.
- FR (Afeji) has a support and respite platform for caregivers in general with its experiences from all Afeji establishments and services dedicated to the elderly.

Because of the cross-border approach, the partners are provided with enough information to create their own Odense house. However, this cross-border approach, as well as the difference in expertise, implies differences in the context of each pilot site and therefore also the set-up of the Odense house. In this part of the report we will go over the different pilot sites, their context and what makes them special.

AFEJI:

Afeji is a French organization that supports inclusion in society from early infancy to old age. The organisation has more than 60 years of experience working with different vulnerable groups in Hauts-de-France region, including aging people and people living with dementia (PLWD). Afeji has gradually extended its formal offer to caregivers through platforms and services dedicated to their specific needs. Through its 110 structures and services, its aim is to ensure people retain as much independence as possible. Their Maison Odense is located in the North of France (Hautmont) and linked to the retirement home Les Tilleuls (Maubeuge area). The rural location of the site poses a real challenge for Afeji. They wanted to include nature in their Odense house, but encountered some difficulties in doing so. Being part of the MONUMENT project is a way to fill this gap and offer reliable support for care in this particular area. Additionally, Afeji focuses on strengthening links between local stakeholders in a rural area and the public and can be seen as a 'third place' which is defined by social interaction, conviviality, and engagement with the local community.

Norfolk County Council:

The difference with the other pilot sites is the setting and scope of the Norfolk Odense House. The project in Norfolk has taken place over multiple locations with the central focus being the rural Gressenhall museum. Not only do they have a countryside setting where the PLWD and caregivers can walk around and enjoy nature, they also have a big museum, a heritage farm, and a café. Their main goal is to enable informal caregivers and PLWD to have better and more comfortable access to the outdoors.

The National Trust:

The National Trust is a conservation organization that wants to conserve and provide visitor experiences at all of their sites. Because dementia cases are predicted to rise greatly in the next few years, the National Trust wants to invest in dementia-friendly spaces. For them the focus is on outdoor spaces that allow easy access to fresh air and exercise, since providing these spaces can improve the wellbeing of people living with dementia and their caregivers. This organization does not have any form of prior knowledge of dementia. Because they are not a dementia-care organization, much of the information they have, or need, is scattered. Therefore, they see the MONUMENT project as a learning opportunity. Though they are not dementia oriented, the National Trust has expertise in aspects that appear valuable in the project as well.

WVO Zorg:

WVO Zorg works closely with Odense House Walcheren. They have their own open-walk-in facility for people with early onset dementia. They already have expertise in providing support to people with dementia and their informal caregivers. Together with Odensehuis Walcheren, they want to increase the connection in the region and promote cooperation between informal caregivers. WVO Zorg and Odensehuis Walcheren offer a trusted place where PLWD can be themselves and where they, together with their informal caregivers, can go for a friendly chat, meaningful activities and mutual support.

Stad Mechelen:

Stad Mechelen is the Lead Partner in this project. They oversee the organization and management of all the partners. In Mechelen a strong base is already established. They have a walk-in centre dementia in place, where they inform and guide PLWD and in particular their informal caregivers to the right service. They have a strong network of care providers and a very thorough understanding of the needs of informal caregivers of people living with dementia. The MONUMENT project offered a supporting framework to dot the I's and cross the t's on their Odense house. The most important message they try to convey is to normalize dementia and informal care, to open up the conversation and reduce the taboo informal caregivers experience.

2. Comparison - regularities and difference

Firstly, as presented above there are great differences between the various pilot sites in terms of context. Some already have a broad frame to fall back on, others have to start from nothing. Depending on the context the organizations situate themselves in, there are clear differences in their general strategies and aims for the project. For example, the organizations that are located in a rural setting are generally more focused on including the outdoors in their project (e.g. the National Trust, Norfolk City Council and Afeji). The organizations that are embedded in a larger network also make greater use of the communication tools they already have at their disposal (e.g. Stad Mechelen and The National Trust). These aspects, and more make the application of the project in each pilot site different. There were varying strengths, outside priorities and challenges, meaning the lessons learnt by each pilot site also differed. In the part that follows, we will clarify some of these differences, explain the different approaches to the project and the different focusses brought about by these varying approaches.

To give a proper overview of what the pilot sites did differently, the following part of the text is divided into two parts. Firstly, we will give an overview of what the pilots believe to be the most important goal and focus of an Odense house, and what makes their Odense house a little different. We will also briefly go over the infrastructure of the Odense House and what the general elements in each Odense House are. Secondly, the focus will shift to the different approaches each pilot site has taken in terms of communication, management and technology.

2.1. The Odense House: goals, target group, etc.

Depending on the context they are in, the goal of the Odense houses can differ greatly. Organizations like Afeji and Stad Mechelen view the Odense house as a place of guidance.

For them it is a tool to help people find the right person, organization, etc. for their specific issue. It is a place where information is bundled. Informal caregivers and PLWD can come to the Odense house to find the correct information and support or are redirected to fitting services. Additionally, the setting of the pilot sites gives a different interpretation to the Odense house, for example in the more rural sites (like Afeji, National Trust and Norfolk County Council) the focus lies on strengthening the bonds with nature. To explore how to help caregivers and PLWD to have better access to outdoor spaces. Furthermore, for Odensehuis Walcheren the Odense houses greatest goal is “connection”: the Odense house serves as a space for personal encounter, where everyone feels connected to each other.

The workings of the Odense house also differ depending on the target group. All organizations focus on both informal caregiver and PLWD, however the emphasis sometimes varies. For the informal caregiver, the aim of the Odense House is to help them form a network with and uncover new information from their peers. The Odense house helps caregivers “to create social links in an informal setting . . . and provide respite for carers and their relatives” (Afeji).

“Connectivity is key” (Norfolk City Council).

By learning from each other, the caregivers can help one another in their daily activities and find some form of relief from their daily duties. However, oftentimes the focus on the caregiver creates difficulties. Informal caregivers already have a lot on their plate. Therefore, it is very difficult to engage the informal caregiver and convince them to give up some of their free time to come to the Odense house. Rather, they want to take that time for themselves. For the person living with dementia, the main focus is on the activities in the Odense house. Here, the focus is on the importance of outdoor activities, cultural activities, etc. Though all pilots put some emphasis on these activities, from the interviews it appeared some found these more important than others. When focusing on the PLWD, pilots like WVO Zorg emphasize the importance of co-creating activities with the PLWD, in order to flaunt their talents and find activities that are best suited to the people and best fit their interests. Furthermore, all Odense houses want to support the PLWD (and their caregivers) by creating a dementia-friendly environment. There are two aspects that are important in that respect: interior design and technology.

Firstly, Stad Mechelen and The National Trust created a dementia-friendly environment by adjusting the furniture and site in order to perfectly align the needs of the PLWD. E.g. Stad Mechelen: their Odense house is based in a local service centre. Which promotes a close connection with their neighbourhood and neighbours. Because of this close connection, informal caregiver and PLWD experience less difficulties to integrate. They also added assistive technology tailored to the needs of the informal caregivers and PLWD in the house, that can be used in home situations.

Additionally, all pilots use technology to support both informal caregiver and PLWD in their daily activities. Each pilot approaches this quite differently. In some pilot sites, like at Stad Mechelen, Odensehuis Walcheren or Afeji, the Odense house serves as a demonstration house, where the visitors can discover technology in a casual way. Informal caregivers can borrow the technology for a short period of time, to make sure it provides a solution to their specific situation, before purchasing it themselves. For others, the technology is mostly supportive in their Odense house. It adds to the experience. The visitors can test it at the Odense house, but it is not meant to take home or use at home. Some examples of the technologies that were used are: the nobi lamp, a magic board, a scooter for outdoor activities, le cousin VIKTOR, the hypnos mask (for the informal caregiver), and many more.

2.2. Approach: general approach, communication strategies, technology

In this part of the report, we will discuss the different approaches the pilots uses to give rise to the Odense house, this entails the general approach to the project, their communication strategies and the use of their technologies.

General Approach

The approaches that each pilot site uses, vary greatly. However, there is a general structure that seeps through the entire project. The project is organized in phases, that each have their specific goals and approaches, to eventually generate a final product of great quality. Although these phases are approximately the same for all the pilot sites, they develop differently in each. Every pilot site finds itself in a different phase, because of certain difficulties they encountered or advantages they received. There are various aspects that can cause these difficulties and advantages:

1) **Cultural context:** How does one look at care in the region? What constitutes informal care? How does care differ in each country? How does one value informal care? etc.

E.g.: In France, there is still a lot of taboo on the topic of dementia, which is less tangible in the other countries. The focus remains on the medical aspect. Conversations on this topic are mostly confined to the family sphere. Additionally, people who are confronted with this disease find it difficult to seek external support. This might explain why Afeji encountered more difficulties than other pilot sites to communicate to and reach the informal caregiver and PLWD.

2) **Context:** the type of organization, the resources and the networks that surround the pilots vary greatly. The absence of, for example, an existing network can result in great differences in approaches of the pilot site (e.g. the approaches on communication). The starting point of the pilot sites (i.e. the network, their expertise, etc.) forms an important base for the rest of the project.

E.g. - advantages: Stad Mechelen and the National Trust already have a great network for marketing, communication, etc. and Stad Mechelen and WVO Zorg already have previous knowledge on how to organize, structure, etc. an Odense house.

E.g. - burden: The National Trust has little to no past experience with dementia and how to work with PLWD. This made the trajectory more challenging. Additionally, the scale of the National Trust as an organisation can cause communication to be very slow.

3) **General approaches to the project:** When looking at the general approach to the project, there are various subcategories that can be distinguished: 1) planning/structure; 2) activities; 3) partnerships. How each partner approaches these categories determines their position in the project, i.e. which phase, as well as which difficulties they encountered.

1. Planning/structure: In order to stay on top of the project and ensure everything is finished right on schedule, it is advisable to make a strong and strict action plan. This action plan should include a clear and accurate communication plan, all agenda items, agreements on who will do what (you, external partners, others), milestones, deadlines, etc.. When strictly following this plan, the pilot should normally be able to complete the project without too many difficulties. Without creating this action plan, various things can go wrong. Nevertheless, unforeseen circumstances can always deter previous plans. For example, throughout this project we suffered the COVID19 pandemic, which was tangible in every pilot site. Due to the COVID restrictions the strict schedules all crumbled down. Many of the pilot sites suffered delays because of the crisis. Additionally, this crisis caused severe issues for the pilot sites who did not yet have an existing Odense house in place.

E.g. - good practices: Stad Mechelen was very quick in this entire process, because they had a very strong action plan. They divided the tasks and set very strict deadlines already early on in the project.

2. Activities: One very important aspect of the Odense houses are the activities that are organized. These should be tailored to the specific needs and interests of the target group. In this small sub-category, we will list some tips or must-do's to ensure qualitative activities for PLWD and their caregivers.

- Try to ensure co-creation of the activities between caregiver/PLWD and the volunteers at the Odense House.

- Try to include a variety of activities: cultural, leisure, outdoor, etc. and ensure some variation in the activities, so as to find activities that touch upon the interests of the majority. *For example: In Odense House Walcheren the PLWD and informal caregivers regularly visit museums.*
- When communicating and organizing your activities try to maintain a structured set-up, i.e. the same location for meet-ups, the same volunteers, etc. This keeps everything clear for the other person/the group.
- Try to find partners that can help implement and create these activities or help with the project in general. *For example: WVO Zorg has a partnership with two observer partners that help organize the activities for PLWD and informal caregivers, these activities are custom-made for their participants, and fit their needs perfectly.*

3) Partnership: throughout the entirety of the project it is always useful to have a strong partnership with other institutions in the region. This helps strengthen the connectivity in the region and offers great help in setting up the Odense House.

E.g.: WVO Zorg has a close partnership with Odensehuis Walcheren. This partnership allows them to use each other's network. There are also short lines of communication with local observer partners, allowing access to their experience/knowledge of the target group and a range of activities.

E.g.: For Afeji, the partnership with the town of Hautmont has had a real impact in reaching out to caregivers and volunteers and in general in including the Odense House in the local community.

However, being dependent on a partner organization can also be a burden. *For example: WVO Zorg suffered some communicative difficulties with Odensehuis Walcheren, causing delays in decision making.* Additionally, things like bankruptcy of the partner, terminating support, etc. can create strenuous situations. Thus, though it can be helpful, you should be cautious when working closely together with an external partner.

In this part we have described all the approaches one could/should take to create a fully functioning, well-structured and welcoming Odense house. Whether you follow these suggestions or not, will determine the pace at which you bring this project to an end.

Communication Strategies

As previously mentioned, having an action plan is essential to bring this project to a satisfactory ending. One key component of any action plan is a clear view on a communication strategy. In this part we will summarize which elements from the approaches seem helpful in order to form a proper communication plan, and whether there are considerations particular to the pilot sites in terms of communication.

What seemed to be very helpful for some of the pilot sites was the presence of a larger network/infrastructure to fall back on. The National Trust, Stad Mechelen and Odensehuis Walcheren (partner of WVO Zorg) each have a strong network for communication: existing connections with radio and television contacts for interviews, previous experiences and their own communication channels. These pilots are well-orientated to communicate externally to large swathes of the public via press releases, media interviews, etc. Additionally, some of the pilot sites (the National Trust and Norfolk County Council) also actively tried to involve the community of PLWD via engaging with local partnerships and existing organizations of PLWD as well as direct communication towards this community. Furthermore, Norfolk County Council also engaged PLWD and in particular their informal caregivers through organising small informal care peer-support sessions and leisure activities. These sessions/activities provided a considerable contact list of caregivers, which they used to communicate and advertise through. This supported the more transient model of their particular Odense pilot. For further publicity many of the pilots used social media marketing, however this was mostly oriented towards the younger informal caregivers. For older caregivers, word of mouth worked best. According to Norfolk County Council, this tactic appeared to be the most powerful in their

communication plan. Furthermore, publicity work was also done in communal spaces, like libraries, cafés, government buildings, etc. Approaching people in daily life activities (like in markets, town hall, local ships, etc.) proved very useful in order to convince those caregivers who did not yet dare to come (Afeji).

By focusing on a variety of different communication methods rather than just relying on one mechanism, many partners were successful in reaching the informal caregivers and PLWD. However, many still faced communication challenges when it came to encouraging informal caregivers to actively take part in the setting up of the Odense house.

Technology

For most of the pilot sites (like Afeji, WVO Zorg, the National Trust, among others) the introduction of technology was an area of difficulty. Most of the pilot partners ascribe this to a lack of interest from PLWD and their caregivers. Additionally, they indicate that the older demographic and the fact that the participants are no digital natives causes the pilot sites to struggle with technology in various aspects, i.e. to reach them digitally (social media, e-mail, etc.) and to enable them to engage with technology at the Odense house (and potentially improve their quality of life). However, although it brings many difficulties, most of the pilot sites do believe that technology is an important factor to consider when wanting to strengthen the wellbeing of the informal caregiver and the PLWD. During the interviews, all partners did indicate the importance of “the how”. When wanting to introduce technology in the lives of the caregiver and the PLWD you should always address the value of technology in their lives: How can it add to their lives? How can it help with daily activities? How can it ease the everyday struggles they encounter? To do so, the Odense house could offer an unthreatening and supportive introduction and network in terms of technology. One could offer assistance just by having the technology at the Odense house. The presence of the technology could reduce some of the barriers. This is because the PLWD and informal caregiver can engage with the technology in a supportive and familiar setting with reassurance available. Additionally, it could also evoke curiosity. Because the MONUMENT project includes technology as one of its outputs, the pilot partners were obliged to introduce technology in their Odense house. Though it was not an easy task to do, it did turn out to be very helpful for the target group.

3. Conclusion

The goal of the MONUMENT-project is to create an Odense house in various cultural settings. During this project, there were strict goals that were set by Interreg. However, even though these goals are rather strict, every pilot site has created an Odense house that is specific to their situation. The context of the pilot sites has caused the final product to differ quite significantly in each location. This is visible in the various goals the pilots ascribe to their specific Odense house (e.g. engage with nature, be a source of information, offer peer-support, recognition, etc.), the different emphasis on who composes the target group, the different ways in which they approach this project, as well as the different difficulties they have encountered along the way.

Throughout this report, we have described the ways in which the pilot sites were similar or entirely different. In this concluding part, we will describe how these differences resulted in a variety of difficulties. To end this paper, we will present the lessons-learned as described by the partners.

Firstly, this project brought its share of difficulties for all the partners. Each partner had their strengths and weaknesses that came to the forefront during this project. For organization like Afeji, the biggest issues were found when carrying out their communication strategy. For some time, they really struggled to reach the informal caregivers. And, like many other pilot partners, after reaching the informal caregiver it was very hard to engage them to take part in the Odense house. This was largely due to the fact that in rural France, talking about dementia is not an easy thing to do, and even less so when it involves opening up to volunteers and not health professionals. Additionally,

for WVO Zorg the context in which they started (i.e. close partners with Odense House Walcheren) posed some difficulties. Since they already had a strong network and a lot of knowledge on the matter, they found the project to be restrictive and at times even confusing. For them, the very strict structure of the MONUMENT project (deliverables, WP, etc.) made it hard to remain true to their notion of the Odense house principles. Furthermore, in Norfolk, they experienced a lot of difficulties working with the informal caregivers. Not only did this appear to be a problem for Norfolk County Council, but almost every pilot partner struggled to draw the informal caregiver to the project. Oftentimes, the cause of this difficulty was the caregiver's fear of leaving the safety of their home., which was also strengthened by the COVID19 pandemic. The partners tried to adjust the site to fit these fears by for example finding qualified volunteers to help in the Odense house. Moreover, Stad Mechelen and the National Trust explained that the greatest difficulty they encountered was finding volunteers for their Odense house. Lastly, for many partners, especially those who had to create their Odense house from scratch, the different phases of development were greatly hindered due to the COVID19 pandemic. Not only did the pandemic cause issues in the infrastructural development (creating, renting and renovating the site) of the pilot site, but also the functional aspect (i.e. reaching the informal caregiver, engaging the informal caregiver and PLWD, finding volunteers, etc.) was greatly hindered.

Thus, every context brought about its difficulties. Therefore, the MONUMENT project, as perfectly described by the National Trust, should be approached as: "a huge learning experience" (The National Trust).

Furthermore, the difficulties the pilot partners experienced, brought about many new opportunities to learn. In this final part I will present the lessons-learnt and the most important take away messages:

1) Communication is key. That means:

- When working with people in a vulnerable situation one should always communicate consistently. There should be consistency in the message, consistency in the medium, consistency throughout the entire project.
- When trying to reach the target group one should always communicate clearly. As mentioned above that means consistently, but also persistently. Reaching the target group takes time, but you should keep trying. If you try hard and long enough, people will come.

2) Work with the people's interests/lives. When engaging the informal caregivers and PLWD or trying to draw them to the Odense house you must be sensitive to their context and their individual situations.

3) Form a network with strong and reliable partners. Partners can add expertise where it might still be missing.

4) You cannot remove caregivers from their responsibilities! Instead, offer moral support and enable them to manage their time.

- Actively engaging the informal caregiver in the Odense house can be a long stretch. Start by welcoming them and offering support, so they can find some relief. Even for just a moment.

5) Supporting the caregiver in their care-task makes them feel less isolated. Try to strengthen the informal caregivers in their care activities by offering them a wide array of supportive resources such as creating a peer-network, offering training sessions, inclusive person-centred activities and the opportunity to try out new technologies in a familiar environment.

6) You have to do your best given the circumstance. Work with what you have got. Does your situation pose difficulties, then you have to work around them. Fit your Odense house

to your situation as best as you can, but do not lose sight of your main goal, i.e. creating a supportive structure that meets the needs of the PLWD and the informal caregiver.

7) Replace shame with recognition: by allowing caregivers to form a network at the Odense house, and allowing them to talk freely about their lives as an informal caregiver. The Odense house creates a non-judgmental, welcoming space where open discussion is encouraged, and new networks can be formed, both formal and informal. This will enable taboos about informal care and dementia to be broken and instead replaced by feelings of recognition and connection.