



Social-Economic Feasibility Study on the Odense Concept for MONUMENT

**MOre NUrturing and More Empowerment
Nested in Technology**

 **UNIVERSITY**
OF APPLIED SCIENCES



Lectoraat
HEALTHY REGION



Interreg 
EUROPEAN UNION
2 Seas Mers Zeeën
MONUMENT

European Regional Development Fund

Hogeschool Zeeland:

Tim van den Broeke Msc.
Dr. Kalina Mikolajczak-Degrauwe
Mareike Millner Msc.
Dr. Ingrid Snijders

Probis:

Justien Desmet
Johan D'Haene

Date: 3 March, 2023

Table of Content

Part I Social Feasibility Study

1. Introduction	6
1.1 Project partners	6
1.2 Aim	7
1.3 Reading Guide	7
2. Methods	9
2.1 Quantitative research – Surveys	10
2.1.1 Coding	10
2.1.2 Data collection	11
2.1.3 Data Management	11
2.1.4 Data Analyses	12
2.2 Qualitative research – Focus groups	12
2.2.1 Data collection and instructions	12
2.2.2 Data Management	12
2.2.3 Data Analyses	12
3. Results	13
3.1 Surveys	13
3.1.1 Sample description	13
3.1.2 Findings	13
3.1.3 Additional post-test findings	16
3.2 Focus groups	20
3.2.1 Sample descriptions	20
3.2.2 Findings	21

Part II Financial Feasibility Study

4. Financial Feasibility Study	27
4.1 Context	27
4.2 Method	27
4.2.1 Variability of opportunity costs	28
4.2.2 Variability residential care costs	29
4.3 Results	30
4.3.1 Opportunity costs	32
4.3.2 Residential care	35
4.3.3 Incremental cost of residential care vs. living at home with supported informal care	36
4.3.4 Long-term incremental cost	37
4.4 Considerations	38

Part III Discussion

5. Discussion	40
5.1 Limitations	40
5.2 Recommendations	41
5.3 Conclusion	42
6. References	43
7. Appendices	45
Appendix A: Questionnaire items	46
Appendix B: Informal caregivers focus group questions	47
Appendix C: Informed consent	48
Appendix D: MeMo results quantitative part	49
Appendix E: Background information qualitative analyses	51
Appendix F: COVID-19 impact on data gathering	53

Part I

Social Feasibility Study Evaluation of knowledge and skills, and resilience of informal carers

By

**HZ University of Applied Sciences
Research Group Healthy Region**

1 Introduction

“The aging of the population and the increasing costs of health services make it important to investigate the benefits for older people”

(Gagliardi & Piccini, 2019)

Among older people, dementia is a growing societal problem. The World Health Organisation considers dementia the number one priority (WHO, 2022). Its high costs are challenging for health systems to cope with the expected future increase in cases. As Wortmann (2012) stated: “Alzheimer’s disease and other dementias have a huge impact on the people with the disease and their families.” One solution lies in the socialisation of care where family caregivers are playing a crucial role. However, informal caregivers of persons with dementia have an increased risk of facing social isolation and burden of care (Dam et al., 2019). The health of informal caregivers suffers as a result. A strong network, more knowledge, insight, and skills among informal caregivers can make a difference in their care of burden. Moreover, technological applications might be serving for persons living with dementia and their informal caregivers. However, they are often unknown, or not developed in collaboration with informal caregivers, and therefore not tailored to their needs. Tools on the market are not sufficiently accessible, cannot be experimented with, and are often not introduced in a timely manner.

Recent studies (e.g., Dequanter et al., 2022; Øksnebjerg et al., 2020), point out that assistive technology is essential for supporting people living with dementia. As Øksnebjerg et al., 2020 stated, “there is a growing awareness of the benefits of user involvement in the design and test of these technologies and the need to identifying applicable and effective methods for implementations” (p. 937). Dequanter and colleagues (2022) also stress that technology offers opportunities to support older adults with the aim to stay independent and socially connected.

Socialisation of care and the use of technology in supporting care for people living with dementia have been tackled in the current MONUMENT project. This has been done by implementing the concept of Odense House in several EU regions (see below for more information) and enabling use of variety of technological innovations at their premises. The impact and results of these social and technological innovations have been monitored by the HZ University of Applied Sciences and are discussed in the current report.

1.1 Project partners

Twelve partners from Belgium (BE), the Netherlands (NL), France (FR) and the United Kingdom (UK) worked together to achieve one common goal, which is to increase the resilience and empowerment of informal caregivers so that people living with dementia can continue to live at home for longer. In doing so, the informal caregiver is recognized as the key actor of effective and integrated services for people living with dementia. The project is committed to innovative, professional and structural support of the informal caregivers and the use of tailored technological solutions.

The Odense Houses in the Netherlands are one of the inspiring examples to create a new support offer in the four participating countries (BE, NL, FR and UK). A digital platform is being developed to get information

and support to people even faster and to promote a dementia-inclusive society. The emphasis is on day-to-day enjoyment and enabling a social life despite the condition.

The project partners face common challenges in socialising care and improving support for family caregivers of people living with dementia. By combining knowledge and good practice the aim was to achieve innovative solutions and improved services in the UK, FR, BE and NL. The countries involved in the 2Seas area have built up different areas of expertise, providing opportunities for mutual growth and co-creation. For instance, NL brings expertise and experience from their implemented Odense Houses. UK brings valuable expertise and experience on dementia-friendly communities and on barriers and specific needs for people living with dementia and their family caregivers in accessing outdoor activities. BE has experience in a preparatory in-home process. Imec brings broad expertise in living labs and technological innovation. The centre of expertise brings knowledge on quality health care. FR has a support and respite platform for caregivers in general (see Expertisecentrum Dementia Vlaanderen, n.d.)

The partners who were involved in the project are: Stad Mechelen (BE), Expertisecentrum Dementie Vlaanderen (BE), IMEC (BE), Norfolk County Council (UK), AFEJI (FR), University of Lille (FR), Euro Santé (FR), HZ University of Applied Sciences (NL), IDROPS (BE), The National Trust for Places of Historic Interest or Natural Beauty (UK) and WVO Zorg (NL).

1.2 Aim

The project's overall objective was to enable people living with dementia to stay at home longer by increasing informal caregivers coping their skills and improving their mutual well-being and the quality of their relationships, based on the Odense House concept.

The MONUMENT project aimed to relieve the burden of informal caregivers of people living with dementia and to provide them respite through professional and structural support. In addition, it aimed to facilitate the use of tailored technological solutions.

To do so, several initiatives were undertaken by the project partners (PP) such as offering support to informal carers of people living with dementia based on the Odense House concept, consolidating and structuring early information, support and recreation. A digital platform was formed by and for informal carers of people living with dementia, consolidating information on dementia friendly services, and enhancing exchange with peers and service centres were adapted to the needs of people living with dementia and their informal carers. A website was adapted to improve the use by people living with dementia and their informal carers, including improvements to signage.

1.3 Reading Guide

The first part of this report, *social feasibility study*, is meant to inform stakeholders about the social part of the evaluation of the MONUMENT project. The following chapters include the method approach that was used to evaluate the social impact of the Odense House concept. In the results chapter, survey findings are discussed for self-efficacy, resilience, isolation, anxiety, depression and burden of care were measured. Focus group findings include access to leisure activities, knowledge and transferable skills, reciprocity and better information.

The second part of this report consists of the *financial feasibility study*. Herein, the goal was to provide insights in how the costs of an Odense House compares to traditional care.

In the third and final part, we provide the discussion based on these feasibility studies. Obstacles and limitations are included as well as a final conclusion for the MONUMENT project's findings.

2 Methods

The evaluation was conducted with quantitative pre- and post-surveys data responses. Since not all the outcomes were not to be measured with quantitative surveys more in-depth investigation was needed parallel to the pilot surveys. Therefore, a qualitative follow-up with informal carers and people living with dementia was held via focus group discussions. The quantitative and qualitative findings complement each other, gaining a better understanding of the evaluation of knowledge and skills, and resilience of informal carers.

To do so, in the quantitative research self-efficacy, resilience, isolation, feelings of anxiety, depression and burden of care were measured based on existing validated scales. In the qualitative research, data was gathered regarding acces to leisure activities, knowledge and transferable skills, reciprocity and better information among people living with dementia and their caregivers. In Table 1.1, an overview of the concepts and measurement of the research is provided.

Table 1.1 Concepts and measurements

How	What	Measure
Quantitative Surveys	Increased self-efficacy in supporting PLWD	Ability to care (from: Adult carer quality of life questionnaire)
	Increased resilience	Resilience scale
	Decreased isolation	Support for caring (from: Adult carer quality of life questionnaire)
	Decreased feelings of anxiety	Carer well-being and support questionnaire
	Decreased states of depression	Caring stress (from: Adult carer quality of life questionnaire)
	Reduced burden of care	Caring Choice (from: Adult carer quality of life questionnaire)

How	What	Measure
Qualitative Focus Groups	Access to leisure activities	<ul style="list-style-type: none"> From your own perspective, do you think the Odense House project has made leisure activities more accessible to informal carers? Can you give examples of that? Since you joined the Odense House, has the number of your leisure activities: increased, remained the same, or decreased?
	Knowledge and transferable skills informal carer	<ul style="list-style-type: none"> Do you feel your knowledge relevant to caring for PLWD has increased, remained the same or decreased by participating in the Odense House project? Can you give examples of that? What specific knowledge did you gain? Are there any specific skills you gained by participating in the Odense House? Can you give examples
	Reciprocity between PLWD and their community	<ul style="list-style-type: none"> Do you feel that the activities of the Odense House have boosted cooperation between PLWD and the inhabitants of the surrounding community? If so in what way? Did you receive support or resources from the inhabitants of the surrounding community in any form? If so in what way?
	Better informed by peers	<ul style="list-style-type: none"> Via the Odense House, you were more in touch with other informal carers. Do you feel that you have learned something new with regard to caring for PLWD from other carers? Can you give examples of that?

Note: PLWD = People living with dementia

The first column indicates how the outcomes were measured – either by questionnaires (quantitative) or by focus groups (qualitative). The second column lists the concepts derived from the project outcomes. In the first row, for example, is the concept of self-efficacy

Ultimately, a questionnaire of 56 items was developed to measure changes in informal carers' attitudes / states / feelings (see Appendix A). The questionnaire is available in three languages, namely: English, Dutch, and French. A few COVID-19-related questions were added to account for the impact of the current situation on the results of the pilots.

2.1 Quantitative research – Surveys

The goal of the quantitative pre-test was to determine baseline of concepts under investigation (e.g., feelings of anxiety or isolation prior to the start of the pilot). In the post-test the same concepts were measured again. The main goal was to compare the results of both pre- and post-test to determine the change in attitudes/ feelings / states of informal carers due to engaging in the pilots.

2.1.1 Coding

Each respondent received a code. This code linked a person's pre- and post-tests. In this way, the precise effect of the pilot was measured with statistical analyses including:

- 1 combination of 3 random letters and 1 digit, examples ABC1, DG2B, K2EV (only known for the pilot partner!)
- 2 number assigned to the participant.

Thus, for example: 1-AB4G-1, 1- AB4G-2, 1-AB4G-3 etc.

Respondents were asked to fill in this code at the beginning of the survey, therefore it was important that they were informed about their personal code before they started filling out the survey. Pilot partners were responsible for providing respondents with the codes. This code, which was a mandatory part, was asked for in the pre-testing (survey 1, before the pilot) as well as in the post-testing (survey 2, at the end of the project). Some of the respondents remembered their code, however a lot of respondents forgot. Therefore, it was important that pilot partners kept the names and codes on their personal computer, that was password protected.

example PPX:

Name	ID number
Adam Smith	1-AB4G-1
John Johnson	1-AB4G-2
Bill Brown	1-AB4G-3
...

2.1.2 Data collection

Pre-test

Each participant had to complete the pre- and post-test. The evaluation partners provided pilot partners with the link to the survey. The pilot partner was responsible for:

- providing the code to the participants of the pilot activity,
- distributing the link to the survey among the concerned participants.

The pre-test had to be filled in before the participants started with the activity. Respondents taking part in numerous activities had to fill in the pre-test survey only once.

Post-test

After all pilot activities had taken place, a post-test was conducted. Again, the evaluation partner provided pilot partners with a link to the survey. The local partners distributed the link among the concerned group. Participants used the same code as in the pre-test, to allow comparison of the data.

2.1.3 Data Management

No personal data such as name/surname/address was gathered in the survey. Instead, each person used an individual code. The code was needed to link a person's pre- and post-tests responses to enable measuring the precise effect of the pilot without gathering respondents' personal data. While the pilot partner could link the codes with names of the respondents, the evaluation partner was only able to link the codes with answers to the survey questions. In this way the individual names were not directly linked to the information gathered from the survey data, assuring the privacy of the respondents.

Moreover, an informed consent was asked from participants at the beginning of the survey. Participation in the survey was on a voluntary basis. The respondent was allowed to stop filling out the survey at any time. After the final data collection (post-tests), the pilot partners were asked to delete the codes of the participants.

2.1.4 Data Analyses

For the quantitative part, data have been gathered by surveys. Since the number of respondents was limited, a comparison of pre- and post-test has been conducted on a sample level, and not on an individual level as hoped for. Also, for the same reason, it was not possible to conduct statistical significance tests. Therefore, all differences in analyses based on descriptive statistics must be taken with caution.

2.2 Qualitative research – Focus groups

The goal of the qualitative part for the post-focus group discussions was to gain a better understanding of how informal carers, people living with dementia, and other stakeholders' reflections. The topics included: more access to leisure activities, knowledge and transferable skills, the effects of reciprocity by a community, and helpful advice to keep better informed. The questions were asked in an interactive group setting initiating participants to talk freely with other group members. It is a valid research method to collect data, through interactive and directed discussions by a research(er)/team (see Creswell, 2003). The questions used for the focus groups in Appendix B.

2.2.1 Data collection and instructions

The focus groups with informal carers were conducted by the pilot partners. However, instructions on how to prepare, organise and conduct the focus groups were given by the evaluation partner. The guidelines to conduct the focus group discussions included practical information such as on the date, time, and location. Further recommendations were given for considering the group size of the focus group between six to ten informal carers who took part in the activities organised by the Odense House.

2.2.2 Data Management

No personal data such as name/surname/address was gathered during the focus group. Instead, each person was appointed an individual code. The participants were asked for their informed consent at the beginning of the discussion (see Appendix C), and the participation within the focus group was on a voluntary basis. Respondents were allowed to stop taking part in the discussion anytime.

2.2.3 Data Analyses

For the analyses of the focus group discussions, the first researcher summarised results according to the more access to leisure activities, increased knowledge and transferable skills of informal carer, increased reciprocity between people living with dementia and their community as well as better informed (informal tricks and tips from peers). The first and second researcher then analysed these findings separately. Several calibration sessions took place to discuss similarities and/or differences. This method of working enabled reliable and independent interpretation. Finally, the general findings were summarised and discussed to find agreement between researchers and verified with two other, objective researchers.

3 Results

In this chapter, first, the quantitative findings will be discussed by sample descriptions of the pre- and post surveys. Furthermore, a comparison of the findings between pre and post test surveys are discussed. Next, additional post-test survey findings are included. Second, the sample description of the qualitative research is presented, followed up by the findings.

3.1 Surveys

3.1.1 Sample description

The pre-test was completed by 53 individuals. Of these individuals 69.8% (37 people) were female. More than half of the respondents completed some form of higher education (41,5%) or completed a PhD 9,4%). In total 28,3% of the respondents completed some sort of further education (e.g., College certificates or apprenticeships). A minority of the respondents completed secondary education (13,2%) or had no formal qualifications (7,5%). The largest group of respondents had been in an unpaid caring role for more than 4 years (37,7%). The groups 1-2 years (26,4%) and 3-4 years (26,4%) in an unpaid caring role were the same size. Only 9,4% of the respondents were in an unpaid caring role for less than a year. In terms of location, more than half of the respondents lived in the United Kingdom (56%). Other respondents were from Belgium (43,4%). The pre-tests were conducted to gather baseline data and establish a starting point for the study.

The post-test was completed by 19 individuals. Of these individuals, 52,6% (10 people) were female. More than half of the respondents completed some sort of higher education (31,6%) or PhD (21,1%). In total 47,3% of the respondents completed secondary education. None of the respondents had no formal qualifications. Most of the respondents were in an unpaid caring role between 3-4 years (47,4%). A smaller number of respondents were in an unpaid caring role for more than 4 years (31,6%). In total 21,1% of the respondents were in an unpaid caring role for between 1-2 years and none of the respondents were in an unpaid caring role for less than a year. More than half of the respondents lived in Belgium (64,2%) while the other respondents were from the United Kingdom (36,8%).

It is important to note that the sample size for the post-test is significantly smaller than the sample size for the pre-test. This could potentially impact the validity and reliability of the study's results, as a smaller sample size can lead to greater variability and a higher risk of sampling error. It may be necessary to consider the impact of this difference in sample size when interpreting the results of the study.

3.1.2 Findings

Self-efficacy in supporting people living with dementia

The ability to care is a measure of an individual's capacity to provide care and support to others. It is an important aspect of the quality of life for adult caregivers, as it reflects their ability to fulfill their roles and responsibilities as caregivers, how they cope with the caring role and how they feel about their competency to care. This concept has been measured using the 'Ability to Care' (AtC) section of the adult care quality of life questionnaire (AC-QoL; Elwick, et al., 2010). This section consists out of five different questions on a scale of 1-4 (never to always). To determine the AtC, the underlying scores of the questions are added together. A higher value indicates better ability to care (here called self-efficacy) (Elwick, et al., 2010).

Table 3.1 Self-efficacy

	N	Minimum	Maximum	Mean	Std. Deviation
AtC pre-test	53	6,00	18,00	11,23	2,50
AtC post-test	19	8,00	20,00	13,21	2,95

In Table 3.1, the comparison of the pre-and post-test in self-efficacy can be found. There was a slight increase in self-efficacy among respondents in the post-test as compared to the pre-test, i.e., the comparison of mean scores was +1,98.

Resilience

Resilience is the ability to bounce back from adversity, stress, or challenge. It is a key factor in determining an individual's mental and emotional well-being and is often seen as a protective factor against the negative effects of stress and trauma. The Resilience Scale Questionnaire (RSQ; Wagnild & Young, 1993) is a tool used to measure an individual's level of resilience. It consists of 25 items on a scale of strongly agree to strongly disagree (5-1) that assesses an individual's ability to adapt and recover from difficult situations, as well as their confidence in their ability to handle stress. The maximum score of the scale is 125 while the lowest score possible is 25. A higher score on the RSQ indicates decreased resilience, while a lower score suggests a higher level of resilience (Fernandesa, Amaralb, & Varajãoa, 2018).

Table 3.2 Resilience

	N	Minimum	Maximum	Mean	Std. Deviation
Resilience pre-test	53	31,00	77,00	57,23	9,97
Resilience post-test	19	32,00	72,00	56,58	10,88

In Table 3.2, the comparison of the pre-and post-test in resilience can be found. The mean score of the participants in the pre and post-tests was below the average of the scale indicating a tendency to high(er) resilience. There was a slight decrease in mean score (-0,65) between the pre and post-test which indicates a slightly higher resilience.

Feelings of isolation

Isolation refers to a reduction in feelings of loneliness and social inclusion. It is an important aspect of a caregiver's quality of life. Caregivers often experience high levels of stress and burden due to their responsibilities, which can lead to feelings of isolation and disconnection from others. The Support for Caring (SfC) section of the Adult Carer Quality of Life Questionnaire (AC-QoL) measures the extent of support carers perceive that they receive, encompassing emotional, practical, and professional support. This section consists out of five different questions on a scale of 1-4 (never to always). To determine the SfC, the underlying scores of the questions are added together. A higher score on this section of the questionnaire indicates that the caregiver has a stronger network of supportive resources, which can contribute to decreased isolation and improved overall well-being (Elwick et al., 2010).

Table 3.3 Feelings of isolation

	N	Minimum	Maximum	Mean	Std. Deviation
SfC pre-test	53	6,00	18,00	11,23	2,50
SfC post-test	19	9,00	17,00	12,42	2,41

In Table 3.3, the results of the pre and post-test can be found. The mean score of the post-test was higher (1,19) indicating a stronger network of supportive resources available and therefore less feelings of isolation in comparison to the pre-test.

Feelings of anxiety

The Carer Well-being and Support Questionnaire (CWASQ; Quirk et al., 2012) is a tool used to assess the mental health and well-being of caregivers, who provide physical, emotional, or financial support to someone with a chronic illness or disability. One of the dimensions measured by the CWASQ are feelings of anxiety. This refers to a reduction in the intensity and frequency of anxious thoughts and feelings experienced by the caregiver. A caregiver with decreased feelings of anxiety may experience less stress and worry and may feel calmer and more composed in their caregiving role. Decreased feelings of anxiety can be an important indicator of overall caregiver well-being, as anxiety can have negative impacts on physical and mental health. It is important for caregivers to manage their anxiety levels and seek support, if necessary, to maintain their own well-being and effectively support the person they are caring for. The CWASQ is a questionnaire consisting of 11 items on a scale of A lot – Not at all (1-5). The higher the score, the better a carer’s well-being where the lowest score is 11 and the highest score is 55 (Quirk et al., 2012).

Table 3.4 Feelings of anxiety

	N	Minimum	Maximum	Mean	Std. Deviation
Well-being Carer pre-test	53	14,00	55,00	30,18	9,70
Well-being Carer post-test	19	14,00	55,00	33,16	10,20

In Table 3.4, the results of the pre and post-test can be found. The mean score of the post-test was higher (+2,99) indicating less feelings of anxiety and an indicator for caregiver well-being.

Depression

To measure depressive feelings among informal caregivers, the Caring Stress (CS) section of the AC-QoL questionnaire has been used. It assesses the level of stress and burden experienced by caregivers of adults with chronic health conditions or disabilities. This section consists out of five different questions on a scale of 1-4 (never to always). To determine the CS, the underlying scores of the questions must be added together. A decreased state of depression may be indicated by a lower score on this section, suggesting that the caregiver is better able to manage the demands and challenges of caring for their loved one. This may be due to a variety of factors, such as having access to adequate support and resources, feeling confident in their ability to provide care, or feeling a sense of fulfillment and meaning in their role as a caregiver. Overall, a Caring Stress section of the questionnaire may be indicative of improved quality of life and well-being for the caregiver (Elwick et al., 2010).

Table 3.5 Caring stress

	N	Minimum	Maximum	Mean	Std. Deviation
Caring Stress pre-test	53	5,00	20,00	10,60	3,07
Caring Stress post-test	19	5,00	20,00	10,37	3,64

In Table 3.5, the results of the pre and post-test can be found. The mean score of the post-test showed a minor negative difference between the pre and post-test (-0,24).

Burden of care

The Caring Choice (CC) section of the AC-QoL questionnaire is designed to assess the level of support and assistance that an individual receives in managing their daily activities and responsibilities. This includes tasks such as bathing, dressing, grooming, and managing medications. This section consists out of five different questions on a scale of 1-4 (never to always). To determine the CC, the underlying scores of the questions must be added together. A reduced burden of care refers to the extent to which an individual can complete these tasks with minimal assistance or support and is an important indicator of the individual's overall quality of life and autonomy. Higher scores indicate higher burden of care and suggest the need for additional support or intervention to improve their quality of life and manage their care while low scores indicate that the individual can manage their care needs effectively (Elwick et al., 2010).

Table 3.6 Burden of care

	N	Minimum	Maximum	Mean	Std. Deviation
Caring Choice pre-test	53	5,00	20,00	11,58	3,91
Caring Choice post-test	19	5,00	20,00	11,89	3,87

In Table 3.6, the results of the pre and post-test can be found. The mean score of the post-test showed a minor positive difference between the pre and post-test findings (+0,31).

3.1.3 Additional post-test findings

Measuring additional post-test findings is important to provide more insight into how often informal carers have used the Odense House during the period that they participated in the pilot. Besides, a more comprehensive understanding of the impact of the MONUMENT project in relation to technology was questioned.

Training sessions

To determine how many training sessions were organised by one of the Odense Houses, a questionnaire was send out to participants.

Table 3.7 Training sessions followed at the Odense House

	Frequency	Percent
0 sessions	6	31,6
1 or 2 sessions	5	26,3
3 or 4 sessions	3	15,8
> 4 sessions	5	26,3
Total	19	100,0

From the 19 participants that participated in the post-test, most of the respondents did not attend a training session organised by the Odense House (31,6%). However, an equal number of respondents participated either in 1 or 2 sessions (26,3%) or more than 4 sessions (26,3%). In total 15,8% of the respondents had participated in either 3 or 4 sessions (See Table 3.7).

Participation in activities

Measuring participation in activities is important for evaluating the impact of the Odense Houses. These questions give a first understanding of the level of engagement and involvement of individuals in various activities, which is important for evaluating the effectiveness of interventions and programs in future.

Table 3.8 Participation in activities organised by the Odense House

	Frequency	Percent
None	5	26,3
1 each quarter	6	31,6
1 each month	5	26,3
1 each week	3	15,8
Total	19	100,0

In total 73,7% of the respondents participated at least once each quarter to activities organised by the Odense Houses. These were divided into different groups. Most of the respondents (31,6%) participated once each quarter to activities organised by the Odense House. Although 26,3% of the respondents did not participate in any activity organised by the Odense House, a minority of respondents (15,8%) participated each week to an activity (See Table 3.8).

Informal care

Measuring the informal care given during the project was important for evaluating the impact of the Odense Houses. Providing informal care is one of the aspects that can affect the outcomes of the intervention. Therefore it is important to understand the amount of informal care given during the project. In Table 3.9 responses of 19 participants in the pre and post test are shown.

Table 3.9 Informal care needed during the project

	Frequency	Percent
Strongly disagree	4	21,1
Disagree	2	10,5
Neutral	10	52,6
Agree	3	15,8
Strongly agree	0	0,0
Total	19	100,0

The mean score (2.63) indicates that the amount of informal care provided by respondents during the pilot, had not increased during the pilot (See Table 3.9).

Technologies

Measuring the awareness of new assistive health technologies, testing of new technologies, and implementation of assistive health technologies among respondents of the Odense Houses is important to determine the effectiveness of the project's goals. According to literature it is important for informal caregivers to understand the need of certain technologies (Dequanter et al., 2022). Therefore, the Odense Houses may provide showcases of assistive health technologies for people living with dementia and their informal caregivers.

Table 3.10 Awareness of new technologies in healthcare

	Frequency	Percent
Yes	11	57,9
No	8	42,1
Total	19	100,0

To understand whether informal caregivers were more aware of technologies in healthcare, participants were questioned whether they tried new technologies that were introduced by the Odense House they visited.

Based on the responses, the Odense Houses made more than half of the respondents (11) aware of new technologies in healthcare they were not familiar with (See Table 3.10).

Table 3.11 New technologies tested at the Odense House

	Frequency	Percent
Yes	3	15,8
No	16	84,2
Total	19	100,0

Within the survey we have asked informal carers whether they tried out technologies by the initiative of the Odense House. Although more than half of the respondents were made more aware of new technologies (Table 3.5), a majority (84,2%) of the participants did not try out new technologies (Table 3.11).

Another additional finding regarding the ideal place to try out technologies for informal carers was taken into account.

Table 3.12 Odense House as the ideal place to try assistive health technologies

	Frequency	Percent
Strongly disagree	0	0,0
Disagree	0	0,0
Neutral	1	5,3
Agree	2	10,5
Strongly agree	0	0,0
Total	3	15,8

Three participants responded to the question whether the Odense House is the ideal place to try out technologies for informal carers. The mean score was 3.67 which indicates that the respondents were more inclined on agreeing to the statement that the Odense House is the ideal place to try out new technologies (See Table 3.12).

Regarding technologies, respondents were also questioned whether they gained more knowledge and confidence in using technologies for informal caregivers.

Table 3.13 Amount of knowledge and confidence gained in using technologies

	Frequency	Percent
Strongly disagree	0	0,0
Disagree	1	5,3
Neutral	5	26,3
Agree	5	26,3
Strongly agree	0	0,0
Total	11	57,9

The mean score of the respondents was 3.36 which indicates that participants have gained more knowledge and confidence in using technologies for informal caregivers (See Table 3.13).

Informal carers were also asked whether they believed that assistive care technologies might improve their well-being and general living conditions.

Table 3.14 Improved well-being and general living conditions due to assistive care technologies

	Frequency	Percent
Strongly disagree	0	0,0
Disagree	1	5,3
Neutral	2	10,5
Agree	7	36,8
Strongly agree	1	5,3
Total	11	57,9

The respondents had a mean score of 3.73 which indicates that respondents think that assistive care technologies can improve their well-being and general living conditions. Only one respondent disagreed with the question and gave a negative answer (See Table 3.14).

Finally, informal caregivers were asked whether they have implemented technologies in the past year at home that helped them in their caring role.

Table 3.15 Implementation of assistive healthcare innovations

	Frequency	Percent
Yes	6	31,6
No	13	68,4
Total	19	100,0

Most of the respondents did not implement technologies to help them as a caregiver at home. Only 31,6% of the respondents did implement technologies (See Table 3.15).

Besides organising activities and training sessions for informal carers, the project also provided a website for informal carers. Responses to the survey about this topic were limited. Information about survey responses to the MONUMENT website can be found in Appendix D.

3.2 Focus groups

3.2.1 Sample descriptions

The number of people living with dementia and their informal caregiver(s) who participated in the focus group informal carers are presented in Table 3.16.

Table 3.16 Sample description of the focus group

City of Mechelen (LP)	AFEJI (PP5)	National Trust (PP11)
Informal carers (6): Details of gender, age, and profession unknown	Informal carers (4): Details of gender, age, and profession unknown	Informal carers (4): Details of gender, age, and profession unknown PLWD (4): Details of gender, age, and profession unknown

Note: Unknown means that the implementation partner did not disclose information regarding age, gender and/or profession of the informal carer or PLWD due to reasons such as privacy. Norfolk County Council (PP4) and WVO Zorg Walcheren (PP12) were unable to provide data for the focus group informal carers.

Note: PLWD = People living with dementia.

3.2.2 Findings

The focus group discussions among informal carers were conducted asking them for their experience regarding leisure activities, knowledge and transferable skills, reciprocity, and, better information. In the following paragraphs, these topics will be further discussed.

Access to leisure activities

Recent studies highlight that informal carers of people living with dementia can often not participate in every day activities such as leisure because they tend to put the needs for care first (Engel et al., 2022; Greenwood et al., 2018). Yet, the lack of access to leisure activities and relaxation can have consequences for the quality of life of informal caregivers and can put them at risk of developing mental health or physical health problems (Greenwood, et al., 2018). In the focus group discussion for the MONUMENT project, access to leisure activities functioned as an indicator to see if the quality of life of the informal carers had improved by having more access to leisure activities by means of the Odense House activities. To measure access to leisure activities among informal carers, the following questions were asked:

- From your own perspective, do you think the Odense House project has made leisure activities more accessible to informal carers? Can you give examples of that?
- Since you joined the Odense House have the number of your leisure activities increase/decreased/ remained the same?

In general, the majority of partners found that the Odense House had not increased the access to leisure activities for informal carers. Informal caregivers in City of Mechelen (LP) and Afeji (PP5) indicated that access to leisure activities had remained the same. They gave different reasons why access to leisure activities had not increased in their cohort. For instance, informal carers in City of Mechelen (LP) found that the leisure activities at the Odense House were not in line with their interests. As a result, they did not participate in the activities on offer, such as day trips to museums or gardens, singing, Petanque, dancing and coffee-drinking hours. In the Afeji focus group, participants described that the primary allure of the Odense House was peer support meetings instead of access to leisure activities. They were already engaged in other leisure activities outside the Odense House. Based on the reaction of respondents, such activities increase their quality of life. Only Cambridgeshire's (PP11) informal caregivers felt they gained more access to leisure activities. These activities included socialising, gardening, crafting, and reading.

In addition to City of Mechelen (LP), Afeji (PP5) and National Trust (PP11), Norfolk County Council (PP4) and WVO Zorg Walcheren (PP12) received positive reactions from informal caregivers during the Odense House trips they organised, illustrating the access to leisure activities. For example, at the buggy self-drive tour at the Watatunga Wildlife Reserve that was organised by Norfolk County Council (PP4), participants were very enthusiastic, saying:

'It was absolutely wonderful, such a rare opportunity for us to be together as a family, doing something fun. We'd never normally take Dad to something like that in the fear he might say or do something strange but turns out he was perfectly fine! It was so reassuring knowing that we were amongst people who understood ... It's a memory we'll treasure forever.'

And,

'It was something completely different, and all the group enjoyed themselves. It brought happy memories back to dad, of his time in Zambia, as he saw the same sort of animals there. He has now been telling everyone we meet about it! I think it was a great family activity and was inclusive of those with poor mobility too. It was nice to be in a group with others so you could chat with new, like-minded people too.'

In reaction to a sailing experience with the Nancy Oldfield Trust organised by Norfolk County Council (PP4), one of the respondents stated:

'Thank you so, so much for yesterday. It was absolutely brilliant, Mum burst into tears after the sailing because she loved it so much, and Dad kept saying how peaceful it all was, and we couldn't remember how long it had been since he'd been out on the broads. We'd have never risked taking him without your support and organisation.'

A participant in WVO Zorg Walcheren (PP12) concluded regarding leisure activities in the Odense House:

'If the Odense House would not exist, I would be at home all week'

These statements are examples of respondents pilot partners gathered. For an overview of the analysis, we provide a summary of the focus group responses on 'more access to leisure activities' which can be found in Table E.1 in Appendix E.

Knowledge and transferable skills informal carers

According to Liddle et al. (2012), dementia symptoms such as communication and memory difficulties can negatively impact the daily routine and relationship between persons living with dementia and their informal care giver(s). Providing knowledge on the disease and teaching transferable skills such as coping strategies to informal carers can improve their quality of life as it reduces conflict and improves interaction (Liddle et al., 2012), reduces depression and care of burden for informal carers (Jensen et al., 2015), and prevents premature institutionalisation of people living with dementia (Liddle et al., 2012; Huis in het Veld et al., 2020). In the projects' focus groups, access to knowledge and transferable skills functioned as an indicator to see if the knowledge and skills concerning dementia of informal carers had improved by going to the Odense House. To measure the knowledge and transferable skills of informal carers, the following questions were asked:

- Do you feel your knowledge relevant to caring for a person living with dementia has increased/ decreased/ remained the same by participating in the Odense House project?
 - Can you give examples of that?
 - What specific knowledge did you gain?
- Are there any skills that you gained by participating in the Odense House? Can you give examples?

In general, all the partners agreed that the knowledge and transferable skills of informal carers had increased by visiting the Odense House.

In the City of Mechelen (LP), Afeji (PP5) and WVO WVO Zorg Walcheren (PP12) the increase in knowledge and transferable skills was mainly attributed to sharing knowledge with peers and receiving training from professionals. The peer and professional sessions helped informal caregivers to gain a better understanding in the dementia process and learn about dementia-friendly tools and locations. It also taught informal carers how to adapt their behaviour and expectations towards people living with dementia, share their burden with others and de-stress.

For example, Norfolk County Council (PP4) organised an outdoor activity at the Bushcraft at RSP Strumpshaw Fen with the Greenlight Trust. In response to that activity one of the participants stated:

‘It was particularly good to be able to talk to other people who were in a caring role, in such a supportive atmosphere. I hadn’t realised just how stressed I had become and I’m afraid I found myself crying as we walked along to the river but the lovely lady I was walking with, who was caring for her mother, was so gentle and understanding that afterwards I felt much better.’

One of the participants at WVO Zorg Walcheren (PP12) had a similar experience as from Norfolk County Council (PP4) highlighting:

“The volunteers truly emphasise with you – they give you advice – they console you – they do everything for you”

A summary of focus group responses on ‘increased knowledge and transferable skills’ can be found in Table E.2 in Appendix E.

Reciprocity between people living with dementia and their community

Within literature (see Hermaan et al; Thijssen et al., 2021) people living with dementia experience stigma in their communities. Over 40% of people hold prejudice and stereotypes against persons living with dementia and they describe that ensuring good quality of care for them means making communities and environments more “dementia-friendly” and, to a degree, more “age-friendly” necessary. To ensure, reciprocity between people living with dementia and their community is needed. Reciprocity means, for example, that people living with dementia feel respected and receive material as well as immaterial support from the surrounding community (Thijssen et al., 2021). In the focus groups, reciprocity between people living with dementia and their community functioned as an indicator to see if the relationship and the mutual support between people living with dementia and the surrounding community improved due to the Odense House. To measure reciprocity between people living with dementia and their community, the following questions were asked:

To measure reciprocity between people living with dementia and their community the following questions were asked:

- Do you feel that the activities of the Odense House have boosted cooperation between people living with dementia and the inhabitants of the surrounding community?
 - If so, in what way?
- Did you receive support or resources from the inhabitants of the surrounding community in any form?
 - If so, in what way?

In general, all partners who attended the focus group discussions did not notice an increase in reciprocity between people living with dementia and their community. However, all of them saw other positive developments. In all three pilots, the interest and/or visibility of people living with dementia increased due to the Odense House activities.

In City of Mechelen (LP), the visibility of dementia increased, mainly because of the dementia choir participating in a neighborhood festival. Due to the exposure, people living with dementia took knowledge of other opportunities to openly discuss their disease/diagnosis and coping situation, which positively impacted them. Informal caregivers in Afeji (PP5) experienced more peer support and exchange. The peer support and exchange led to an influx of volunteers interested in supporting the growth of the Odense House. A local social work school in the greater community has expressed interest in sending four students to intern at the Odense House. National Trust (PP11) informal caregivers noticed an uprising in interest in dementia by the Town Council. People living with dementia and the informal caregivers are happy that the Odense House gives them a platform to form and foster informal connections. Resources and support were received by the Odense House, but mostly from close friends and family of the Odense House participants. To illustrate one of the positive examples of the impact of the Odense House activities on interaction between different parties (e.g., informal caregivers, people living with dementia, friends, family, relations, and stakeholders), one of the respondents indicated:

“I think you feel more part of that community that applies to all the groups that we used to go to and now are restarting. This is a community within a community”.

An informal caregiver in the Odense House WVO Zorg Walcheren (PP12) seemed to agree with this assessment, and described as follows:

‘Everyone gives some and takes one’

A summary of focus group responses on ‘increased reciprocity between people living with dementia and their community’ can be found in Table E.3 in Appendix E.

Better informed by peers

Many informal carers are unprepared for the complexities of caring for someone with dementia. They often lack the background or training which help them to tackle their care activities (Peterson et al., 2016). Aside from care information often being limitedly available from primary care providers, other studies also show that receiving information from fellow informal carers may be more effective than from professionals because peers can empathise with each other’s experiences (see e.g., Carter et al., 2020). Furthermore, Charlesworth et al. (2016) suggest that being educated by peers on the psych-social aspects of living with dementia can ultimately lead to informal caregivers perceiving an improvement in the relationship with the person living with dementia (Charlesworth et al., 2016).

In the focus groups of the MONUMENT project, better informed by peers, functioned as an indicator to see if informal carers' knowledge and skills regarding dementia improved by going to the Odense House. To measure if informal carers felt better informed after talking to peers the following questions were asked:

- Via the Odense House you were more in touch with other informal carers. Do you feel that you have learned something new with regard to caring for people living with dementia from other carers?
 - Can you give examples of it?

In general, all partners unanimously reported that informal caregivers felt better informed after interacting with peers in the Odense House.

Informal carers in City of Mechelen (LP) exchanged contacts and practical advice regarding finances, administration, legal issues, and tricks on adapting their behaviour and expectations towards people living with dementia. At National Trust (PP11), informal caregivers felt better informed because they could exchange information about dementia-friendly places with their peers. Afeji (PP5) informal caretakers felt that they had grown on an emotional level. They learned from their peers that they could get respite by being open and sharing their experiences with other people. An informal caregiver at National Trust (PP11) accurately described this feeling from the Afeji (PP5) group:

"I think you do feel more supported because, you know, that people are there, you know, rather than sometimes struggling on your own, you can yeah, you know, that people here that you can, you know, speak to and ask things."

In addition, Norfolk County Council (PP4) learned during the Odense House activities that informal caregivers felt better informed about the number of possibilities that were open to them and their people living with dementia:

"It's so lovely; you've really opened our eyes to other opportunities and experiences that we wouldn't have thought about or thought was possible for him. It makes such a difference being able to go somewhere and not have to worry or explain about his condition."

A summary of focus group responses on 'better informed by peers' can be found in Table E.4 in Appendix E.

Part II

Financial Feasibility Study

**By
Probis**

4 Financial Feasibility Study

To understand the financial feasibility of this project, the impact of the professional (residential) care versus home care was tested. The incremental cost (=more-cost) of residential care versus living at home with supported informal care was mapped, both from the perspective of the care recipient and the government/society. In specific, this study provides answers to the following questions:

- What are the financial costs of implementing the three key actions within the MONUMENT project and how do these costs compare to the professional (residential) care provision?
- What is the financial gain of this approach compared to the professional (residential) care?
- What is the long-term financial impact?
- What does the cost-benefit analysis, on which policymakers can base their own actions?

4.1 Context

This study was based on the operation and figures of the City of Mechelen (LP) project. This means that besides the operating costs of the City of Mechelen project, other figures were based on the Mechelen region and, by extension, Flanders. Therefore, the figures and conclusions in this study cannot be simply copied to other regions, figures are influenced by context and numerous variables. The multitude of variables were not captured in this study. The study assumed a few 'standard situations' and averages, so the figures and conclusions in this study should be interpreted with caution and nuance. However, this study can serve as a guide for other cities and regions wishing to engage in inclusion of people living with dementia. Therefore, this study also includes an excel calculation tool, which can be useful in an international context. This tool includes a basic structure for mapping the financial impact of the MONUMENT project, based on the figures, context, and basic principles applicable in other regions. The tool thus offers the possibility of customisation.

4.2 Method

All cost elements were calculated per user monthly, from the perspective of both society and the user. 'Society' in this study includes government agencies that charge healthcare costs to the user through health insurance or provide direct operating subsidies to residential care. 'The user' is the person living with dementia and/or his/her informal caregiver(s). The informal caregiver who uses the services of the MONUMENT project, without the person living with dementia, also contributes to achieving the objective of ensuring that the person living with dementia can live longer at home. The study assumed 71 unique users, according to the above definition. Below it is described which costs were identified for each key action. All costs were indexed based on the June 2022 index.

'Services and miscellaneous supplies', 'personnel costs' and 'depreciation costs' were charged as expenses. The level of staff costs depended on the extent to which volunteers could be called upon for the coordination and operation of the Odense House. In City of Mechelen (LP), the level of staff costs depended on professional staff from the city. Furthermore, the calculation tool allowed other situations (read: more volunteer deployment instead of professional staff) to be mapped financially.

There can be assumed that there is a high user intensity: when the number of users decreases, the cost per user increases. With an increase in the intensity of use, there may be considered renting external infrastructure for certain larger activities on a project basis. In the end, no costs were passed on to users of the Odense House (informal caregiver(s) and people living with dementia).

The funding of the MONUMENT project was not considered. In this way it was possible to identify the intrinsic value of the MONUMENT project. Funding should not have affected the calculation of the incremental cost of residential care versus living at home with supported informal care and was thus outside the scope of this study. Funding of the project is an important consideration for policymakers when making the decision to establish an Odense House. Funding can take different forms: investment grants, operating grants, project grants, in-kind contributions, crowdfunding, and others.

The costs associated with the digital platform¹ were the development, maintenance, management, and hosting costs. For the development costs, it was assumed that there was a depreciation period of three years. The cost of the digital platform was largely fixed, regardless of the number of users. The calculation of the cost per month per user was based on the number of unique users of the Odense House. The costs to purchase technology were always charged with a depreciation period of three years. This was based on the principle that one copy of each technology is made available at the Odense House for on-site testing. Further expansion of the borrowing capabilities will require the purchase of multiple copies of certain technologies based on demand. As the borrowing capabilities in the City of Mechelen (LP) project were only started during the implementation of this study, insufficient data were available to quantify demand.

4.2.1 Variability of opportunity costs

To identify the incremental costs of residential (professional) elderly care versus 'living at home with supported informal care', it was essential to also identify the opportunity costs. Opportunity costs are the costs linked to the home situation, which would disappear when moving to an assisted living centre. Therefore, these costs are directly linked to the choice to continue living at home. These costs should be added to the MONUMENT project costs to get the most accurate view of the real incremental costs. The costs were broken down into care, housing and living costs. Housing and living costs were based on the average expenses of a person aged between 50 and 59 (cf. the target group of the MONUMENT project).

Opportunity costs can vary widely depending on the personal characteristics and situation of the person living with dementia. To delineate the variability, the study identified two variables that have a major impact on opportunity costs: family composition and the degree of need for care.

First, opportunity costs depend strongly on the user's family composition. Therefore, to identify the opportunity costs of the two most common family compositions in this study two scenarios were used:

- Scenario 1: The person living with dementia lives with partner/caregiver:
 - Housing costs
 - Housing costs will remain in place if the person living with dementia moves to the WZC.
 - Housing costs are not opportunity costs and are therefore not counted in the costs of home.

¹ 'MeMo by Monument' is a platform for informal carers of people living with dementia. The platform supports and connects informal carers. The platform includes relevant information on dementia, tips from informal carers, technological tools and interesting activities for informal carers and people living with dementia.

- Living expenses
 - Living costs of the person living with dementia are opportunity costs (because they fall away when someone moves).
 - Living costs of the informal carer living at home are not opportunity costs (they remain after the person living with dementia moves).
- Scenario 2: The person living with dementia lives alone:
 - The housing and living costs of the person living with dementia are opportunity costs, as they fall away when moving to the HZC.

Besides the family composition, another important factor that has a significant impact on the opportunity cost is the degree of care dependency and the external care because of this care dependency. In terms of care needs, the two most common scenarios were identified as follow:

- Scenario 1: The person living with dementia uses home care (home care and nursing):
 - The cost of home care and nursing services is an opportunity cost and have a significant impact on the additional costs depending on whether the person living with dementia relies on home care and nursing care.
 - The cost can vary greatly depending on the intensity of care and services provided. The cost charged in the study is an average cost.
- Scenario 2: The person living with dementia uses home care and attends a day care centre (CSP) three days a week:
 - The cost of a day care centre (CSP) is an opportunity cost.
 - The day-care centre costs considered in the study are from the society's perspective the basic care allowance (BTZ 2022) and from the user's perspective, the daily price of the Mechelen Day Care Centres.
 - This study assumes an average intensity of use of three days per week of CDV combined with one day of Odense House (see above).

The calculation tool allows to adjust the number of days of CSP per week and thus provides refinement in the calculation.

Furthermore, medical costs (fees, medicines, hospital costs) were not considered as they were not considered incremental costs. Lastly, although described in the literature due to the high variability and complexity, the cost of informal care was not considered. The costs concern, for example, costs and income missing related to working less due to taking up care.

4.2.2 Variability residential care costs

Finally, costs of residential care were identified. Again, both the cost to society and the user of residential care were identified.

The cost of residential care to society consists of the following components:

- The basic care allowance (BTZ)
 - This is the amount that each residential care centre (HSC) is allowed to bill per day per resident to the care funds. The amount depends heavily on a few residents and staff indicators of the WZC in question.
 - The study calculated a weighted average BTZ 2022 of Mechelen residential care centres.

- The incontinence
 - This is a consolidated allowance for the cost of incontinence materials granted to each WZC resident.
- The infrastructure
 - This is a grant awarded to residential care centres to finance major infrastructure investments (renovation or new construction), so that part of the investment costs is not passed on to residents.

The cost to the user consists of the daily rate billed by the residential care centre to the resident monthly. No allowance was made for any supplements, as in most cases these were not incremental costs compared to the home situation.

4.3 Results

The costs applicable to the Odense Inn in 2021, indexed to 2022 are presented in Table 4.1. These costs were converted to a cost per user per month. There were 71 individual Odense House users included in this study.

Table 4.1 Costs of Odense Houses

t Monument (Odense House Mechelen) - 2022			
	Amount	Per month	Per user/month
Purchases, services, and miscellaneous supplies	€ 20.019	€ 1.668	€ 23
Staff costs	€ 250.015	€ 20.835	€ 293
Depreciation charges	€ 18.752	€ 1.563	€ 22
Other costs	€ 0	€ 0	€ 0
Financial costs	€ 0	€ 0	€ 0
Total costs t Monument	€ 288.786	€ 24.066	€ 339
Revenue t Monument	€ 0	€ 0	€ 0
Net costs Monument	€ 288.786	€ 24.066	€ 339

Note: t Monument is the name of the Odense House in the city of Mechelen.

The cost of the Odense Houses to society was €339 euros per user per month. As mentioned before, no costs were passed on to the user of the Odense House. Consequently, the cost of the Odense House to the user was €0 euros per user per month. Neither for society nor for the user were there any financial returns associated with the Odense House.

The cost per user per month of the digital platform from society's point of view table is presented in Table 4.2. The cost to society of the digital platform per user per month was €28 euros. As with the Odense house, there are no costs associated with digital platform for the users (€0/user/month). The digital platform has no revenue either for the society or for the user.

Table 4.2 Digital platform costs

Digital platform - Total			
	Amount	Per month	Per user/month
Development costs	€ 60.000	€ 1.667	€ 23
Maintenance costs	€ 0	€ 0	€ 0
Management costs	€ 2.194	€ 61	€ 1
Domain names costs	€ 252	€ 21	€ 0
Hosting fees	€ 7.395	€ 205	€ 3
Total cost digital platform	€ 69.841	€ 1.954	€ 28
Revenue 't Monument	€ 0	€ 0	€ 0
Net costs digital platform	€ 69.841	€ 1.954	€ 28

The costs to society associated with technological developments are shown in Table 4.3. The cost of the technologies to society was €1.15 euro per user per month. There were no costs to the user, society or the user that had a return linked to technological developments.

Table 4.3 Costs of technological developments

Technological developments			
	Amount	Per month	Per user/month
Phone with photo keys	€ 50	€ 1,39	€ 0,02
Komp	€ 559	€ 15,53	€ 0,22
Interactive Robot Cat	€ 129	€ 3,58	€ 0,05
Spotter GPS Watch air	€ 148	€ 4,11	€ 0,06
Nobi	€ 1.502	€ 41,71	€ 0,59
Simple remote control	€ 20	€ 0,56	€ 0,01
BBrain - Family D2 with Visual Calling	€ 299	€ 8,31	€ 0,12
OER music player	€ 159	€ 4,42	€ 0,06
Talking calendar clock Bbrain Basic	€ 79,95	€ 2,22	€ 0,03
Total cost technological developments	€ 3.479	€ 81,82	€ 1,15

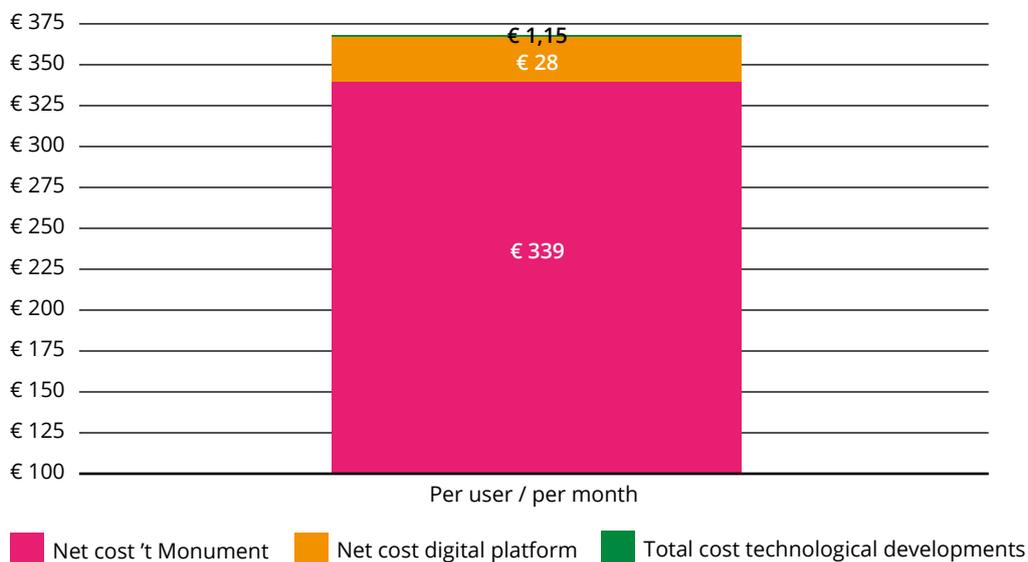
In addition, Table 4.4 gives an overview of the total cost of the MONUMENT project per user per month. For the total project, the cost to the society were €368 per user per month.

Table 4.4 Total costs MONUMENT project

	Amount	Per month	Per user/month
Net cost of Odense house 't Monument	€ 288.786	€ 24.066	€ 339
Net cost digital platform	€ 69.841	€ 1.954	€ 28
Total cost technological developments	€ 2.945	€ 82	€ 1,15
TOTAL COSTS MONUMENT PROJECT	€ 361.573	€ 26.101	€ 368

For the user, the MONUMENT project entailed no costs. There were no revenues associated with the project, either for society or for the users (see Chart 4.1).

Chart 4.1 MONUMENT: cost per month per user



4.3.1 Opportunity costs

Table 4.5 shows the opportunity cost, or the cost that would be eliminated when moving to the residential care home.

Table 4.5 Opportunity costs

				USER			
Care				Care			
			Per person/ month				Per person/ month
Home care services			€ 370	Home care services			€ 86
Home nursing			€ 120	Home nursing			€ 40
Home care			€ 250	Home care			€ 46
Day care centre		per diem		Day care centre			
Basic care allowance CSP	€ 56,96		€ 740	Daily price CDV Mechelen	€ 23,45		€ 305
Total Opportunity Cost Care			€ 1.110	Total Opportunity Cost Care			€ 391
Living				Living			
					Per person/ year		Per person/ month
Housing and housing costs				Housing and housing costs			€ 585
							€ 7.024

USER				
Life		Life		
		Per person/ year	Per person/ month	
		Food & drinks	€ 3.130	€ 261
		Clothing & shoes	€ 620	€ 52
		Transport	€ 1.966	€ 164
		Communications	€ 577	€ 48
		Culture and leisure	€ 1.245	€ 104
		Restaurant and catering	€ 722	€ 60
		Body care and services	€ 1.665	€ 139
		Total opportunity cost of living		€ 827
TOTAL OPPORTUNITY COST society	€ 1.110	TOTAL OPPORTUNITY COST user	€ 1.803	

Not all the opportunity costs listed below apply in every situation as mentioned before. Depending about the person living with dementia, all or part of the costs below were added to the MONUMENT project cost to calculate the incremental cost of residential care as accurately as possible. The findings are presented in the following charts 4.2, 4.3 and 4.4.

Chart 4.2 Opportunity costs – Costs of living at home with informal care: Society

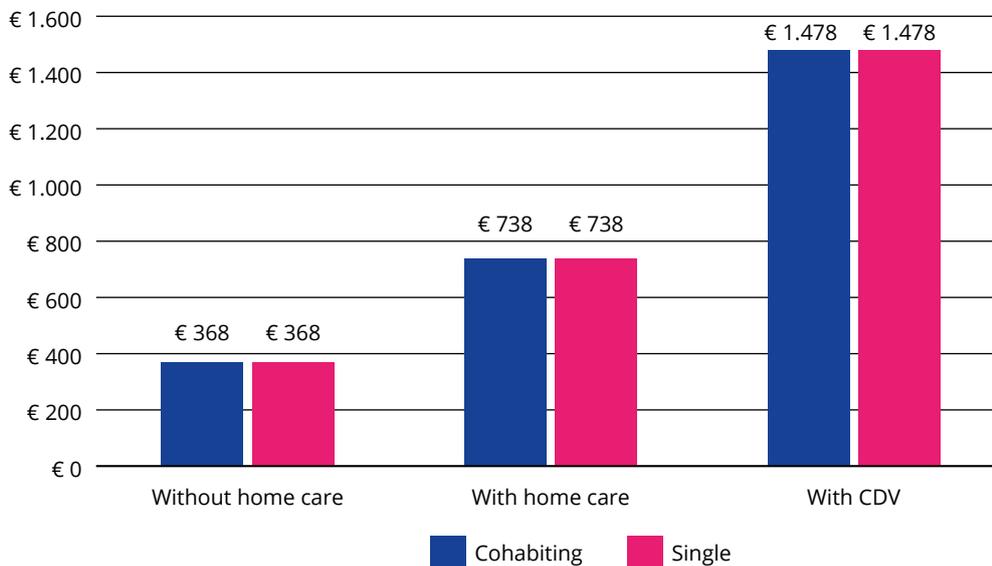


Chart 4.3 Opportunity costs – Costs of living at home with informal care: User

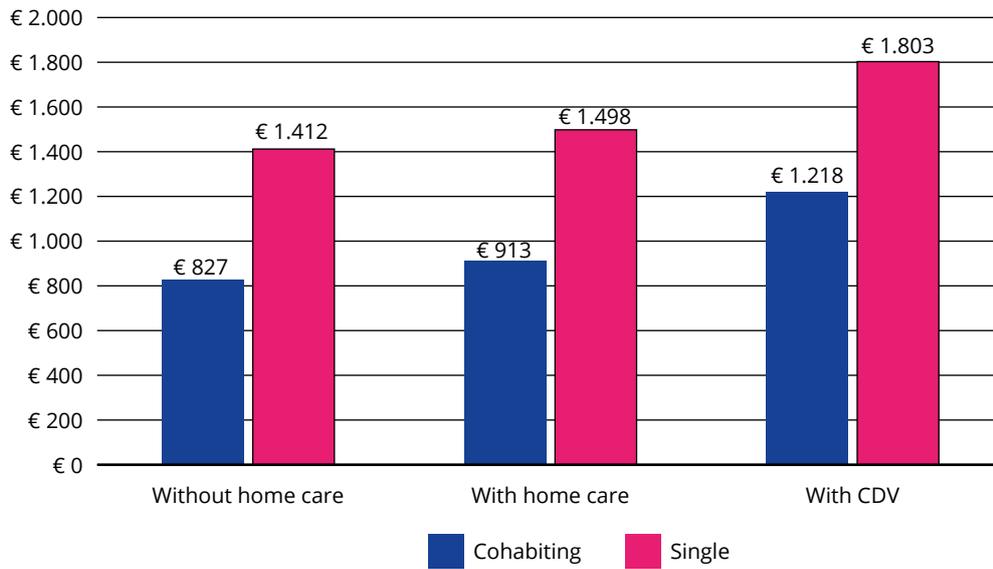
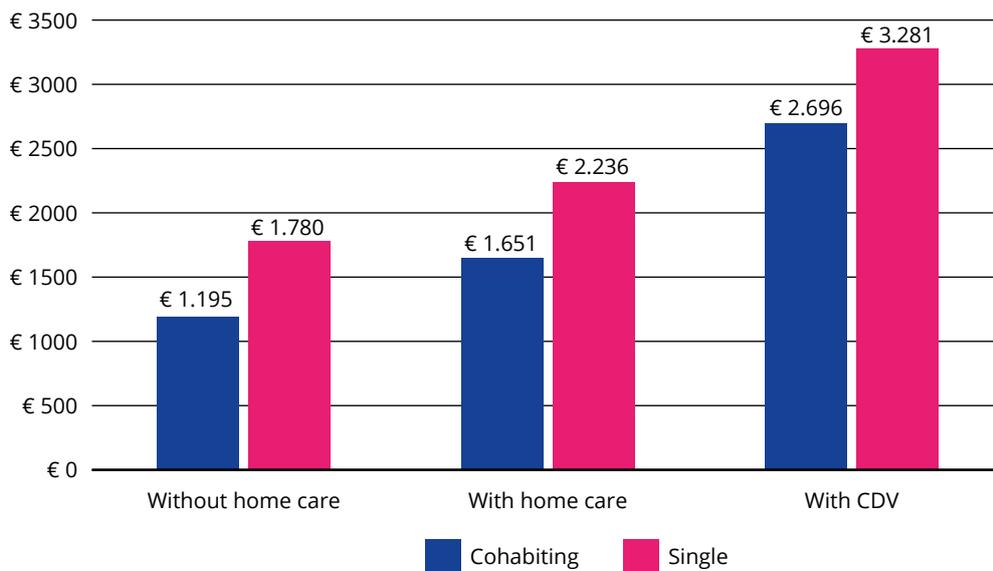


Chart 4.4 Opportunity costs – Costs of living at home with informal care: Total



4.3.2 Residential care

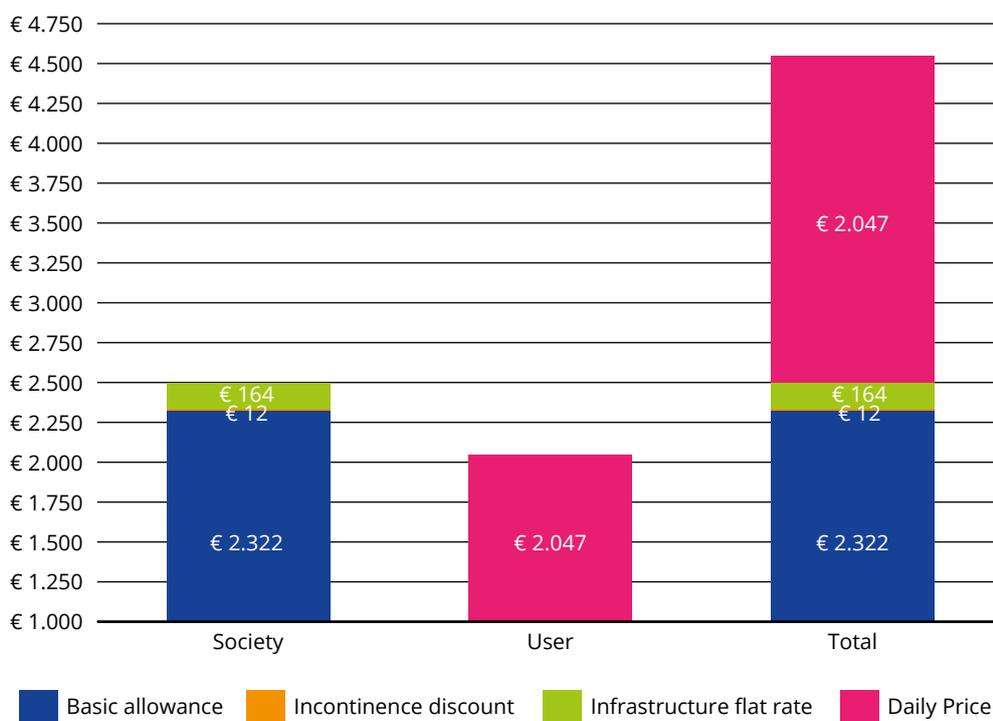
Table 4.6 presents the cost of residential care per user per month, from the perspective of both society and the residential care home user. For the society, one user's stay costs €2,498 monthly.

Table 4.6 Residential care costs

			USER		
Care			Care		
	Per day	Per user/ month			
Average BTZ WZC	€ 76,35	€ 2.322			
Incontinence fee	€ 0,38	€ 12			
Living			Living & Living		
Infrastructure flat rate	€ 5,40	€ 164		Per day	Per user/ month
			Average weighted daily price	€ 67,31	€ 2.047
			Mechelen 1p room 2021		
TOTAL COST WZC - SOCIETY		€ 2.498	TOTAL COST WZC - USER		€ 2.047

For the user himself, the cost is €2,047 per month. The findings are presented in Chart 4.5 Cost of residential care per user per month.

Chart 4.5 Cost of residential care per user per month



4.3.3 Incremental cost of residential care vs. living at home with supported informal care

The difference between the cost per month of a person with dementia living in the residential care home and a person living with dementia living at home (with informal care and support from the MONUMENT project) is presented in Table 4.7.

The incremental costs from the perspective of society, the user and in total were compared for each of the three situations:

- Without home care.
- With home care, but without using a day care centre.
- With home care, but with participation in a day care centre.

Positive amounts indicated the additional cost of residential care compared to informal care. In the case of negative amounts, residential costs were cheaper than informal care.

Table 4.7 Costs without home care and with home care

Difference cost/month/user (B) - (A)					
	Society	User		TOTAL	
		Living together	Single	Living together	Single
Total without home care	€ 2.130	€ 1.220	€ 635	€ 3.351	€ 2.765
Total with home care, without CSP	€ 1.760	€ 1.134	€ 549	€ 2.895	€ 2.309
Total with home care, with CSP	€ 574	€ 829	€ 244	€ 1.849	€ 1.264

The following charts (4.6 and 4.7) show the cost per month per user for residential care and informal care, to show in each case the incremental cost of residential care relative to informal care.

Chart 4.6 Incremental costs per month per user - Cohabiting

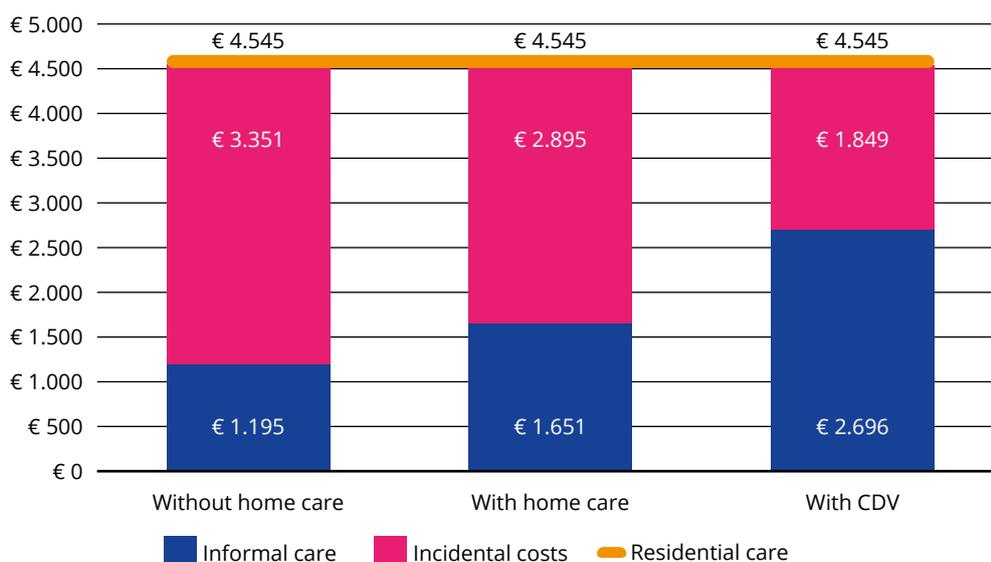
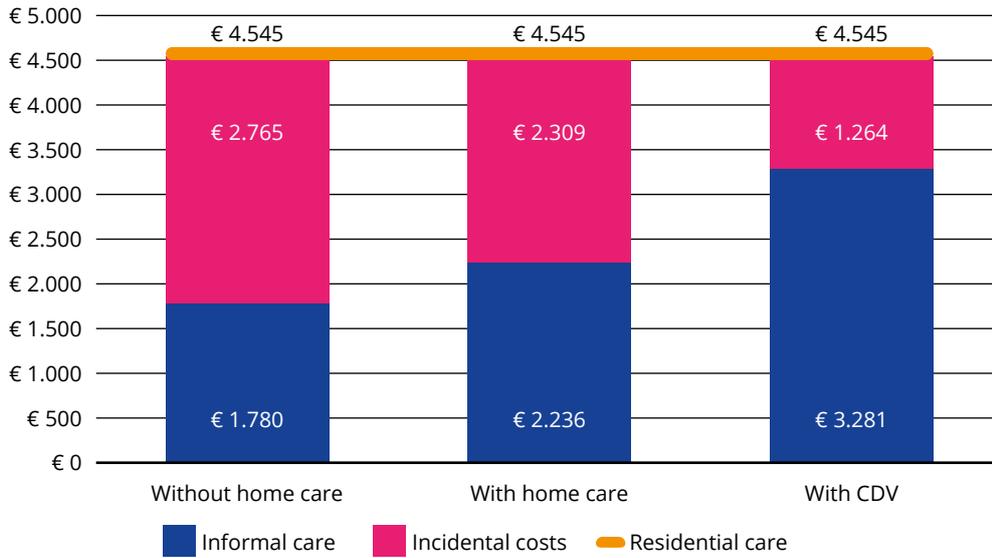


Chart 4.7 Difference in costs per month per user - Single



4.3.4 Long-term incremental cost

The long-term financial impact depended on the extent to which moving to a residential care home can be postponed by the concept of 'living at home with supported informal care'. No unambiguous and reliable data were (yet) available on this.

The charts 4.8 and 4.9 show the incremental cost of residential care in the long term (up to 12 months), based on the cost per month calculated in this study and considered the different situations described in this study.

Chart 4.8 Incremental costs long-term – Single

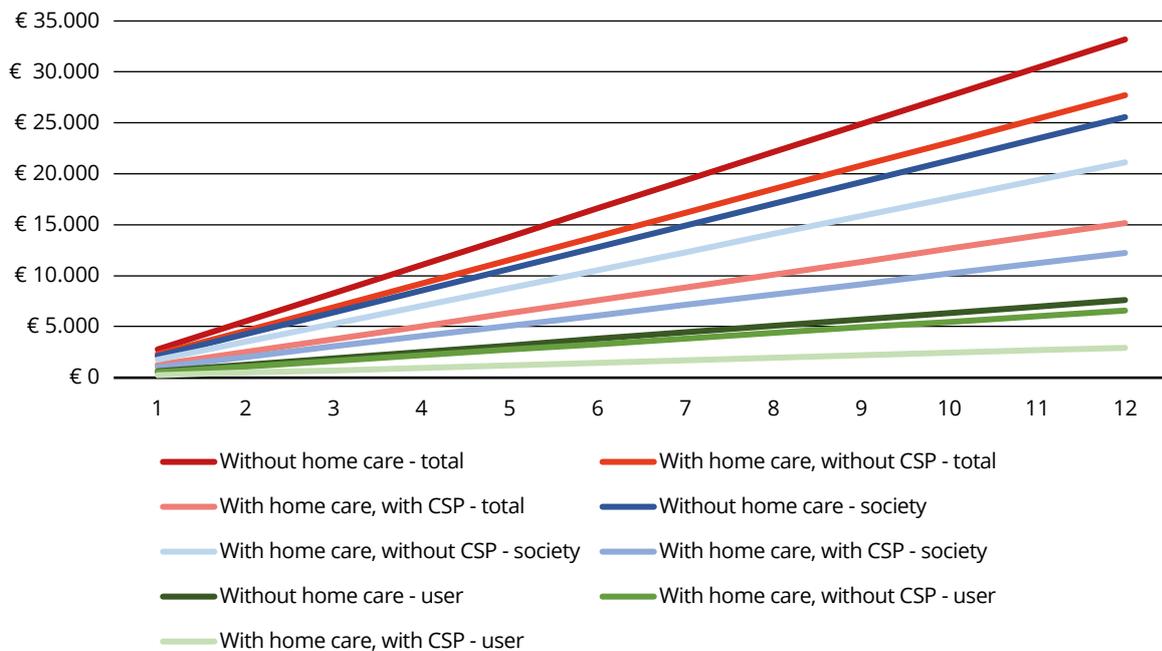
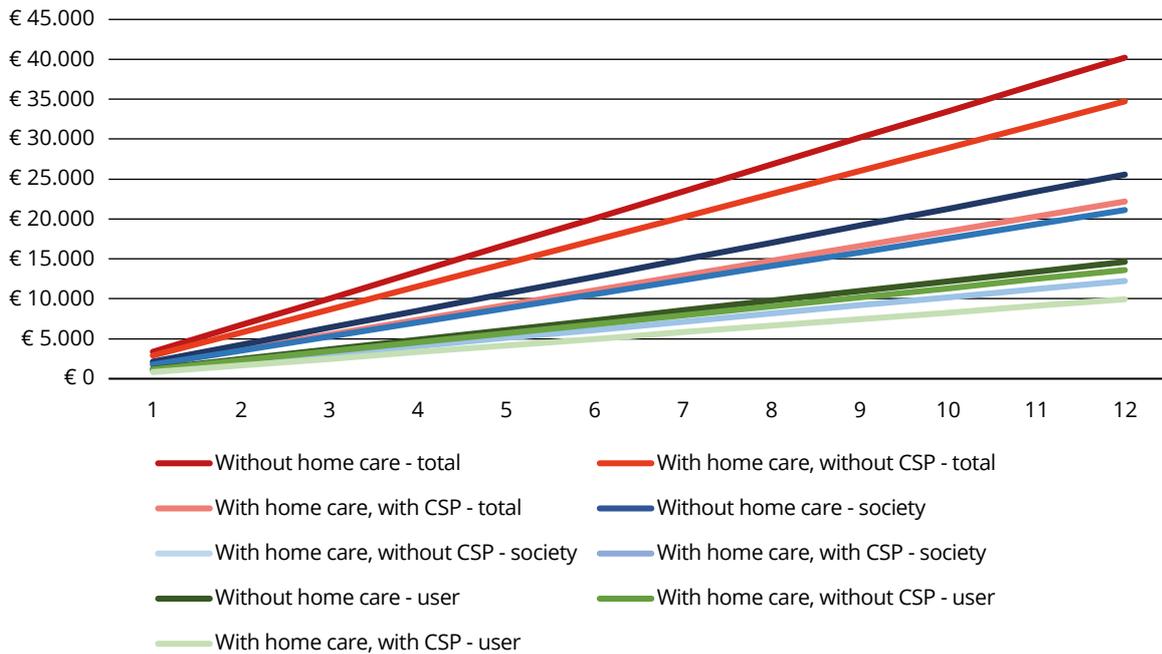


Chart 4.9 Incremental costs long-term – Living together



4.4 Considerations

Mapping the incremental cost of residential care relatively to living at home with supported informal care requires nuance. Based on the existing source material, the cost of residential care can be calculated accurately from both society's and the user's point of view. However, the opportunity cost of living at home was characterised by great diversity depending about the person in question. Family form, living situation, lifestyle and need for care are determining elements that have a large and highly varied impact on opportunity costs. Therefore, a few standard scenarios and average amounts were used in this study to identify the opportunity cost and to calculate the incremental cost of residential care.

For each standard situation the cost of residential care was mapped higher than the cost of living at home with supported informal care. This was from the perspective of both society and the resident. The incremental cost of residential care was lowest for a single person living with dementia who relied on home care and made use of a day care centre. The highest incremental cost was seen among people living together with dementia who did not use either home care or a day care centre. From the financial scope of this study, the MONUMENT concept constitutes a valid and considerable alternative to complement professional residential care.

Part III

Discussion

By

**HZ University of Applied Sciences
Research Group Healthy Region**

5 Discussion

In part I, the social feasibility study was presented according to the project's deliverables and was performed by HZ University, Healthy Region Research Group. For the quantitative research, results from the surveys were presented. The qualitative research consisted of the focus group discussions' findings. In part II, Probis delivered insights for the financial aspects of an Odense House and their findings are reported in the financial feasibility study. In the last part, we discuss the findings of both studies, provide a general conclusion considering the MONUMENT project and end with recommendations.

Within the MONUMENT project, there were significant differences in phases of setting up an Odense House in the pilot regions. Where some partners had already experience with organising and running an Odense House, some partners still had to make plan where and how to start an Odense House. This had a direct effect on the amount of as well as sort of activities planned by Odense Houses in different regions e.g., in/ outdoor activities, but also different opening hours and locations of the Odense House setting. Therefore, the findings of the project can be suitable for many different organisations for 1) starting an Odense House, or 2) learning from best practices aiming for improvement of the use of technology via the Odense House. The comparison of findings among the pilot partners are based on their specific position regarding their experience with the Odense House concept.

Since partners are situated within Europe, healthcare systems and legislation and regulations may differ. This can pose a challenge in ensuring cultural compatibility of the study results and conclusions. Cultural differences can impact the acceptability and implementation of the study findings. For example, attitudes towards certain health interventions may vary from country to country, which have not been measured in this study, this could lead to different levels of participation or adherence to study protocols. Additionally, cultural norms and values can influence the interpretation and understanding of study results, leading to potential misunderstandings or misrepresentation of the data.

Due to the COVID-19 pandemic that took place and restrictions within the project's aims, the focus became more on people living with dementia as a vulnerable group of people, especially concerning their health. Some of the aims of the project could therefore not fully met, e.g., opening and reflecting on the Odense House start-up. To give an idea of the impact COVID-19 had on the pilot partners' activities, we include an overview of the reactions by partners (see Appendix F).

5.1 Limitations

The social feasibility study took only one specific aspect into account, i.e., burden of care, and may not address other important considerations such as its cultural or political feasibility. The quality of the data collected may be limited by the participants' willingness to provide accurate information, together with a small sample size, this could influence the generalisability of the findings.

In the quantitative research, the initial idea was to provide every respondent with a unique code to fill out the questionnaire for both pre- and post-surveys. Coding respondents for pre- and post-surveys is a method used to ensure that the survey results can be properly analysed and linked together with limited privacy concerns. It is important as it allows researchers to compare the results of the same individuals over time. However, due to the low number of respondents in the pre and post survey, it became difficult to identify

and track specific individuals and see how their responses have changed over time. The sample size was not representative of the population, which lead to a lack of statistical power if we used the codes provided

For the qualitative research, pilot partners were asked to conduct focus group discussions. Although instructions were given in advance, there were major differences in the way the focus group findings were reported and conducted. That makes a comparison between pilot partners' results complicated. Besides, although every pilot partner aimed to conduct the focus group discussions, due to COVID-19 and organisational issues, not everyone succeeded in the desired group size to found (dis)agreement on the topics to be discussed. Therefore, the findings should be considered with caution.

The capacities of the target group to be surveyed were considered to measure the impact of the pilot activities. The aim was to measure 60% of the informal carers indicating better health, less feelings of anxiety, depression, and isolation; reduction of burden of care; better informed by peers; gaining new skills, and more access to leisure activities. Furthermore the goal was that in total, 320 informal carers and 320 people living with dementia took part in empowering bottom-up leisure activities and each country will receive 100 visitors per year in their Odense pilots. Based on the data, no firm conclusions can be related tot the potential impact of the pilot activities. However, the findings are indicative and useful for the future.

The financial feasibility study was performed by Probis. The findings of this study indicate that the cost of residential care can be calculated fairly accurately. However, the opportunity of cost of living at home with supported informal care is highly varied and depends on many factors such as family form, living situation, lifestyle, and need for care. The study used standard scenarios and average amounts to identify the opportunity costs and to calculate the incremental cost of residential care. The study found that for each standard situation, the cost of residential care is higher than the cost of living at home with supported informal care, from the perspective of both society and the resident. The incremental cost of residential care was found to be lowest for a single person living with dementia who relies on home care and uses a day care centre, and highest for people living together with dementia who do not use either home care or a day care centre. The study also found that the Monument concept is a valid and considerable alternative to complement professional residential care and offers a financial gain over professional residential care in all scenarios. However the study is based on the City of Mechelen (LP) experience with the Odense House concept and activities which could limit the generalisability of the findings. The financial aspects of running an Odense House indicated by this study are context related, therefore, future initiatives of (re-)starting an Odense House should be considered. Nevertheless, we believe that those findings are valuable for other partners and future ideas. Because of a lack of data and insighst into costs in the other areas, there was no other option than to give the study in Mechelen as a starting point. However, the results from Mechelen are an indication of the Belgian situation, they are helpful for other regions, but not simply replicable to all areas.

5.2 Recommendations

The results of Øksnebjerg and colleagues (2020) underline “the need for well-designed high-quality research into all the aspects that are essential to deliver applicable, effective, and sustainable assistive technology to support self-management of people living with dementia” (p. 937). However, they claim that there is a need for evidence-based methods to promote and qualify user involvement, dissemination, and adoption. Based on the MONUMENT project's findings, we cannot show evidence-based data on assertive technology. Moreover, the study by Dequater and colleagues stress to further investigate technology acceptance among older adults with cognitive impairments with the aim to know how to remove use barriers. Therefore, we

recommend to include a research design to put into practice, for instance, at running Odense Houses in Europe with the aim to test technologies and monitor how people living with dementia and their caregivers positively and negatively experience these possibilities.

In the MONUMENT project's social feasibility study, we measured several concepts i.e., with surveys by valid questionnaires. In the qualitative research, we explored relevant concepts e.g., access to leisure activities and social support. Examining these concepts adds to the existing literature and best practices in the field. As these ideas are new, therefore, we recommend to proceed and further explore these concepts among Odense Houses, informal caregivers and other stakeholders.

In the financial feasibility study only financial elements were included. However, financial elements are only one of many elements to be considered e.g., quality of life indicators. Regarding the financial aspects, policymakers and promoters can use the calculation tool to generate a tailor-made calculation but should consider their local and regional context.

5.3 Conclusion

Based on the social feasibility study, the results indicate that the activities grounded in the Odense House concept are valuable for both people living with dementia and their informal caregivers. For the persons living with dementia, the Odense House seems a trustful place to go to in company with their informal caregiver(s). The activities and interactions with peers seem to add value to the persons living with dementia and informal caregivers' state of mind regarding their resilience.

Every pilot partner within the MONUMENT project had a different way to include the Odense House concept. For some the focus was more on outdoor activities and for others there were more indoor activities. The main reason for the choice of activities was based on the pilot partner's phase i.e., starter or experienced with the Odense House concept.

In the financial feasibility study, all scenarios mapped resulted in a 'financial gain' of the MONUMENT concept compared to professional residential care. However, a human life is difficult to summarise into a standard scenario. Therefore, the necessary nuance is appropriate here too. Nevertheless, this study provides useful insights for policymakers and initiators considering starting a MONUMENT project.

In conclusion, based on the social feasibility study, the findings indicate that **informal carers' knowledge** regarding dementia friendly places and possibilities for leisure activities have (slightly) **increased**. Overall, participants who took part of the Odense House's activities that pilot partners organised, expressed that they were very **positive** as it **adds value to their quality of life** and that of the people living with dementia who they care for. The experiences of the use of **technological possibilities** differs per pilot partner. Not only by providing information, but also the implementation of technological solutions as this is very much **related to the specific context/situation**. More **knowledge** and **participation** in Odense House-activities also increased the feeling of informal carers' resilience as -although the sample was limited- the findings indicate that they feel **more supported**, and, have other and different options to share their care for the persons living with dementia.

6 References

Carter, G., Monaghan, C., & Santin, O. (2020). What is known from the existing literature about peer support interventions for carers of individuals living with dementia: A scoping review. *Health & social care in the community*, 28(4), 1134–1151. <https://doi.org/10.1111/hsc.12944>

Charlesworth, G., Burnell, K., Crellin, N., Hoare, Z., Hoe, J., Knapp, M., Russell, I., Wenborn, J., Woods, B., & Orrell, M. (2016). Peer support and reminiscence therapy for people with dementia and their family carers: a factorial pragmatic randomised trial. *Journal of neurology, neurosurgery, and psychiatry*, 87(11), 1218–1228. <https://doi.org/10.1136/jnnp-2016-313736>

Creswell, J.W. (2003) Research design: Qualitative, quantitative and mixed methods approaches. 2nd ed. Thousand Oaks, CA: Sage. ISBN 13 978-0761924425.

Dam, A. E., Christie, H. L., Smeets, C. M. et al. (2019). Process evaluation of a social support platform 'Inlife' for caregivers of people with dementia. *Internet Interventions*, 15, 18–27. <https://doi.org/10.1016/j.invent.2018.09.002>

Dequanter, S., Fobelets, M., Steenhout, I. et al. (2022) Determinants of technology adoption and continued use among cognitively impaired older adults: a qualitative study. *BMC Geriatr* 22, 376. <https://doi.org/10.1186/s12877-022-03048-w>

Elwick, H. & Joseph, S. & Becker, S. & Becker, F. (2010). Manual for the Adult Carer Quality of Life Questionnaire (AC-QoL). London: The Princess Royal Trust for Carers. ISBN 13 9780853582748.

Engel, L., Loxton, A., Bucholc, J., Muldowney, A., Mihalopoulos, C., & McCaffrey, N. (2022). Providing informal care to a person living with dementia: the experiences of informal carers in Australia. *Archives of Gerontology and Geriatrics*, 102, 104742. <https://doi.org/10.1016/j.archger.2022.104742>

Expertisecentrum Dementie Vlaanderen, <https://www.dementie.be/themas/monument/overmonument/>

Gabriela F., António Amaral, João V., (2018), Wagnild and Youngs's Resilience Scale Validation for IS Students, *Procedia Computer Science*, 138, 815–822. <https://doi.org/10.1016/j.procs.2018.10.106>.

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A systematic review of dementia-related stigma research: Can we move the stigma dial?. *The American Journal of Geriatric Psychiatry*, 26(3), 316–331. <https://doi.org/10.1016/j.jagp.2017.09.006>

Huis In Het Veld, J. G., Verkaik, R., van Meijel, B., & Francke, A. L. (2020). A systematic meta-review of self-management support for people with dementia. *Dementia (London, England)*, 19(2), 253–269. <https://doi.org/10.1177/1471301218772894>

Greenwood N, Mezey G, Smith R. (2018) Social exclusion in adult informal carers: A systematic narrative review of the experiences of informal carers of people with dementia and mental illness. *Maturitas*, 112, 39-45. <https://doi.org/10.1016/j.maturitas.2018.03.011>

Liddle, J., Smith-Conway, E., Baker, R., Angwin, A., Gallois, C., Copland, D., ... Chenery, H. (2012). Memory and communication support strategies in dementia: Effect of a training program for informal caregivers. *International Psychogeriatrics*, 24(12), 1927–1942. <https://doi.org/10.1017/S1041610212001366>

Øksnebjerg, L., Janbek, J., Woods, B., & Waldemar, G. (2020). Assistive technology designed to support self-management of people with dementia: User involvement, dissemination, and adoption. A scoping review. *International Psychogeriatrics*, 32(8), 937–953. <https://doi.org/10.1017/S1041610219001704>

Peterson, K., Hahn, H., Lee, A. J., Madison, C. A., & Atri, A. (2016). In the Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC geriatrics*, 16(1), 1–13. <https://doi.org/10.1186/s12877-016-0338-7>

Quirk, A., Smith, S., Hamilton, S., Lamping, D., Lelliott, P., Stahl, D., Pinfold, V. and Andiappan, M. (2012), Development of the carer well-being and support (CWS) questionnaire, *Mental Health Review Journal*, 17(3), 128–138. <https://doi.org/10.1108/13619321211287184>

Thijssen, M., Daniels, R., Lexis, M., Jansens, R., Peeters, J., Chadborn, N., ... & Graff, M. (2022). How do community-based dementia-friendly initiatives work for people with dementia and their caregivers, and why? A rapid realist review. *International Journal of Geriatric Psychiatry*, 37(2), 1-14. <https://doi.org/10.1002/gps.5662>

Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement*, 1(2), 165–178.

World Health Organization, 2022, <https://www.who.int/news-room/fact-sheets/detail/dementia>

Wortmann, M. (2012). *Dementia: a global health priority-highlights from an ADI and World Health Organization report*. *Alzheimer's research & therapy*, 4, 1-3. <https://doi.org/10.1186/alzrt143>

7 Appendices

Appendix A: Questionnaire items

Appendix B: Informal caregivers focus group questions

Appendix C: Informed consent

Appendix D: MeMo results quantitative part

Appendix E: Background information qualitative analyses

Appendix F: COVID-19 impact on data gathering

Appendix A: Questionnaire items

	Carer Well-being and Support
	During the past 4 weeks, how concerned were you about...
1	not having enough time to yourself?
2	having to put the needs of the person you care for ahead of your own needs?
3	not being able to take a break from caring?
4	not being able to plan for the future?
5	not being able to continue caring due to reasons beyond your control (e.g. becoming ill yourself, looking after very young children)?
6	strains in your relationship with the person you care for?
7	the person you care for being too dependent on you at the moment?
8	the person you care for becoming too dependent on you in the future?
9	the person you care for saying things that upset you?
10	feeling irritable with the person you care for?
11	reaching 'breaking point', where you feel you can't carry on with things as they are?
	Resilience Scale
1	When I make plans, I follow through with them
2	I usually manage one way or another
3	I am able to depend on myself more than anyone else
4	Keeping interested in things is important to me
5	I can be on my own if I have to
6	I feel proud that I have accomplished things in life
7	I usually take things in stride
8	I am friends with myself
9	I feel that I can handle many things at a time
10	I am determined
11	I seldom wonder what the point of it all is
12	I take things one day at a time
13	I can get through difficult times because I've experienced difficulty before I have self-discipline
14	I have self-discipline
15	I keep interested in things
16	I can usually find something to laugh about
17	My belief in myself gets me through hard times
18	In an emergency, I'm someone people can generally rely on
19	I can usually look at a situation in a number of ways
20	Sometimes I make myself do things whether I want to or not
21	My life has meaning
22	I do not dwell on things that I can't do anything about
23	When I'm in a difficult situation, I can usually find my way out of it
24	I have enough energy to do what I have to do
25	It's okay if there are people who don't like me
	Ability to care
1	I have a good level of emotional support
2	My needs as a carer are considered by professionals
3	I am happy with the professional support that is provided to me
4	I feel able to get the help and information I need
5	I have all the practical support I need
	Support for Caring
1	I am satisfied with my performance as a carer
2	I can take care of the needs of the person I am caring for
3	I feel I am able to make the life of the person I am looking after better
4	I can manage most situations with the person I care for
5	I am able to deal with a difficult situation
	Caring Stress
1	I feel depressed due to caring
2	I feel worn out as a result of caring
3	I am mentally exhausted by caring
4	I am physically exhausted by caring
5	I feel stressed as a result of caring
	Caring Choice
1	I feel that my life is on hold because of caring
2	My social life has suffered because of caring
3	I feel I have less choice about my future due to caring
4	I feel I have no control over my own life

Appendix B: Informal caregivers focus group questions

Introduction of Focus Group

“Thank you for participating in this focus group discussion. The session’s goal is to understand your experiences with the OH concept. We conduct this focus group as part of the MONUMENT project, a European project aimed to diminish the burden on informal carers of people living with dementia by providing professional, structural and/or technological support.

With this group discussion, we hope to learn from your experiences, such as, if you have experienced a change in reciprocity between PLWD and the community as well as how the project has influenced your knowledge, transferable skills and self-efficacy.

Your answers will be anonymised and cannot be traced back to you, so please feel free to answer honestly and freely. The session will be recorded for transcription purposes only. The recording will be deleted as soon as the discussion has been transcribed.

Are there any questions before we start? If not, let’s get started.”

Focus Group Questions

Topic	Questions
More access to leisure activities	<ul style="list-style-type: none"> - From your own perspective, do you think the Odense House project has made leisure activities more accessible to informal carers? Can you give examples of that? - Since you joined the Odense House have the number of your leisure activities <ul style="list-style-type: none"> • a) increased • b) decreased • remained the same
Increased knowledge and transferable skills informal caregivers	<ul style="list-style-type: none"> - Do you feel your knowledge relevant to caring for PLWD has <ul style="list-style-type: none"> • a) increased • b) decreased • remained the same by participating in the Odense House project? Can you give examples of that? What specific knowledge did you gain? - Are there any skills that you gained by participating in the Odense House? Can you give examples? <ul style="list-style-type: none"> • Prompts: <i>Communication, Organisational & Team skills, Motivation & Confidence, Resilience</i>
Increased reciprocity between PLWD and their community	<ul style="list-style-type: none"> - Do you feel that the activities of the Odense House have boosted cooperation between PLWD and the inhabitants of the surrounding community? If so, in what way? - Did you receive support or resources from the inhabitants of the surrounding community in any form? If so, in what way? <ul style="list-style-type: none"> • Prompts: <i>funding, donations, help with organising activities, people volunteering as staff or helping with administrative tasks</i>
Better informed (informal tips and tricks from peers)	<ul style="list-style-type: none"> - Via the Odense House you were more in touch with other informal carers. Do you feel that you have learned something new with regard to caring for PLWD from other carers? Can you give examples of it?

Note: PLWD = People Living With Dementia

Appendix C: Informed consent

INFORMED CONSENT FORM FOCUS GROUPS

Title of Project: MOre NUrturing and More Empowerment
Nested in Technology (MONUMENT)

Please tick box if

agreed

1. I confirm that I have understood the information provided and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
3. I understand that any personal information that I provide to the researchers will be kept strictly confidential.
4. I agree to be recorded in group discussions and understand that it is not possible to remove individuals from group recordings in the event of withdrawal from the study.
5. I agree to the use of my anonymised answers and quotes in publications resulting from the study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of person giving consent <i>(if different from Participant)</i>	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix D: MeMo results quantitative part

From the 19 participants that participated in the post-test, 26,3% (5) were known with the MeMo by Monument website. More than 73,7% of the participants did not know about the 'MeMo by Monument' website (Table D.1).

Table D.1 Frequencies whether participants were known with the MeMo by Monument website

Are you known with the 'MeMo by Monument' website?		
	Frequency	Percent
Yes	5	26,3
No	14	73,7
Total	19	100,0

From the 5 participants that were known with the 'MeMo by Monument' website, 3 participants visited the website (Table D.2).

Table D.2 Frequencies whether participants visited the MeMo by Monument website

Did you visit the 'MeMo by Monument' website?		
	Frequency	Percent
Yes	3	15,8
No	2	10,5
Total	5	26,3

The 3 participants that visited the 'MeMo by Monument' website gave a positive net promotor score about the 'MeMo by Monument' website (Table D.3).

Table D.3 Frequencies about the net promotor score of the MeMo by Monument website

On a scale of 1-10, to what extent would you recommend the 'MeMo by Monument' website to other informal carers?		
	Frequency	Percent
6	1	5,3
7	1	5,3
8	1	5,3
Total	3	15,8
Mean	7,00	

In total 1 participant answered that the 'MeMo by Monument' website attributed to more awareness about information that can be used for informal carers (Table D.4).

Table D.4 Frequencies increased awareness of useful information for informal carers

The 'MeMo by Monument' website attributed to more awareness about information that I can use during my informal care.		
	Frequency	Percent
Strongly disagree	0	0,0
Disagree	0	0,0
Neutral	2	10,5
Agree	1	5,3
Strongly agree	0	0,0
Total	3	15,8
Mean	3,33	

Appendix E: Background information qualitative analyses

Table E.1 More access to leisure activities

D1.3.1-D1.3.2 Post-focus group informal carers					
	City of Mechelen (LP)	Norfolk County Council (PP4)	Afeji	National Trust (PP11)	WVO Walcheren (PP12)
Access to leisure activities	No; need more leisure activities in line with their interests	Not delivered	No, more interested in peer support than partaking in leisure activities	Confirmed; making new friends; feeling more supported; feeling more part of the community and less isolated by activities, e.g. the garden;	Not delivered

Note: PLWD = People Living With Dementia

Table E.2 Increased knowledge and transferable skills informal carers

D1.3.1-D1.3.2 Post-focus group informal carers					
	City of Mechelen (LP)	Norfolk County Council (PP4)	Afeji	National Trust (PP11)	WVO Zorg Walcheren (PP12)
Knowledge and transferable skills informal carers	Confirmed; by talking to other carers; understanding and adapting to dementia and PLWD; letting go; asking for help	Not delivered	Confirmed; understanding dementia; aids for dementia; gaining perspective; letting go; relax	Confirmed; by talking to other carers, knowing dementia-friendly places, establishing a network.	Not delivered

Note: PLWD = People Living With Dementia

Table E.3 Increased reciprocity between PLWD and their community

D1.3.1-D1.3.2 Post-focus group informal carers					
	City of Mechelen (LP)	Norfolk County Council (PP4)	Afeji	National Trust (PP11)	WVO Zorg Walcheren (PP12)
Reciprocity between PLWD and their community	No, however, increased visibility	Not delivered	No, however, better reciprocity between local informal caregivers and increased interest in PLWD.	No, however, an uprising interest for PLWD; more resources from informal connections, e.g., with family and/or friends.	Not delivered

Note: PLWD = People Living With Dementia

Table E.4 Better informed by peers

D1.3.1-D1.3.2 Post-focus group informal carers					
	City of Mechelen (LP)	Norfolk County Council (PP4)	Afeji	National Trust (PP11)	WVO Zorg Walcheren (PP12)
Better informed by peers	Exchange of contacts and practical advice help with adaptation to the informal carer situation	Not delivered	Be open and share experiences with others.	Dementia-friendly places to go to	Not delivered

Note: PLWD = People Living With Dementia

Appendix F: COVID-19 impact on data gathering

COVID-19 was not mentioned explicitly in the focus groups to investigate the knowledge and skills and resilience of informal caregivers. However, it was discussed during other research activities. In table F.1, and overview is presented of the partners' impressions.

Table F.1 COVID-19 obstructions

Question	City of Mechelen (LP)	Norfolk County Council (PP4)	Afiji	National Trust (PP11)	WVO Zorg Walcheren (PP12)
Pre-focus group informal carers and PLWD					
What are some of the difficulties you encounter in daily life/when taking care of a person living with dementia?	x	x	x	x	"Social isolation, especially now with COVID-19. The supermarket is too much of a stimulus. Going to a shop is already a high threshold. You have to wear a mouth mask, disinfect your hands and keep your distance. Many people living with dementia try to avoid this."
What is the hardest part of having dementia?	"Important to be challenged, man is in his cocoon, does ask to sit together, time takes a long time, sitting alone, COVID-19 takes even longer, difficult of doing nothing."	x	x	x	x
What is the biggest obstacle in receiving or providing care?	x	x	x	x	"Sometimes the informal carers experience powerlessness. Getting angry only results in struggle, but it is often a matter of finding the balance. Sometimes compromise or accommodation is not possible. "Because of the lockdown, we can't just go to the bookstore. That is really not possible, there is no compromise. Then diversion is often the only option, but that doesn't always work.""
What type of support (professional/ structural/technological) do you think the project should develop?	x	Positive about outside activities → "Following COVID-19 restrictions it is nice to see and speak to people."	x	x	x

Question		City of Mechelen (LP)	Norfolk County Council (PP4)	Afeji	National Trust (PP1)	WVO Zorg Walcheren (PP12)
Pre-focus group stakeholders	Is there anything you need before you can decide to implement the Odensehuis concept in your organisation?	x	x	"Hurdles highlighted: funding, accessibility/transport, COVID-19 crisis"	x	x
Post-informal carers	What type of support (professional/structural/technological) do you think the project should develop?	x	"Overcoming the fear and anxiety of getting out and about caused and exacerbated by COVID-19 lockdowns."	x	x	x
Post-stakeholders	What did you expect from the OH? How satisfied are you with the results?	x	"C. Expecting training and link to hear the activity finder and platform. Numbers on training are good – beyond expectations If COVID-19 hadn't hit, could have done even more"	x	x	x

Note: In the pre-focus group informal carers of the WVO Zorg Walcheren (PP12), informal carers talked about their difficulties due to COVID-19. These difficulties included social isolation, overstimulating environments, keeping up with safety measures, and providing diversions for their PLWD. Informal carers in City of Mechelen (LP) and Norfolk County Council (PP4) agreed with the WVO Zorg Walcheren (PP12) on the difficulties surrounding social isolation. The informal carers in City of Mechelen (LP) described COVID-19 induced social isolation as the hardest part of having dementia since it resulted in PLWD having to sit at home instead of being challenged by outside influences and activities. The feedback in Norfolk County Council (PP4) followed a similar trend.

The pre-focus group stakeholders of Afeji highlighted COVID-19 as one of the aspects that needed to be addressed before they could implement the Odense House concept in their own organisation. Norfolk County Council (PP4) stakeholders, on the other hand, talked about COVID-19 in relation to additional structural support.

During the post-focus group stakeholders, Norfolk County Council (PP4) highlighted that the pandemic had an impact on their organisation's goals. They believed that they could have trained more volunteers without the interference of COVID-19 measurements.

Note: PLWD= People living with dementia