

# The implementation of EHealth in dementia care

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**THE IMPLEMENTATION OF  
EHEALTH IN DEMENTIA CARE:  
LESSONS LEARNED**

Hannah Liane Christie

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# THE IMPLEMENTATION OF EHEALTH IN DEMENTIA CARE: LESSONS LEARNED

PROEFSCHRIFT

Ter verkrijging van de graad van doctor aan de Universiteit Maastricht,  
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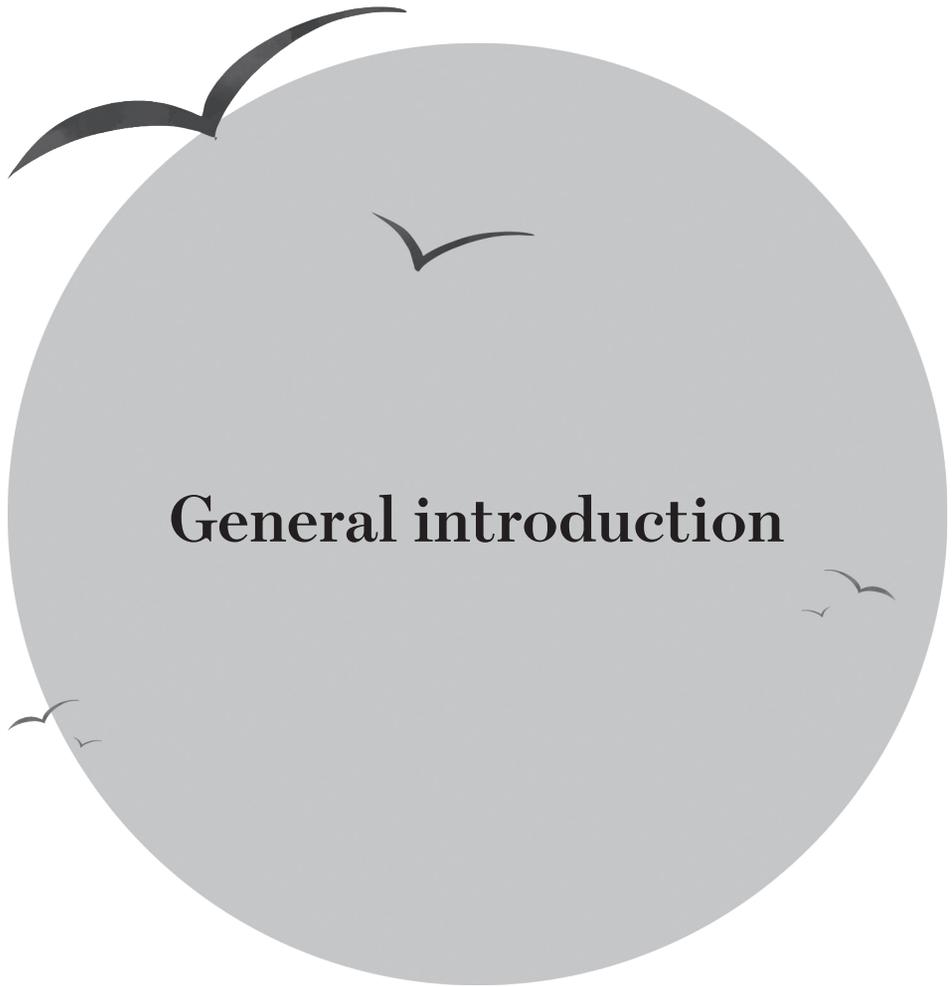
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# General introduction



# 1 DEMENTIA AND INFORMAL CAREGIVING

The combination of an ageing population and declining birth rate is proving a significant challenge for many modern health care systems, resulting in rising costs and spending cuts<sup>1</sup>. In particular, policy makers are worried about the rising cost of dementia care, as there are currently 50 million people with dementia, and this number is set to triple by 2050<sup>2</sup>. Dementia is a progressive, neurodegenerative disease accompanied by cognitive decline in multiple domains, as well as mood and behaviour changes<sup>3</sup>. Dementia has many subtypes, of which the most common subtype is Alzheimer's dementia<sup>4</sup>. Informal caregivers, who are often friends, family, or neighbours of the person with dementia, provide essential care to people with dementia<sup>3</sup>. Informal caregiving is associated with both positive and negative changes for the caregivers and their relationship with the person with dementia. These positive and negative changes can occur at the same time, though the negative changes are often more at the forefront. Positive changes include enrichment of relationships and increased sense of purpose<sup>5,6</sup>. Negative changes include chronic stress, caregiver overburdening, depression, anxiety, social isolation, financial burden, and disturbed sleep<sup>6-9</sup>.

## 2 EHEALTH INTERVENTIONS FOR CAREGIVERS OF PEOPLE WITH DEMENTIA

Recently, eHealth interventions have shown promise as potential solutions to these challenges faced by health care systems, people with dementia, and their caregivers. 'eHealth' is *"the use of information and communication technologies (ICT) for health"*<sup>10</sup>. eHealth interventions are *"treatments, typically behaviourally based, that are operationalised and transformed for delivery via the Internet"*<sup>11</sup>. eHealth interventions can take the form of a web-based course, accessed via desktop; they can also be smartphone or tablet applications aimed at providing support through the expertise of peers.

In general, the advantages of eHealth interventions include easy personalisation, fast delivery, and real-time feedback<sup>12</sup>. In the context of today's ageing population and society's increasing reliance on informal caregiving, eHealth is an especially suitable tool. In this regard, benefits include the potential of eHealth to widen service access to more remote areas, lower thresholds to participation, improve service efficiency, and reduce costs<sup>12,13</sup>. eHealth interventions can also offer dementia-specific advantages, as they can be personalised and adapted to the progressing stages of dementia, offer caregivers psychoeducation without requiring them to leave the person with dementia home alone, and provide support without facing the stigma often present with a dementia diagnosis.

For these reasons, eHealth has become an integral part of many dementia policy plans. In its *eHealth Action Plan 2012–2020*, the European Commission advocated developing more eHealth services, in line with their proposed 'citizen-centric' system of care, which increases socio-economic inclusion and patient empowerment<sup>14</sup>. The Council of the European Union also called for discussions on the use of eHealth and other tools to support people with dementia and their caregivers<sup>15</sup>. Moreover, one of the targets of the WHO action plan for dementia is to *"facilitate access to affordable, evidence-based resources for caregivers to improve knowledge and skills, reduce emotional stress and improve coping, self-efficacy, and health by making use of information and communication technologies such as Internet and mobile phone technologies"*<sup>16</sup>. Such policy plans have created an impetus for change, resulting in the allocation of considerable funds for the development and testing of eHealth interventions.

The subsequent research has produced evidence of the effectiveness of these interventions in improving a wide range of outcomes for caregivers of people with dementia, including increased self-efficacy and dementia caregiving knowledge, as well as the reduction of symptoms of depression and anxiety<sup>17-23</sup>. Regarding which types of eHealth interventions for dementia caregivers are most effective, interventions that are tailored to the individual and multicomponent interventions (interventions with two or more intervention components<sup>24</sup>) have been shown to be more effective than both untailored and single-component interventions<sup>25</sup>. Also, studies have demonstrated that the addition of a coach or other form of person-to-person interaction, also known as the 'blended' aspect of an intervention, significantly enhances outcomes for caregivers of people with dementia<sup>18</sup>.

# 3 IMPLEMENTING EVIDENCE-BASED INTERVENTIONS

In this section, we first discuss the broader context of the implementation of psychosocial interventions for dementia. Next, we introduce the implementation of eHealth interventions in general. Finally, we zoom in on the focus of this thesis, the implementation of eHealth interventions for caregivers of people with dementia. The following section also introduces the theoretical frameworks applied in this thesis, originating from a variety of different disciplines and sectors. These include psychological intervention design and research, implementation science, and (commercial) business modelling.

## 3.1 Psychosocial interventions for dementia

Previous research into psychosocial interventions to support informal caregivers of people with dementia has shown that less than 3% of evidence-based interventions are implemented into practice<sup>26</sup>. Here, implementation refers to *“the process of putting to use or integrating evidence-based interventions within a setting”*<sup>27</sup>. In large part, this is due to a lack of information on barriers and facilitators to their implementation and translation into clinical practice. A contributing factor to this knowledge gap on contextual factors is the current golden standard of randomised controlled trials (RCTs) for effectiveness testing, which often lack the qualitative implementation data necessary to ensure the sustainability of psychosocial interventions<sup>28</sup>. Instead, there is a marked focus on effectiveness research. A frequently used framework that guides much of this intervention effectiveness research is the Medical Research Council’s (MRC) framework for complex interventions<sup>29</sup>. It has been used in a variety of contexts to develop and evaluate complex interventions, including interventions in dementia care<sup>30,31</sup>. Happily, the updated MRC guidelines do emphasise the additional value of a process evaluation along with the effect evaluation. This allows for distinct assessments of intervention fidelity and implementation quality, as well as the identification of contextual implementation determinants<sup>32</sup>. In this manner, the updated MRC framework guides this thesis with its emphasis on investigating contextual determinants and other process characteristics through process evaluations.

## 3.2 eHealth interventions

Regarding the implementation of eHealth specifically, previous research has shown that, like psychosocial interventions in general, its implementation into routine practice has proven challenging<sup>13,33,34</sup>. Again, studies point to a lack of insight into eHealth interventions’ contextual determinants and process changes as important factors in the slow implementation of many eHealth interventions<sup>35</sup>. Common challenges in

implementing eHealth interventions include sparse evidence of their demonstrable effects on improving outcomes for health care organisations, sceptical attitudes from care professionals, insufficient coordination and management of the eHealth intervention, and lack of involvement of end-users in the eHealth development<sup>36</sup>. Moreover, eHealth bypasses traditional care delivery structures. Care organisations and governing bodies have reported that this significantly complicates the implementation of the interventions, as these existing structures and norms are difficult to adapt to adequately integrate eHealth<sup>37</sup>. Decision-makers wishing to implement eHealth have reported little public awareness and confidence in eHealth, lacking evidence of the cost-effectiveness of interventions, insufficient legal clarity (in particular concerning data security and reimbursement), and high start-up costs<sup>38</sup>. For these reasons, there has been a call for more realistic, efficient research designs that take the context of the eHealth intervention into account<sup>39</sup>. Therefore, the second framework applied in this thesis is used to map this underexplored context. This framework is the Consolidated Framework for Implementation Research (CFIR)<sup>40</sup>. The CFIR is an established framework for mapping the implementation of evidence-based interventions, also for eHealth interventions<sup>41</sup>. The CFIR aims to describe determinants, which can be both barriers and facilitators, that affect implementation outcomes. The CFIR is made up of five domains (Intervention characteristics, Outer setting, Inner setting, Characteristics of individuals, and Process), containing 39 implementation constructs. By exploring implementation from a more organisational and longer-term perspective, the CFIR enables the exploration of a broad spectrum of factors related to the successful implementation of interventions, after the trial phase.

Past studies have also advocated borrowing approaches more commonly found in industry and applying this more commercial perspective to the implementation of eHealth interventions<sup>36</sup>. Indeed, there are many commercial eHealth interventions on the market that are not reliably tested for effectiveness<sup>42</sup>. Meanwhile, evidence-based interventions struggle to find their way into the market, partially due the lack of information on the optimal pricing and financing of eHealth implementation<sup>43</sup>. To help address this issue, the final framework shaping this research is the Business Model Canvas (BMC)<sup>44</sup>. The BMC maps a product or service's value proposition, key activities, key resources, key partners, cost structure, customers relationships, distribution channels, and revenue. The BMC has previously been used to map business models for eHealth<sup>45-48</sup>. Applying the BMC to eHealth interventions for caregivers of people with dementia that are already being used in practice, enables the investigation of factors relating to the sustainable success of these interventions and their potential market.

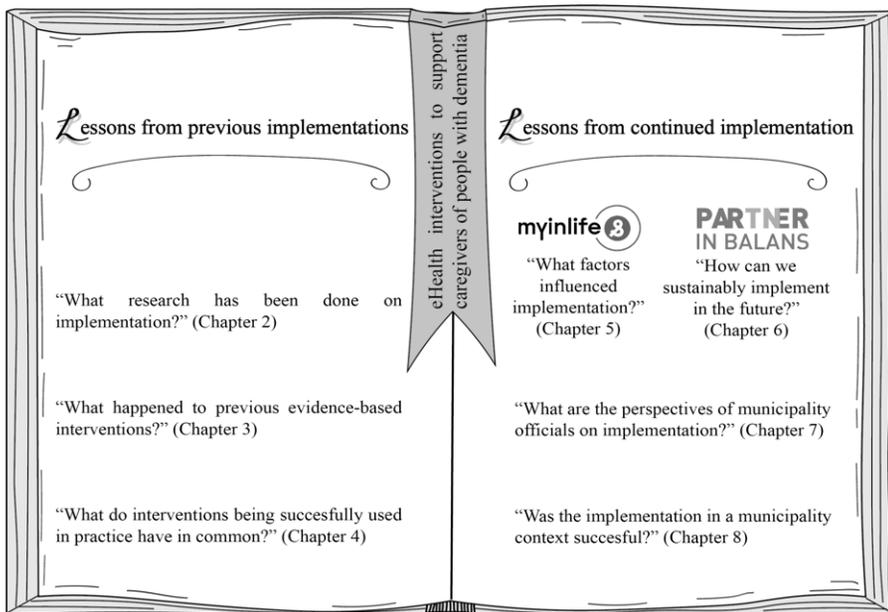
### **3.3 eHealth interventions for caregivers of people with dementia**

Previous research on the effectiveness of eHealth interventions for caregivers of people with dementia has pinpointed a number of implementation challenges specific to the dementia caregiving target population. For instance, the older age of many dementia caregivers is a barrier. Their declining motor, cognitive, and perceptive abilities, as well as the difficulties accompanying the rapidly changing technological market have been described as age-related challenges<sup>49-51</sup>. However, many older adults do show high levels of digital literacy<sup>52</sup>. Research into older adults' attitudes towards eHealth interventions has shown mixed results<sup>53,54</sup>, with evidence suggesting that older adults living in more rural areas show less interest and capacity in adopting eHealth<sup>55</sup>. However, there has been very little systematic, theory-based implementation research regarding the implementation of these eHealth interventions for dementia caregivers outside of an academic research context.

## 4 AIMS AND OUTLINE OF THE THESIS

This introduction makes clear that eHealth interventions show promise as a potential solution to tackle various challenges associated with dementia caregiving, and that more research is needed on how to bring these evidence-based interventions into practice. Therefore, the aim of this thesis is to gain insight into the factors that influence the implementation of eHealth interventions for caregivers of people with dementia. To accomplish this, this thesis explores this topic in two parts.

In part 1, we examine existing eHealth interventions for caregivers of people with dementia, to derive lessons learned from previous, often discontinued, implementations. In part 2, we carry out our own continued implementation of two evidence-based eHealth interventions for caregivers of people with dementia (Myinlife and Partner in Balance), taking into account lessons learned in part 1. The specific chapters and research questions are discussed below, with Figure 1 depicting a visual overview.



**Figure 1.** Overview of the research

In part 1, this project investigates what can be learned from examining previously developed interventions. On the one hand, this approach consists of exploring the existing scientific literature on eHealth interventions for caregivers of people with dementia, that have

been developed in an academic context. To accomplish this, two studies were conducted. The first study is a systematic literature review investigating what previous studies have reported on the implementation of eHealth interventions for caregivers of people with dementia (Chapter 2).

*What has previous research reported concerning the implementation of eHealth interventions for caregivers of people with dementia?*

The second study follows up on a widely-cited systematic review from 2014, to ascertain what happened to promising interventions and map their implementation trajectories (Chapter 3).

*What can be learned from the current implementation status of previous, evidence-based eHealth interventions for caregivers of people with dementia?*

On the other hand, this approach also consists of examining interventions already being used in practice (which did not necessarily originate in an academic context). Hence, the third study explores the business models of eHealth interventions recommended by experts, that are already being used in practice (Chapter 4).

*What can be learned from eHealth interventions for caregivers of people with dementia that are already used in practice?*

In part 2, this project investigates what can be learned from the continued implementation of two existing, evidence-based interventions for caregivers of people with dementia, previously developed and evaluated by the Alzheimer Centre Limburg: Partner in Balance and Myinlife. On the one hand, this consists of conducting more implementation research on these specific interventions. This is done through a process evaluation for Myinlife (Chapter 5) and a Partner in Balance implementation case study (Chapter 6).

*Which factors influenced the implementation of Myinlife?*

*How can Partner in Balance be sustainably implemented in the future, and how can this facilitate the sustainable implementation of future eHealth interventions for caregivers of people with dementia?*

On the other hand, this continued implementation consists of implementing Partner in Balance and Myinlife into a municipality context, through the euPrevent Senior Friendly Communities (SFC) INTERREG project<sup>56</sup>. First, the perspectives of municipality officials on the implementation of eHealth interventions for caregivers of people with dementia in their communities are explored and future implementation strategies are formulated (Chapter 7).

*What are the perspectives of municipality officials on the implementation of eHealth interventions for caregivers of people with dementia in their communities?*

In the next step, this implementation of Partner in Balance and Myinlife in a municipality context is evaluated (Chapter 8).

*Was the implementation of eHealth interventions for caregivers of people with dementia successful in the municipality context, and why?*

Finally, Chapter 9 provides a general discussion and describes the implications of the main findings of this thesis.

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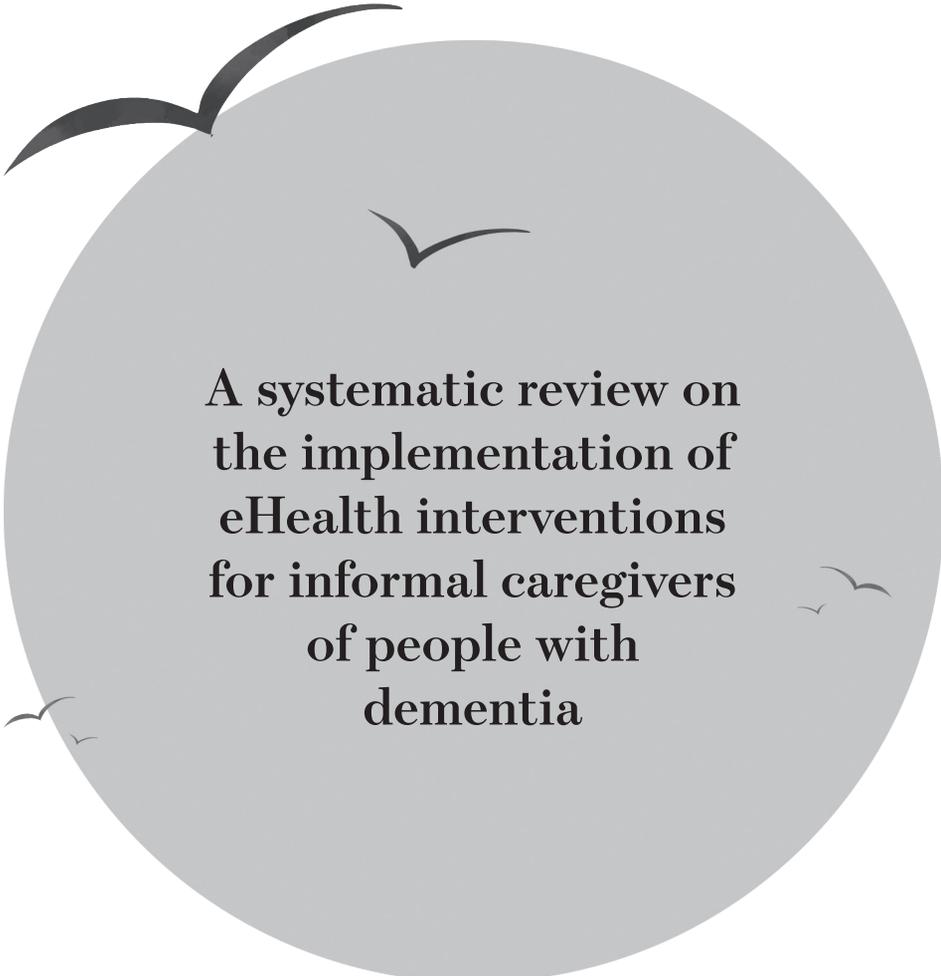
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I



**Lessons from  
previous  
implementations**

2



**A systematic review on  
the implementation of  
eHealth interventions  
for informal caregivers  
of people with  
dementia**

*Internet Interventions, 2018*

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# ABSTRACT

**Objectives:** The objectives were to (1.) systematically review the literature on the implementation of eHealth interventions for informal caregivers of people with dementia, and (2.) identify determinants of successful implementation.

**Methods:** Online databases were searched for articles about eHealth interventions for informal caregivers of people with dementia, providing information on their implementation. Articles were independently screened and inductively analysed using qualitative analysis. The analysis was mapped onto the Consolidated Framework for Implementation Research (CFIR)<sup>1</sup>.

**Findings:** 46 articles containing 204 statements on implementation were included. The statements on implementation were grouped into four categories: Determinants associated with the eHealth application, informal caregiver, implementing organisation, or wider context. Mapping of the determinants on the CFIR revealed that studies have focused mostly on characteristics of the intervention and informal caregiver. Limited attention has been paid to organisational determinants and the wider context.

**Conclusions:** Despite prolific effectiveness and efficacy research on eHealth interventions for caregivers of people with dementia, there is a critical dearth of implementation research. Furthermore, there is a mismatch between eHealth intervention research and implementation frameworks, especially concerning organisational factors and wider context. This review underscores the importance of future implementation research in bridging the gap between research and practice

# 1 INTRODUCTION

Informal caregivers are essential to providing home-based care for people with dementia. Research has shown that the quality of care received by a person with dementia positively relates to a longer time spent being cared for at home, which is critical to the physical and mental health of the person with dementia<sup>2,3</sup>. However, informal caregivers of people with dementia often experience significant physical and psychological problems themselves as a result of this caregiving process, including increases in depression, stress, social isolation, financial burden, and disturbed sleep<sup>4</sup>.

Given these adverse consequences, it is crucial to provide caregivers with tools to help them receive caregiving support, as well as to allow them a life outside of caregiving. With the dementia population (47 million people worldwide) expected to grow threefold by 2050<sup>5</sup>, this increasing need for support has led to many innovative approaches, including those emerging from the promising field of eHealth research. The term 'eHealth' describes "the use of information and communication technologies (ICT) for health"<sup>6</sup>. eHealth interventions are "treatments, typically behaviourally based, that are operationalised and transformed for delivery via the Internet"<sup>7</sup>. For instance, eHealth interventions can take the form of an online course, administered via computer; they can also be smartphone or tablet applications designed to provide psychological support from peers and professionals alike. eHealth interventions have the advantage of a lower threshold of access for participation, as well as the ability to reach more isolated populations who struggle to access traditional services<sup>8</sup>. Recent reviews have shown that eHealth interventions for informal caregivers of people with dementia are effective in improving a range of psychological outcomes in caregivers, such as the reduction of caregiver depression, anxiety, stress and burden, as well as increasing positive aspects of caregiving, caregiver self-efficacy, and confidence<sup>9-14</sup>.

However, despite this proven efficacy, little is known about how to ensure that these interventions are successfully implemented (i.e. put into practice). Previous research on eHealth interventions has shown that, despite their proven efficacy, as well as enthusiasm regarding eHealth from funding and policy institutions, the implementation of eHealth interventions in ageing populations has proven difficult. Reasons for this include older individuals' changes in their perceptual, cognitive, and motor abilities, in combination with the continuing rapid development of new technologies<sup>15</sup>. The objectives of this review are (1.) to explore the evidence on the topic of implementing eHealth interventions for informal caregivers of people with dementia, and (2.) to identify determinants that influenced whether the intervention was successfully implemented. The results of this study will help bridge the gap between our knowledge of the efficacy of eHealth interventions for informal caregivers of people with dementia, and the translation of this knowledge into practice.

## 2 METHODS

### 2.1 Search strategy

A systematic literature search of bibliographic databases PubMed, CINAHL, PsycINFO, Cochrane Library, and Web of Science was conducted in May 2017. The search was aimed at finding articles that contained information on which factors determined the implementation of eHealth interventions for caregivers of people with dementia. In order to accomplish this, the aforementioned databases were searched for articles that contained terms related to all three of the following main concepts: 'dementia', 'eHealth', and 'caregivers'. Relevant MeSH and Thesaurus terms were used, as well as additional non-MeSH terms, so as to identify the full range of indexed and non-indexed articles. Appendix 1 details the employed search strategies: First the union ('OR') of terms to capture articles related to each single main concept, and second the intersection ('AND') of main concepts to focus on the purpose of this review.

The search strategy does not contain relevant terms related to 'implementation' (such as 'facilitators and barriers', 'determinants', or 'implementation'), because the authors anticipated that such terms are often not mentioned in the title and/or abstract. Instead, implementation issues may only be discussed in the body of the text, potentially using different terms. This information could only be assessed by reading the full-texts in a later, post-abstract screening phase. Thus, we aimed to have a complete overview of all research on implementing eHealth interventions for caregivers of people with dementia, without missing important information due to terminology constraints.

### 2.2 Study selection

Titles and abstracts of the identified citations were imported into citation software *Endnote*, deduplicated and independently evaluated by first reviewer (HLC) and second reviewer (SLB). Included references had to involve an (1.) eHealth (2.) intervention for (3.) informal caregivers of people with dementia and (4.) provide information on its implementation. In order to assess whether references met criterion 4 (provides information on implementation), the full-texts were scanned for the presence of determinants of implementation. These were statements about factors that either facilitated or impeded the process.

Non-intervention studies such as reviews, trial protocols, book reviews, and consensus papers were excluded. Otherwise, any design was judged as suitable for inclusion. Studies on assistive technology that were not specifically designed to improve caregiver well-being, as well as telephone-only, video-only, and CD-ROM-based interventions were also not included. Non-English-language publications and articles published before 2007 were

excluded from this review. 2007 was chosen as the cut-off year for this review. It was believed that studies from more than 10 years ago would not provide much additional, relevant information due to the evaluated technologies having become outdated, as well as policies and organisations having changed greatly in the interim. After searching for eHealth “All Fields”, the PubMed-generated histogram ‘Results by year’ showed a rise in eHealth research after 1994, followed by a plateau from 1998 to 2007. After 2007, the number of references recommenced its rise. The authors concluded that 2007, the year of the first iPhone, signified a turning point in mobile technology<sup>16</sup> and a relevant cut-off point. Any disagreements about inclusion were resolved through a consensus meeting consisting of three reviewers; HLC, SLB, and MEdV.

### **2.3 Data extraction**

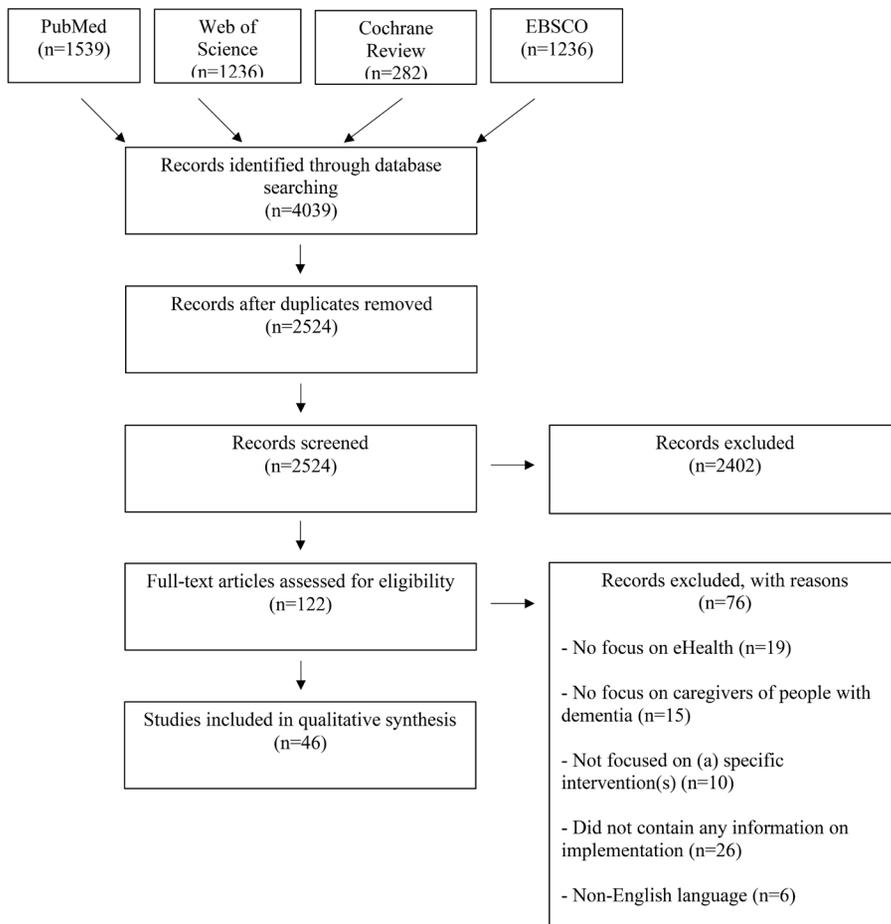
Articles that met all four criteria were compiled into a standardised data extraction instrument as recommended by Cochrane Handbook for Systematic Reviews of Interventions<sup>17</sup> (see link in Appendix 2) detailing primary study characteristics (author/year, design, setting, study population, intervention, measures, findings, and country of study), as well as the extracted determinants. The PRISMA guidelines<sup>18</sup> were used to guide the process of study selection and data analysis. However, not all elements of this guideline were followed as this systematic review focused on process characteristics and not on effectiveness.

### **2.4 Data analysis**

A qualitative thematic analysis was performed in which statements related to eHealth implementation (“the process of putting the intervention into practice”) issues were coded and labelled ‘determinants’. The determinants were inductively grouped to form thematically similar categories, subcategories and groups. The authors opted for an inductive method in order to best scope the available literature and contrast the findings with existing implementation frameworks. Reviewers HLC and SLB independently coded and mapped these determinants by hand, identifying the article as 0 (contains no determinants) or 1 (contains determinants) and mapping these determinants into inductive categories using an online ‘mind mapping’ tool (Google Mindmup 2 software, October 2017 version, developed by Sauf Pompier Ltd.; <https://drive.mindmup.com>). In the next step a consensus meeting was held between reviewers HLC and SLB, with the input of reviewer MEdV. Finally, to structure and contextualise the findings, the resulting analysis was compared and mapped onto the Consolidated Framework for Implementation Research (CFIR)<sup>19</sup>. The CFIR was chosen because it is a commonly used, practical set of constructs, which were readily applicable to eHealth intervention research for caregivers of people with dementia.

### 3 RESULTS

Figure 1 depicts a flow chart illustrating the process of inclusion and exclusion. The search strategy described in Appendix 1 resulted in a total of 2524 records after deduplication. 2401 articles were excluded because they did not meet the criteria of involving an (1.) eHealth (2.) intervention for (3.) informal caregivers of people with dementia. After screening these full texts for the fourth criterion (“provides information on implementation”), 46 records were included, which contained 204 determinants of implementation.



**Figure 1.** Flow chart of process of inclusion and exclusion

The results of this search strategy show that only two of the included 46 references were implementation studies<sup>20,21</sup>. The results of this search strategy show that only one of the included 46 references used the term 'implementation' in the title<sup>22</sup> and one study used the term 'process evaluation' in the title<sup>23</sup>. Four more studies were designed as retrospective evaluations of barriers and facilitators to the development and implementation of eHealth interventions for caregivers of people with dementia<sup>24-27</sup>. The included papers could be classified by type of study as RCTs (n=16), pre-test and post-test mixed methods studies (n=15), qualitative analyses of interviews and other text-based sources (n=14), and quantitative studies, like questionnaires (n=2). When classifying the references by type of intervention, the vast majority of the included interventions concerned web-based platforms for psycho-education and support (n=38). The remaining interventions (n=9) were adaptations of existing in-person psychosocial interventions to technological platforms including individual videophone, group and individual teleconference, and group virtual reality sessions. For a more detailed overview of the types of included interventions, see the Extraction Table included as a link in Appendix 2. The determinants have been grouped together inductively in four thematic categories, namely 'Determinants associated with the eHealth application', 'Determinants associated with the informal caregiver', 'Determinants associated with the implementing organisation' and 'Determinants associated with the wider context'. In the following sections the main findings are presented. Table 1 is an overview of the thematic categories and subcategories.

**3.1 Determinants associated with the characteristics of the eHealth application** The largest thematic category of determinants was 'Characteristics of the eHealth application': 116 of the 204 determinants fell into this category. A large group of the determinants in this category described ways of facilitating the implementation process by making the eHealth application itself more user-friendly. For instance, application developers must make hyperlinks to navigate through the application easily identifiable and consistent. In terms of the development process of the interventions, the importance of user-involvement throughout the whole process and allowing for enough time to improve the website were recurrently identified as important facilitating factors.

**Table 1.** Overview of themes, categories and subcategories, with references

Theme 1: Determinants associated with the eHealth application		Theme 2: Determinants associated with the informal caregiver	
Categories and Subcategories	References	Categories and subcategories	References
<b>User-friendliness</b>	22,23,28-38	<b>Psychological factors</b>	
Development Process	39-42	<i>Expectation of use</i>	36,41
<b>Features of the intervention</b>		<i>Psychological state</i>	22,58,62,63
<i>Suggested improvements</i>	23,32,36,37,39,43,44	<i>Trust</i>	27
<i>Link to social media</i>	36,40,45,32,36,46,47	<i>Autonomy</i>	64
<i>Embodied experience</i>	37,48,49	<i>Motivation</i>	34,36,39
<i>Security</i>	37,50	<i>Confidence</i>	64
<i>Importance of personal contact</i>	51	<i>Frustration</i>	22,42,56
<b>Simplicity</b>	49,51-53	<i>Cyber rapport</i>	22,56
<i>Importance of simplicity</i>	23,24,32,40,46,54,55,27,32,36,56,57	<i>Privacy</i>	25,34,54,57
<i>Security problems with complexity</i>	51,52	<b>Knowledge</b>	
<i>Simple language</i>	24,30,37,38,45,58	<i>Digital literacy</i>	23,24,40,48,54,59,64,65
<i>Information dosage</i>	27,34,40,45,	<i>Mental health literacy</i>	24,27,54
<i>All information in one place</i>	30,32	<i>Learning</i>	24,34
<b>Compatibility</b>		<b>Demographic variables</b>	
<i>Convenience of home</i>	45,57,59	<i>Education</i>	44,58,63
<i>Time</i>	54,55,60	<i>Ethnicity and culture</i>	30 58,66
<i>Cost</i>	32,48	<i>Gender</i>	46,58
<b>Trial factors</b>		<i>Age</i>	26,58,63
<i>Recruitment</i>	40,41,52,59,61	<b>Participation</b>	
<i>Outcomes</i>	32,45,47	<i>Reasons to withdraw</i>	22,34,41
<b>Adaptability</b>	26,27,29,32,34,42,45,49,54	<i>Reasons to participate</i>	64,67
		<b>Relation to person with dementia</b>	
		<i>Dementia diagnosis</i>	40,63
		<i>Relationship</i>	46,58,63
		<b>Workload</b>	27,58,68
		<b>Social Support</b>	69
		<b>Regular usage</b>	54

**Table 1.** Continued

Theme 3: Determinants associated with the implementing organisation		Theme 4: Determinants associated with the wider context	
Categories and Subcategories	References	Categories and subcategories	References
<b>Staff factors</b>		<b>Care policy</b>	48,66,67
<i>Lack of staff</i>	40	<b>Country-specific problems</b>	29,42,61,67
<i>Lack of staff interaction</i>	56	<b>Ethics</b>	
<i>Staff training</i>	44	<i>Informed consent</i>	57
<i>Staff replacement</i>	48	<i>Equal access</i>	57,61
<i>Types of support</i>	30,36,41,42,54,64,70		
<i>Staff attitudes</i>	42,64		
<b>Financial factors</b>			
<i>Funding</i>	40,48		
<i>Face-to-face</i>	23		
<i>Profit</i>	48		
<b>Time available</b>			
<i>Trial period too short</i>	36,39-41,57,60		
<i>Planning</i>	41		
<b>Organisational factors</b>			
<i>Provider collaboration</i>	48,49,64		
<i>Size of organisation</i>	48		
<i>Teamwork</i>	42		
<b>Integration</b>	48,54,56,61,62,64		
<b>Strategies</b>	27,64,71		

Additionally, the included articles listed many 'lessons learned' and a great number of determinants described ways in which the features of the applications could be optimised. First, several determinants specified additional features. A frequently mentioned request from participants was for the addition of a 'search function' to the platform. Next, many determinants stressed the importance of appropriate content: The determinants suggested that the content should take into account the phase of dementia and preferred themes of instruction, and that the developers must also invest in keeping the content up-to-date. Another important feature of an application is its link to social media: The included articles contained several determinants describing the positive effects of social media on the intervention's content and reach. Additionally, one study determined that 'embodied experience' was important for online engagement, and several studies stressed how applications must take appropriate measures to include the maximum amount of security. For instance, several determinants mentioned that continuous troubleshooting

support was essential and that participants experienced concern about a lack of security as a significant barrier. Finally, many determinants proposed that a sense of adaptability and personal contact is what made the intervention effective.

Simplicity was a recurring subject of many implementation determinants. Application users stressed the importance of reducing the amount, spread and complexity of information, adding that complexity is associated with increased security risks. They also preferred the language used to be as simple as possible. Compatibility was another common theme, where determinants described the convenience of the at-home setting of eHealth interventions, the effect of time on both the emergence of effects, as well as on the changing needs of the users and the cost. A large number of determinants described the effect of the trial setting on the interventions and the implementation difficulties these restrictions caused. Finally, human interaction with application featured strongly in the literature, most noticeably in how the participants wanted their application to be adaptable and personalised to their needs.

### **3.2 Determinants associated with the informal caregiver**

The second largest thematic category was 'Determinants associated with the informal caregiver'. Sixty-nine of the 204 determinants fell in this category. Many implementation determinants described certain psychological characteristics of the informal caregiver that facilitated or impeded implementation. These characteristics included the caregiver's expectation of use, their psychological state (though studies reported both positive and negative effects of higher burden on engagement with the intervention), trust, autonomy, motivation, confidence, frustration, cyber rapport and privacy. Of note is that the largest group is 'Privacy', with statements emphasising the anxiety often felt by participants about using technology to document personal issues, and the need to address this barrier.

Another factor that determined an intervention's success in being translated into practice was the informal caregiver's knowledge. For instance, (especially a lack of) digital literacy and mental health literacy, as well as the caregivers' learning styles, were mentioned as determinants by the included studies. Moreover, certain demographic variables such as gender and age were identified as implementation determinants. In particular, ethnicity and culture were frequently mentioned, with determinants suggesting that interventions could have minority-specific effects. Interestingly, education was not described as having a large impact. The informal caregiver's relation to the person with dementia was seen as important. For example, increased severity of the dementia diagnosis was a barrier, though the presence of a formal diagnosis was seen as beneficial. Additionally, the type of relationship to the person with dementia (spouse, child, neighbour, etc.) also played a role. For instance, in one study<sup>46</sup> the relationship correlated with program opinion (husbands

and sons were more positive about the program). Caregiving workload was also identified as an important factor, in that the busier caregivers were, the less usage took place. Finally, social support and regular usage were each reported (once) as facilitating factors.

### **3.3 Determinants associated with the implementing organisation**

This category contained 46 of the 204 determinants. Quite a few included studies mentioned determinants associated with the staff of the implementing organisation. A lack of staff and a lack of interaction with staff were described as barriers to implementation. Staff training, replacement when staff leave, and the presence of staff practitioners were described as facilitators. Certain staff attitudes were cast as negative determinants of implementation. Reluctance about the technology, as well as insecurities (about both ethical and technological issues) were reported as impeding implementation within the organisational context.

Many determinants focused on the barriers posed by financial and time constraints. It was reiterated that including a face-to-face element to the intervention is beneficial, though it increases costs considerably. Some studies specified certain characteristics of the implementing organisation itself. For instance, five determinants stressed that researchers need an intervention “provider” to collaborate with in implementing the intervention. Determinants also stressed the importance of teamwork and highlighted that smaller organisations struggle to provide the necessary support and up-to-date content previously described, due to lack of a PR department and other necessary facilities. The articles also included determinants detailing the barriers posed by this necessary integration of the intervention into existing (care) systems. Among them are privacy issues, competition between organisations, and gatekeeping by members of the organisation. Finally, suggested implementation strategies included reconciling community and organisational characteristics, streamlining processes for monitoring intervention fidelity, and active facilitation of the service uptake.

### **3.4 Determinants associated with the wider context**

This final category is the smallest and contains 20 determinants. Care policy was described in a few articles as an important determinant of implementation. In particular, the limited capability of health insurance authorities to support innovation, and their preference for classically delivered care was identified as a significant barrier. Moreover, many municipalities do not see the added value of a disease-specific tool. However, it was also stated that an important facilitator was that eHealth and its philosophy of self-management fits within recent policy developments. A country-specific facilitator was the Affordable Care Act in the U.S.A. Country-specific barriers included the slow availability of broadband in the Netherlands, and the difficulties associated with Spanish-language

websites, such as barriers with international search engines. Finally, 11 determinants also discussed certain ethical issues encountered in their study, that posed potential barriers in successfully implementing the intervention. In this regard, requirements concerning informed consent were described, as well as a number of issues pertaining to equal access. For instance, within a trial context, all users should be offered training, support, internet access, and all necessary equipment free of charge.

### **3.5 Mapping the determinants**

The Consolidated Framework for Implementation Research (CFIR)<sup>19</sup> offers a framework to contextualise and structure the identified determinants. The CFIR is composed of five major domains: Intervention Characteristics, Outer Setting, Inner Setting, Characteristics of the Individuals Involved, and Process of the Implementation. These domains each contain a number of constructs, which are not discussed in detail here<sup>19</sup>. The majority of the determinants (see the link to the Extraction Table, Appendix 2) identified by this review can be situated under the domain Characteristics of the Intervention and the domain Characteristics of the Individuals Involved (normally, the implementing organisation; here, the informal caregivers) that used them. Very little work has been done on continuing the interventions past their trial phase<sup>72</sup> and evaluating factors associated with the Process, Inner Setting, and Outer Setting. Table 1 confirms that the majority of determinants provide information on how the application and user characteristics might influence successful implementation, while much less is being said about the determinants associated with the implementing organisation and the wider context.

## 4 DISCUSSION

### 4.1 Overview of the existing implementation research

The first objective of this study was to explore what research had been done concerning the implementation of eHealth interventions for caregivers of people with dementia given the abundance of effectiveness trials for these interventions<sup>9-14</sup>. The fact that only one study could be found referring to 'implementation' in its title suggests that implementation research on eHealth interventions for caregivers of people with dementia is still in its infancy<sup>22</sup>. Indeed, the implementation literature is dwarfed by the efficacy literature, though this is by no means specific to eHealth interventions<sup>73</sup>.

### 4.2 Summary of identified determinants of implementation

Despite the paucity of specific implementation research, there were many studies that described valuable experiences and 'lessons learned' in putting interventions into practice. In relation to this study's second objective, summarising what the literature has described as determining factors for implementation, this review has identified four main groups of determinants. This has resulted in a useful overview of the current literature for future researchers to inform the development and implementation of their eHealth interventions for caregivers of people with dementia. For instance, when it comes to designing an eHealth intervention to facilitate implementation, a number of recommendations have been made to increase user-friendliness and design features relevant to caregivers. Furthermore, it is important for applications to be flexible, personalised, and adaptable to the individual needs of the participants. Previous eHealth studies have also underscored the importance of personalisation<sup>74-77</sup>, citing the effect of the perceived increased personal relevance of the intervention. Moreover, this review provides evidence that there are a number of important factors associated with the person of the caregiver. Psychological factors, prior knowledge and learning styles, demographic variables, reasons to participate/withdraw, the relationship of the caregiver to the person with dementia, the availability of social support, and the caregivers' workload and regular usage of the intervention were all reported to influence engagement and subsequent implementation. This (in addition to the frequently mentioned prerequisite of 'personalisation') suggests that there is no 'one size fits all' implementation approach to eHealth for caregivers of people with dementia. As is typical for psychological interventions, it is a matter of 'what works for whom'<sup>78</sup>. The fairly limited amount of studies that discussed determinants associated with the implementing organisation emphasised the importance of staff factors, financial resources, time, organisational factors, and integration into existing systems, in addition to recommending a number of specific strategies. When it came to the wider context, studies stressed the effect of local care policies, as well as ethical dilemmas, that influenced implementation.

### 4.3 A mismatch between implementation research and eHealth research

The two largest themes of determinants were mapped onto the CFIR domains Characteristics of the Intervention and Characteristics of the Individual. There was a marked absence of studies going into depth on the CFIR domains Process, Inner Setting, and Outer Setting. This uneven distribution showcases an important finding of this review: There is a mismatch between the focus of research being conducted on eHealth interventions for caregivers of people with dementia, and the focus of implementation frameworks to guide and assess their implementation.

On the one hand, the focus of the research being conducted on eHealth interventions for caregivers of people with dementia does not match the existing implementation frameworks very well. Specifically, there are two implementation blind spots in the current literature on eHealth interventions for caregivers of people with dementia. First, there is a noticeable lack of research examining the effect of contextual factors, such as the organisation and wider context. This is evidenced by the relatively few articles in the themes 'Determinants associated with the implementing organisation' and 'Determinants associated with the wider context'. The absence of knowledge on the contextual environment creates significant difficulties for health system planners and implementers who aim to translate these interventions into practice<sup>72,79</sup>. Indeed, Goldzweig, et al.<sup>80</sup> propose that, despite its many advantages, the paucity of information on contextual factors and process changes has contributed to the slow implementation of eHealth in general. Second, very few studies place emphasis on the process and time-related factors. For instance, there is a need for studies discussing the iterative process of adapting both the intervention and the organisation (redefining and remodelling, respectively)<sup>81</sup>, and formatively evaluating this adaptation process. Furthermore, the included studies mostly focused on putting the interventions into practice merely in the context of academic research, with very little work being done on continuing the interventions past their trial phase. The CFIR is not alone in emphasising the importance of these contextual and time-related factors, as these are dimensions that recur frequently in many common implementation frameworks<sup>82-85</sup>.

On the other hand, the focus of the implementation frameworks does not match the conducted eHealth research well. Implementation frameworks struggle to encompass the wealth of information from eHealth studies at the level of the end-user (in this case, the informal caregiver). Though the second largest group of identified determinants fell under the theme 'Determinants associated with the informal caregiver', the CFIR and other implementation frameworks have little room to place these end-user determinants. While there are more psychology-related models that emphasise the perspective of the end-user<sup>86-88</sup>, there remains a lack of suitable implementation models to map the complexity of end-users' determinants and interactions with the application. Instead, as is the case

with the majority of implementation frameworks<sup>82-85</sup>, the CFIR describes implementation from the perspective of the implementing organisation: The domain 'Characteristics of the Individual' again refers to the individuals within the organisation, and not the end-users (informal caregivers).

In sum, both eHealth intervention research and organisational implementation research contain gaps of understanding, and future implementation research must take an integrative and multidisciplinary approach in order to be effective. Frameworks such as the Medical Research Council's (MRC) framework for complex interventions<sup>89</sup> can provide guidance for eHealth solutions by placing emphasis on investigating contextual determinants and other process characteristics through process evaluations.

#### **4.4 Limitations**

This study has some limitations. First, the employed search strategy did not include methods of searching grey literature or studies that have not been written up in English. By not including these sources, we may have missed valuable information. Second, because this review's focus was on implementation characteristics, articles were not selected based on the quality of their effectiveness study. However, the included articles were sourced from peer-reviewed journals, signifying that they are all of an academic quality and level. Finally, this review draws on secondary analyses. This highlights the lack of readily available primary data on eHealth intervention implementation, illustrating the need for the collection of such implementation data in future research.

## 5 CONCLUSIONS

This review aimed to explore what is known about the implementation of eHealth interventions of caregivers of people with dementia. Its findings illustrate that little attention has been paid to their implementation in the real world, outside of the academic intervention research context. When research does mention implementation, it is often limited to the characteristics of the application and of the end-users (in this case the informal caregivers). Practical implementation issues, systematically involving organisational factors, and taking into account contextual and societal factors, have largely been neglected. Conclusions drawn from the included non-implementation research nonetheless give insight into a range of ways in which characteristics of the eHealth application, informal caregiver, implementing organisation, and wider context can facilitate their successful implementation.

eHealth interventions show promise for improving the lives of informal caregivers, and reducing future strain on health care services by enabling caregivers to care longer and more ably for their loved ones with dementia. Moreover, eHealth interventions are uniquely suited for widespread implementation due to their low cost, low threshold of access, and potential for personalisation to achieve tailor-made solutions. However, it is imperative that future research prioritises implementation research and evaluates barriers and facilitators to long-term use in the community. Finally, without evidence-based knowledge of effective implementations strategies, researchers developing eHealth interventions for caregivers of people with dementia will be hard-pressed to convince the necessary stakeholders and decision makers of their practical use, and thus allow these innovative and exciting interventions to make a difference in the lives of the caregivers who would (and should) benefit from them.

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# SUPPLEMENTARY DATA

## Appendix 1. Search strategy

1 **PubMed:**((“telemedicine”[All Fields] OR digital[All Fields] OR (“videotape”[All Fields] OR “recording”[All Fields]) OR “videotape recording”[All Fields] OR “video”[All Fields] OR (“telecommunications”[MeSH Terms] OR “telecommunications”[All Fields] OR “telecommunication”[All Fields]) OR telecoaching[All Fields] OR (“telecommunications”[MeSH Terms] OR “telecommunications”[All Fields] OR “teleconference”[All Fields]) OR (“telephone”[MeSH Terms] OR “telephone”[All Fields]) OR “technology”[All Fields] OR (“educational technology”[MeSH Terms] OR “technology”[All Fields] OR “educational technology”[All Fields]) OR (“communication aids for disabled”[MeSH Terms] OR “communication aids for disabled”[All Fields]) OR (“self-help devices”[MeSH Terms] OR “self-help devices”[All Fields] OR “assistive technology”[All Fields]) OR (“internet”[MeSH Terms] OR “internet”[All Fields]) OR virtual[All Fields] OR digital[All Fields] OR (“computers, handheld”[MeSH Terms] OR “computers”[All Fields] OR “handheld computers”[All Fields] OR (“computers”[All Fields] AND “handheld”[All Fields]) OR “computers, handheld”[All Fields]) OR online[All Fields] OR (“electronics”[MeSH Terms] OR “electronics”[All Fields] OR “electronic”[All Fields]) OR game[All Fields] OR gaming[All Fields] OR chat[All Fields] OR skype[All Fields] OR (“smartphone”[MeSH Terms] OR “smartphone”[All Fields]) OR iPad[All Fields] OR web-based[All Fields] OR ICT[All Fields] OR (“blogging”[MeSH Terms] OR “blogging”[All Fields] OR “blog”[All Fields]) OR (“social media”[MeSH Terms] OR “social”[All Fields] AND “media”[All Fields]) OR “social media”[All Fields]) OR “online social networks”[All Fields] OR “text messaging”[All Fields] OR “communications media”[All Fields] OR “multimedia”[All Fields])

**PsychInfo and CINAHL:** ( DE “Assistive Technology” OR DE “Electronic Communication” OR DE “Blog” OR DE “Computer Mediated Communication” OR DE “Electronic Learning” OR DE “Social Media” OR DE “Text Messaging” OR DE “Blog” OR DE “Computer Mediated Communication” OR DE “Electronic Learning” OR DE “Social Media” OR DE “Online Social Networks” OR DE “Text Messaging” OR DE “Communication Systems” OR DE “Telephone Systems” OR DE “Communications Media” OR DE “Audiovisual Communications Media” OR DE “Mass Media” OR DE “Multimedia” OR DE “Telecommunications Media” OR DE “Distance Education” OR DE “Internet” OR DE “Mobile Devices” OR DE “Cellular Phones” OR “assistive technology” OR “electronic communication” OR “blog” OR “computer mediated communication” OR “electronic learning” OR “social media” OR “online social networks” OR “text messaging” OR “communications systems” OR “internet” OR “telephone systems” OR “communications media” OR “audiovisual communications media” OR “mass

media" OR "multimedia" OR "telecommunications media" OR "distance education" OR "mobile devices" OR "cellular phones" OR "smartphone" OR "computer" OR "technology" OR "digital" OR "e-health")

**Web of Science:** (telemedicine OR digital OR video OR telecommunications OR teleconference OR telephone OR technology OR "communication aids for the disabled" OR "educational technology" OR "self-help devices" OR "assistive technology" OR internet OR virtual OR digital OR computers OR electronics OR game OR gaming OR chat OR blog OR Skype OR smartphone OR iPad OR web-based OR ICT OR "social media" OR "online social networks" OR "text messaging" OR "communications media" OR multimedia)

**Cochrane Library:** (telemedicine OR digital OR video OR telecommunications OR teleconference OR telephone OR technology OR "communication aids for the disabled" OR "educational technology" OR "self-help devices" OR "assistive technology" OR internet OR virtual OR digital OR computers OR electronics OR game OR gaming OR chat OR blog OR Skype OR smartphone OR iPad OR web-based OR ICT OR "social media" OR "online social networks" OR "text messaging" OR "communications media" OR multimedia)

- 2 **PubMed:** (("dementia"[MeSH Terms] OR "dementia"[All Fields]) OR "alzheimer's disease"[All Fields] OR "vascular dementia"[All Fields] OR "frontotemporal dementia"[All Fields] OR "dementia with Lewy Bodies"[All Fields])

**PsychInfo and CINAHL:** (MM "Dementia" OR MM "AIDS Dementia Complex" OR MM "Dementia with Lewy Bodies" OR MM "Presenile Dementia" OR MM "Semantic Dementia" OR MM "Senile Dementia" OR MM "Vascular Dementia" OR DE "Alzheimer's Disease" OR "dementia" OR "AIDS dementia complex" OR "dementia with Lewy Bodies" OR "semantic dementia" OR "senile dementia" OR "vascular dementia" OR "Alzheimer's disease")

**Web of Science:** (dementia OR alzheimer's OR "vascular dementia" OR "frontotemporal dementia" OR "dementia with Lewy bodies")

**Cochrane Library:** (dementia OR alzheimer's OR "vascular dementia" OR "frontotemporal dementia" OR "dementia with Lewy bodies")

- 3 **PubMed:** ((caregiv[All Fields] OR caregive[All Fields] OR caregivees[All Fields] OR caregiven[All Fields] OR ("caregivers"[MeSH Terms] OR "caregivers"[All Fields] OR "caregiver"[All Fields]) OR caregiver'[All Fields] OR caregiver's[All Fields] OR caregivering[All Fields] OR caregiveris[All Fields] OR ("caregivers"[MeSH Terms] OR "caregivers"[All Fields]) OR caregivers'[All Fields] OR caregivers'anxiety[All Fields] OR caregivers'burden[All Fields] OR caregivers'complex[All Fields] OR caregivers'coping[All Fields] OR caregivers'efforts[All Fields] OR caregivers'experiences[All Fields] OR caregivers'guides[All Fields] OR caregivers'interest[All Fields] OR caregivers'perception[All Fields] OR caregivers'perceptions[All Fields])

OR caregivers'perseverance[All Fields] OR caregivers'practice[All Fields] OR caregivers's[All Fields] OR caregivers'spouses[All Fields] OR caregivers'status[All Fields] OR caregivers,[All Fields] OR caregiversas[All Fields] OR caregiversassessing[All Fields] OR caregiverschildren[All Fields] OR caregivership[All Fields] OR caregiversrehabilitation[All Fields] OR caregiverss[All Fields] OR caregiverssthe[All Fields] OR caregiverteam[All Fields] OR caregivervoices[All Fields] OR caregives[All Fields] OR caregiving[All Fields] OR caregiving'[All Fields] OR caregivinghood[All Fields] OR caregivingxtemperament[All Fields] OR ("family"[MeSH Terms] OR "family"[All Fields]) OR partner[All Fields] OR "informal caregiver"[All Fields] OR ("spouses"[MeSH Terms] OR "spouses"[All Fields] OR "spouse"[All Fields]) OR ("spouses"[MeSH Terms] OR "spouses"[All Fields] OR "husband"[All Fields]) OR ("spouses"[MeSH Terms] OR "spouses"[All Fields] OR "wife"[All Fields]) OR "significant other"[All Fields] OR ("family"[MeSH Terms] OR "family"[All Fields]) OR ("caregivers"[MeSH Terms] OR "caregivers"[All Fields] OR "carer"[All Fields]))

**PsychInfo and CINAHL:** ( DE "Caregivers" OR DE "Spouses" OR DE "Husbands" OR DE "Wives" OR "caregiv\*" OR "spous\*" OR "husband" OR "wives" OR "wife" OR "family" OR "partner" OR "carer" )

**Web of Science:** (caregiv\* OR carer OR family OR partner OR spouse OR husband OR wife OR "significant other")

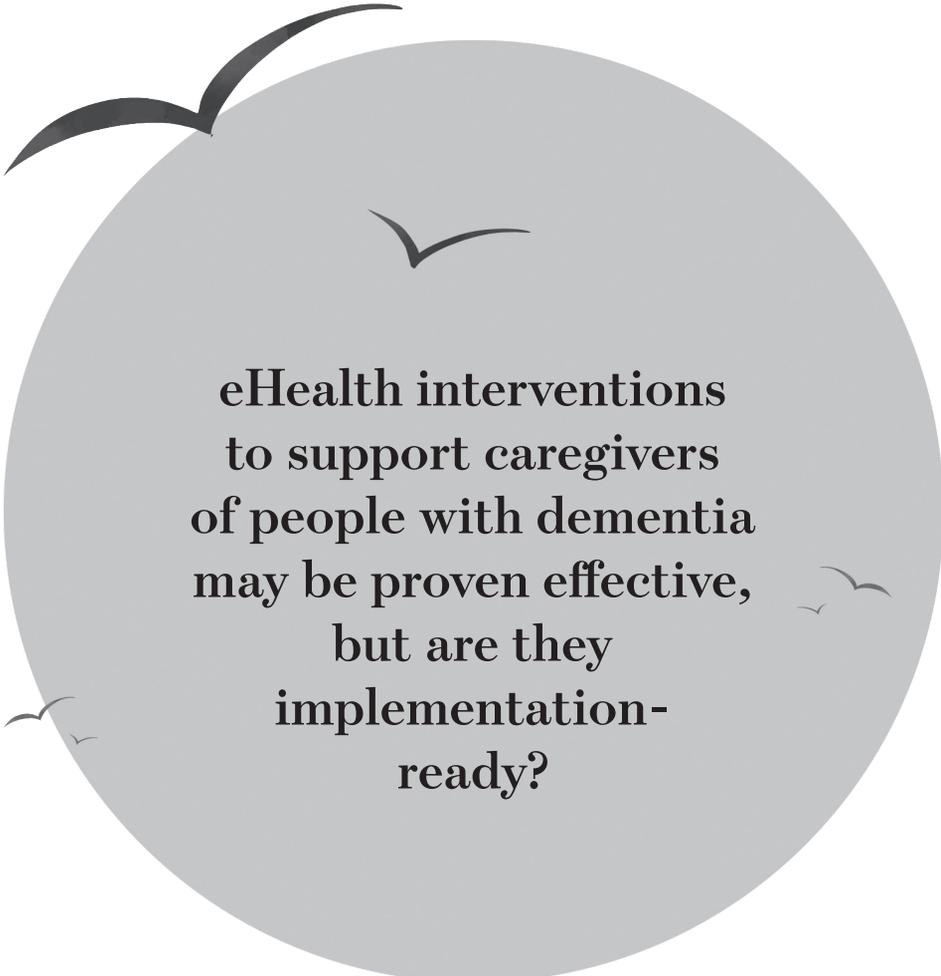
**Cochrane Library:**(caregiv\* OR carer OR family OR partner OR spouse OR husband OR wife OR "significant other")

#### 4 #1 AND #2 AND #3

### Appendix 2. Extraction Table

See: [https://www.researchgate.net/publication/327621396\\_Appendix\\_B](https://www.researchgate.net/publication/327621396_Appendix_B)

3



**eHealth interventions  
to support caregivers  
of people with dementia  
may be proven effective,  
but are they  
implementation-  
ready?**

*Internet Interventions, 2019*

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# ABSTRACT

**Objectives:** A variety of health services delivered via the Internet, or “eHealth interventions,” to support caregivers of people with dementia have shown evidence of effectiveness, but only a small number are put into practice. This study aimed to investigate whether, how and why their implementation took place.

**Methods:** This qualitative study followed up on the 12 publications included in a widely cited systematic review on eHealth interventions for informal caregivers of people with dementia<sup>1</sup>, in order to explore further implementation into practice. Publicly available online information, implementation readiness (Impress checklist scores), and survey responses were assessed.

**Findings:** Two interventions were freely available online, two were available in a trial context, and one was exclusively available to clinical staff previously involved in the research project. The remaining seven were unavailable. All scores on the ImpRes checklist were at 50% or lower of the total, indicating that the interventions were not ready to implement at the time of the review, though some interventions were scored as more implementation-ready in subsequent follow-up publications. Responses to the survey were received from six out of twelve authors. Key learnings from the survey included the importance of the involvement of stakeholders at all stages of the process, as well as the flexible adaptation and commercialisation of the intervention.

**Conclusions:** In general, low levels of implementation readiness were reported and often the information necessary to assess implementation readiness was unavailable. The only two freely available interventions had long-term funding from ageing foundations. Authors pointed to the involvement of financial gatekeepers in the development process and the creation of a business model early on as important facilitators to implementation. Future research should focus on the factors enabling sustainable implementation.

# 1 INTRODUCTION

Globally about 50 million people are living with dementia. This number is expected to triple by 2050<sup>2</sup>. Informal caregivers often experience substantial physical and psychological problems as they care for people with dementia<sup>3,4</sup>.

Regarding psychosocial interventions to support informal caregivers of people with dementia, Gitlin, et al.<sup>5</sup> reported that less than 3% of these interventions that are effective in research studies, are put into practice. This is due to a lack of research into facilitating and impeding factors for the continuation of use in clinical practice, insufficient theories to understand implementation challenges, lack of funding, and ill-fitting financial frameworks for sustaining interventions. One type of psychosocial intervention that may help informal caregivers maintain their well-being and so cope better for longer, is eHealth. eHealth interventions can be defined as “*treatments, typically behaviourally based, that are operationalised and transformed for delivery via the Internet*”<sup>6</sup>. These interventions often include self-guided, interactive, and personalised programs. Reported benefits to using eHealth interventions (not specifically for caregivers of people with dementia) over traditional face-to-face interventions include relatively easy scale-up, wide accessibility despite differences in the socioeconomic and demographic backgrounds of users, personalisation, instant delivery, and real-time feedback<sup>7</sup>.

eHealth has so far generated much enthusiasm from funding and policy institutions. In the Netherlands, the national dementia action plan, the *Deltaplan Dementie*<sup>8</sup>, includes the promotion of innovations in eHealth as one of its goals to improve dementia care practices for both people with dementia and caregivers. In its *eHealth Action Plan 2012-2020*, the European Commission asserted that eHealth enables a more ‘citizen-centric’ system of care by increasing socioeconomic inclusion, patient empowerment, and access to services and information<sup>9</sup>. The Council of the European Union called for discussions on the use of eHealth and other tools to support and care for people with dementia and their caregivers<sup>10</sup>. Moreover, one of the target goals of the WHO action plan for dementia is to “*facilitate access to affordable, evidence-based resources for carers to improve knowledge and skills, reduce emotional stress and improve coping, self-efficacy, and health by making use of information and communication technologies such as Internet and mobile phone technologies*”<sup>11</sup>. Such action plans have created a political impetus for change, resulting in the allocation of resources for the development and evaluation of eHealth interventions.

Numerous systematic reviews report improvements in informal caregivers’ well-being through eHealth interventions<sup>1,12-18</sup>. Generally, studies find positive gains in caregivers’ self-efficacy, competence, and knowledge about dementia, as well as a reduction of depressive

symptoms. Multicomponent interventions (interventions with two or more intervention components<sup>19</sup>) are often more effective than interventions focused on one area alone<sup>20</sup>. Some examples include online self-management courses for dementia, via desktop browser; other examples are apps to deliver and facilitate psychological support from both fellow caregivers and health care professionals.

Christie, et al. <sup>21</sup> showed that the bulk of research on eHealth interventions for caregivers of people with dementia has focused on the trial phase, with almost no studies examining their implementation. Decision-makers looking to implement these interventions also find there is a lack of public awareness and confidence in eHealth, limited evidence of the cost-effectiveness of interventions, lack of legal clarity (especially with regard to data protection and reimbursement), and high start-up costs<sup>22</sup>. Moreover, implementing eHealth interventions for ageing populations has specific challenges, including changes in motor, cognitive, and perceptive abilities with age, in combination with the continuing, fast-paced evolution of modern technologies<sup>23</sup>. These implementation barriers hinder the use of eHealth interventions across various fields in practice<sup>24</sup>. Instead of doing another systematic review on the effectiveness of eHealth interventions for caregivers of people with dementia, the aim of this study was rather to better understand the implementation trajectories of evidence-based eHealth interventions for informal caregivers of people with dementia and how they can be implemented in practice, by the follow-up of the interventions highlighted in a previous systematic review<sup>1</sup>.

## 2 METHODS

### 2.1 Study selection

Due to this study's aim to follow up on a select sample of evidence-based interventions from a high quality and highly-cited systematic review, only studies from a single systematic review were included. Boots, et al.<sup>1</sup> was selected, as it was widely-cited (171 citations reported by Google Scholar as of January 2019) and presented data on 12 studies of 'internet-based' interventions for informal caregivers of people with dementia, published between 1995 and 2013. At the time of its publication, eHealth was an established field with many intervention studies published. Earlier reviews (pre-2014) tended to include more studies of interventions containing technology that is no longer in use or that is incompatible with current software and hardware requirements. On the other hand, the authors propose that a more recent review (between 2014 and 2017, the time of this study's design) would not have allowed for sufficient time to implement the interventions, as it is the authors' understanding that the eHealth implementation process tends to take several years post-efficacy trial. The inclusion criteria for the Boots, et al.<sup>1</sup> review were that the study (i) reported the effects of an intervention; (ii) was Internet-based; and (iii) was aimed at informal (nonprofessional) caregivers; of (iv) people with mild cognitive impairment or dementia. Examples of reviewed eHealth interventions include: Online psychoeducation courses with and without coach, web-based support via video conferencing, caregiver-therapist email support, etc. More details on the included studies' efficacy and outcomes can be found in Boots, et al.<sup>1</sup>.

### 2.2 Study design

This is an exploratory, qualitative study using data gathered from following up on a sample of studies, using information publicly available on the internet, information on the implementation readiness reported by the publications, and authors' survey responses.

### 2.3 Data collection

First, data was collected on what information about the 12 eHealth interventions could be found by searching the internet. A data extraction form listing the studies' intervention descriptions, funding, number of citations, availability, follow-up information, and survey participation was compiled (Appendix 1). Furthermore, in order to assess the most recent studies investigating the same or a later version of the intervention, a PubMed and Google Scholar search looking for articles including the intervention name, and published after the included article date, was conducted. Additionally, publications from the involved authors were scanned to assess whether any new publications referenced new iterations of the original intervention (perhaps now under a different name).

Second, implementation readiness of both the original articles included in the Boots, et al.1 review and the follow-up articles identified by the PubMed and Google Scholar search was assessed using the ImpRes checklist, a checklist for evaluating readiness for implementation of manualised interventions<sup>25</sup>. This instrument was chosen as it was developed to assess whether evidence-based interventions are ready to implement following their efficacy trials, prior to identifying an organisational implementation context. The ImpRes checklist consists of 26 questions (Box 1), grouped into ten themes and scored with 0, 1, or 2 points per question, making for a minimum total score of 0 and a maximum total score of 52. A score of 0 signifies that no information was provided, a score of one signifies that the question was partially answered, and a score of two signifies a fully answered question. Themes are not weighted and the total score serves as the indication of implementation readiness. The coding was carried out by author HLC. The ImpRes scores were compiled for both the included interventions from the Boots et al. review<sup>1</sup>, as well as for their follow-up studies identified by the internet search, described above (if applicable). Filling in the ImpRes checklist for these subsequent studies was done to take into account the fact that implementation information is sometimes not reported in efficacy studies. Assessing the follow-up publications was deemed necessary to provide more insight into how these interventions develop and how implementation readiness may or may not have been reported since the effectiveness study. This is because effectiveness studies do not provide much information about implementation issues and subsequent publications often do. It was thought that all checklist themes, including the themes measuring the employee and manager support were a relevant and necessary part of all eHealth interventions, including the psychoeducation platforms. This is at the least true for the reason that the software must be consistently updated, but also for keeping the information provided up-to-date.

Finally, a survey of open-ended questions about the researchers' experiences with the development and implementation of their eHealth interventions was developed, examining the current status of the intervention, the latest evidence of the effectiveness, and perceived facilitators and barriers to its development and implementation. The survey was piloted and reviewed by a researcher from Maastricht University involved in the development of an eHealth intervention for informal caregivers of people with dementia, not included in the review. Based on the feedback from this piloting, necessary modifications to the survey (including more specifically worded questions) were made. Box 2 contains the questions included in the final version of the survey. The survey was sent to the authors via email, and respondents were given two weeks to complete the survey. Multiple reminders were sent after the two-week period to encourage response. If there was no response by the first author, the last author was then invited to complete the survey and reminders were sent after two weeks. Researchers who did not agree to the informed consent were not included in this study.

<b>Box 1. ImpRes questions</b>		
Theme	Question	
Motivation	1.	Does the existing evidence suggest the intervention is likely to be cost-effective?
	2.	Does the existing evidence suggest the intervention is likely to be effective for the primary outcome?
	3.	Does the existing evidence suggest the intervention is likely to be effective for other key outcomes?
	4.	Are there other benefits for the patient (qualitative)?
	5.	Are there benefits for the organisation?
Theory of change	6.	Are the outcomes clearly defined?
	7.	Is how the intervention works clearly defined?
	8.	Is the design suitable for the kind of intervention (RCT)?
Implementation	9.	Is there a coherent theoretical base?
	10.	Is the intervention standardised?
Experience	11.	Can it be widely implemented into practice (following on from a research setting)?
	12.	Are the skills and experience of the person delivering the intervention clearly described?
Planning consultations	13.	Is there monitoring of the delivery (attendance/adherence) of the intervention?
	14.	Is the amount of time necessary to set up the intervention specified?
Delivery collaborations	15.	Is the planning and setting up of the sessions clearly defined?
	16.	Does it specify the amount of time required for each session and for the duration of the programme?
Manager support	17.	Are the potential facilitator and barriers to the delivery of the intervention described?
	18.	Is the level of managerial support described during the intervention/evaluation?
Employee support	19.	Is the level of support required by staff members to deliver the intervention described?
Resources	20.	Are the resources required to deliver the intervention specified?
	21.	Are the training costs specified?
	22.	Are the training materials specified?
	23.	Are there manuals for the intervention?
	24.	Are the materials easy to source?
Population characteristics	25.	Are the population characteristics specified?
	26.	Does it specify who benefits most from the intervention?

**Box 2.** Survey questions

1. Is the intervention currently available to purchase or otherwise obtain?
2. If yes, how can someone get access the intervention? Who is this intervention available to?
3. Are you aware of it being used in practice now (please provide details)?
4. Is there any additional evidence (besides the effectiveness paper included in Boot's 2014 review) on the intervention's effectiveness?
5. What were barriers to the development of the intervention?
6. What were barriers to the implementation of the intervention?
7. What were facilitators to the development of the intervention?
8. What were facilitators to the implementation of the intervention?
9. How widespread is its use?
10. Which countries is it used in?
11. Do you have any recommendations for developing and implementing eHealth interventions for caregivers of people with dementia (lessons learned)
12. Did you use any theoretical models for the development/implementation of your intervention (for example, the MRC framework)? If so, what were your experiences with the model(s)?

**2.4 Data analysis**

By compiling information on the interventions' content, funding, number of citations, availability, follow-up information, and survey participation (Appendix 1), the authors compared these characteristics in the interventions that could still be found online, versus these characteristics in the interventions that could not be found. When comparing the two groups regarding these characteristics, the authors attempted to discern whether there were any characteristics that typified either group, and whether they might contribute to enduring intervention use. The survey responses were compiled and analysed using thematic content analysis<sup>26,27</sup>. Two researchers (JC and HC) performed the analysis independently, using inductive reasoning and constant comparison, in order to identify categories across the questions asked in the survey. In doing so, open codes were applied to survey responses. After thorough reading, categories and higher-order themes were constructed by merging the open codes. A consensus meeting was held with the two analysers and MdV to discuss and resolve any discrepancies in the two analyses. Analysis was performed with the software package Atlas.ti 8.2 for Macintosh (Atlas.ti Scientific Software Development GmbH, 2018) and mind maps were created.

## 3 RESULTS

### 3.1 Available online information

The initial internet search investigated the current status and focus of the interventions listed in the review (see Appendix 1). If no up-to-date information could be found through a Google search using the intervention's and/or author's name, it was assumed that the intervention was no longer available. If up-to-date information could be found, the interventions were referred to as 'still- available'. This search showed that websites of five of the interventions appeared to be up and running: Four under the same intervention name<sup>28-31</sup> and one under a changed name<sup>32</sup>, while no up-to-date information could be found for the remaining seven interventions. The content of these still-available interventions could be grouped into web- and peer-based support (1) and psychoeducation (4). The interventions' associated publications had been cited a median of 46 times, ranging between 5 and 322 (as of November 2018). Funding for the interventions (and their associated publications) could be categorised into six groups: National health and ageing institutes (4), regional ageing institutes (3), university department grants (2), national ministry of economic affairs (1), Alzheimer's foundation (1), and unknown (2).

The PubMed search for subsequent publications using the intervention's name resulted in a total of five follow-up publications (Appendix 1). Two papers were about the randomised controlled trials (RCTs) of adapted versions of the interventions<sup>33,34</sup>, one paper was a qualitative analysis based on the same study as the original included publication<sup>35</sup>, one publication was a study examining clinicians' and clients' satisfaction with intervention training and delivery of a later version of the intervention<sup>36</sup>, and one publication was a cost justification analysis<sup>37</sup>. Otherwise no follow-up publications examining subsequent implementation were found. Of the five interventions with a follow-up paper, two are still available to use<sup>29,32</sup>.

### 3.2 Implementation readiness

In order to assess whether the included studies were indeed ready to be implemented at the time of their publication, the studies included in the Boots et al. review<sup>1</sup> were scored using the Implementation Readiness (ImpRes) checklist<sup>25</sup>. The ImpRes checklist was derived from a set of criteria for evaluating the quality of reporting of the implementation of workplace interventions, and was adapted using the Medical Research Council framework to assess more implementation barriers for cognitive stimulation therapy (CST). The checklist is a new tool, with little usage and reliability data available, though it demonstrated a 99,4% inter-rater reliability during development<sup>25</sup>. It was chosen for its unique ability to assess implementation readiness of evidence- based interventions, without requiring the intervention to have yet been implemented in an organisational

context, as this is often not yet the case in effectiveness trials. One publication<sup>30</sup> could not be accessed - both author Boots and author Coulehan corresponded that they were no longer in possession of the original publication, a conference presentation. The average checklist score was 19. The scores ranged between 13 and 26 (out of a maximum of 52). Overall, the results showed that the publications included in Boots, et al.<sup>1</sup> achieved the highest ImpRes scores for the themes Theory of change, Implementation, and Population characteristics. These publications achieved the lowest ImpRes scores for the themes Manager Support, Employee Support, and Resources (Table 1).

The five follow-up studies found through the PubMed and Google Scholar search achieved an average ImpRes total score of 27 (range 8-26), with an average improvement of 5 points with the original article's score (Table 2).

### **3.3 Survey responses**

The overall participation rate for the survey was 6/12 (50%). Five authors filled in the survey, one responded to the email and provided a written update on the intervention in question. Two additional authors declined to participate. No response was received from the remaining four authors, who could not be traced.

The responses to the survey came from authors involved in the interventions tested in Coulehan<sup>30</sup>, Lewis, et al.<sup>29</sup>, Marzali and Garcia<sup>32</sup>, Ducharme, et al.<sup>31</sup>, and van der Roest, et al.<sup>38</sup>, with additional email correspondence from the first author of the Beauchamp, et al.<sup>39</sup> publication. Three of the respondents reported that their interventions<sup>29,38,39</sup> were no longer available for use. Three of the respondents reported that their interventions<sup>30-32</sup> were currently still available. Of these interventions that were still available, one<sup>32</sup> had been integrated into a larger portal that develops patient-owned electronic health records, one<sup>30</sup> is aided by funding from the National Institute on Aging of the interventions, and one is still being tested in an academic trial setting<sup>31</sup>.

Based on the survey responses, three themes emerged from the researchers' responses to the questions in Box 1. These themes were the 'Iterative Development Process', the 'Flexible and Personalised Content', and the 'Integrated Delivery of the Intervention' (Table 3). The themes are illustrated by quotations in the next sections.

#### **3.3.1 Iterative Development Process**

The first theme that arose out of the data is the 'Iterative Development Process'. When questioned about their experienced implementation facilitators, respondents emphasised the following facilitators: The involvement of stakeholders at all stages of the process (development, evaluation, and implementation).

*"Involve your target audience as much as possible from the earliest stage of development (needs assessment stage)." Respondent A*

*"Conduct a pilot-study with few caregivers before a larger study. From the beginning of the project, involve a community organisation supporting caregivers to ensure the sustainability of the intervention." Respondent B*

When asked about their recommendations for future developers of eHealth interventions for caregivers of people with dementia, respondents recommended a non-linear process for solving technical problems. Some respondents noted that during the research phase, researchers should start with feasibility tests of small samples.

*"Testing user-friendliness and usefulness in one study is not the best thing to do. If people cannot work with the tool, the usefulness will not be salient, because the tool will not be used. Better to test in two separate studies. And test effectiveness only when a product is in the final stage."*  
Respondent C

### **3.3.2 Flexible and Personalised Content**

The theme of 'Flexible and Personalised Content' highlights the importance of the flexible adaptation of the intervention. One recommendation was:

*"Adapt the content and the technology to the target audience as much as possible." Respondent A*

Researchers also provided responses to questions inquiring as to the various psychosocial theories that guided content development. One respondent stated that the standardised education model of the intervention in question was no longer used, as new interventions instead emphasised flexibility. In its further development and current iteration, the focus was placed on tailoring intervention content and technology to the caregivers' needs.

*"Since the 2014 publication intervention has been further developed with emphasis on caregivers/ patients taking the lead in customising change behaviours based on their self-defined needs."*  
Respondent D

Other theories that were reported to have influenced the intervention's design and content were Social Cognitive Theory, Stress Process Model, and Cognitive Behavioural Psychology.

**Table 1.** ImpRes scores

Author(s)/year from Boots et al. <sup>1</sup>	Total score  (max score 52)	ImpRes	Summary scores	
		Motivation  (max score 10)	Theory of change  (max score 8)	Implementation  (max score 4)
Beauchamp et al., 2005	21	6	8	2
Brennan et al., 1995	25	4	8	3
Chiu et al., 2011	23	3	8	3
Ducharme et al., 2011	21	5	8	3
Glueckauf et al., 2004	20	2	8	3
Kelly, 2004	8	2	2	2
Lai et al., 2013	13	1	7	2
Lewis et al., 2010	21	6	8	3
Marziali and Garcia, 2011	26	4	8	2
Torp et al., 2008	17	4	5	3
van der Roest et al., 2010	13	4	5	2
Average total score	18,9	3,7	6,8	2,5
Average percentage max score	36%	37%	85%	64%

**Table 2.** ImpRes follow-up scores

Author(s)/year from Boots et al. <sup>1</sup>	Author(s)/year of follow-up article	Total follow-up ImpRes score  (max score 52)	Summary scores	
			Motivation  (max score 10)	Theory of change  (max score 8)
Brennan et al., 1995	Payton et al., 1995	36	6	8
Chiu et al., 2009	Chiu & Eysenbach, 2011	24	3	8
Lewis et al., 2010	Griffiths et al., 2015	26	6	8
Marziali and Garcia, 2011	Nalder et al., 2018	29	5	8
van der Roest et al., 2010	Van Mierlo et al., 2015	19	5	6
Average total		26,8	5,0	7,6
Average percentage max score		52%	50%	95%

Experience (max score 4)	Planning consultations (max score 4)	Delivery collaborations (max score 4)	Manager support (max score 2)	Employee support (max score 2)	Resources (max score 10)	Population characteristics (max score 4)
0	0	2	0	0	0	2
1	1	3	0	1	0	4
3	0	2	0	0	0	4
3	0	2	0	0	0	4
2	1	2	0	0	0	2
0	1	0	0	0	0	1
0	2	0	0	0	0	1
0	0	0	0	0	0	4
2	2	4	0	0	2	2
0	0	3	0	0	0	2
0	0	0	0	0	0	2
1,0	0,6	1,6	0,0	0,1	0,2	2,5
25%	16%	41%	0%	5%	2%	64%

Implementation (max score 4)	Experience (max score 4)	Planning consultations (max score 4)	Delivery collaborations (max score 4)	Manager support (max score 2)	Employee support (max score 2)	Resources (max score 10)	Population characteristics (max score 4)
3	3	1	3	3	1	4	4
3	3	0	3	0	0	0	4
3	2	1	2	0	0	0	4
4	2	2	4	0	0	2	2
2	2	0	2	0	0	0	2
3,0	2,4	0,8	2,8	0,6	0,2	1,2	3,2
75%	60%	20%	70%	15%	10%	12%	80%

**Table 3.** Summary of survey themes and subthemes

1. Iterative Development Process	2. Flexible, Personalised Content	3. Integrated Delivery of Intervention
a. Early involvement of stakeholders	a. Tailoring to needs caregiver	a. Cooperation from health care organisations
b. Small sample tests	b. Theoretical models <i>Standardisation</i> <i>Social Cognitive Theory Stress</i> <i>Process Model Cognitive</i> <i>Behavioural</i>	b. Commercialisation and early development of business model
c. Non-linearity		c. Funding

### 3.3.3 Integrated Delivery of the Intervention

The last theme from the survey responses regards those facilitators mentioned by the respondents that related to the 'Integrated Delivery of the Intervention'. One recurring facilitator was the continuing involvement of all stakeholders in ensuring the interventions be sustainably implemented into practice and reach the informal caregivers, through collaboration with health organisations, research institutions, non-governmental organisations, or private companies. Survey respondents viewed this integrated delivery of their interventions as important and considered the fragmentation of care systems to be a barrier to doing so. Commercialisation and having a business plan were identified as facilitators to implementation.

*"A business model that promotes shared responsibility for maintenance of [intervention C], instead of responsibility with one party."* Respondent C

*"We believe that only by commercialisation will it be possible to disseminate and mobilise use of [intervention D]."* Respondent D

*"There were several thoughts about ways to get it out to the public, but I don't believe they materialised. I no longer work for the company that created it, and in fact, the company has folded."* Respondent E

*"Fragmentation and changes within care landscape, makes it difficult to get an up-to-date overview of available services. Information on care organisations necessary to develop demand driven ontology and algorithms are not always easy available. Collaborations with researchers, end-users and developers/programmers is not easy because of different perspectives."* Respondent C

One respondent mentioned organisational sponsorship as an important facilitator, but also said that the professionals' lack of training on eHealth interventions or reluctance to depart from traditional interventions could be a barrier to collaboration. The unfamiliarity of both caregivers and staff with the intervention technology was seen as a barrier to implementation.

*"The greatest barrier has been health care professionals' and organisations' reluctance to use technology (largely group video conferencing) to deliver online evidence-based intervention programs – preferring to continue to use interventions aligned with their professional training."*

Respondent D

*"Based on my experience with the [intervention F] trial, and thinking beyond the trial to broader dissemination/implementation, I think some kind of organisational sponsorship – a health care company, an insurer, the Alzheimer's Association – is imperative. These kinds of e-education programs make the most sense when they are linked to and integrated with the larger service delivery system."* Respondent F

### 3.4 Integrated results

Comparing the results of the internet search and the ImpRes scores, it appeared that, while the intervention with the highest ImpRes score was still available<sup>32</sup>, the two next-highest were not<sup>40,41</sup>. Of the four studies scoring in the 20-21 range, three were still available and one was not. None of the four publications scoring lower than 20/52 were still available.

Regarding the results of the internet search and the survey responses, the findings indicated that, 3/5 of the authors of the still-available interventions took part in the survey, versus 3/7 of the authors of the discontinued interventions. Based on the available online information and the responses received from the authors, it could be deduced that, of the five still-operating interventions, two were exclusively available through participating in a trial<sup>29,31</sup>, one was only available to select clinical staff previously associated with the research project<sup>32</sup>, and two were freely available online<sup>28,30</sup>. The most commonly reported facilitator (mentioned in four out of six responses), developing a commercialisation and/or business plan, did not appear to be a guarantee of success. It was mentioned by one of the three respondents with still-available interventions, but also by three out of three of the respondents with interventions that were no longer in use.

Concerning the results of the ImpRes scores and the survey responses, the themes with the lowest average scores on the ImpRes checklist (Manager Support, Employee Support, and Resources) were reflected by survey respondents' answers grouped into the theme 'Integrated delivery of the intervention'. Here, organisational sponsorship was highlighted as an important facilitator. Respondents also mentioned professionals' lack of training on eHealth interventions as a barrier.

## 4 DISCUSSION

The findings of this study emphasise the key difficulties in translating useful interventions into practice. Only two out of the twelve interventions appeared to be still available to caregivers outside of a trial context, and they were both freely accessible dementia care websites. Three interventions were only available via an ongoing research project. The remaining seven interventions were unavailable or no information was found on their availability. Though it was assumed that the intervention was no longer available, it is possible that the search missed still-available interventions and the assumption of unavailability may well be false. However, it is probable that someone wishing to access the promising, evidence-based intervention based on the information in its efficacy trial study would most likely not be successful. Although this was not mentioned by our survey respondents, it is also important to take into consideration that factors unrelated to implementation issues might be influencing the long-term success of some of the interventions. For instance, despite the overall positive effects discovered in the review of Boots, et al.<sup>1</sup>, the specific challenges associated with eHealth for elderly populations (including changes in motor, cognitive, and perceptive abilities with age, as well as unfamiliarity with new technologies and motivational barriers) may also have contributed to some of the interventions having been discontinued<sup>23,42</sup>.

In contrast to the pharmaceutical industry, there is no well-established mechanism for acquiring funding to market and implement eHealth interventions in practice. Hence, of the two interventions that were still available, both had received long-term, external aid from a funding body. Furthermore, the three additional interventions that were exclusively accessible through research also relied on long-term funding. Of course, having aid from national funding bodies was not a guarantee of enduring use - there were also interventions funded by these same types of funding bodies, which were no longer available. Indeed, most evidence-based interventions are funded by short-term, finite grants, centred around the creation of ever more new interventions, leading to the replication and eventual abandonment of increasingly similar interventions. In general, funding bodies focus on new development, rather than sustainability and long-term implementation, meaning most academically-developed interventions reach very few caregivers<sup>5</sup> (Gitlin et al., 2015). Interestingly, only one of the survey respondents mentioned this support from community and government organisations as a facilitator for long-term implementation, though lack of funding in general was mentioned as a barrier. In the theme 'Iterative Development Process', a number of the surveyed authors pointed to the creation of a business model early on as important facilitator to implementation. However, the evidence suggests that none of the interventions from the Boots, et al.<sup>1</sup> review developed a self-sustaining, commercial

business model, and were instead reliant on external funding. Conversely, there are many commercially- developed interventions on the market that are not scientifically tested for effectiveness<sup>43</sup>. This is in part caused by the golden standard of randomised controlled trials (RCTs) for eHealth research. While RCTs do provide valuable insights to eHealth effectiveness and mechanisms, they are time- consuming, resource-intensive, and often lacking important, qualitative implementation data<sup>44</sup>. Much like this study's survey respondents, Baker, et al.<sup>45</sup> suggest considering alternative, more efficient research designs. Moreover, there are differing concepts of success for academically versus commercially-developed eHealth interventions: For researchers something is successful if it works, whereas for commercial parties something is successful if it sells. Another potential solution is for policy makers and funding bodies to dedicate more funding to the sustainability and long-term development of evidence-based eHealth interventions. Good examples of recent projects addressing these issues by focusing on improving accessibility of existing eHealth interventions through national implementation platforms include Sweden's Health Innovation Platform<sup>46</sup>, Spain's AppSalut<sup>47</sup>, and the UK's NHS and NICE collaboration<sup>48</sup>. In this regard, it is also important to note that so far this article has discussed 'available interventions', rather than 'implemented interventions'. While availability can be assessed with an internet search, for an intervention to be called an 'implemented intervention', the intervention should be not only proven-effective and available, but also show a good fit with a specific context on the basis of experiential findings concerning what might succeed in that context<sup>49</sup>. Thus, this good fit with clinical practice could also mean funding in routine care instead of funding from a research context.

Articles with lower levels of implementation readiness did not show evidence of enduring use, while the relationship between high levels of reported implementation readiness and enduring use was less clear. The average reported implementation readiness rose from 36% to 52% in the five studies identified by the follow-up search, compared to the original included studies. While it is encouraging that the follow-up average implementation readiness is above 50%, it must also be noted that no follow-up study could be identified for the majority of studies. This is in line with earlier research, indicating that there is a lack of implementation research for eHealth interventions for caregivers of people with dementia<sup>21</sup>. It would also seem that follow-up research might contribute to lasting use, as the two interventions that were still available were both discussed in follow-up studies, signifying another argument for funding more implementation research. In the theme 'Integrated Delivery of the Intervention', survey respondents also cited professionals' lack of training in the eHealth interventions and difficult collaboration with the clinicians and financial gatekeepers (health care organisations, health insurers, advocacy groups, as well

as business and commercialisation partners) as important barriers to successful implementation. eHealth interventions circumvent the normal delivery methods and care structures, leaving many professionals, health care organisations, and governing bodies unprepared to adopt and assimilate the interventions and unable to adapt existing structures and norms to incorporate the interventions<sup>50</sup>. A recent systematic review has pointed at workload concerns (resulting from both technical problems and the time needed to convert clinical data into digital formats and learn new forms of communication), a lack of incentives, perceived threats to autonomy, liability concerns, and lack of organisational support and cooperation as barriers contributing to professionals reluctance to embrace eHealth<sup>51</sup>. Studies have suggested embedding eHealth care skills within training and education for health care professionals<sup>52,53</sup>. Currently, this is difficult in the limited time frame of effectiveness studies and the prevalent 'design-build-run and see what happens' approach<sup>53</sup>. Again, funding research into longer-term implementation studies and shedding light on organisational and contextual factors will also help address these professional reluctance issues and aid interventions in sustainably finding their way into practice.

### **Limitations**

The limited participation rate remains low due to the sample being constrained by the number of authors included in the Boots et al. review<sup>1</sup>. This modest participation rate may have several causes. First, researchers may have declined to participate in the study if the technologies used in their interventions were out-of-date, or if their interventions were not implemented. Because of these issues, there is some risk of non-response bias in this study. Additionally, despite contacting multiple authors per intervention, this study only contains information from a single, self-report point of view on the intervention, which could introduce further bias. Furthermore, although a recent review was selected, several of the included publications were quite old. Due to the nature of eHealth, it is to be expected that some of the older technologies have become outdated and are therefore no longer in use. Next, the ImpRes checklist was not developed to assess the implementation of eHealth interventions, but rather of manualised interventions<sup>25</sup>. As a result, not all items are optimally suited for assessing eHealth. For instance, it is possible that some of the included interventions did not use manuals, meaning they could potentially not meet the one item on the checklist referring to the manuals. Furthermore, is also important to note that the checklist score is based on what was reported in the article. It is possible the assessed interventions were more implementation-ready than was reported in the article. Moreover, the ImpRes checklist is a newly developed, experimental tool and for this reason has yet not been tested for internal and external validity. Finally, it must be acknowledged that there is a possibility for bias influencing the results, as the authors of this study

filled in the ImpRes checklist, and not the authors of the original studies. This was done because it would not be possible to acquire this perspective on all of the included interventions, due to the fact that half of the authors did not reply to the survey request. Nonetheless, the choice was made to use the ImpRes checklist due to its high face validity, its strong base in and synthesis of the existing literature, and the fact that it was viewed as the most suitable tool for taking the varied aspects of implementation readiness into account.

## 5 CONCLUSIONS

The available evidence suggested that most interventions in our sample could not be considered 'implementation-ready', based on the implementation reporting in the included articles, and most eHealth interventions for people with dementia seemed to be unavailable to the caregivers after the effectiveness study. Results from the online search, implementation readiness assessment, and survey could suggest that the presence of long-term funding and considering real-world implementation from the start were the two most important factors determining whether the interventions in this sample were still available. However, the evidence is thin because of this study's missing information and small sample size. Nevertheless, policy makers and funding bodies should consider shifting focus from developing ever more and newer interventions, to funding sustainable implementation of evidence-based interventions, that explore organisational and contextual success factors, from conception to daily practice.

### **ACKNOWLEDGMENTS**

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### **DECLARATIONS OF INTEREST**

None.

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## SUPPLEMENTARY DATA

### Appendix 1. Extraction form

Author(s)/year	Description (from Boots et al. <sup>1</sup> )	Citations
Beauchamp et al., 2005	Caregivers' friend: dealing with dementia: web- based multimedia intervention, text material, and videos. Tailored to the individual through a questionnaire. Three modules; aimed at knowledge, cognitive, and behavioural skills, affective learning. Only online modules and reminder e-mails	189
Brennan et al., 1995	ComputerLink: website (information, decision support, and communication); enhancing self-care; understanding of AD; promoting health management of the care recipient.	322
Chiu et al., 2009	Caregiver-therapist e-mail support and bilingual information web portal	51
Coulehan, 2011	Educational and peer- support website.	5
Ducharme et al., 2011	Online Stress Management Training Program: individual work + exchange with other caregivers online; seven psycho- educational sessions (60–90 min, once a week); exercises with specific individual objectives and learning activities; online coaches, three times per week online Q&A at set times.	30
Glueckauf et al., 2004	Support Online (AlzOnline): telephone and Internet: six 45- min live, interactive classes on stress, interpersonal communication + family relationships, emotional well- being and setting/ implementing personal caregiving goals; communication via chat box and telephone.	107
Kelly, 2004	Link2Care: information library: fact sheets, articles, website links, "Ask the Expert," personal consultation with technical experts in caregiving, law, and health; peer-moderated support group; personal e-journal; current caregiver news; periodic e-mail communication.	10
Lai et al., 2013	Gingko: website; 7-week online training workshop + online support forum.	14
Lewis et al., 2010	Internet-Based Savvy Caregiver (IBSC) program: Internet-based program: four modules: effects of dementia, taking charge and letting go, providing practical help and managing daily care and difficult behaviour; videos, written descriptions, examples of typical caregiver responses + strategies for caregivers to use.	85
Marziali and Garcia, 2011	Online Dementia Caregiver Information Handbook; e-mail list of group members, chat forum, video conferencing link for group meetings, library of educational videos; two groups: (1) CG: access to information handbook and six videos (24/7); (2) VG: psychotherapeutic support group intervention (1 h once a week).	95

Funding	Availability	Follow-up	Survey ?
National Institute of Aging	Not available online	n/a	Yes
National Institute of Aging	Not available online	Payton et al. (1995)	No
Unknown	Not available online	Chiu & Eysenbach (2011)	No
National Institute on Aging (Grant #R43AG026227)	Freely available online	n/a	Yes
Fondation de l'Institut universitaire de gériatrie de Montréal, Desjardins Sécurité Financière and the Social Sciences and Humanities Research Council of Canada.	Available through participating in trial	n/a	Yes
State of Florida Department of Elder Affairs and the Robert Wood Johnson Foundation to Robert L. Glueckauf	Freely available online	n/a	No
Unknown	Not available online	n/a	No
Central Research Grant, The Hong Kong Polytechnic University. Grant Number: G-T901	Not available	n/a	No
NIH	Available through participating in trial	Griffiths et al. (2015)	Yes
Ontario Ministry of Health and Long-Term Care	Available to select hospital staff involved in the research	Nalder et al. (2018)	Yes

### Appendix 1. Extraction form

Author(s)/year	Description (from Boots et al. <sup>1</sup> )	Citations
Torp et al., 2008	ACTION: ICT course, three 3- h classes (in 3-week period): disease information, care for patients, nutrition, social services, being a family carer + online discussion forum; option to interact with other participants via videophone + 3-h Internet training in using and collecting information	41
van der Roest et al., 2010	DEM-DISC (Dementia- specific Digital Interactive Social Chart): clarifying needs to specific demands in a three-step procedure, general and tailored information on available dementia care and welfare services, information on caregiving.	30

Note: Adapted from Boots et al.<sup>1</sup>

Funding	Availability	Follow-up	Survey ?
Directorate for Health and Social Affairs and the Norwegian Association of Local and Regional Authorities	Not available online	n/a	No
Dutch Ministry of Economic Affairs under contract BSIK 03025, Dioraphte Foundation, RCOAK, NHDI, Foundation Het Zonnehuis, Province Noord-Holland and Stichting Alzheimer & Neuropsychiatrie Foundation	Not available online	Van Mierlo et al. (2015)	Yes

4



**Business model case studies  
of eHealth interventions to  
support informal caregivers  
of people with dementia  
in the Netherlands**

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# ABSTRACT

**Objectives:** In academic research contexts, eHealth interventions for caregivers of people with dementia have shown ample evidence of effectiveness. However, they are rarely implemented into practice and much can be learned from their counterparts (from commercial, governmental, or other origins) that are already being used in practice. This study aimed to (1.) examine a sample of case studies of eHealth interventions to support informal caregivers of people with dementia, that are currently used in the Netherlands; (2.) investigate what strategies are used to ensure the desirability, feasibility, viability, and sustainability of the interventions, and (3.) apply the lessons learned from this practical, commercial implementation perspective to academically developed eHealth interventions for caregivers of people with dementia.

**Methods:** In step one, experts (N=483) in the fields of dementia and eHealth were contacted and asked to recommend interventions that met the following criteria: (1.) delivered via the internet, (2.) suitable for informal caregivers of people with dementia, (3.) accessible in the Netherlands, either in Dutch or in English, and (4.) used in practice. The contacted experts were academics working on dementia and/or psychosocial innovations, industry professionals from eHealth software companies, clinicians, patient organisations, and people with dementia and their caregivers. In step two, contact persons from the suggested eHealth interventions participated in a semi-structured telephone interview. The results were analysed using multiple-case study methodology.

**Findings:** Twenty-one eHealth interventions for caregivers of people with dementia were suggested by experts. Nine of these 21 interventions met all four criteria and were included in the sample for case study analysis. Four cases were found to have developed sustainable business models. Five cases were implemented in a more exploratory manner and relied on research grants to varying extents, though some had also developed preliminary business models.

**Conclusions:** These findings suggest that the desirability, feasibility, and viability of eHealth interventions for caregivers of people with dementia are linked to their integration into larger structures, their ownership and support of content internally, their development of information and communication technology (ICT) services externally, and offering fixed, low-level pricing. The origin of the case studies was also important, as eHealth interventions that had originated in an academic research context less reliably found their way to sustainable implementation. In addition, careful selection of digital transformation strategies, more intersectoral cooperation, and more funding for implementation and business modelling research are recommended to help future developers bring eHealth interventions for caregivers of people with dementia into practice.

# 1 INTRODUCTION

A recent systematic review by Christie, et al.<sup>1</sup> showed that very few evidence-based eHealth interventions for informal caregivers of people with dementia are implemented in practice. eHealth, which the WHO defines as “*the use of information and communication technologies (ICT) for health*”<sup>2</sup>, has the potential to help many people living with physical and mental health issues, including informal caregivers of people with dementia. Informal care constitutes a significant part of dementia care<sup>3,4</sup> and can include aid in household chores, errands, facilitating social engagement, and the coordination of professional care. In the Netherlands, it has been estimated that about 10% of its 16 million inhabitants offer some form of informal care<sup>5</sup>. However, informal caregivers have also been shown to experience physical and psychological complaints as a result of this caregiving process<sup>6</sup>. Previous research has shown that eHealth interventions to support these caregivers have been effective in improving caregiver outcomes such as self-efficacy, competence, and knowledge about dementia, as well as in reducing depressive symptoms<sup>7-14</sup>.

In general, eHealth has many potential benefits, compared to more traditional face-to-face interventions: It is relatively easy to implement on a larger scale, it has the potential to reach users from various socioeconomic and demographic backgrounds, and it can include extensive personalisation, instant delivery, and real-time feedback<sup>15,16</sup>. Unfortunately, the implementation of eHealth is often fragmented, short-lived, and without sufficient vision and strategy<sup>17</sup>. In addition to the eHealth interventions being developed in an academic research context, there is also eHealth being developed outside of academia, for instance by industry and health care organisations<sup>18</sup>, from which much can be learned to aid the implementation of eHealth interventions for caregivers of people with dementia originating from the research context. For the most part, these non-academic interventions are not included by the search strategies employed in systematic reviews, as their development and testing are usually not published in academic journals. Therefore, this study aimed to explore how lessons learned from interventions currently being used in practice can aid the implementation of evidence-based interventions for informal caregivers of people with dementia. To accomplish this, this study had three aims: (1.) examine a sample of case studies of eHealth interventions to support informal caregivers of people with dementia, that are currently used in the Netherlands; (2.) investigate what strategies are used to ensure the desirability, feasibility, viability, and sustainability of the interventions and, (2.) formulate lessons learned to facilitate the implementation of future eHealth interventions.

## 2 METHODS

### 2.1 Data collection

Data collection took place in two steps. Figure 1 depicts the flowchart of case study inclusion.

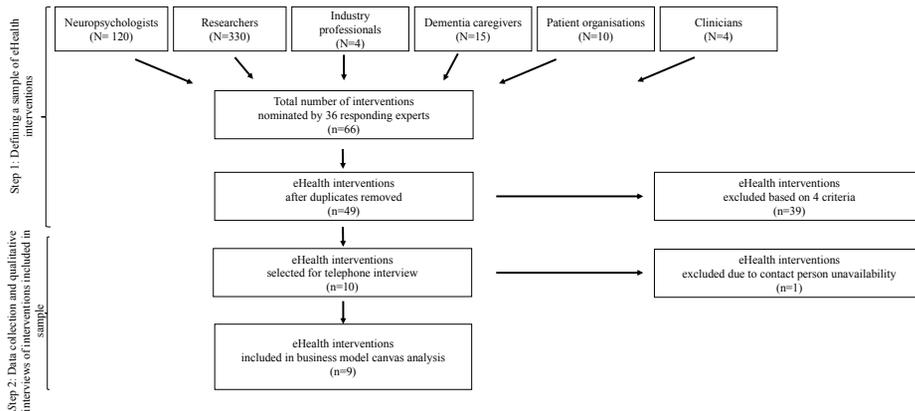


Figure 1. Flowchart of case study inclusion

#### 2.1.1 Step 1: Defining a sample of eHealth interventions for caregivers of people with dementia

**2.1.1.1 Contacting experts.** First, in order to acquire a sample of eHealth interventions to support caregivers of people with dementia that are being used in practice, experts (N=483) in the field of eHealth, dementia, and caregiving were contacted via email. Experts in the academic field were approached via the INTERDEM mailing list. INTERDEM is an international research network focusing on psychological care for dementia. Additionally, four emails were sent to experts in industry, ten were sent to representatives from dementia and caregiver patient organisations, four to clinicians in the field of dementia care, and the question was also posed to 15 dementia caregivers during a dementia client panel meeting at Maastricht University. Finally, a notice was placed on the social media channels (Twitter, Facebook, and LinkedIn) of the NVN (*Nederlandse Vereniging voor Neuropsychologie*, the Dutch Association for Neuropsychology), which was clicked on 120 times across channels, according to NVN. This data was collected between December 2018 and June 2019. The suggested interventions were not meant to serve as an exhaustive overview of all available eHealth interventions for caregivers of people with dementia in the Netherlands. Rather, they are a sample of this type of intervention, defined with a systematic approach.

*2.1.1.2 Inclusion criteria.* The experts were asked to provide the names of interventions meeting four inclusion criteria. The inclusion criteria were as follows: The eHealth intervention is (1.) delivered via the internet, (2.) suitable for informal caregivers of people with dementia, (3.) available in the Netherlands, either in Dutch or in English, and (4.) used in practice.

### **2.1.2 Step 2: Data collection and qualitative interviews of included interventions**

Next, the researchers reached out to the interventions' contact people with an invitation to participate in a telephone interview about their experiences with their intervention's implementation. In total, nine interviews were conducted via telephone and transcribed verbatim. The respondents were informed of the study's purpose and gave their consent to the interview being recorded and analysed anonymously. However, it was not possible to guarantee total anonymity, due to the fact that the interventions themselves would be discussed by name. The participants consented to this and a 'member check' was conducted<sup>19</sup>, where participants were sent the resulting transcript for approval. These interviews were conducted between December 2019 and January 2020. The average interview was 25 minutes long.

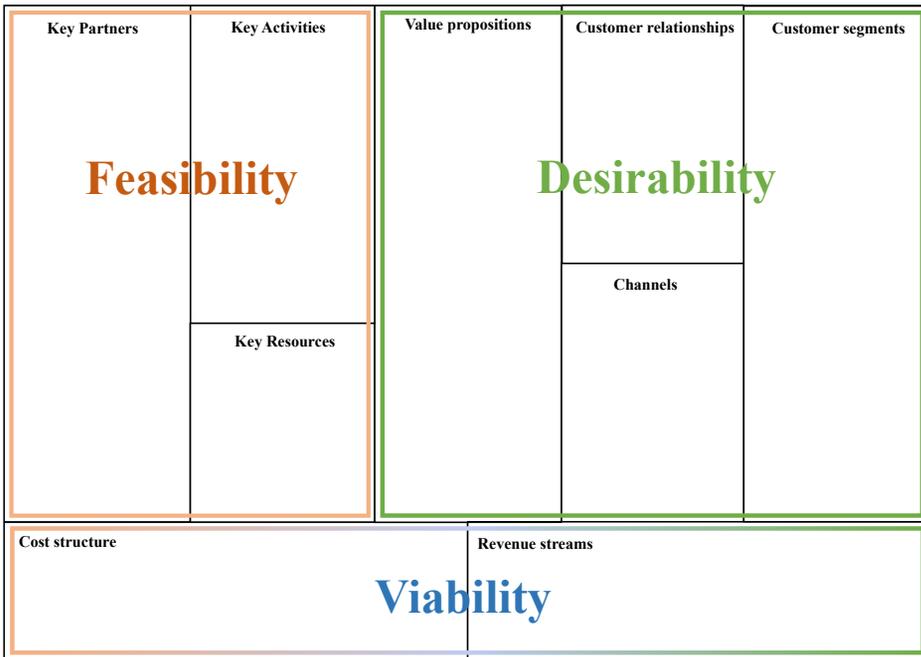
## **2.2 Measures**

For the nine included case studies, interview data was collected concerning the desirability, feasibility, and viability of the included eHealth cases, based on the Business Model Canvas framework<sup>20</sup>, and how these aspects relate to case study sustainability. Figure 2 is an illustration of how the nine elements of the Business Model Canvas can be grouped into the larger themes of desirability, feasibility, and viability. This semi-structured interview consisted of nine questions. The interview guide can be found in the Appendix. Additionally, data was collected on the interventions' descriptions, current use, and business model, and is represented in an extraction table (see results, section 3.1.2).

## **2.3 Data analysis**

The data was analysed using qualitative, multiple-case study methodology<sup>21</sup>. This methodology was chosen for its ability to qualitatively explore complex phenomena within their contexts and explore differences within, as well as between, cases<sup>22</sup>. The focus is on collecting in-depth data on a limited number of cases. In this 'explanation-building' study<sup>23</sup>, the narratives from the interviews were used to describe the sampled interventions in detail, describing common and differential characteristics, to guide an explanation of which characteristics can contribute to intervention viability and sustainability. Author HC conducted the initial analysis using the questionnaire responses, extraction table, and interview transcripts. The results of the initial analysis were discussed with the authors HC, LB, HT, MG, and MdV in a consensus meeting, where differences in interpretation were resolved and external validity supported. In particular, the authors discussed the value

propositions of the included cases, their common characteristics in terms of desirability, feasibility, and viability, as well as their respective implementation phases and business models. The previously described member check of the transcripts with the case study respondents served to support the analysis' internal validity.



**Figure 2.** Desirability, feasibility, and viability of business models. Adapted from Osterwalder and Pigneur20

## 3 RESULTS

### 3.1 Interventions suggested by experts

#### 3.1.1 Overview

Thirty-six responses were received (14 from researchers, ten from patient organisations, three from industry professionals, four from clients, and five from clinicians), with a total of 66 interventions being nominated to be part of the sample (some respondents suggested multiple interventions, while other respondents did not suggest any interventions). There were 49 unique interventions, of which 39 were excluded, based on the four described criteria. The contact person for one of final ten interventions could not be reached during the study duration. As a result, this intervention was excluded, resulting in a total of nine interventions included as case studies.

#### 3.1.2 Included case studies

In total, nine interventions met all four criteria required to be included as case studies. Table 1 is an extraction table detailing the included case studies' names, number of nominations, descriptions, and current use. The name of Case study 5 has been redacted. This is because the interview respondent requested to not use the name of the intervention. Dementie.nl and Myinlife are discussed together, as Myinlife has been integrated into the broader Dementie.nl platform.

### 3.2 Case study characteristics

#### 3.2.1 Strategies relating to case study desirability, feasibility, and viability

Table 2 contains an overview of the case studies' current desirability, feasibility, and viability characteristics, as reported across interview respondents.

*3.2.1.1 Desirability.* The interventions included as case studies were targeted at informal caregivers of people with dementia. However, many case studies also decided to target formal care, by developing aspects of their platforms for health care professionals.

*“Well you notice that there is a lot of demand from health care professionals. So people say “Gosh, we find this interesting” and recommend it to their clients, to know what is going on and what they are getting, before they give advice about which modules exist. It should be used that way. That the caregiver can initiate, but also the health care professional, and they both have need of that knowledge.” – Respondent OPEM*

**Table 1.** Extraction table

Case study	Intervention name	Nominations	Description	Current use
1	Partner in Balance	5	Online intervention to support caregivers and promote self-management, with coach (a formal caregiver), for informal caregivers (academic origin)	Available online (only in participating areas), 200 euros per caregiver per year
2	STAR eLearning	1	Online intervention to improve dementia caregiving skills for both formal and informal caregivers (academic origin)	Available online, 25 euros per year
3	OZOverbindz org	1	Online platform to connect care partners, for informal caregivers to invite formal caregivers (non-academic origin)	Available online (only in participating regions/municipalities). Health insurer and municipality jointly pay 1 euro per user (calculated over region).
4	Carenzorgt	5	Online platform to facilitate the organisation of care for people with dementia, for both formal and informal caregivers (non-academic origin)	Available online, free
5	{redacted}	4	Online intervention to provide tips for caring for a person with dementia, with a coach, for both formal and informal caregivers (partial academic origin)	Available online, free if person with dementia is registered with care organisation (name redacted), 500 euros for course if not registered with care organisation (name redacted), Currently not accepting new applicants
6	Thinkability	1	Online Cognitive Stimulation Therapy intervention, to improve quality of life, for both people with dementia and informal caregivers (academic origin)	Available in App Store and Google Play, 4.99 pounds

**Table 1.** Continued

Case study	Intervention name	Nominations	Description	Current use
7	Dementie.nl (& Myinlife)	7	Online platform for dementia care (included caregiver test, online dementia training, and 'ask an expert'), for informal caregivers. Includes Myinlife, an online platform to facilitate the organisation of care for people with dementia (partial academic origin)	Available online, free
8	OPEM	1	Online platform that contains both internal and external modules informing about dementia care, for formal and informal caregivers (partial academic origin)	Available online, free if caregiver is a client with Innovate (organisation), otherwise 10 euros
9	Nachtrust bij Dementie	1	Online intervention to inform about night-time unrest in a person with dementia and provide non-pharmaceutical tips, for informal caregivers (academic origin)	Platform online, though coaching not currently available due to lack of resources (otherwise free)

Interestingly, even in blended interventions, where the guidance of a health care professional is necessary, the eHealth platform was not targeted at these care professionals. In all cases, there remained a primary focus on the needs of the informal caregiver. Next, a common characteristic was the overall relatively low pricing of the eHealth (see Table 1). The eHealth platform was often also incorporated in larger systems. These could be online platforms, such as was the case with Carenzorgt (Nedap), OPEM (Ohmymood), or offline systems, such as with Dementie.nl & Myinlife (Alzheimer Netherlands) and STAR eLearning (Dementia Meeting Centres).

*"I think an advantage of our situation at the university is that we have a national network of meeting centres. There are already 160 of them in the Netherlands, which come together once a year, where we inform them about all kinds of interesting developments for them, also the STAR course."* – Respondent STAR

**Table 2.** Common case study characteristics, as reported in case study interviews

Common characteristics	Case studies
<u>Desirability</u>	
Targeted user is mostly caregiver	Partner in Balance, Carenzorgt, Case study 5, Dementie.nl (& Myinlife), Nachtrust bij dementie
Low price (see Table 1)	Partner in Balance, STAR eLearning, Carenzorgt, Case study 5, Thinkability, Dementie.nl (& Myinlife), OPEM, Nachtrust bij dementie
Incorporated into larger systems	STAR eLearning, OZOverbindzorg, Carenzorgt Case study 5, Dementie.nl (& Myinlife)
Up-to-date content	Partner in Balance, STAR eLearning, OZOverbindzorg, case study 5, Thinkability, Dementie.nl (& Myinlife), OPEM, Nachtrust bij dementie
Community creation	Partner in Balance, STAR eLearning, Carenzorgt, Dementie.nl (& Myinlife), OZOverbindzorg, Case study 5
<u>Feasibility</u>	
Self-ownership of content	Partner in Balance, STAR eLearning, OZOverbindzorg, Carenzorgt, Case study 5, Thinkability, Dementie.nl (& Myinlife), OPEM, Nachtrust bij dementie
ICT platform supplied by third party	Partner in Balance, STAR eLearning, OZOverbindzorg, Case study 5, Thinkability, Dementie.nl (& Myinlife), OPEM, Nachtrust bij dementie
Helpdesk and implementation support services supplied internally	Partner in Balance, STAR eLearning, OZOverbindzorg, Carenzorgt, Case study 5, Thinkability, Dementie.nl (& Myinlife), OPEM, Nachtrust bij dementie
Limited internal marketing capabilities	Partner in Balance, STAR eLearning, OZOverbindzorg, Case, study 5, Thinkability, OPEM, Nachtrust bij dementie
<u>Viability</u>	
Variable price for different packages of services, for a fixed amount of time, for caregivers, for health care organisations, and for municipalities and health insurers	STAR eLearning, OPEM
Fixed price for access to information/services	Partner in Balance, OZOverbindzorg, Case study 5, Thinkability
Increasing the attractiveness of a larger health care platform	Carenzorgt
Supplying information and services at no cost	Dementie.nl (& Myinlife), Nachtrust bij dementie

This integration significantly increased the visibility of the case study and provided a supportive structure. All case studies mentioned the time and effort needed to keep eHealth content relevant and up-to-date as a significant, but necessary drain on resources. Finally, many case studies emphasised the importance of creating a community around the eHealth intervention. These communities were places where caregivers could contact each other and share experiences about the eHealth intervention and dementia caregiving in general. These communities sometimes took place on a designated forum on the intervention website, or via social media channels, such as a closed Facebook group.

*3.2.1.2 Feasibility.* Most of the cases were developed by groups with specific expertise on dementia and caregiving. Most of the studied cases chose to develop the content themselves (and hence owned this content), while hiring an external party to help build and maintain the online platform. Often, it was the expertise party who ran a helpdesk and support service for users, forwarding technical questions to the hired software party. In this case, these support tasks were either part of a research position at a university, or on a volunteer basis. Most of the studied cases did little in the way of marketing. In general, their aim seemed to be to sustain the eHealth, rather than to scale it up.

*“So when regions report that this sounds good, they also want this, then we start. But we do not actively search for regions where we can implement OZOverbindzorg. We do not think that is societally appropriate. So no, they come to ask us.” – Respondent OZOverbindzorg*

This is because none of the cases aimed to make a profit (see 3.2.1.3). Payment was mentioned as a barrier multiple times, with respondents warning that setting up a secure payment system takes considerable time and effort, and that their older demographic is not always comfortable with solutions such as PayPal.

*3.2.1.3 Viability.* Four different types of viability strategies were observed in the nine cases. The majority of interventions (Partner in Balance, STAR eLearning, OZOverbindzorg, OPEM) opted to vary their prices for different ‘subscription packages’ of services. They did this both in terms of content and in volume. Other case studies (like Thinkability) offered their eHealth interventions online for a fixed price, after which the buyer had access to the service indefinitely. Indeed, in this sample, Thinkability is the only intervention whose cost structure was centred around direct download from the internet by the caregiver, without mediation by an existing health care system. STAR eLearning and the OPEM modules are also available for the caregiver to access without a health care organisation, though these are also at least partly integrated into existing

dementia care systems, such as dementia meeting centers and a care organisation, respectively. Finally, some cases, like Carenzorgt and Dementie.nl (& Myinlife), made no revenue, but instead existed to increase the attractiveness of a larger health care platform and/or organisation.

*“We mainly make software for health care institutions, especially in elderly care and disabled care and a bit in mental health care. Nine years ago, we thought it was important to involve the client’s family in the process. This also helps health care professionals do better. So we said, we will make this platform. We think it’s important for the entire infrastructure that we have this and offer it for free.” – Respondent Carenzorgt*

Finally, other case studies (like Dementie.nl, Myinlife) existed to supply information and services at no cost to caregivers and were financed in large part through sponsorships.

### **3.2.2 Sustainability of business models**

It was clear that while all the case studies had been included due to their use in practice, the levels of use varied strongly. Table 3 shows the implementation phases and business models of the included case studies.

Four cases were considered by the research team to be in the Sustainable Implementation category. This was because they were judged to largely recover their operational costs and were not financially dependent on research grants (though they may have originally been developed using research subsidies). Next, the methods with which they did this were examined. Two of these cases had set up successful subscription models, though with different types of clients. OZOverbindzorg is paid for by municipalities and health insurers (but freely used by caregivers in the participating regions), while STAR eLearning is paid for by the caregiver or by a health care organisation that buys access for its associated caregivers. The other two cases included in this category were both free to use. In the case of Dementie.nl, this was because the site is kept running by the broader not-for-profit Alzheimer Netherlands, which can rely at least in part on sponsorships and donations. In the case of Carenzorgt, this was because its vendor wanted to increase the attractiveness of its online platform for health care organisations, by offering a free online service for caregivers. Interestingly, it seems that two of these sustainably implemented case studies did not originate in academic research context: OZOverbindzorg and Carenzorgt. STAR eLearning was originally a research project, and Dementie.nl also has links to research, including through its subdomain Myinlife (which was originally also a research project).

**Table 3.** Implementation phase and business models of the case studies

Implementation of case studies	Business models
<i>Sustainable Implementation</i>	
OZOverbindzorg	Subscription (paid by municipalities and health insurers)
Carenzorgt	Incentive (free in order to increase attractiveness of larger platform)
STAR eLearning	Subscription (paid individually by caregiver or in bulk by organisation, with varying options)
Dementie.nl (& Myinlife)	Sponsorship (free through sponsor support to Alzheimer Netherlands)
<i>Developing Implementation</i>	
Partner in Balance	Grants, with a plan for subscription model (paid by municipalities and organisations)
Thinkability	Combination of fixed price and grants (one-time download from App Store and Google Play)
OPEM	Combination of fixed price and grants (paid individually by caregiver or in bulk by organisation, with varying options) for non-organisation members, free if organisation member
Case Study 5	Fixed cost (paid individually by caregiver or in bulk by organisation, with varying options) for non-organisation members, free if organisation member
Nachtrust bij Dementie	Grants (research project )

Five cases were considered by the research team to be in the Developing Implementation category. This was because they were all judged to not recover their operational costs independently from research grants. These cases all relied at least partly on research grants. However, some of the cases had also developed business models and partnerships aimed at making the interventions independently sustainable. These business models varied, with Partner in Balance opting for a licensing/subscription model, Thinkability for fixed-price download, and OPEM also opting for licensing/subscription model, but only for their external clients. In Case Study 5, an initial business model had been drafted, but was no longer being applied due to lack of resources. Finally, Nachtrust bij Dementie was at the beginning of its implementation. While it was available for access online, it was still best classified as a research project.

### 3.3 Lessons from respondents

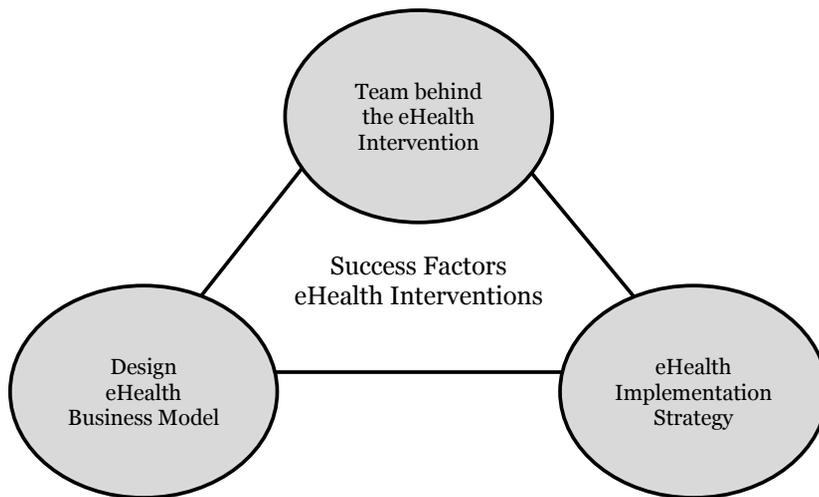
During the interviews, respondents from each case study were asked to formulate recommendations for future eHealth developers, based on their experiences in bringing eHealth for dementia caregivers into practice. The first column of Table 4 lists the lessons learned, as reported by the case study interviews. In the second column, these lessons on practical implementation have been applied to the research context to inform the future development of evidence-based eHealth interventions in research contexts.

**Table 4.** Application of lessons learned to research contexts

Lessons learned by respondents	Application to research contexts
Make use of an innovation consortium	Chose a supplier, an implementer, and a financier at the start of the project
Provide a good fit with context	Adapt the intervention to country-specific needs
Ensure long-lasting PR	Identify organisations and structures that could promote the intervention in the long-term
Start implementing and learning, rather than waiting and perfecting designs	Consider other and more flexible research designs than costly and time-consuming randomised controlled trials (RCTs)
More implementation budget is crucial	Advocate more implementation subsidies, but also budget more for a sustainable implementation phase in grant applications
Commercial collaboration is a big help	Identify local commercial organisations that would be willing to help on a research project (marketing firms, ICT companies, sales and legal experts, ...)
Health insurer collaboration is advantageous	Consult with local health insurers at the start of the project to see what their priorities are
Co-design	Involve users in whole process as much as possible

## 4 DISCUSSION

The findings from these case studies have led to the following recommendations for the design, the implementing team, and the suggested implementation strategies of a core business model, to help achieve the long-term implementation of eHealth interventions for caregivers of people with dementia. Figure 3 depicts the proposed core business model.



**Figure 3.** Success factors of eHealth interventions for caregivers of people with dementia

### 4.1 Design of eHealth business models

First, the design of this proposed core business model is based on the findings concerning the case studies' desirability, feasibility, and viability characteristics. A first key element of this potential core model's design concerns its desirability, specifically through the incorporation of the eHealth interventions into larger, pre-existing health care structures. In this regard, the case study interview respondents mentioned that developing interventions to have a good fit with existing organisational goals and contexts was an important part of intervention desirability, separately from any financial considerations. This is in line with previous studies on the implementation of eHealth interventions in other populations<sup>24-26</sup>. Indeed, contextual integration is an important part of many established implementation frameworks, including the Consolidated Framework for Implementation Research<sup>27</sup> and Normalization Process Theory<sup>28</sup>. A second key element of the proposed design concerns the observed similarities in the interventions' feasibility characteristics.

The case studies tend to supply the dementia-specific content and helpdesk of the eHealth internally, while the ICT and software services are outsourced to an external party, which does not own the content. In other words, the execution of these ICT-related key activities are shifted to key partners. Previous research has discussed the frequent outsourcing of services in ICT<sup>29</sup> and emphasised the importance of trust between involved parties in constructing these types of business models in eHealth<sup>30</sup>. These studies recommend knowledge-sharing experiences between the involved parties to foster trust, which has been shown to help attain the desired benefits of the outsourcing. Finally, the third key element of this proposed core model's design pertains to its viability. It would appear that a prevalent, sustainable cost structure is a fixed price for access to the eHealth information or services, paid by health care organisations. Another viable option for sustainability seems to be, again, integration into a larger, existing platform that sponsors the eHealth intervention so no cost is charged to the caregiver. Here again, it is clear that when considering the viability of a dementia eHealth business model, viewing the eHealth within its health care context can facilitate its sustainable implementation, as argued by van Limburg, et al.<sup>31</sup>. This pertains to both the desirability of the intervention through its fit with the context, as well as the financial viability of the intervention through its support and use of revenue structures already in place in existing systems. A good example of the successful application of these three core model elements is OZOverbindzorg, which makes use of fixed price, low cost, equal buy-ins from collaborations between health insurers and municipalities per participating region. This is in line with principles discussed in previous research, namely that costs and benefits should be balanced between parties in eHealth, and one party should not disproportionately benefit from something that is financed by the other party<sup>32</sup>. Here, the benefits are shared between the care organisations and the community well-being, so it is fair that both equally contribute to the costs.

#### **4.2 Team behind the eHealth intervention**

Next, a main finding of this study concerns the question of who is implementing these interventions. In this study, case studies that did not originate in an academic research context more successfully achieved sustainable implementation, compared to the case studies that did originate in an academic research context. There is a noticeable absence of eHealth interventions that originated as research projects in the identified, sustainable financing models used in practice. Indeed, most academic interventions are constrained by expiring funding<sup>33</sup> and integration within existing structures appears crucial. Hopefully, future interventions can also facilitate this integration by making use of timely business modelling. In this regard, this research underscores the need for more implementation funding and research into business modeling of evidence-based eHealth interventions to help reduce this constrained implementation of academically developed eHealth interventions for caregivers of people with dementia<sup>34,35</sup>. In addition, more traditional research methods such as the randomised controlled trial (RCT) are not time-

or resource-efficient and can impede researchers from reaching this implementation stage<sup>36</sup>. The use of alternative, more flexible research designs, with faster iteration and earlier consideration of implementation determinants, could also help overcome this barrier<sup>37</sup>. The benefits of sustainably implementing these academically developed eHealth interventions for caregivers of people with dementia include avoiding squandering public money on failed implementations, better allocation of research resources, and realising the anticipated benefits for intended users<sup>38</sup>. Moreover, commercially developed interventions tend to supply users with what they like, while the translation of academically developed interventions into practice can offer users what they need. The success of the former is determined by what is financially viable, while the latter is determined by proven effectiveness. In short, there seems to be a lack of business modelling know-how in the teams who are implementing these academically developed interventions. In this regard, much can be learned from the commercial sector, in order to bring the numerous described benefits of academically developed interventions into practice.

#### **4.3 eHealth implementation strategy**

Finally, an important question is “*Which strategies can help bring the proposed core business model into practice?*”. As interventions developed in an academic research context seem to experience the described implementation difficulties, it may be useful to gain inspiration from business. There, digital transformation strategies are a key part of bringing business models into practice by coordinating and prioritising many different aspects of digital transformation<sup>39</sup>. In this context, previous research has pointed to the importance of community creation in generating revenue through ‘freemium’ business models<sup>40</sup>. A freemium business model involves “*offering a basic version of the product or service free of charge, while the premium version is made available against additional payment*”<sup>41</sup>. Community creation refers to forming and maintaining a community of intervention users, who are in contact with each other through the intervention. While there was no clear example of a ‘freemium’ business model in this sample, community creation was an important part of many of the included case studies, even more so among those grouped in the sustainable implementation category. Future research could test the proposed core model for external validity and investigate the effectiveness of community creation as part of digital implementation strategy to increase the sustainability of eHealth interventions for caregivers of people with dementia. Here too, alternative, flexible research designs offer possibilities to compare and evaluate innovative implementation strategies<sup>42</sup>.

#### **4.4 Strengths and limitations**

This study helps alleviate a significant problem in the field of eHealth interventions for caregivers of people with dementia: A lack of information on financially viable, long-term implementation trajectories. By taking an intersectoral perspective and learning from interventions already being used practice, this research reaches broader than most studies, which are often limited to studying interventions developed in an academic research context. This approach made use of a systematic method to select interventions for case studies, based on expert opinion and pre-defined criteria.

This study also has a number of limitations. First, there is a possibility of selection bias, as the definition of this sample required responses from the authors' own dementia and eHealth networks. As a result, a first possible bias is towards experts from academia, who are overrepresented in this sample. Second, there is likely a higher than average degree of sample familiarity with the authors' own interventions, Partner in Balance and Myinlife, as the contacted experts belong to the same networks (such as INTERDEM), and are often exposed to other members' research. Moreover, the authors acknowledge potential bias in reporting the results concerning Myinlife and Partner in Balance, as they were involved in their development and evaluation. Third, it is likely that more interventions originating from the Southern Netherlands were included (as this is where the authors' research group is based), while interventions from elsewhere in the Netherlands remained underrepresented. However, it is important to reiterate that the case studies included in this study are not meant to serve as an exhaustive overview of all available eHealth interventions for caregivers of people with dementia in the Netherlands. Instead, the included studies are to be seen as a sample of these interventions, which was defined with a systematic approach. Despite the potential for bias, this sample still provides a novel perspective on potential implementation trajectories and lessons for eHealth interventions for caregivers of people with dementia, using systematic and transparent methodology. A second limitation concerns the potential self-report bias of the included case study respondents to emphasise positive aspects of their own interventions, and minimise difficulties in the responses about their learned lessons. However, it remains relevant to know how respondents look at their own cases and what they consider to be the most important strengths that lead to successful implementation. However, we must acknowledge that there might be some underreporting of potential barriers. These reporting tendencies stem from a logical academic or financial self-interest. These are also an important consequence of publication bias, where studies with reporting significant results are more likely to be published, compared to studies with non-significant results<sup>43</sup>. A final limitation concerns the fact that this study did not guarantee respondents total anonymity, due to the fact that interventions would be referred to by name (unless respondents explicitly requested otherwise, as in Case Study 5) the intervention could

conceivably be linked to one of a few possible intervention respondents. This was discussed prior to the interview and agreed to by the respondents, who also provided a member check, approving the interview transcript. This lack of total anonymity could have impeded respondents from discussing more sensitive implementation topics candidly, out of fear of (social) repercussions from collaborators. However, when this issue arose (as in Case study 5), it was possible to remove the intervention name. As no other respondent deemed this necessary, it is reasonable to assume they felt comfortable discussing the interview topics. Another possible consequence of this lack of anonymity, is that the eHealth contact persons might not have wanted to share important details of their business plans, to remain competitive. Nevertheless, the interviews resulted in many candid insights, shedding much needed light on the business plans of these interventions.

## 5 CONCLUSIONS

Case studies that did not originate from an academic research context seemed to achieve more sustainability, while case studies from academic research contexts experienced barriers to financial independence from research grants. Examining common and differential characteristics of these case studies resulted in the proposal of a core business model for eHealth interventions for caregivers of people with dementia, derived from a sample of case studies currently being used in practice. This proposed core business model suggests increasing desirability, feasibility, and viability by integrating into larger structures, owning and supporting content internally while developing ICT services externally, and offering fixed, low-level pricing. Together with the origin of the case studies, these elements contributed to case study sustainability. Finally, targeted digital transformation strategies, more intersectoral cooperation, and more financial incentives for research on sustainable business models are recommended to help future developers bring eHealth interventions for caregivers of people with dementia into practice.

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# SUPPLEMENTARY DATA

## **Appendix. Semi-structured interview questions**

### Desirability

1. Who is this intervention aimed at?
2. What is the advantage of this intervention for its clients?

### Feasibility

3. What needs to be done (internal and external) to enable the intervention?

### Viability

4. How does the intervention generate returns? License, advertisement, payment model...?
5. What are the major cost drivers and how are they linked to the revenue?

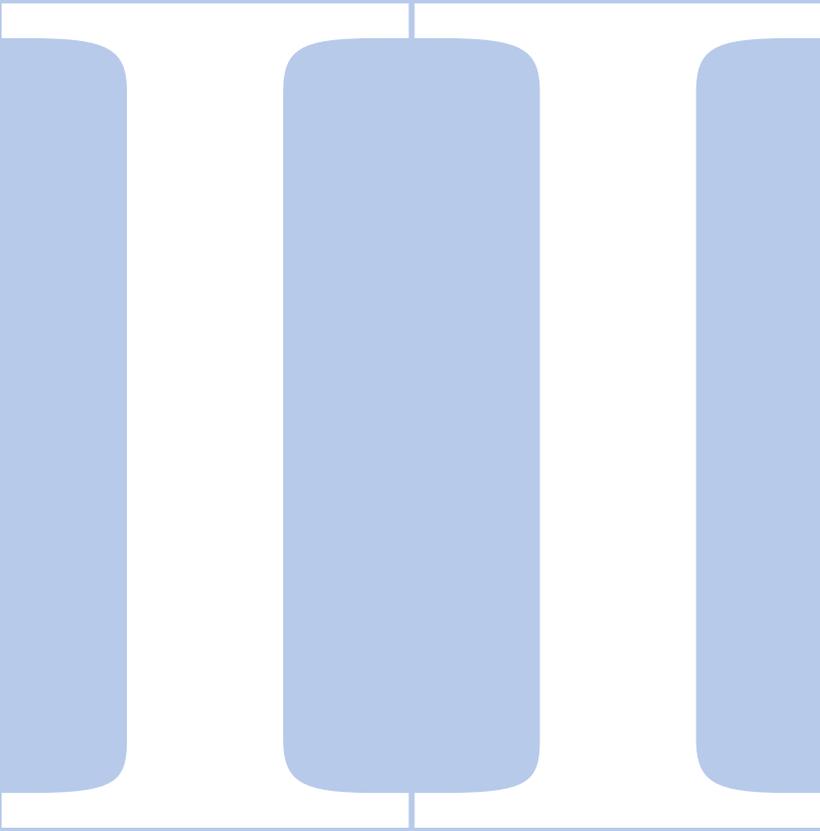
### Other questions

6. How many people were involved?
7. Do you have any lessons about successful implementation that you want to share with us?
8. Have you gained inspiration from certain other interventions or theoretical frameworks?

### Ending

9. Do you have any questions or things that would be interesting for me to know?







**Lessons from  
continued  
implementation**

5



**Process evaluation of a  
social support platform  
'Myinlife' for caregivers of  
people with dementia**

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# ABSTRACT

**Introduction:** Informal caregivers of persons with dementia have an increased risk of facing social isolation. Online social media interventions might offer a new opportunity to increase access to social support. An online social support platform, 'Myinlife', was developed and launched in the Netherlands to enhance social support, positive interactions, and information sharing in informal support networks.

**Objective:** A process evaluation was performed to evaluate the internal and external validity of the Myinlife intervention.

**Methods:** Implementation, sampling, and intervention quality were evaluated by both qualitative and quantitative methods. Analyses were performed using descriptive statistics and inductive content analysis. Analyses were conducted following participants' completion of the intervention after 16 weeks.

**Results:** The overall participation rate in the study was 27% (96/351). The Myinlife intervention was generally well received by the primary caregivers. Myinlife facilitated empowerment, openness, involvement, and efficient care organisation. Still, adherence was not optimal for all Myinlife users. Determinants for Myinlife use were identified on the level of the Myinlife innovation, the users, and the socio-political context.

**Conclusions:** Myinlife was evaluated as a useful instrument for efficient central care coordination and mutual involvement. This study emphasises that the personal attitudes of the Myinlife users to seek and provide support warrant attention, next to the characteristics of the actual Myinlife innovation for optimal intervention uptake. Online and offline support might be integrated to raise awareness of caregiver social support needs and attitudes, and provide insight into caregivers' available social capital.

# 1 INTRODUCTION

Informal caregivers of persons with dementia have a significant role in caring for their relatives with dementia. Much of the care and support for people with dementia is provided by informal caregivers, such as family, friends, and neighbours<sup>1,2</sup>. The care process might be demanding due to the progressive functional decline during the disease process<sup>3</sup>. Caregiving has negative as well as positive impacts on daily life. Although some caregivers report enrichment of relationships<sup>4</sup>, others experience heavy burden and social isolation<sup>3</sup>. Therefore, psychosocial interventions for caregivers are essential to enhancing a supportive environment and preventing overburdening. Research findings have demonstrated that supportive multicomponent interventions that focus on stimulating both the capacities of the person with dementia and the caregiver in the early phase of the disease are most effective<sup>5,7</sup>. Recently, innovative eHealth interventions have shown beneficial results for caregiver self-efficacy, feelings of competence, and depression<sup>5</sup>. Social media interventions could have the potential to stimulate positive interaction and capacities of people with dementia and their informal caregivers, regardless of time and mobility constraints. Hence, in the Netherlands, an innovative intervention was designed entitled 'Myinlife': An online social support platform to increase positive interaction and social support within the social network of the person with dementia<sup>8</sup>.

The development and evaluation of Myinlife were structured according to the guidelines of the Medical Research Council (MRC) framework for developing and evaluating complex interventions<sup>9</sup>. According to this framework, randomised controlled trials (RCTs) are considered the gold standard for evaluating the effectiveness of the intervention<sup>10</sup>. Recently, the updated MRC guidance recognised the added value of a process evaluation prior to an effectiveness evaluation to disentangle intervention fidelity and quality of implementation, and to identify contextual factors that might affect future implementation<sup>11</sup>. Although the MRC framework recommends potential elements to be included in a process evaluation (e.g., fidelity, reach, and contextual factors)<sup>11</sup>, it does not provide consensus regarding the essential elements or the best model to conduct a process evaluation. Therefore, the present process evaluation will be structured according to the model described by Leontjevas<sup>12</sup>. This model is commonly applied to conduct process evaluations of psychosocial interventions in dementia care<sup>13</sup>. It provides information on first order process data (sampling and intervention quality such as fidelity, dose, and reach), and on second order process data (e.g., contextual barriers and facilitators). These data might aid future implementation of the intervention and interpretation of the effectiveness and generalisability of the results by understanding the context in which the intervention was delivered. The objective of this process evaluation is the evaluation of the internal and external validity of the newly developed Myinlife intervention by examining sampling, intervention quality, and potential determinants for use.

## 2 METHODS

This process evaluation was performed prior to the effectiveness study. This study was structured according to a randomised waiting list-controlled design. In order to provide a clear context for this process evaluation in this section we first describe the design of the RCT. The details of the method can be found elsewhere in the complete study protocol<sup>14</sup>. This section is followed by a description of the method used to conduct the process evaluation.

### 2.1 Study design and participants

A RCT was undertaken in the Netherlands, alongside the process evaluation (described below). Based on our power calculation, we originally aimed to include 122 primary caregivers (due to recruitment difficulties, 96 were eventually successfully recruited). Caregivers were recruited via regional and national dementia community services, and online channels. A waiting list-controlled design was chosen to optimise acceptability and adherence to the research protocol in the control group and decrease attrition effects<sup>9</sup>. Data were collected at four time points: Pre-intervention ( $T_0$ ), 8-week follow-up ( $T_1$ ), 16-week follow-up ( $T_2$ ), and 42-week follow-up ( $T_3$ ). The 16-week follow-up assessment served as a primary endpoint to compare group effects. In- and exclusion criteria were being a primary caregiver of a person with dementia (all sub- types of dementia), having access to the Internet, basic (tablet) computer skills and with at least two social network members who are willing to join the Myinlife platform. The exclusion criteria were being overburdened, having serious health problems that could interfere with participation (e.g., burn-out or surgery) as assessed by the study staff rated in the telephone screening, and being unavailable for more than four weeks during the study period. A detailed description on the study design and participants can be found elsewhere<sup>14</sup>.

### 2.2 Intervention

Myinlife is an online social support platform for caregivers of people with dementia aiming to enhance positive interaction, involvement, and social support. Myinlife was developed in an iterative development process together with potential users, clinicians, and web-designers. Details about the developmental process are described elsewhere<sup>8</sup>. On the Myinlife platform, the primary caregiver can invite friends, family, and significant others into three personal support Circles (i.e., inner, middle, and outer Circle, depending on the closeness of the relationship), with different privileges. The platform consists of the following functionalities: Profile, Circles, Timeline, Calendar, Helping, Personal Messages, Care book, and Compass. These functionalities provide opportunities to share care information, messages, pictures, and requests for support. Details about these functionalities can be found elsewhere<sup>8</sup>. Participants could access the platform via (tablet)

computer and smartphone by using a personal username and password. The RCT was conducted over a period of 16 weeks. Participants could use Myinlife at their own pace, and the platform remained accessible after the intervention period. Participants in the control group remained on the waiting list for 16 weeks, receiving care as usual. After the 16-week follow-up assessment (T<sub>2</sub>), they had the opportunity to register on the Myinlife platform.

### **2.3 Design of the Process Evaluation**

The present process evaluation, which was conducted alongside the RCT, was based on methods used in previous research<sup>11-13</sup>. Both first- and second-order data were collected to provide a complete overview of the trial quality and the implementation process. The process data were evaluated prior to the effectiveness analysis.

#### **2.3.1 First Order Process Data**

For evaluation of *sampling quality* (e.g., recruitment, reach), we examined the procedures for recruitment, informed consent, treatment allocation, reach, and barriers and facilitators of recruitment. Data were extracted from the digital case record files designed for this study, contained in an online system including demographic information of the participants, contact information, and contact history entered into text fields. A case record was kept for each participant, including the answers provided during telephone calls. This data was exported and files were analysed by summing up the responses and grouping qualitatively similar answers (by author CMJS).

For evaluation of *intervention quality* (e.g., relevance, feasibility, adherence to protocol), data was extracted from the program participation questionnaire (PPQ), which was completed by 36 responders in the intervention group after the 16-week follow-up (T<sub>2</sub>) to evaluate the feasibility of and satisfaction with the Myinlife platform. Answers on the PPQ were provided on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), with higher scores reflected greater feasibility. Furthermore, we collected qualitative data from semi- structured interviews (n=10) to examine the feasibility and relevance of the intervention. The topic list is depicted in the Appendix. This subsample of participants in the intervention group that completed the 16-week follow up (T<sub>2</sub>) was selected to participate in the interviews by a randomisation procedure stratified for gender and user activity.

The interviews were conducted face-to-face in the home setting of the participants by one of the authors (AD). The interviews lasted about an hour. The topic list depicted in the Appendix was designed together with researchers, clinicians, and experts knowledgeable about implementation of innovative psychosocial interventions (MdV, MvB).

### **2.3.2 Second Order Process Data**

Second order process data regarding the implementation of Myinlife (e.g., barriers and facilitators) was collected by semi-structured interviews with a randomised selected subsample (n=10, see Appendix) of caregivers participating the intervention group for 16- weeks.

### **2.4 Analysis**

The quantitative data of the PPQ was analysed using descriptive statistics (SPSS version 24.0). The qualitative interviews were audiotaped and transcribed verbatim. Subsequently, the qualitative data were analysed using Atlas.ti (Version 1.0.14 for Apple Macintosh). Two authors, AEHD and HLC, performed inductive content analysis<sup>5</sup>. In the inductive content analysis, open coding, continuous examination, and comparison by the two researchers resulted in categories and themes emerging from the data. Open codes that were frequently reported were grouped into categories and these categories are grouped into higher-order themes. After thorough discussion between the researchers, consensus was reached about the categories and themes (AEHD, HLC, and MEV).

## 3 RESULTS

### 3.1 First-order process data

#### 3.1.1 Sampling quality

*3.1.1.1 Recruitment and randomisation.* For the RCT, 475 primary informal caregivers of people with dementia were recruited via the Dutch Alzheimer Association (*Alzheimer Nederland*) and caregiver support services (e.g., day care centres, caregiver support groups), online advertisements (e.g., Facebook, online newsletters), written advertisements (e.g., local newspapers), and via brochures distributed on regional memory and mental health clinics. These 475 caregivers received information, were contacted, and screened for eligibility. 351 met the inclusion and exclusion criteria and were eligible to participate. If interested, caregivers were sent an information letter (n=267) and those who declined were asked for their reason to decline. A total of 96 of the eligible caregivers agreed to participate in the study and signed the informed consent form (27%, 96/351). Reasons for declining to participate in the study are depicted in Table 1. After the baseline assessment, participants (N=96) were randomly assigned to either an intervention group (n=48) or a waiting-list control group (n=48). A computer program controlled by an independent researcher performed the randomisation. The self-reported follow-up measurements were completed online through a custom and confidential questionnaire system. The 16-week follow-up measurement was the primary endpoint for evaluation of the group differences<sup>14</sup>. In total, 92.7% of the caregivers (n=89) completed the 16-week follow-up assessment. The number of non-responders included five in the intervention group and two in the control group.

*3.1.1.2 Barriers and facilitators for recruitment of participants.* Data on barriers and facilitators for recruitment was extracted from the digital case record files including contact history, participants responses, and responses from health care professionals that assisted in the recruitment. Barriers for recruitment included concerns of additional burden or lack of willingness of caregivers' social network members to participate in the Myinlife Circles. Case managers who assisted in recruitment process reported that having a small network size and concerns about the use of online technological devices were primary barriers, whereas being younger and having familiarity with online devices facilitated program recruitment. Since the recruitment turned out to be more challenging than expected, the recruitment period was extended with three months.

**Table 1.** Caregiver reasons for declining to participate in the Myinlife RCT

<b>Reason</b>	<b>Number of caregivers who declined to be sent the information letter</b>	<b>Number of caregivers who declined after being sent the information letter</b>
Intervention was considered too time-consuming or burdensome	21	25
Inability to be contacted	18	17
Not enough interest within the personal network	12	18
A social network that was too small (<2 persons)	6	23
Already using other available online care tools	0	20
No current need for support	13	0
Having other expectations of the intervention	6	9
No current need for support	13	0
Unknown	6	5
Feeling unfamiliar with using online devices	0	7
The person with dementia rejects support or is suspicious	0	3
Health problems of the person with dementia	1	2
Not willing to participate in academic research	1	0
Problems with privacy on the web	0	1

*3.1.1.3 Reach.* An estimated total of 971,304 caregivers of people with dementia were reached through various recruitment methods. The reach was approximately 0.05%. 475 out of these 971,304 caregivers contacted the authors for more information on the trial. Data was collected on the recruitment method through which they were reached: Through flyers (38 recruited from 500 flyers distributed), Alzheimer Netherlands Facebook, website ads and online newsletters (240 recruited from 950,000 cumulative page views), as well as ads in local parish newsletters (19 recruited from 20,528 parish newsletters distributed), community services (56 recruited from 101 attendees of local Alzheimer Cafés or caregiver meetings), case-manager referrals (25 recruited from 25 referrals), caregivers known to the research group through previous studies (82 recruited from 150), and communication with known relatives or acquaintances (n=15). 351 of these caregivers were eligible to participate in the trial. In total, 96 caregivers participated in the trial.

### **3.1.2 Intervention quality**

Qualitative data on the relevance and feasibility of the Myinlife intervention was derived from the semi-structured interviews. Characteristics of the interviewed caregivers are shown in Table 2. Seven themes emerged from the inductive content

analysis (Table 3). The themes shown in these tables are solely based on the qualitative analysis of the interviews and these themes are supported in the next sections by quantitative data on the usability and user- friendliness of Myinlife collected from the Myinlife Program Participation Questionnaire (PPQ), that was completed after the 16-week follow-up (T<sub>2</sub>) by 36 participants in the intervention group (five did not fill in any questionnaire of the 16 week follow-up and seven participants declined to fill in this final survey, the PPQ).

**Table 2.** Background characteristics of the interviewed caregivers (n=10)

<b>Respondent (R)</b>	<b>User Activity</b>	<b>Gender</b>	<b>Caregiver Relationship</b>	<b>Age</b>	<b>Years of caring</b>	<b>Hours of caring Per week</b>
1	High	Female	Daughter	54	5	12
2	High	Female	Grand-Daughter	26	6	30
3	Low	Female	Daughter	49	4	10
4	High	Male	Spouse	59	9	85
5	High	Male	Spouse	63	4	14
6	Low	Female	Daughter in law	60	0.5	3
7	Low	Male	Spouse	71	6	1.5
8	Low	Male	Son	64	6	12
9	High	Female	Daughter	59	3	20
10	Low	Female	Daughter	62	7	12

A sub-sample that completed the 16-week follow-up measurement (T<sub>2</sub>) was selected to participate in the interviews by a randomisation procedure stratified by user activity and gender. Classification of high and low user activity in the intervention group was based on a mean split of the total clicks on the Myinlife platform after 16 weeks (mean=1617).

*3.1.2.1 Reasons for Myinlife use.* Some caregivers had altruistic motives for participation such as contributing to academic research, development of new technologies, or the improvement of future dementia care. Others were interested in specific features of Myinlife, such as the support Circles and Calendar that could assist with care planning and involvement in the social network.

*“For the future, that has actually been one of my reasons for participation. I think my children will at least have to know that such a thing exists” (R6, Daughter-law, 60 years, low- active user)*

*3.1.2.2 User-friendliness of Myinlife.* Participants used both the website and the app version. The app version for smartphones and tablets had added value since it enabled faster information transfer wherever and whenever, even in the moment.

Participants reported that the structure and layout of Myinlife were clear. Data collected from the PPQ (i.e., using a 5-point Likert scale) demonstrated that the structure of the Dashboard (M 3.9, SD 1.1) and clear symbols (M 4.0, SD 0.8) enabled easy navigation on the website (M 3.9, SD 1.1). The circular structure of Myinlife was valued (M 3.7 SD 1.1) for the privacy and autonomy, since carers could decide for themselves what was shared with whom. This setup increased feelings of control. The instructions were evaluated as sufficient (M 3.9, SD 0.9). Some participants mentioned that instructions on paper could have been a helpful addition.

*“We have the first Circle with the people who provide immediate care. The second Circle was just the family that often visits. In addition, the third Circle was then family, or more friends who once wanted to do something or contributed to the front yard for example. It enabled us to share everything around the care, such as the medication with the first Circle, the second Circle does not have to know that.”* (R5, Husband, 63 years, high-active user)

**Table 3.** First order data: Themes and Categories Process Evaluation (n=10)

<b>Theme</b>	<b>Category</b>
Reasons for Myinlife use	Care planning Involvement with others Using specific Myinlife features Altruistic motives (i.e., improve care/research)
User-friendliness of Myinlife ( <i>First order data</i> )	Clear navigation via Circles Clear colours and symbols
Usage of Myinlife	Circles: Useful for privacy Calendar: Planning of appointments Timeline: Sharing on daily basis Helping: Overview of needs and offers Care Book: Transfer of care Personal Messages: Quick messaging Compass: Finding information
Relevance of Myinlife (Advantages/disadvantages)	Increased feelings of control Central care organisation (i.e., monitoring) Openness and connectedness Addressing stigma Limited effects on feelings of well-being and support Disappointment due to lack participation
Satisfaction and Recommendations for the improvement of Myinlife	Customer journey (i.e., minimise logins) Layout changes (i.e., positioning dyad) Add content or functionalities (i.e., video calling)

3.1.2.3 *Usage of Myinlife.* The goal, content, and number of functionalities were considered appropriate (M 4.0, SD 0.8) and offered the possibilities that the participants expected (M 3.6, SD 1.1). However, the distinction between the different functionalities was sometimes not clear (e.g., the Personal Messages and Timeline were sometimes used interchangeably). The Calendar was used for planning appointments and requesting support for a specific moment. The Helping functionality was used to convey requests and offers of support. These help-seeking functionalities were not used regularly. Caregivers reported that either help was not yet needed or that caregivers preferred to ask for help in person, outside the online context of Myinlife. The Timeline was used to share information, pictures, and activities on a daily basis.

*"I think the power is that Myinlife works with photos, that you do not have to read. Take a look, oh nice, the lightness of the photos lets them speak for themselves and place the accents on the good moments, which are mainly achieved through photographs."* (R9, Daughter, 59 years, high-active user)

The Personal Messages were used for quick messaging with (groups of) individuals. The Care Book functionality assisted in the transfer of care-related information.

*"In the Care Book, I wrote things that I thought were important when others go out with her (the person with dementia). So that others know what they can and cannot expect."* (R1, Daughter, 54 years, high-active user)

The Compass provided specific dementia-related information. Participants did not regularly consult the Compass. It was suggested that more updated information could be provided. It was reported in the interviews and shown by the number of clicks on the website that the Calendar and Timeline were used most frequently (Table 4).

3.1.2.4 *Relevance of Myinlife.* Overall, Myinlife was experienced as useful (M 3.5, SD 1.2), and it moderately assisted in the organisation of care (M 2.9, SD 1.3). The interviewed caregivers reported qualitatively that Myinlife is a promising online tool to ease the organisational burden of care, serving as a convenient platform for central care organisation:

*"The good part is that I already find an incredibly big plus of Myinlife, that you can refer people to a place and usually they do that themselves. I think that in its totality it just strengthens the whole picture of the situation and the support, under which some people not only say that they want to help more, but also do that."* (R4, Husband, 59 years, high-active user)

**Table 4.** Percentages of clicks per Myinlife functionality within the intervention group during the 16-week study period.

Myinlife functionalities	Percentage (%) of clicks per functionality <sup>a</sup>
Viewing Timeline	23.7
Viewing Calendar	14.8
Posting Calendar	6.8
Viewing Circles	4.7
Viewing Personal Messages	3.8
Viewing Helping	2.6
Adapting Helping Preferences	2.3
Posting Timeline items	1.8
Viewing Care Book	1.6
Posting Personal Messages	1.3
Adapting Care Book	0.8
Requesting/Providing support in Calendar	0.6
Total clicks within the functionalities <sup>a</sup>	64.8 (n=22994)
Other clicks on the webpage <sup>b</sup>	35.2 (n=12486)
Total clicks on the webpage	100 (n=35480)

<sup>a</sup> This table includes percentages of clicks per functionality on the Myinlife webpage. Note, clicks on the mobile app are not included in this overview (64.7% n=42121/n=77601, total clicks on webpage and mobile app), since these were not measured separately per functionality by the system.

<sup>b</sup> Other clicks contain clicks outside the functionalities such as viewing the homepage, logins, and adjusting messages or pictures.

Additionally, Myinlife contributed to feelings of control over care, a sense of involvement in daily life, and openness and connectedness within the social network. Although it was reported that Myinlife increased involvement within the social network (M 3.0, SD 1.4), it did not directly facilitate seeking online support (M 2.7, SD 1.4). However, some caregivers reported that Circle members were triggered to offer more implicit offline support in daily life because participation in Myinlife facilitated up-to-date information on the current situation of the caregiver and person with dementia.

*“You have the communication flow on Myinlife and it is because of that, that beyond Myinlife it has become easier because you know, well, we are all part of Myinlife too.”* (R8, Son, 64 years, low-active user)

In sum, it was reported that Myinlife is an accessible medium for central care coordination that enables the monitoring and safe exchange of information on a daily basis, which otherwise might not have become visible for all other involved network members. The increased visibility of the daily life of the caregiver and person with dementia not only

increased openness but was also helpful to address stigma around the topic of dementia, since the topic was discussed more openly. Although Myinlife was experienced as helpful in alleviating the care process, it was felt that it did not directly improve experienced well-being, due to the on-going challenges faced by the caregiver during the progressive disease trajectory. Furthermore, we identified some unexpected side effects. Primary caregivers reported that it was sometimes difficult to motivate network members to join the Myinlife network or to get them involved. Some network members were reluctant to post reactions on Myinlife, which occasionally caused disappointment and frustration and, in some cases, prevented Myinlife usage.

*“I was disappointed that people were not willing to participate and that also the involved care institution said no, I did not expect that.” (R10, Daughter, 62 years, low-active user)*

**3.1.2.5 Satisfaction and recommendations for improvement of Myinlife.** In general, participants were satisfied with the possibilities that Myinlife offered (M 3.8, SD 1.0). Participants found the platform meaningful (M 3.4, SD 1.4) and would recommend it to other caregivers (M 4.2, SD 1.1). Myinlife received a sufficient feasibility rating on a scale ranging from 1 to 10 (M 7.6, SD: 1.6). Participants suggested improvements in Myinlife for the customer journey (e.g., reducing the number of logins, ability to upload documents, increasing text layout options), the content (e.g., including a chat function, video conferencing) and the layout (e.g., visual disconnection of the dyad members). Furthermore, it was suggested to make Myinlife accessible for caregivers of people with other (chronic) conditions.

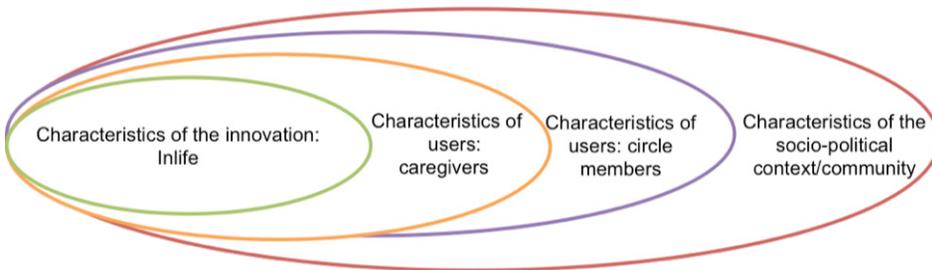
### **3.1.3. Adherence to the protocol**

Caregivers reported spending approximately 1.1 hour per week on the Myinlife platform. Users also reported spending enough time on Myinlife to understand the functionalities (M 3.7, SD 1.3). The most clicks were registered on the Calendar and Timeline. Primary caregivers invited (M 6.3, SD 5.4, range 0-20) network members into their Circles. Having a minimum of two Circle members was a prerequisite to participate on Myinlife. However, five participants were unsuccessful in inviting at least two Circle members. The primary study period was 16 weeks. After this period, participants in the waiting-list control condition (n=48) could start using Myinlife. Of the participants (n=48) randomised into the intervention group, 47 registered on the Myinlife platform. Based on the log data, 76.5% (36/47) continued usage of the platform for at least 16 weeks. During the 16-week study period, user activity (operationalised as the total number of clicks on the Myinlife webpage and mobile app) varied widely (M 1651, SD 2165, range 2-10699). The majority of the participants in the intervention group that used Myinlife for at least 16 weeks also continued to use it after the 16-week study period (range 17 – 73 weeks).

### 3.2 Second order process data

#### 3.2.1 Determinants for Myinlife use

The determinants that were reported in the semi-structured interviews (N=10) either facilitating or impeding the use of Myinlife could be divided into different levels: The level of the Myinlife application, the level of the users (i.e., primary caregiver and their Circle members), and the socio-political context (see Box 1 and Table 5).



**Box 1.** Second order data: Levels of determinants for use and suggested implementation strategies (for details see Table 5)

*3.2.1.1 Determinants of the level of the innovation.* The Myinlife application contained elements that were considered user-friendly (e.g., clear symbols, colours, and Circles). However, some elements warrant attention such as the login procedure and uploading pictures. Ease of use of the innovation was considered a significant factor for successful implementation. In addition, positive user experiences determined continued use of Myinlife to a large extent.

*“It worked because I receive reactions, When I sent a personal message, people often tend to forget about it. Or say “Oh, I’ll do that later”, but if they see something with a photo and they also see that she (the person with dementia) is enjoying her food, so that she is in her element, then they think “Oh, nice” and then they react immediately, it triggers earlier.” (R2, Granddaughter, 26 years, high-active user)*

**Table 5.** Second order data: Themes and Categories (n=10)

Theme	Category
Determinants of Myinlife use (Barriers and Facilitators)	Level of the innovation: Myinlife User (un)friendliness (i.e. workflow) Positive user experiences Level of the users: caregiver Personal attitudes (i.e. stigma, burdening, seeking support) Central coordinator/motivator Care needs depending on dementia phase Level of the users: Circle members Personal attitudes (i.e. offering online support) Circle size & responsiveness Information and communication technology (ICT) skills Establishing routine/time investment Level of socio-political context/community Familiarity of generation with ICT Privacy in an online context
(Second order data, Box 1)	Available all-round online tools (i.e. WhatsApp, Facebook)
Suggested strategies for future implementation	Level of the innovation: Myinlife Start-up information ( <i>best-practice stories, paper manual</i> ) Personalised reminders/notifications: Push messages Level of the socio-political context/community Broader brand recognition
(Second order data, Box 1)	Personal contact: <i>Coach, family meeting, Alzheimer Cafés</i>

3.2.1.2 *Determinants at the level of Myinlife users (caregivers and Circle members).* The level of engagement with Myinlife was determined by the current dementia phase, caregiver needs, and prevailing attitudes of both the caregiver and the Circle members concerning seeking and providing support. Because of these personal attitudes, caregivers might feel reluctant to share information on Myinlife:

*“You don’t want to see your mother with dementia like that. So, if you keep it for yourself then it is not so severe, then it is not that bad. But if it is communicated with the outside world, then it is also true and then I have to deal with it myself, otherwise I can also leave it behind me. Myinlife will open the doors and then it may also be seen.”* (R10, Daughter, 62 years, low-active use)

Myinlife was implemented more easily when there was a primary caregiver that actively motivated Circle members and referred continuously to Myinlife for central care coordination so that it could become part of the daily routine.

*“People have to get used to Myinlife. And you have to continue to stimulate because if it does not come from the other person, I also noticed that if I did not send something out to the person, then it would stop being used.” (R10, Daughter, 62 years, low-active user)*

In addition to sufficient computer and information and communication technology (ICT) knowledge and skills, the characteristics of the involved Circle members were important determinants for implementation. In particular, the overall network size and the number of reactions or posts by network members determined continued use of Myinlife.

*3.2.1.3 Determinants at the level of the socio-political context.* The prevailing view that Internet usage is not yet widely accepted in all layers of society (e.g., depending on age, computer literacy) impeded participants from actively using Myinlife or inviting others into their Circles. Furthermore, uncertainty about the security and privacy affected the usage.

In contrast, the presence of other widespread online tools (e.g., WhatsApp) influenced involvement with Myinlife. People were sometimes inclined to use WhatsApp instead of Myinlife, because it was more routinely used in their daily practice.

### **3.2.2. Suggested strategies for future implementation**

The final theme that emerged described potential implementation strategies. On the socio-political level, caregivers reported that guidance by volunteers or coaches in the community would have been valuable to provide additional user guidance and awareness of social support opportunities. Furthermore, better profiling of the Myinlife brand could increase participation.

*“It would be nice if you are able to speak to someone who also uses Myinlife. Then, you both know what you are talking about and then you can also explain the possibilities. Not that I know everything. However, I know how it works ... I think for Myinlife itself it is of course nice if you can reach as large an audience as possible. And it is a pity if people drop out because they do not find it clear enough. It might be easy if someone who is very positive about it shares the experiences and shows you what we use it for. (R1, Daughter, 54 year, high-active user)*

Improvements at the level of the Myinlife application itself could facilitate future implementation. For example, a visual step-by-step manual provided after the first login was proposed, which could potentially help Circle members to start using the application. It was suggested that personalised notifications sent by the system could potentially stimulate Circle members to post pictures on the Timeline after they finished their appointment as planned in the Calendar.

## 4 DISCUSSION

This process study examined the quality, relevance, and determinants of implementation of the Myinlife intervention. First-order and second-order process data was evaluated to gain insight into the internal and external validity to guide interpretation of the effectiveness and generalisability of the results.

### 4.1 First-order data

#### 4.1.1 Sampling quality and randomisation

The overall participation rate in the study was 27% (96/351), which was lower than expected. Despite the various recruitment strategies and the extension of the recruitment period, the intended goal to include 122 participants was not accomplished. The response rate in caregiver intervention studies is often problematic and depends on the recruitment strategies, selection criteria, and content of the intervention<sup>16</sup>. In line with previous studies, online advertisements and mailings were the most effective recruitment strategies (i.e. 240/475, 50.5%)<sup>16,17</sup>. Because of the smaller sample size, the statistical power might be limited to establish significant differences between the groups in the effectiveness evaluation.

The primary recruitment barriers were unfamiliarity with online devices, unwillingness of the social network to participate, and considering the intervention too time-consuming or burdensome. Caregivers who already experienced a high burden might have been more inclined to reject participation. Moreover, experiencing stigma and a high threshold to seek support might explain the high refusal rate<sup>18</sup>. This study might be subject to selection bias, since people that have better health and computer literacy are more likely to participate<sup>19</sup>, which might influence the external validity of the results.

#### 4.1.2. Intervention quality

Overall, Myinlife users were positive about the content, functionalities, and opportunities that Myinlife offered. The structure, layout, and content of Myinlife were considered clear and user-friendly. In particular, our target group appreciated the Circle structure and clear symbols for navigation. Myinlife was generally evaluated as a beneficial instrument to efficiently coordinate care in one central place and exchange information on a daily basis that otherwise might not have been visible. In addition, Myinlife enabled increased feelings of connectedness, control, and empowerment. Notably, Myinlife also had side effects, such as frustration and disappointment when Circle members did not actively participate. Possibly, Myinlife might have created awareness that not enough support was available, which in the usual care situation would have remained unnoticed. The reported side effects might explain why the adherence was not optimal. However, it is

not uncommon in eHealth research to find low adherence rates<sup>20</sup>. The present study provided room for improvement in the customer journey, content, and layout of the Myinlife system.

With regard to the first order data, in general, the Myinlife intervention was received well. This finding validates the evaluation of the results for a future effectiveness study. However, the internal and external validity warrants attention due to the suboptimal participation and adherence rates.

#### **4.2 Second-order data**

Our findings emphasise that, in addition to determinants of the innovation (e.g., user-friendliness) and determinants of the socio-political context (societal acceptance of technology), determinants of the users are important for the uptake of Myinlife (see Table 2). Not only were positive user-experiences and an enthusiastic central care coordinator important, but the Circle's reactivity, as well as the prevailing beliefs and attitudes regarding providing and offering support, also determined Myinlife uptake. In this respect, a previous study demonstrated that cognitive biases play a role in seeking support<sup>21</sup>. Caregivers and their social network members tend to think for others and therefore are reluctant to seek or provide actual support. Although there is not much evidence of the role of personal attitudes in informal care, it has been demonstrated that access to formal care services is also influenced by personal beliefs, such as a perceived lack of support need or awareness<sup>22</sup>.

Myinlife was most successful when Circle members were responsive and had an open mind towards online technology and support. However, participants frequently reported that online support was not yet needed since it was too early in the disease process. This finding is in line with previous research indicating a support paradox: Caregivers in a later phase regret that they did not use available support in an earlier phase<sup>23</sup>.

On the one hand, we showed that determinants on the level of the user are important since the uptake of Myinlife could have been driven by deeply rooted beliefs and implicit personal attitudes (i.e., fear for stigma, seeking support or burdening others). Surprisingly, on the other hand, we found that the implementation strategies suggested by the subsample of interviewed participants did not address these personal barriers for use. Instead the suggested implementation strategies focus mainly on adapting the Myinlife intervention (e.g., adding notifications) or on the socio-political context (e.g., guidance by a peer, volunteer or coach in the community) and not on changing personal attitudes of the users themselves (Table 2). Therefore, future implementation plans should not only focus on improving the product itself, but also on creating

awareness of psychological barriers of potential users. Early identification of social support barriers and awareness might be essential for successful engagement with online innovations.

#### **4.3 Lessons learned for future research and clinical implementation**

Our findings reveal that not all identified determinants for Myinlife use are addressed by participants in their suggested implementation strategies. Future implementation plans should include also psychological factors that determine intervention use. Potentially, some caregivers lack insight such that prevailing personal beliefs and attitudes might actually impede seeking active online support. Therefore, it is essential that health care professionals within dementia-friendly communities<sup>24,25</sup> raise awareness about the importance of timely access to social support. Therefore, an intervention such as Myinlife could have more potential if embedded in local and national dementia community services. For example, within the context of Alzheimer Cafés or in regional and national dementia care services, awareness could be raised concerning social support needs, attitudes, and support opportunities. Furthermore, face-to-face personal contact might increase adherence to the Myinlife intervention and enable the sharing of best-practice stories of Myinlife users. In addition, as observed in the interviews, caregivers had the tendency to underestimate the richness of their own social network. Therefore, potential adaptations to the customer journey to proactively think about existing social ties and social capital might increase user adherence, such as by completing a survey or online ecogram after the first login to the Myinlife platform, which would give users a better insight in their potential support network upfront. Providing insight into caregivers' individual social capital might increase interactions on Myinlife. Previous research has demonstrated that available social capital is associated with increased social engagement and mental health<sup>26,27</sup>.

#### **4.4 Strengths and limitations of the present study**

In line with the updated MRC framework, the added value of this process evaluation alongside the RCT is that it aids the interpretation of the results of the effectiveness analysis and provides valuable insights and recommendations for future implementation. This process evaluation also had some limitations. First, the evaluation focused mainly on the primary caregiver, and it would be valuable to additionally interview other stakeholders, such as the person with dementia (if possible), involved Myinlife Circle members, and health care professionals.

Second, the qualitative analysis was conducted in a sub-sample only. Although we used a stratified sampling procedure, it might be possible that caregivers who encountered barriers dropped out before conducting the qualitative interviews after 16 weeks, and as a consequence the sample might be biased to some extent. Moreover, we only selected

a sub-sample of participating caregivers for the interviews. This might have reduced the transferability of the results. However, the participants were randomly selected for the qualitative interviews and none of them declined the invitation for an interview. Furthermore, the researchers observed saturation in the data after interviewing ten caregivers in the intervention group indicating that no new themes or categories could be obtained from the data.

## 5 CONCLUSIONS

The present study was a crucial step in evaluating the innovative Myinlife intervention, resulting in promising insights that should be evaluated in an upcoming effect evaluation and incorporated into the next version of Myinlife. Furthermore, this study provided insight into factors that might improve implementation of Myinlife on a broader scale. Our data indicated that Myinlife contributes to feelings of empowerment, openness, involvement, and facilitates more efficient care organisation. The adherence was not optimal for all users due to disappointment and frustration caused by a lack of responsiveness of Circle members.

Determinants of Myinlife use were identified on the level of the innovation, the users, and the socio-political context. Surprisingly, not all indicated determinants for Myinlife use were addressed by participants in their suggested implementation strategies. More specifically, our study emphasises that the personal attitudes of the Myinlife users to seek and provide support warrant attention, next to characteristics of the actual product and socio-political context in future implementations plans. To improve implementation and engagement with Myinlife, online and offline support should be integrated to raise awareness of social support needs and attitudes, and to provide more insight to future users regarding their available social capital.

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### **DECLARATIONS OF INTEREST**

None.

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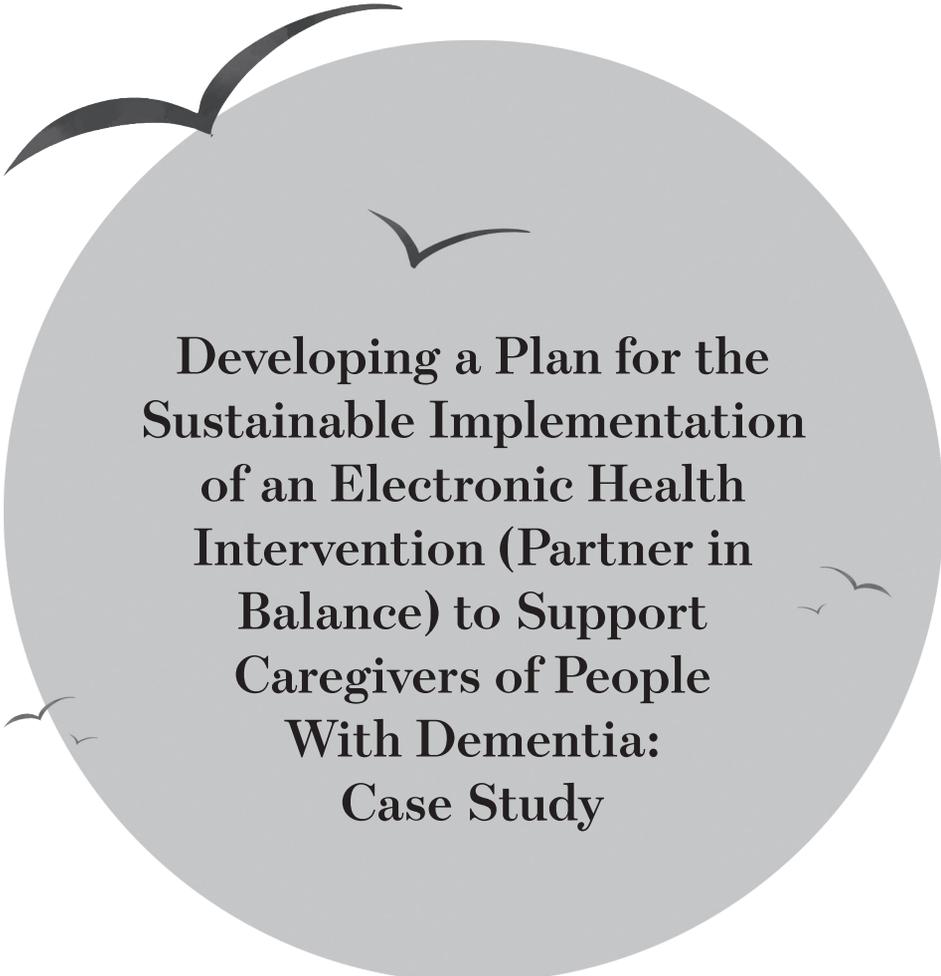
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6



**Developing a Plan for the  
Sustainable Implementation  
of an Electronic Health  
Intervention (Partner in  
Balance) to Support  
Caregivers of People  
With Dementia:  
Case Study**

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*JMIR Aging, 2020*

# ABSTRACT

**Background:** Given the increasing use of digital interventions in health care, understanding how best to implement them is crucial. However, evidence on how to implement new, academically-developed interventions into complex health care environments is lacking. This case study offers an example of how to develop a theory-based implementation plan for Partner in Balance, an eHealth intervention to support caregivers of people with dementia.

**Objectives:** The specific objectives of this study were to (1.) formulate evidence-based implementation strategies, (2.) develop a sustainable business model, and (3.) integrate these elements into an implementation plan.

**Methods:** The case study concerns Partner in Balance, a blended care intervention to support caregivers of people with dementia, which is effective in improving caregiver self-efficacy, quality of life, and experienced control. This large-scale implementation of Partner in Balance took place in local dementia case-management services, local care homes, dementia support groups, and municipalities. Experiences from real-life pilots (N=22) and qualitative interviews with national stakeholders (N=14) were used to establish an implementation plan, consisting of implementation strategies and a business model.

**Results:** A main finding was the need for a business model to facilitate decision-making from potential client organisations, who need reliable pricing information before they can commit to training coaches and implementing the intervention. Also, knowledge of the organisational context and wider health care system is essential to ensure that the intervention meets the needs of its target users. Based on these findings, the research team formulated implementation strategies targeted at engagement of organisations and staff, dissemination of the intervention, and facilitation of long-term project management in the future.

**Conclusions:** This study offers a theory-based example of implementing an evidence-based eHealth intervention in dementia health care. The findings help fill the knowledge gap on the eHealth implementation context for evidence-based eHealth interventions after the trial phase, and they can be used to inform others working to develop and sustainably implement eHealth.

# 1 INTRODUCTION

## 1.1 Dementia and caregiving

The combination of an ageing population and declining birth rate is proving a significant challenge for many modern health care systems, resulting in rising costs and spending cuts<sup>1</sup>. In particular, policy makers express concerns about the rising cost of dementia care, as there are currently 50 million people with dementia, and this number is set to triple by 2050<sup>2</sup>. Policy makers and governing bodies have expressed enthusiasm for eHealth as a solution to tackle these current health care challenges<sup>3,4</sup>. Informal caregivers of people with dementia, such as spouses, friends, and other loved ones, provide a large part of the necessary care for people with dementia at home<sup>5</sup>. However, the informal caregiving process often results in chronic stress, leading to caregiver overburdening, depression, and anxiety<sup>6</sup>.

## 1.2 eHealth as a potential solution

Various eHealth interventions have shown evidence of effectiveness in improving outcomes for caregivers of people with dementia, such as self-efficacy, dementia knowledge, as well as reduced depressive and anxious symptoms<sup>7-13</sup>. eHealth interventions are defined as *“treatments, typically behaviourally based, that are operationalised and transformed for delivery via the Internet”*<sup>14</sup>. eHealth interventions provide specific advantages to caregivers of people with dementia, as they can be personalised and adapted to the stage of dementia, allow caregivers to receive psychoeducation without leaving the person with dementia home alone, and seek help without facing the stigma associated with dementia. For these reasons, eHealth is also mentioned as an important part of the Dutch *Deltaplan Dementie*<sup>15</sup> and in the Council of the European Union’s dementia policies<sup>16</sup>. Of course, there are also specific challenges associated with implementing eHealth for caregivers of people with dementia, including the advanced age of many dementia caregivers. While many older adults do show high digital literacy, impaired motor, cognitive, and perceptive abilities can constitute significant barriers<sup>17-19</sup>.

## 1.3 Implementing eHealth for caregivers of people with dementia

Unfortunately, the implementation of evidence-based eHealth interventions into routine practice has proven challenging<sup>20-22</sup>, and previous research has shown that very few eHealth interventions for dementia are implemented into practice<sup>23</sup>. Here, implementation is defined as *“the process of putting to use or integrating evidence-based interventions within a setting”*<sup>24</sup>. A lack of insight into eHealth interventions’ contextual determinants and process changes is an important factor in the slow implementation of many eHealth interventions<sup>25</sup>. Additionally, challenges in implementing eHealth include thin evidence of their demonstrable effects on improving health care outcomes, sceptical attitudes from

health care professionals, a lack of coordination and management of the intervention within health care organisations, and the often peripheral position of potential end-users in eHealth development<sup>26</sup>. Many of these issues result from problematic, atheoretical implementation and insufficient implementation strategies<sup>27</sup>, which are *“methods or techniques used to enhance the adoption, implementation, and sustainability of a clinical program or practice”*<sup>28</sup>. This lack of successful implementation is an important missed opportunity for the health care system, as advantages of eHealth interventions include the potential to widen access to more remote areas, lower thresholds to participation, improve quality through increased opportunities for personalisation, improve service efficiency, and reduce costs<sup>22,29</sup>. To facilitate the sustainable success of these promising interventions, it has been argued that the development of a business model is paramount<sup>30</sup>. Here, business models are defined as *“the rationale of how an organisation creates, delivers, and captures value”*<sup>31</sup>. Business modelling can be seen as part of an effective implementation strategy, primarily through its potential to both aid sustainable financing and identify value-drivers to ensure the relevance of the interventions to the target users<sup>32</sup>. Finally, it is important to note that the specific challenges experienced in implementing eHealth interventions for caregivers of people with dementia can differ across settings. In this study, we explore the at-home setting of Partner in Balance, which is implemented through health care organisations.

#### **1.4 The intervention: Partner in Balance**

One example of such an eHealth intervention to support caregivers of people with dementia is Partner in Balance. Partner in Balance is an online tool to support caregivers of people with dementia at home, applied in a ‘blended’ eight-week eHealth intervention. This ‘blended’ aspect entails that Partner in Balance is delivered through a coach. These coaches are part of participating health care organisations (for example, dementia case management organisations), who have agreed to offer the Partner in Balance intervention to their clients. Partner in Balance coaches are required to have experience (1.) in health care and (2.) with dementia. The coaches are required to take part in a two-hour Partner in Balance training course, were the intervention is presented and the coaches take part in various coaching exercises.

Afterwards, caregivers first meet the coach face-to-face for an intake session, where together they choose the relevant modules to help the them adapt to their new role. At home, the caregivers complete the chosen modules, which consist of caregiver tips, video vignettes, self-reflective assignments, and online feedback from the coach. Finally, the coach and caregiver meet for an in-person evaluation session. Partner in Balance is currently available in Dutch, French, German, and English. The development and testing of Partner in Balance made use of the stepwise approach of the Medical Research Council (MRC) Framework for complex interventions<sup>33</sup>. More information on the results of the needs assessment<sup>34</sup>, pilot

study<sup>35</sup>, randomised controlled trial (RCT)<sup>36</sup>, and process evaluation<sup>37</sup> has been published previously. These last two studies showed that Partner in Balance increased caregiver self-efficacy, sense of competency, and quality of life, and was positively evaluated by both caregivers and coaches.

### **1.5 Aims and objectives**

This paper describes the implementation of Partner in Balance (an evidence-based eHealth intervention for caregivers of people with dementia) as a use case to inform developers of other evidence-based eHealth interventions for caregivers of people with dementia. Using the insights from real-life pilots and stakeholder interviews, the aim of this study is to shed more light on the implementation context and aid future researchers in the implementation of similar interventions. The specific objectives of this study are to (1.) formulate evidence-based implementation strategies, (2.) develop a sustainable business model, and (3.) integrate these elements into an implementation plan.

## 2 METHODS

### 2.1 Explorative implementation

#### 2.1.1 Real-life pilots

To acquire these insights, real-life pilot implementations of Partner in Balance in local care organisations were conducted. Here, the goal was to let the organisations implement Partner in Balance at their own discretion, free from the more rigid protocols of an RCT. These pilots ran from September 2016 to September 2019. Organisations participating in the real-life pilots were recruited through two channels. First, Partner in Balance was offered as one of the 15 activities through the euPrevent Senior Friendly Communities (SFC) project<sup>38</sup>. In this project, 32 municipalities in the Netherlands, Germany, and Belgium had the option to implement Partner in Balance for free through local care organisations in their communities. Second, in 2017 Partner in Balance won the Dutch ZonMw *Medical Inspirer Prize*<sup>39</sup>, resulting in public attention on the intervention and a budget to implement Partner in Balance in interested organisations for a limited time. During the real-life pilots, data was collected on the number and type of participating organisations, as well as the number of active coaches and participants.

#### 2.1.2 Stakeholder interviews

From April to June 2019, fourteen semi-structured qualitative interviews were conducted with stakeholders from patient organisations (n=2), a municipality implementing Partner in Balance (n=1), dementia case management organisations (n=2), mental health care providers (n=3), an eHealth expertise centre (n=1), health insurers (n=3), an academic hospital (n=1), and a care research funding body (n=1). These interviews were all conducted in the Netherlands and in Dutch, ten in person and four via Skype. Participants signed an informed consent. The interviews were recorded and transcribed verbatim. Two researchers (HC and LB) applied inductive thematic analysis by independently coding the transcripts and subsequently grouping these codes into higher level categories and themes<sup>40</sup>. A meeting was held with a third researcher (MdV) to discuss differences in coding and to reach consensus. The stakeholder interview questions can be found in the Appendix.

### 2.2 Sustainable implementation

#### 2.2.1 Overview

The goal of this project was to develop an implementation plan, based on the information gathered during the Explorative Implementation. Figure 1 is an overview of the Partner in Balance implementation trajectory.

#### 2.2.2 Selection of implementation strategies

The first step in the development of the sustainable implementation plan was the

selection of implementation strategies. Based on the information acquired in the previous research and Explorative Implementation phases, these strategies were formulated by the researchers on the Partner in Balance implementation team (which consists of researchers, the software partner, a coach organisation, and the Knowledge Transfer Office).

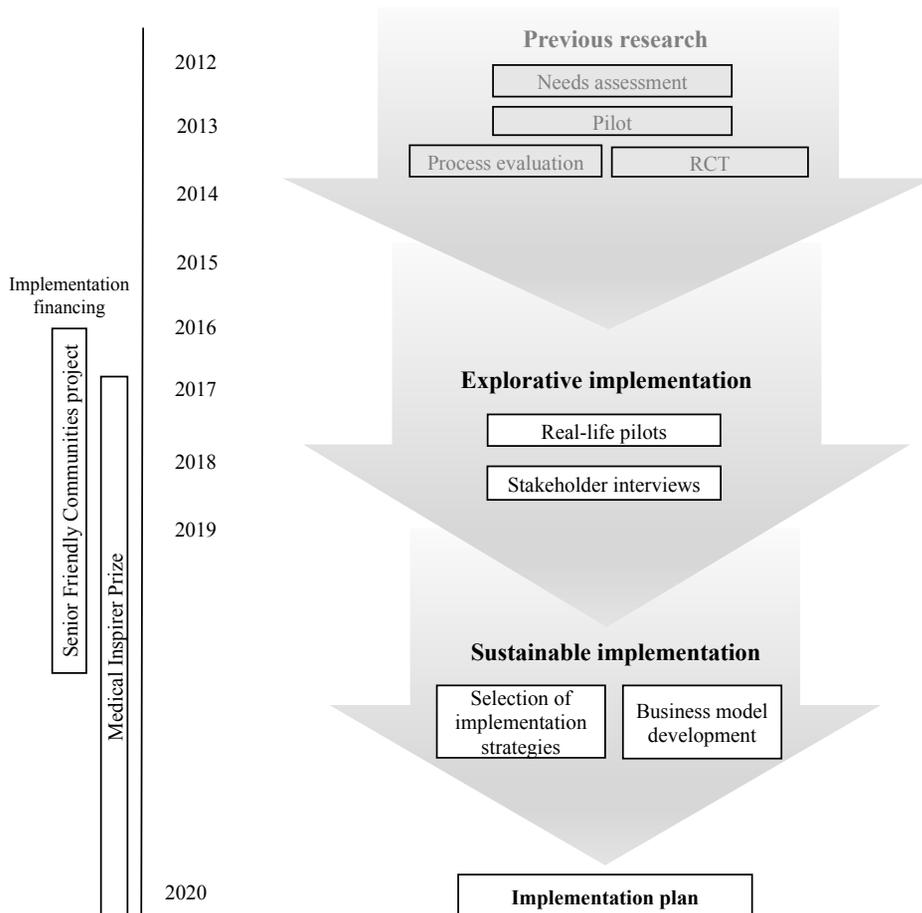
The selection of strategies was guided by the Consolidated Framework for Implementation research (CFIR)<sup>41</sup>. The CFIR is an established framework for mapping implementation, also for eHealth interventions<sup>42</sup>. The CFIR aims to describe determinants, which can serve as barriers and facilitators, that affect implementation outcomes. The CFIR is made up of five domains (Intervention characteristics, Outer setting, Inner setting, Characteristics of individuals, and Process), containing 39 implementation constructs. The CFIR has been used both to retrospectively evaluate implementation, and to prospectively design future implementation strategies<sup>43</sup>.

### **2.2.3 Development of business model**

The second component of this sustainable implementation plan was the development of a business model. The Partner in Balance business model was developed using the Business Model Canvas<sup>31</sup>. The Business Model Canvas is a popular framework that aims to develop new and document existing business models, by mapping the value proposition, key activities, key resources, key partners, cost structure, customer relationships, distribution channels, and revenue of a product or service. The Business Model Canvas has often been used to map business models for eHealth<sup>32,44-46</sup>. The Partner in Balance business model canvas was co-developed and its face-validity jointly assessed with the involved software partner. The model was iteratively adapted by both parties in reaction to feedback from potential clients. This was done to be able to offer participating organisations some certainties concerning the intervention's future availability and pricing, as this had already been reported in previous research as a barrier to the adoption of Partner in Balance<sup>37</sup>.

### **2.2.4 Ethical approval**

Ethical approval for these studies was granted by Maastricht University's Medical Ethical Oversight Commission (METC), under approval number 2018-0489.



**Figure 1.** Partner in Balance development and implementation trajectory

## 3 RESULTS

### 3.1 Overview

The following section describes this study's findings from Explorative Implementation (the real-life pilots and stakeholder interviews), while the subsequent section describes how these findings are integrated to achieve this study's objectives concerning sustainable implementation (devising implementation strategies and a business model). The final section integrates these findings into a concrete implementation plan.

### 3.2 Explorative implementation

#### 3.2.1 Real-life pilots

Four and a half full-time equivalent (FTE) researchers worked part-time on the implementation of the Partner in Balance project, recruiting organisations, providing technical and implementation support, managing relationships with organisations and the technology partner, planning and carrying out coach trainings, and developing new content modules. In the context of the SFC project, three municipalities in the Netherlands, one municipality in Belgium, and one municipality in Germany chose to implement Partner in Balance in their communities. The remaining 27 municipalities (84%) in the SFC project chose to implement other projects. In the context of the Medical Inspirer Prize, 19 organisations chose to implement Partner in Balance for their clients. Table 1 provides an overview of some characteristics of the real-life pilots, including the finding that not all trained coaches ended up coaching participating caregivers.

**Table 1.** Overview of real-life pilots

Real-life pilot characteristics	N
Type of organisation	22
<i>Hospitals</i>	6
<i>Companies</i>	1
<i>Municipalities</i>	5
<i>Case management organisations</i>	4
<i>Mental health care organisations</i>	4
<i>Care homes</i>	3
<i>International research projects</i>	1
Total number of trained coaches	128
Total number of coached participants	122
Average number of participants per organisation	10
Average number of coaches per organisation	7

### 3.2.2 Stakeholder interviews

The inductive interview analysis of the interviews with the potential stakeholders (N=14) resulted in five themes, with their own categories and subcategories presented in Table 2. The aim of the interviews was to gain insight into stakeholders' views on barriers and facilitators to the sustainable implementation of Partner in Balance.

**Table 2.** Inductive interview themes

Themes	Categories ( <i>Examples of answers</i> )
1. Future of Partner in Balance	1.1 Good content ( <i>Self-management, Sustainability, Blendedness, Personalized, Evidence-based, Positive health</i> ) 1.2 Need for Partner in Balance ( <i>Not suited for everyone, As addition to offline services, Psychoeducation, Partner in Balance is needed, An opportunity for a research project to grow, Meets caregivers needs, Digital factor is a challenge</i> ) 1.3 Extra Partner in Balance functions ( <i>Modules for new populations, Extra workshops, Chat function, More structural support, Reminders when inactive, Facilitator/contact person, Forum, Return meetings, No changes necessary</i> )
2. eHealth experiences	2.1 Lack of suitable options 2.2 Works better in younger adult populations 2.3 Good investment 2.4 Easier than physical services 2.5 The provider has to be pushing the implementation 2.6 Important to some health insurers 2.7 Not often user-friendly
3. Caregiving experiences	3.1 Caregiving support ( <i>Where can caregivers go for support?, Often still new for care teams, Importance of case management, Financing of caregiving support</i> ) 3.2 Policy
4. Financial context	4.1 Financing models ( <i>Public money, Subscriptions and licensing</i> ) 4.2 Potential financers ( <i>Caregivers, Organisations, Municipality, Labour market, Health insurer</i> )
5. eHealth implementation process	5.1 Purchase process ( <i>Pilots by providers, Importance of municipality policy and budget, Collaboration with organisations, Decision levels</i> ) 5.2 Evaluation criteria ( <i>Financial plan, Form of eHealth, Who is the eHealth owner, Connection to research, Necessary information</i> ) 5.3 Outcomes of success ( <i>Waiting lists for care support go down, Caregivers satisfied, Less case management hours, More referrals, More caregivers supported, More caregivers able to safely live at home, Positive real-time evaluations, More care efficiency, Acquiring of cost-effectiveness data</i> )

3.2.2.1 *The future of Partner in Balance.* The first theme concerns the views stakeholders had on what was good about Partner in Balance and what could be improved in the future. The first category of this theme, 'Good content', showed that all groups of stakeholders had positive

attitudes towards the Partner in Balance content and thought many of its components were useful and timely. The second subtheme refers to how the stakeholders (especially policy makers and health care professionals) thought that Partner in Balance met caregiver needs, but emphasised that they saw it as complementary to - and not as a substitution of - face-to-face caregiving services. In the final category of this theme, stakeholders suggested options for additional Partner in Balance functions. These mostly centred around more contact and support, either online (through chat functions and forums) or offline (through meetings, symposia, and a contact person).

*3.2.2.2 eHealth experiences.* The second theme discusses what stakeholders mentioned concerning the broader eHealth context. In the experience of health care professionals, eHealth is rather difficult to implement, especially in older populations. They also felt that the topic of eHealth was important to health insurers, and the implementation often needed to be pushed by the eHealth provider. Several groups of stakeholders mentioned that eHealth is often not very user-friendly and saw this as an important barrier.

*3.2.2.3 Caregiving context.* In the third theme, 'Caregiving context', stakeholders sketched the context in which dementia caregiving support usually takes place, as well as the associated challenges. These challenges included health care professionals unfamiliarity with the topic, as well as the importance of case management and how it (and dementia caregiver support in general) is organised. In terms of policy, a trend emerged across the different stakeholders. For policy makers, health care professionals, and health insurers, policy tended to focus less on caregiving, and more on self-management, personalisation, and positive health. These policy trends were in line with the Partner in Balance content and this match between the intervention and current policy trends was considered a notable intervention selling point.

*3.2.2.4 Financial context.* The fourth theme groups the stakeholders' views on the financial context of Partner in Balance. This included responses from policy makers on whether it was ethical to market an intervention developed with public money, as well as different options and calculations for various subscription and licensing models. Regarding the latter, large variations in suggested price were observed, ranging from caregiver contributions of 0, 1, 25, 35 euros for a full course (as a way to ensure adherence), to 200-700 euros paid by the care organisations (including the costs of training, coaching hours, and hosting costs). However, the majority of stakeholders did not think that informal caregivers should be the ones paying for the intervention, but rather that this should fall to the care organisations, municipalities, or health insurers (no stakeholders suggested the intervention be somehow free for all parties). The health care professionals favoured a year's subscription model, where organisations could buy licenses for the desired amount of participants. In the

second category, 'Potential financiers', the Dutch national health care insurance system and how it related to the municipal prevention mandate was the main topic of discussion. In particular, the classification of Partner in Balance as a tool for prevention (as buying a license could then be more suited to a municipality) or treatment (as buying a license could then be more suited to a health care insurer) was important. Other potential financing options were interested parties from the labour market (to combat loss of workforce to caregiver burden), and buy-in care networks (where local dementia care organisations group together in care networks).

*3.2.2.5 eHealth implementation process.* The final theme groups stakeholders statements on the process for their organisations to potentially adopt, disseminate, and implement new eHealth interventions for caregivers of people with dementia. Concerning the first category, 'Purchase process', the policy makers emphasized the need for the intervention be approved at many levels, including in the budget and policy (especially for municipalities), as well as the added value of testing interventions through pilots with local collaborations. A number of evaluation criteria used by their organisations to decide whether or not to implement an intervention were discussed (see Table 2). Most importantly, health insurers repeatedly mentioned the need for data on effectiveness and cost-efficiency. Interestingly, they emphasised that the data could be speculative and qualitative (and not necessarily longitudinal, or randomised controlled). Useful outcomes with which health care organisations (such as dementia case management organisations) could measure implementation success were waiting list reductions, less case management hours, more referrals, more supported caregivers, more caregivers able to safely live at home, positive real-time evaluations, and more care efficiency.

### **3.3 Sustainable implementation**

#### **3.3.1 Selection of implementation strategies**

The devised implementation strategies were principally aimed at helping integrate Partner in Balance more into the coach organisations, as well as motivating and engaging these coaches and their management more effectively (CFIR domain 'Inner setting and Characteristics of the individuals'). This was based on the finding from the usage data that not all trained coaches ended up coaching. In order to enhance the attractiveness of Partner in Balance to potential clients, more financial insights into the pricing and long-term business modelling of Partner in Balance were necessary (CFIR domain 'Characteristics of the Intervention'). Additionally, strategies meant to streamline Partner in Balance administration and project management were formulated (CFIR domain 'Process'), as well as to expand and disseminate its use (CFIR domain 'Outer setting'). Table 3 lists the CFIR domains and corresponding implementation strategies.

### 3.3.2 Development of business model

Figure 2 is a depiction of how sustainable implementation could hypothetically be achieved, based on the insights from the previous implementation phases and the stakeholder interviews. Partner in Balance has added value for caregivers, health care organisations and municipalities (see 'Value propositions'), and together with the 'Channels' and 'Customer relationships', this helped the team form a better view of the intervention's desirability to potential customers. In the proposed business model, three distinct types of customers were identified (see 'Customer segments'). As a result, it was decided that two of these customer segments required specific licensing models (see 'Revenue streams'). First, health care support providers, such as case management organisations, require no help with recruitment as they can supply their own coaches in house and are targeted with Package 1. Second, municipalities are targeted with a package that additionally includes identifying which local organisations can provide coaches (Package 2). These revenue streams would in turn finance the main cost drivers of Partner in Balance described in 'Cost structure', which are made possible by the 'Key Partners', 'Key Activities', and 'Key resources'. The development of this business model and the collaboration with the Knowledge Transfer Office (KTO) and the software partner is crucial to the sustainability of the implementation plan, through its provisions for long-term financing of the Partner in Balance intervention.

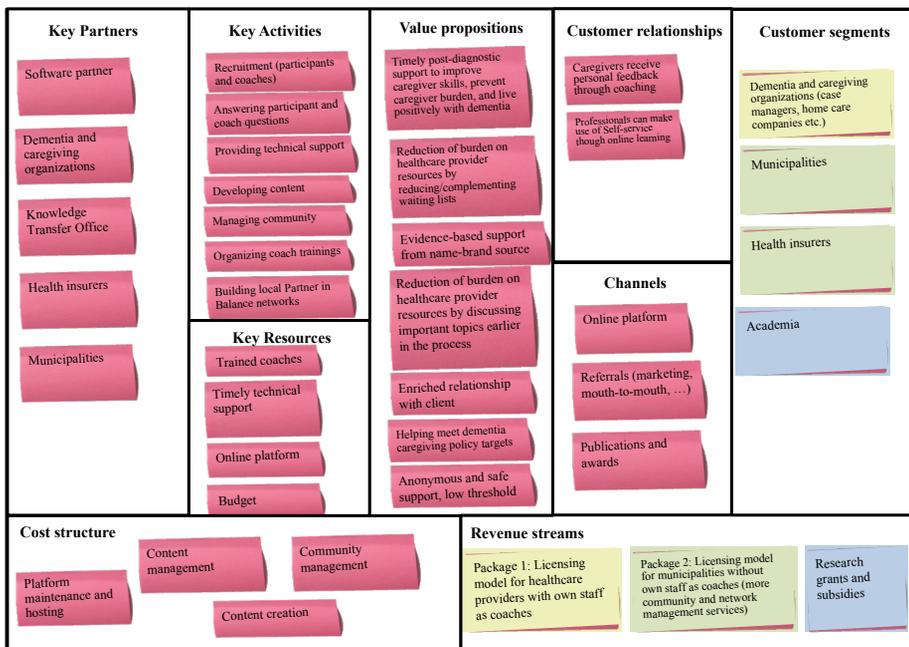


Figure 2. Partner in Balance Business Model Canvas

**Table 3.** Partner in Balance implementation strategies and Consolidated Framework for Implementation Research (CFIR) domains

CFIR domains	Partner in Balance implementation strategy	Targeted CFIR subdomain(s)
Characteristics of the intervention	Assess Partner in Balance's effect on organisation's care costs	Evidence strength and quality, Relative advantage, Adaptability, Complexity
	Develop more detailed financial models	Cost, Trialability, Design quality and packaging, Interventions source
Outer setting	Explore integrating Partner in Balance in case management in the Netherlands, also outside of Limburg	Cosmopolitanism, Patient needs and resources
	Subsidy applications and participation in networking and knowledge sharing events	External policies and incentives, Cosmopolitanism, Peer pressure
Inner setting	Integrate Partner in Balance within Help with Dementia Limburg (case management organisation)	Structural characteristics, Organisational incentives and rewards, Goals and feedback, Readiness for implementation
	Further development and embedding of inspiration sessions through integration in coach training	Tension for change, Relative priority, Access to knowledge and information
Characteristics of the individuals	Development of content for inspiration sessions and online coach training	Knowledge and beliefs about the intervention, Self-efficacy, Individual stage of change
	Pilot inspiration sessions and online coach trainings	Individual identification with the organisation, Other personal attributes
Process	Evaluate coach training (by participants) + evaluation of online training	Reflecting and evaluating, Engaging (Champions)
	Disseminate progress	Engaging (Formally appointed implementation leaders)

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### Operationalization

Determine the intended effect on various aspects: reduced experienced workload, shorter waiting time for case management, lower time investment for case manager, longer estimated period as full-time informal caregiver, less/later requirement for home care, less / later crisis relief. Comparison of this longitudinal use of health care data during Partner in Balance deployment with control group for the introduction of Partner in Balance using register health insurers. Also comparison for (baseline) measurement and follow-up measurement of maintenance time in cohort of clients who receive Partner in Balance.

Determine costs of required resources

Comparison of necessary case management hours and waiting list before and after implementing Partner in Balance. Mapping responsible budgets.

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Overview of bottlenecks and facilitators to offer Partner in Balance in the Netherlands, also outside of Limburg.

Subsidy application, involving crucial implementation partners in innovation cluster. Overview experiences and lessons learned by other innovation clusters.

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Prepared supervision plan for new clients in which Partner in Balance offer is included as a fixed part.

Online inspiration session including video material in which case managers and caregivers explain the use and the added value.

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Inspiration session content and guide

Online coach training content.

Custom inspiration session and online coach training based on feedback from current coaches.

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Overview of the number of chosen “live” or “online” trainings, including qualitative evaluation by participants on the quality, method and content of the training.

Short progress reports distributed among case managers (Help with Dementia newsletter) and nationwide (Alzheimer NL / dementie.nl).

**Table 3.** Continued

CFIR domains	Partner in Balance implementation strategy	Targeted CFIR subdomain(s)
	Write scientific publications and policy reports	Engaging (Opinion leaders)
	Report to the public	Engaging (External agents of change)
	Organize symposium	Engaging (External agents of change), Reflecting and evaluating
	Project coordination	Planning
	Define go – no go moments and possible next steps	Executing

### 3.4 Integration

The six components of the implementation plan are presented in this section. The operationalisations of the targeted CFIR subdomains were combined into components 1-5, while the business model canvas led to component 6. Based on these inputs, the components of the integrated plan for the sustainable implementation of Partner in Balance were: (1.) a ready-to-use Partner in Balance inspiration and intervision session format (live and online version and online coach training) to stimulate inner setting enthusiasm, (2.) a guide for the implementing organisation, in which Partner in Balance is included as a fixed offer in the first phase after diagnosis, (3.) the writing of a report on financing options and cost-effectiveness, (4.) efficient communication of project results through different channels, and (5.) a coordination plan and division of responsibility, including risk management, and finally, (6.) a sustainability plan including a license model. This licensing model is currently structured for an organisation to pay for the coaching one client per payment. The coach's organization or municipality chooses how many coaches licenses they wish to buy. Additionally, implementation costs are charged, depending on the type of package desired by the implementing organisation.

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### Operationalization

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Scientific publication in peer-reviewed professional journal and policy report (communication to contacts within the Ministry of Health, Welfare and Sport).

Lay report.

Symposium, including communication and feedback of results to society.

Overview of project members in the lead and coordination tasks.

Qualitative inventory of existing barriers and facilitators for scaling up and use.

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## 4 DISCUSSION

### **4.1 Addressing the lack of information on long-term financing of the intervention**

In previous research, the Partner in Balance process evaluation<sup>37</sup> reported that initial implementation challenges were related to a lack of financing and time necessary to implement the intervention. The findings from this study's real-life pilots and stakeholder interviews made it possible to more precisely describe these previously identified issues and devise solutions by constructing a preliminary business model. In this study, stakeholders reported an unwillingness to commit resources to an intervention that might not be available in the future (or that they might not be able to afford). This is in line with previous research, that also advocated the application of business models to evidence-based interventions to facilitate long-term implementation<sup>32,47</sup>. Thus, this study contributes to the literature on the implementation context by providing insight into this important implementation barrier, namely the lack of reliable pricing information for implementing evidence-based eHealth interventions to support dementia caregivers<sup>48</sup>. Additionally, the implementation strategies developed in this study using the CFIR helped ensure that the different components of successful implementation were considered in the business model.

### **4.2 Addressing the lack of information on the organisational context**

There has been little research on the perspectives of the parties involved in the real-life implementation of evidence-based eHealth interventions for caregiver of people with dementia<sup>23</sup>. For this reason, it was necessary to formulate a targeted implementation plan for Partner in Balance, which would help tailor Partner in Balance to this relatively underexplored dementia health care context. The implementation strategies and proposed business model resulted in an implementation plan that aimed to facilitate the integration of this evidence-based intervention into the organisational structures found in clinical practice. In this study, stakeholders in the domains of eHealth and dementia care perceived eHealth as difficult to implement and the usage data showed that 84% of SFC municipalities chose to implement other dementia-related projects instead of Partner in Balance, underscoring the role of organisations as gatekeepers in the implementation of evidence-based eHealth interventions for caregivers of people with dementia. This is in line with previous eHealth research, which has cited the unfamiliarity of both implementing staff and the target population with online support tools as important barriers to implementation<sup>17,19</sup>. Additionally, the fact that eHealth circumvents traditional health care delivery structures contributes to the difficulty many care organisations and governing bodies experience in implementing the interventions and adapting existing structures and norms to integrate them<sup>49</sup>. However, in the context of eHealth for dementia, the stakeholders did see Partner in Balance as needed and timely, particularly as it fits into

current trending policy targets of self-management, personalisation, and positive health, which is also advocated by the literature<sup>50-52</sup>. These findings confirm that it is important to continue to investigate and accommodate the evolving role of dementia care professionals in the context of emerging eHealth innovations and consider embedding eHealth care education into training programs for health care professionals<sup>53,54</sup>, as proposed by the strategies integrated into this study's implementation plan for Partner in Balance.

#### **4.3 Recommendations from the Partner in Balance case study to aid the implementation of future eHealth interventions support caregivers of people with dementia**

It is the authors' aim that the findings presented in this study also inform future eHealth interventions for caregivers of people with dementia, and facilitate a more efficient development and implementation. Below, we have listed some recommendations, based on the lessons learned throughout the various phases of the Partner in Balance implementation:

1. Health care organisations are often willing to pay for eHealth for their dementia caregivers, as long as the price of implementation is set, the evidence base is reliable, and the benefits to the organisation are clear.
2. It is recommended to form an 'innovation cluster' with dementia health care institutions (the implementers, such as dementia case management organisations), together with parties who can buy licenses (such as municipalities), while other organisations (such as health insurers) reimburse the health care organisation's staff hours.
3. eHealth interventions to support caregivers of people with dementia cannot be implemented as a ready-to-go, one size fits all project. Offline guidance and tailoring will always be necessary. Therefore, it is important to budget for this and identify which partners will be a part of the so-called 'innovation cluster', to ensure a realistic implementation plan.
4. Finding the balance between these differing prioritisations and identifying which of the involved parties should be the financer and which should be the implementer in to the dementia health care context is a challenge best addressed early in the development process (preferably even before the effectiveness trial).
5. It is important to emphasise to potential eHealth buyers that eHealth should always be complementary to other offline dementia caregiving services, and not a replacement of the existing face-to-face services.
6. Constructing a preliminary business model canvas at the start of implementation (before the effectiveness trial), in order to identify all relevant partnerships, customer relationships, and revenue streams in the local dementia health care context is recommended. Doing this will allow researchers to create a product that is attuned

to its specific market and context. If possible, it is also recommended to work with a commercial partner from the start. Using the business model canvas to inform our pricing and implementation plan was very helpful.

7. Future developers should incorporate an explorative implementation phase, after the trial context. It is necessary to flexibly explore different pricing models and iteratively address real-world implementation challenges prior to actually charging organisations.
8. Using the CFIR helped to formulate implementation strategies targeted at many different aspects of implementation. It was particularly helpful in structuring thinking on project management, as well the engagement of the implementing organisation's staff and management.

This study has helped fill the knowledge gap concerning the implementation context for eHealth interventions for caregivers of people with dementia in two important ways. It has added to the existing literature by providing an example of a business model to aid the implementation of an evidence-based eHealth intervention for caregivers of people with dementia, as well as specific implementation strategies to facilitate its integration into the dementia health care context. Future research should evaluate which types of implementation strategies are most successful at achieving long-term implementation. In particular, as concluded from the stakeholder interviews, a more in-depth cost-effectiveness study is needed to encourage more active participation from health insurers and health care organisations.

#### **4.4 Strengths and weaknesses**

This study has unique and important strengths. This study makes use of well-established theoretical frameworks to guide implementation, using the MRC framework for the development and evaluation of the intervention's effectiveness, as well as the CFIR and Business Model Canvas. Second, despite its theory-driven approach, this study also illustrates a practical and real-world representation of the implementation of an evidence-based eHealth intervention. By iteratively adapting the intervention, and being able to adapt with more agility to implementation issues than is normally possible in a strict trial context, this study provided a realistic view of the implementation process and context.

This study also had several weaknesses. First, though it was intended as a 'real-world' illustration of bringing an evidence-based eHealth intervention to market, the actual implementation was still very much dependent on the researchers guiding and facilitating this implementation through the research project. However, this study still provides a useful view of the steps necessary to construct a realistic implementation plan. Next, several of the interviewed stakeholders had been involved in the Partner in Balance

development in the past (four out of 14 stakeholders). This could have resulted in a bias to look favourably on the intervention's future implementation. However, the authors believe this was necessary to also include some interview participants who had real knowledge of Partner in Balance's workings. Finally, caregivers of people with dementia were not included as stakeholders in this study. This is because the intervention was developed together with caregivers of people with dementia, and exists in its current form as a result of their needs and wishes. The focus of this study's stakeholder interviews was rather on the surrounding implementation context and organisational determinants. Furthermore, the use experiences of the intervention from the perspective of the caregivers was explored in depth in the Partner in Balance process evaluation<sup>37</sup>.

#### **4.5 Future research areas**

Future research will include an evaluation of the proposed implementation plan. In particular, as concluded from the stakeholder interviews, a more in-depth cost-effectiveness study is needed to encourage more active participation from health insurers and health care organisations.

## 5 CONCLUSIONS

Stakeholders saw eHealth as difficult to implement, but needed and timely, particularly as it fits into current trends of self-management, personalisation, and positive health. Applying the CFIR to devise theory-driven implementation strategies was primarily useful for targeting often overlooked implementation aspects, such as ensuring effective and sustained engagement of coaches, streamlining project management, expanding and disseminating the intervention, and enhancing insights into pricing and long-term business modelling, in order to achieve sustainability. Insights from the business modelling resulted in two different kinds of licensing agreements: One for municipalities and one for organisations. Finally, the authors recommend to thoroughly explore the organisational and health care context of the intervention and then form 'innovation clusters' (consisting of, for example, a technology developer, research team, intervention provider, and health insurer/other funder) from the start of the eHealth development. This will help ensure that the intervention meets the needs of its target users, for both the end-users and the implementing staff.

### **ACKNOWLEDGEMENTS**

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### **CONFLICTS OF INTEREST**

None declared.

### **ABBREVIATIONS**

CFIR: consolidated framework for implementation research

FTE: full-time equivalent

KTO: knowledge transfer office

MRC: Medical Research Council

RCT: randomized controlled trial

SFC: Senior Friendly Communities

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# SUPPLEMENTARY DATA

## Appendix. Stakeholder interview questions

### I. General

Theme 1: Current online informal care support of the organisation

1. What is used within this organisation for:
  - a. Informal care support?
  - b. eHealth in general?
  - c. What is your experience with this?
2. Process:
  - a. Who decides within your organisation on the purchase of these products?
  - b. Is there an evaluation process to purchase products? What are the criteria in this process? What information is needed for this decision and payment?
  - c. How are they paid (with which funds)?
  - d. What are the barriers to these products?
    - i. to implement
    - ii. to fund
    - iii. to use?

Theme 2: Application to Partner in Balance

3. Is there a need for Partner in Balance?
4. Who would decide on the purchase of Partner in Balance?
5. How would this be funded?
6. What information is needed for this decision?
7. What are the barriers to paying and using Partner in Balance?
8. When was the implementation successful? Which outcomes must be met?

Theme 3: Financial

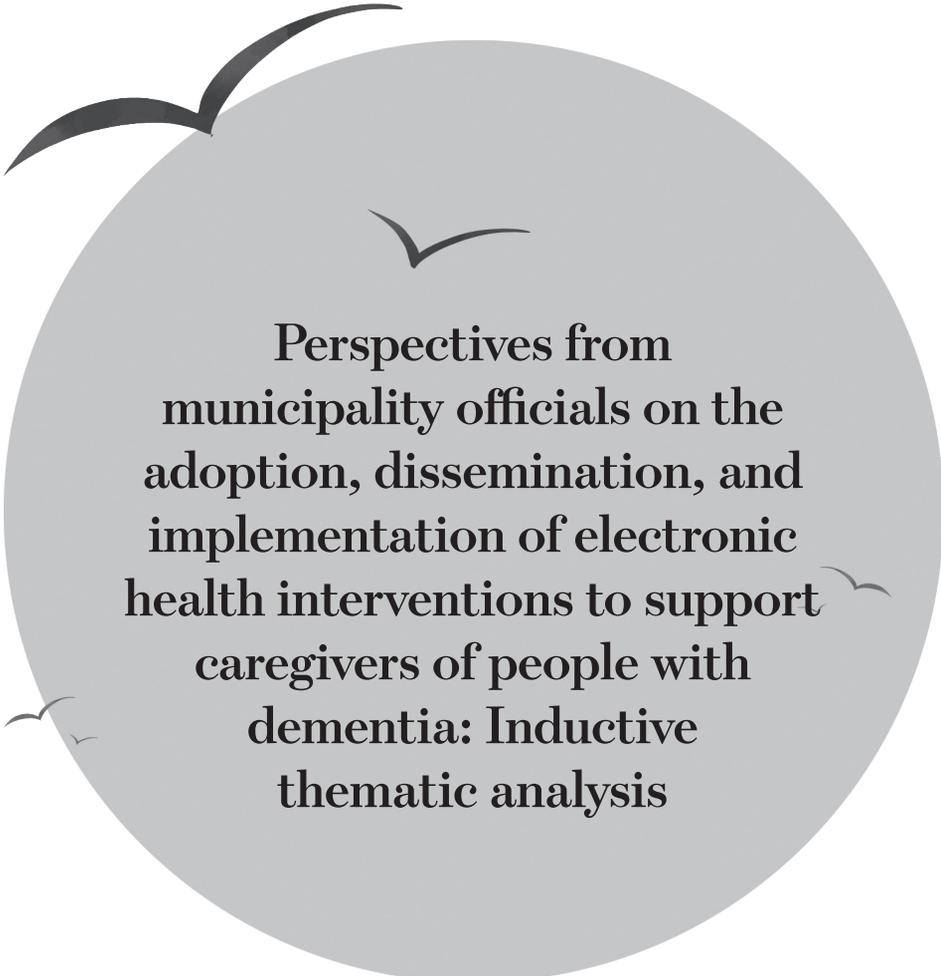
9. How much do you now pay for informal care support/eHealth?
10. Would you pay more for more modules?
11. Would you pay more for different support options?
12. What support options would be needed?

## II. Specific for different stakeholders

1. Insurers:
  - a. What is the experience so far with informal care support within your organisation? Which initiatives already exist?
  - b. How can informal care support be funded/reimbursed (within the premium)?
  - c. Can online informal care support be funded from the health insurance policy and under what conditions?
  - d. How much can organisations pay for Partner in Balance? What is a better model: organisation or participant? Why?
  - e. Prevention vs. treatment: Preference?
2. Municipalities:
  - a. Can Partner in Balance be financed by the municipality/WMO?
  - b. Who could still finance Partner in Balance in this municipality? For example, companies (for their staff)?
  - c. What would be a better model for you – payment by organisation or participant? Why?
3. Clinicians (psychologists and general practitioners)/hospitals:
  - a. Can the care time (face-to-face) be declared to the health insurer?
  - b. Can the product itself be financed (independently of the face-to-face care time)?
  - c. Can hospitals link Partner in Balance to diagnostics?
  - d. Management: What could be a realistic price? Can you compare this with existing products for caregivers? Which model (payment by organisation or by participant) would be better? Why?
  - e. Clinicians: What could be a realistic price? Can you compare this with existing products for caregivers? What is your experience with this?
4. Funding bodies: What can organisations pay? What is a good/realistic price? Can we compare Partner in Balance with other products? If so, what is the price structure of these products?







**Perspectives from  
municipality officials on the  
adoption, dissemination, and  
implementation of electronic  
health interventions to support  
caregivers of people with  
dementia: Inductive  
thematic analysis**

*JMIR Aging, 2020*

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# ABSTRACT

**Background:** Very few evidence-based eHealth interventions for caregivers of people with dementia are implemented into practice. As part of a cross-border collaboration focusing on dementia and depression in older people, two eHealth interventions for caregivers of people with dementia ('Myinlife' and 'Partner in Balance') were adopted by nine municipalities in the Euregion Meuse-Rhine.

**Objectives:** The objectives of this study were to (1.) identify determinants for the implementation of eHealth interventions for caregivers of people with dementia in a municipality context and (2.) formulate implementation strategies for these interventions.

**Methods:** Eight municipality officials were interviewed using open-ended, semi-structured interviews about their background, thoughts on the implementation of the intervention, recommended strategies, and thoughts on eHealth in general. One additional municipality discontinued the implementation project and submitted answers to the interview questions via email. The interviews were transcribed and independently analysed using inductive thematic analysis.

**Results:** The interviews provided information on the perspectives of municipality officials on implementing eHealth for caregivers of people with dementia in their local communities. Key findings from the inductive thematic analysis included the importance of face-to-face interviews in developing tailor-made implementation plans, the need for regular meetings, the enthusiasm of municipality officials to implement these interventions, the need for long-term sustainability planning through collecting data on the required resources and benefits, and the effect of name brand recognition in adoption.

**Conclusions:** The findings contribute towards filling the previously identified gap in the literature on the implementation context of eHealth interventions for caregivers of people with dementia. Municipality officials' views indicated which implementation determinants they expected would influence the adoption, dissemination, and future implementation of eHealth interventions for caregivers of people with dementia in a municipal context. These insights were applied into tailored implementation strategies to facilitate the future implementation of interventions like Myinlife and Partner in Balance.

# 1 INTRODUCTION

## 1.1 eHealth and dementia caregiving

Informal caregivers provide essential care to people with dementia, and this can have both positive and negative effects on the caregivers' daily lives<sup>2-4</sup>. Previous research has shown that these positive effects can include an enriched relationship with the person with dementia, while the negative effects include burn-out and social isolation. eHealth interventions are "*treatments, typically behaviourally based, that are operationalised and transformed for delivery via the Internet*"<sup>5</sup>. eHealth interventions for caregivers of people with dementia have shown evidence of effectiveness at improving a wide range of negative outcomes for these caregivers, including the reduction of depressive symptoms, anxiety, and burden<sup>6-9</sup>. In addition to the evidence of their effectiveness for caregivers, eHealth interventions have the potential to meet the challenges faced by many modern health care systems as result of aging populations and declining birth rates<sup>10</sup>. For instance, eHealth interventions can provide a lower threshold to participation, more opportunities for personalisation, instant delivery, real-time feedback, and increased accessibility for reaching more isolated populations who experience difficulties in gaining access to traditional services<sup>11,12</sup>.

However, very few psychosocial interventions for caregivers of dementia find their way from effectiveness trial to practice<sup>13</sup>, including eHealth interventions for caregivers of people with dementia<sup>14</sup>. Bringing these evidence-based interventions into practice would be beneficial in a number of ways, including a more efficient allocation of research resources, a reduction of unnecessary research replication, and their eventual benefit to caregivers through sustainable implementation. Previous research has pointed towards the absence of knowledge on the contextual environment as a significant barrier for health system planners and implementers in translating these interventions into practice<sup>5,16</sup>. For instance, as eHealth interventions bypass the traditional delivery methods and care structures, many health care professionals and governing bodies don't know how to implement the interventions and modify existing structures and norms to incorporate them<sup>17</sup>. An important reason for this absence of knowledge on contextual factors is the golden standard of randomised control trials (RCTs) as evidence, which often lack crucial, qualitative implementation data<sup>18</sup>. There has been a call for more realistic, efficient research designs that take the context of the eHealth intervention into account<sup>19</sup>. For eHealth, this involves gaining insight into the relevant aspects/factors of organisations and communities in the real-life contexts where the interventions will be implemented. An example of such an implementation context is municipalities looking to offer online support to caregivers of people with dementia.

## 1.2 Study aims

The aims of this study were twofold. First, this paper aimed to gain insight into the views of municipality officials on the upcoming implementation of two eHealth interventions in their communities, in order to shed light on their reasons for adopting the technology and their strategies for dissemination and implementation. The two studied interventions were Myinlife, an online platform to organise dementia care, and Partner in Balance, an online course (see Methods). This study's findings will help identify potential implementation determinants and fill the knowledge gap on the environmental and contextual factors that influence sustainable eHealth adoption, dissemination, and implementation. Second, this paper aimed to translate the insights from these interviews into implementation strategies, to aid researchers in implementing evidence-based eHealth for dementia caregivers. The definitions for these terms as employed in this paper are "*the decision of an organisation or a community to commit to and initiate an evidence-based intervention*" for adoption, "*the active approach of spreading evidence-based interventions to the target audience via determined channels using planned strategies*" for dissemination and "*the process of putting to use or integrating evidence-based interventions within a setting*" for implementation<sup>20</sup>.

## 2. METHODS

### 2.1 Study setting

This study took place in the context of the euPrevent Senior Friendly Communities project<sup>21</sup>, involving 32 municipalities from the Euregion Meuse-Rhine. Here, a municipality refers to a town or district that has a local government. Municipalities' governing functions differ between countries, though in general they are responsible for local services that can include health care, education, recreation and sport. This project ran from September 2016 to December 2019 and was implemented in the Euregion Meuse-Rhine, a border region covering parts of Belgium, Germany and the Netherlands, which contains 150 municipalities. Thirty-two municipalities signed up to take part in the broader SFC project on a *first come, first serve* basis. The project first made an inventory of how the communities were already supporting their aging population and what they could still improve in this regard<sup>22</sup>. Next, municipalities chose activities from a so-called 'activity buffet', consisting of 15 pre-existing activities. These activities addressed the mental health of older people, paying particular attention to dementia and age-related depression, including cultural activities, such as a theatre production, a photo exhibition, consultations with experts on various topics, educational sessions on relevant topics and psycho-education, creation and organisation of local social networks of elderly, and outreach activities. They also included two eHealth interventions to support caregivers of people with dementia: 'Partner in Balance' and 'Myinlife'. On average, the municipalities each chose to implement four activities.

### 2.2 Studied interventions

#### 2.2.1 Partner in Balance

Partner in Balance is a blended care, eight-week, self-management intervention which helps caregivers of people with dementia adapt to their new roles. Detailed information about the program components and development is presented elsewhere<sup>23</sup>. In short, the blended care self-management program PiB consists of: (1) a face-to-face intake session with a personal coach to familiarise participants with the program, choose online modules, and set goals; (2) tailored online thematic modules, including psychoeducation, behavioural modelling, reflective assignments, change plans, and email feedback from the coach over eight weeks; and (3) a face-to-face evaluation session with the coach evaluating previously set goals. The coaches are health care professionals with experience in dementia care (for example, in the Netherlands, the Partner in Balance coaches are often dementia case managers). In a recent randomised control trial (RCT), Partner in Balance was shown to be effective in improving caregivers' sense of competency, self-efficacy and quality of life<sup>23,24</sup>.

### **2.2.2 Myinlife**

Myinlife is an online platform for caregivers of people with dementia to involve their social network in organising care and share positive caregiving moments. In the Netherlands, Myinlife has been integrated into the national Alzheimer's Association website, [www.dementie.nl](http://www.dementie.nl). Myinlife has the potential to simplify caregiving and provide caregivers with more control over their agendas<sup>25,26</sup>. The platform consists of the following functionalities: Profile, Circles, Timeline, Calendar, Helping, Personal Messages, Care book, and Compass.

### **2.3 Study design**

In total, nine of the 32 SFC municipalities opted to implement one of the two available eHealth interventions for caregivers of people with dementia in their communities: six municipalities chose Partner in Balance (four in the Netherlands, one in Belgium, and one in Germany), while three chose Myinlife (two in Belgium and one in Germany). The method of semi-structured interviews was chosen due to its suitability to small-scale and flexible research, which matched the setting of this implementation study<sup>27</sup>. In each participating municipality, an open-ended, semi-structured interview was conducted with the municipality official responsible for the implementation of the intervention. The interviews were on average 18.79 minutes long and took place in the period of about six months between the municipalities' decision to adopt the interventions and their actual implementation. The interview questions asked about the municipality official's background, expectations concerning the implementation of the intervention, recommended strategies, and thoughts on eHealth in general. The complete interview guide can be found in the Appendix.

### **2.4 Participants**

In total, eight in-person interviews were conducted. A ninth municipality chose to discontinue the implementation and delivered written answers to the interview. The reasons for this are discussed in results section. The officials interviewed in the remaining eight participating municipalities had varying job descriptions. The majority described themselves as municipality policy officials, while some described themselves as employees responsible for specific activities concerning seniors, volunteers, demography, or specific local care facilities. Table 1 lists some specific characteristics of the nine communities who had originally chosen Myinlife or Partner in Balance from the activity buffet. As the participating municipalities wished to remain anonymous, any identifying information has been left out.

**Table 1.** Characteristics of the participating municipalities

Number of municipalities that chose Partner in Balance	6
Number of municipalities that chose Myinlife	3
Municipality average general population	36376
Municipality average population age >65	7349
Municipality average estimated dementia population	1434

*Population statistics sourced from the euPrevent Senior Friendly Communities project<sup>21,28</sup>.*

## 2.5 Data collection

Ethical approval for the study was granted by Maastricht University's Medical Ethical Oversight Commission (METC), under approval number 2018-0489. The eight in-person interviews were conducted by author HC at each municipality's town hall or equivalent, between July 2018 and December 2018. Each participant received an information sheet about the background and aims of the study, in addition to information on how their data would be processed and stored. Each participant agreed to and signed an informed consent form. Interviews were conducted using a semi-structured interview guide (Appendix). Five interviews were conducted in Dutch, one in English, one in French, and one in German, by author HC. The municipality that discontinued the implementation delivered written answers to the interview questions via email in Dutch.

## 2.6 Data analysis

The interviews were transcribed verbatim using transcription tool F5. If conducted in a different language, transcriptions were translated into Dutch by authors HC and MS. The method of inductive analysis was chosen in order to explore the current perspectives of municipality officials, as this domain has not been much researched and there was little notion of the factors and themes that might emerge<sup>29,30</sup>. Based on the inductive analysis with no pre-existing categories or themes, individual codes were grouped into themes and categories. Next, the themes and categories were compared in a consensus meeting with author MdV to resolve any differences of opinion, resulting in the final thematic analysis. Authors HC and MS independently coded the interviews using the described inductive thematic analysis method and software tool Atlas.ti for Macintosh (Atlas.ti Scientific Software Development GmbH, 2018).

## 3 RESULTS

### 3.1 Main findings

Four main themes emerged from the inductive thematic analysis: The eHealth intervention, the users, the organisation, and the wider context. Within the themes, categories and groups were formed (Table 2). These themes can be seen as concentric circles, where the constructs in each widening circle are further removed from the smallest circle. The circles all interact with and influence each other. For the purposes of clarity and as a reflection of the chronological process, the following sections will start by discussing the outermost circle (the wider context) and then work inwards towards the innermost circles (the organisation, the users, and the eHealth intervention).

### 3.2 Wider context

The term wider context refers to the social, political, and economic settings in which the municipality resides. The results of the inductive thematic analysis indicated that the municipality officials viewed a number of social, political, and economic factors as contributors to the choice to adopt Partner in Balance and Myinlife. Examples of this include the increase in older people and people with dementia in the municipality, and the municipalities seeing the future as increasingly digital.

*“All over the community it’s the digital things that are successful and also the future and so, it would be strange if the medical part doesn’t take part.” (Respondent 6)*

**Table 2.** Interview themes and categories

Theme	Categories and subcategories
1. Wider context	1.1 Municipality’s context and political climate
	1.2 Bottom-up versus top-down push for eHealth
	1.3 Municipality values
	1.3.1 <i>Staying close to the citizen</i>
	1.3.2 <i>Sustainability</i>
	1.3.3 <i>Valuing volunteers</i>
	1.4 Societal factors
	1.4.1 <i>Self-management in health care</i>
	1.4.2 <i>Sustainable integration with daily practice</i>
	1.4.3 <i>Brand value</i>
	1.4.4 <i>Increased needs for dementia care</i>
	1.4.5 <i>Political support for digital future</i>

**Table 2.** Continued

<b>Theme</b>	<b>Categories and subcategories</b>
2. Organisation	2.1 Internal: The municipality 2.1.1 <i>Implementation strategies</i> 2.1.2 <i>Attitudes</i> 2.2 External: Collaboration with local organisations 2.2.1 <i>Emphasise added value to external organisation</i> 2.2.2 <i>Improving quality of care</i> 2.2.3 <i>Financial sustainability planning</i>
3. Users	3.1 Caregivers 3.1.1 <i>Dissemination: Through media, Convincing through personal contact, Gaining attention, Events</i> 3.1.2 <i>Involving users</i> 3.1.3 <i>Personalisation</i> 3.1.4 <i>Involvement in the implementation</i> 3.2 Coaches 3.2.1 <i>Difficult to find/train/guide coaches</i> 3.2.2 <i>Resource shortage</i> 3.3 Lack of users' digital abilities 3.3.1 <i>Caregivers</i> 3.3.2 <i>Coaches</i>
4. Intervention	4.1 Thoughts on eHealth 4.1.1 <i>Must keep modules up-to-date</i> 4.1.2 <i>Netherlands and Scandinavia at the forefront</i> 4.1.3 <i>Risks around data leaks</i> 4.1.4 <i>More familiarity with data systems than with apps</i> 4.1.5 <i>Easier to reach people than traditional interventions</i> 4.2 Experiences with eHealth 4.2.1 <i>As a database for patient information</i> 4.2.2 <i>In an educational context</i> 4.2.3 <i>In the media</i> 4.2.4 <i>No experience</i> 4.3 Expectations about future success of intervention implementation 4.3.1 <i>Ideal situation</i> 4.3.2 <i>Expectations</i>

Also, the fact that the intervention was evidence-based and had an academic 'name brand recognition' resulting from its origins as a university research project, was a facilitating factor for some municipalities. Municipality officials mentioned that their choice of intervention depended on whether the intervention was in line with the values and policy of the municipality. In this regard, they mentioned that Myinlife and/or Partner in Balance matched their work on sustainability, caregiver support, and 'staying close to the citizen'. When choosing which interventions to adopt for the project, the majority of

municipalities reported having made the choice internally. However, two municipalities assembled a panel of lived- experience experts in dementia and caregiving and chose those activities which the panel identified as most relevant for their community. A final recurring theme regarding the choice to adopt the interventions, was the bottom-up vs. top-down approach to eHealth. Some respondents felt that eHealth is mainly pushed through top-down initiatives but that the population of their municipality does not express a desire for it.

*“Then you have the bottom-up or top-down approach, there is something to be said for both of them. Now you started with the bottom-up, and yes, we are going to see how that goes and if that does not work, then we have to see if top-down might be feasible. Then we have to see from which top we are going to start, so to speak.”* (Respondent 5)

The reasons for adopting Myinlife and Partner in Balance seemed similar for both interventions. It is interesting to note that municipalities that had chosen to implement Partner in Balance emphasised both the advantages of the intervention for the caregiver, as well as for the coach.

Besides adoption, the wider context also played a role in planning the upcoming dissemination and implementation of the interventions in the communities. For instance, politically, imminent elections and the merging of three municipalities into one municipality made concrete planning difficult, as the budget and officials responsible might change.

### **3.3 Organisation**

When mapping the organisations involved in implementing Myinlife and Partner in Balance, the organisations were divided into two groups: Internal (the municipality) and external (all local organisations they wanted to involve in the implementation). Concerning the internal attitudes of the municipality employees on the upcoming implementation, it appeared that the more familiar they were with the intervention, the more enthusiastic they were. Several long and short term implementation strategies were identified, such as appointing a contact person responsible for the intervention in the municipality, frequently checking up on and facilitating the intervention, and having a clear time plan.

*“It’s not like it’s ready-made. It’s still about people, you have to remember that, you have to facilitate that, you have to motivate that. If you don’t do that... everything depends on it, especially in this kind of work. If you think: Yes, now... I have thought it up nicely and it will come naturally... that will not work.”* (Respondent 2)

Concerning the external cooperation with local organisations, the responses showed that municipalities felt it was particularly important that the eHealth intervention should improve health care in their community. In particular, they hoped it would connect various links in the local care network. Examples of organisations the municipalities wished to collaborate with for the upcoming implementation were local care homes, case management organisations, geriatric departments of hospitals, caregivers' associations and support groups, GPs and other clinical professionals' practices, social work, dementia expertise centres, and home care organisations. The municipality officials expressed some wariness towards the online aspect of the interventions, and emphasised that the interventions would only be useful if there were demonstrable improvement in local health care services, although they noted that this would be hard to measure. This described external involvement of local organisations can also be seen as a kind of implementation strategy, and it was mentioned in every interview. For Myinlife, the external cooperation mostly served the purpose of aid in advertising and publicising, in order to disseminate the intervention to the target users. For Partner in Balance, the external cooperation with local health care organisations was an essential part of recruiting the platform's coaches, as they needed to have experience with both dementia and health care.

*“But, yes, or that, will it make a difference later in care? When you talk about ‘care’ - because that is central - I don’t know, does [Myinlife] contribute to increasing the quality of care?”*  
(Respondent 4)

The respondents also foresaw significant barriers to implementation: Finding the time necessary to invest in publicising and communicating about the intervention finding coaches for Partner in Balance; convincing the older population of the platforms' advantages; and financially guaranteeing the sustainability of the interventions. The municipality that discontinued the implementation and subsequently submitted answers to the questions by email, chose to focus on this topic. This municipality felt that the inability of Partner in Balance to guarantee what a license would cost after the project's end was a significant barrier. They also said the following:

*“There were too many unclear circumstances. Our neighbourhood teams had already started, the cooperating partners had full agendas and it was not clear what the costs were after the project.”* (Respondent 9)

### 3.4 Users

The theme 'users' groups all statements from the municipality officials regarding who would be using the interventions. Based on their responses, two user groups were identified: the caregivers themselves and the coaches. The user group of the coaches

is specific to Partner in Balance and does not apply to Myinlife. This finding of the coaches as a user group was interesting, as it had been expected that the coaches would be seen more as a part of the implementing staff described in 3.2 (Table 2). However, it appeared that both the caregivers and the coaches were seen as target users of the platform by the community officials, both of whom required recruitment with specific dissemination strategies.

*“So finding the coaches of course and maybe... finding the coaches is of course natural, but it is a real challenge. And, of course, reaching sufficient informal caregivers who want to sign up for this.” (Respondent 4)*

Concerning the recruitment of caregivers, municipality officials recommended focusing on younger caregivers, such as the children or grandchildren of people with dementia; involving local people with dementia and their caregivers in the implementation by consulting with them; being inclusive by trying to reach caregivers from all different backgrounds; and making sure the approach was personalised, as everyone has unique situations and needs. Specific dissemination strategies included media attention through both social media and press conferences, convincing local groups of the advantages of participation, and organising face- to-face events. In this regard, the municipalities thought maintaining human contact was an essential part of the dissemination strategy. They proposed organising stakeholder and caregiver meetings, rather than relying on digital and print communication.

*“I think, if we are going to focus purely on the partners of people with dementia, that we are only going to be able to reach very few people effectively. Because with a biased prejudice, maybe I am wrong, but I have this idea that older people are less open to online assistance than the younger generation. But I also know that there are many children who care for their mother or father with dementia, and we can reach them and if they have that knowledge they can hopefully also pass it on to the partner, so that we can also reach them directly. But I think that online data is difficult. Plus, yes, it is now a one-off initiative - it has to be supported from [higher-up], and that must also remain on the agenda.” (Respondent 5)*

Concerning the recruitment of coaches, again, municipality officials stressed a lack of resources on the coaches' side, such as time and money, as a foreseeable barrier to effective dissemination and subsequently, implementation. As described in 3.2 (Table 2), most municipalities were keen to recruit both professionals and volunteers from local care organisations. However, one municipality also wanted to offer caregivers of people with dementia the chance to be coaches for Partner in Balance. They emphasised that it was important that these prospective lived-experience coaches would also be supported by a

local dementia association. Also, municipalities often thought that both the caregivers and coaches of the target group would have a hard time with the online aspect of the eHealth interventions.

*“Yes, most are actually received positively. The only thing is, we don't know how many people are going to respond, so is it going to take off? (laughing) That is also a consideration, that you sometimes hear, that I have heard a few times. But is there enough interest for that kind of stuff? You will only know that by trying and making it known and then seeing how much response there is.” (Respondent 5)*

### **3.5 Intervention**

This theme describes the municipality officials' thoughts on both the chosen platforms specifically, and on the idea of eHealth in general. Though they did expect the online aspect of the interventions to be a complicating factor, there were predominantly positive attitudes towards eHealth. However, most had not yet worked with eHealth themselves, and had only heard about it. Of those that did have experience with eHealth, it was common that they had come into contact with it in an educational context, such as at a university or in a training workshop. Respondents were, in general, more familiar with eHealth in the context of online databases for patient information, than with apps. Taking into account the limited sample size, there were no obvious relationships between the age or job description of the participants and their experiences with eHealth. Most respondents were optimistic about the chances of successfully implementing the intervention in their communities, but some also felt that it would not be suitable for everyone, or that it could only be really successful in the future (but not right now). When asked what the ideal implementation of Myinlife or Partner in Balance in their communities would look like two years from now, municipality officials said they would like to see it be an integrated part of local care services. Some also gave indications of the minimum number of users they would like to be on the platforms. These were quite small, the largest number being 30.

*“Well, ideal for me would be that it is well known, that it is completely embedded in the guidance of caregivers. That it is well-known to everyone who is confronted with dementia, that you can also get support from it as an informal caregiver, in addition to the regular care of course, the most optimal care for the person with dementia themselves. I think that's important. And that we have enough coaches, who are motivated to do this motivated and who experience this as a meaningful activity.” (Respondent 3)*

## 4 DISCUSSION

### 4.1 Principle findings

This study examined municipality officials' views on the adoption, dissemination, and implementation of evidence-based eHealth interventions for caregivers of people with dementia in their local communities. The resulting inductive themes provided interesting insights that helped meet this study's two objectives. First, these findings help fill the gap in the literature concerning the organisational and contextual factors that influence this process by identifying potential implementation determinants. Second, these findings aid the future implementation of eHealth interventions such as Myinlife and Partner in Balance by using these insights to formulate specific implementation strategies.

### 4.2 Mapping the implementation context and identifying potential determinants

Regarding the first, more general objective of mapping the implementation context in order to identify determinants that influence implementation, the following lessons were learned. The first lesson concerns the level of enthusiasm, both from the municipality officials and the target group(s). The interviews demonstrated that municipalities were enthusiastic about the idea of implementing eHealth to support caregivers of people with dementia in their communities. Indeed, nine out of 32 municipalities in the Euregion chose to adopt and implement the two eHealth interventions on offer in the activity buffet. Previous research has explored the views of stakeholders concerning the implementation of health technologies, including care professionals, managers within home care or social work organisations, technology designers, and policy makers<sup>31,32</sup>. However, to our knowledge, none have explored the views of municipality officials. Knowing that municipalities are enthusiastic about these interventions is important for future developers looking for a viable implementation environment for their interventions. For instance, municipalities in the Netherlands are responsible for supporting their local caregivers and have funds allocated for this<sup>33</sup>. As the municipalities seem to have positive attitudes towards eHealth, as well as available funds and incentives to support caregivers, implementing eHealth through municipalities seems to be a viable option, especially if they focus on caregiver support. Belgian and German municipalities are not necessarily responsible for municipal caregiver support, though they do facilitate care support through collaboration with local organisations and health care providers<sup>21</sup>. It is, however, important to note that the municipalities did mention experiencing a top-down push for eHealth and doubted whether their current older population would have an interest in using these interventions. Research into older adults' attitudes towards eHealth interventions has shown mixed results<sup>34-36</sup>, with evidence suggesting that older adults living in more rural areas (such as many of those included in this study) express less interest and

capacity to use eHealth<sup>37</sup>. However, studies have also shown positive attitudes towards the use of eHealth both in older populations<sup>38</sup> and for younger caregivers<sup>39</sup>. Previous eHealth research has also mentioned enthusiasm from both target groups as well as the implementing organisations as an important implementation determinant<sup>40</sup>.

The interviews demonstrated that, despite the online and remote nature of eHealth interventions, the municipality officials all emphasised the importance of organising face-to-face meetings with stakeholders and prospective users to facilitate a successful implementation. This builds on the findings from previously conducted Myinlife pilot studies, RCTs, and process evaluations, which showed a lack of effects on the trial's quantitative outcomes<sup>25,41</sup>. In particular, the process evaluation<sup>26</sup> provided qualitative insights that led to continued implementation of Myinlife, such as the overwhelmingly positive user experiences. For instance, the Myinlife process evaluation emphasised that online and offline support was necessary to facilitate the caregivers' knowledge of their own social support needs and available social capital. This is in line with municipality official's views in the current study, as they often mentioned the desire to organise meetings with the local caregivers. Future implementers should take into account that using events to promote the intervention and engage the target audience is recommended, especially for this older population, who might be harder to reach through online dissemination channels, such as social media<sup>42</sup>. Additionally, when comparing the concentric circles of influencing factors described here and in the Myinlife process evaluation<sup>26</sup>, it is important to note that there is no circle discussing the influence of organisational factors in the Myinlife process evaluation. As is the case with many process evaluations, this is due to the fact that the process evaluation took place in a trial context and there was no 'external' implementation, as the implementation was carried out by the research team. However, it is important for researchers to consider these 'internal' organisational factors in the process evaluation as well, in order to facilitate the following implementation steps<sup>44</sup>. This need for more detailed information on the offline implementation aspect has been discussed in previous research<sup>43</sup> and would provide future implementers with useful information to make decisions regarding the viability of the intervention in its organisational context.

Next, the interviews also demonstrated that the municipalities considered the targeted recruitment of not only the caregivers, but also of the coaches, as an important contributor to successful implementation. Previously, the Partner in Balance process evaluation<sup>44</sup> had highlighted the importance of tailoring interventions to user characteristics and needs, as well as the need for more research on the implementation process and context. While the process evaluation did recommend an active role for health care professionals in guiding caregivers through the caregiving process, researchers had previously not considered the Partner in Balance coaches to be a part of the 'user group'. They had instead seen them

as a part of the implementing organisation. This is contrasted by the findings from the current study, where municipality officials saw both the caregivers and the coaches as two separate user groups that required specific recruitment strategies. While disseminating the intervention to coaches using specific implementation strategies is resource intensive, there is evidence to show that the addition of this ‘blended’ aspect to an eHealth intervention significantly enhances outcomes<sup>7,45,46</sup>.

The uncertainty around how long the interventions would continue to be available after the project and how much they would cost, was a significant barrier. Indeed, this issue caused one municipality to discontinue the implementation of Partner in Balance. The necessity of long- term business modelling to ensure sustainable implementation of eHealth interventions is in line with previous research, both for dementia<sup>47</sup> and other populations<sup>48</sup>. In this regard, mapping the surrounding health care context and other financial stakeholders in relation to the intervention characteristics is essential, for instance by applying the Business Model Canvas<sup>49</sup>. Insight into whether and how much municipalities would be willing to pay is essential to sustainably implement these interventions.

Importantly, the responses from the municipality officials show that the ‘name brand’ (in this case, the name of Maastricht University and the Alzheimer Center Limburg) behind the eHealth intervention was an important factor in the decision to adopt the interventions. Not only the fact that they were evidence-based, but also the fact that a reputable organisation could vouch for the interventions was considered important. This is supported by previous research on health care provider adoption of eHealth<sup>32</sup> and emphasises that developers of future interventions should consider highlighting the ‘name brand’ value of their interventions, if applicable.

Finally, the process of conducting the qualitative, semi structured interviews with the municipalities was a very helpful exercise. These interviews helped avoid surprises in planning the later implementation by making expectations and agreements concrete. This fostered a sense of trust and understanding of the other parties’ needs. The interviews also allowed for the development of tailor-made implementation strategies, as recommended by Damschroder<sup>50</sup>. These tailor-made strategies also help provide a sense of ownership to the municipality, as they have a hand in designing them so that they fit the local context and stakeholders. Future eHealth developers looking to implement in municipalities or other organisations should consider holding similar ‘baseline interviews’.

### **4.3 Translating insights into specific implementation strategies**

Regarding the second, more specific objective of formulating implementation plans for

eHealth interventions like Myinlife and Partner in Balance, based on the insights into municipality implementation determinants, the following strategies can be applied to aid researchers in their future implementation into practice:

1. *Regularly contacting municipality officials:* There will be one municipality official responsible for implementing the interventions in the municipality, as an official contact person. It is important that the research team has regular contact with this person by having regular meetings, in order to create goodwill and a productive rapport.
2. *Organising face-to-face meetings with both local stakeholders and caregivers:* It is important to organise events to provide caregivers with information on caregiving and offering eHealth as a support tool. The municipalities' wish to organise events to disseminate and promote the interventions further underscores this point that eHealth interventions, whatever their original design or intent, necessitate some amount of human contact and personal tailoring. Each community will organise a stakeholder meeting and a caregiver meeting in order to embed the interventions in the local, unique care landscape.
3. *Making use of existing local services:* Local dementia services in each municipality will be contacted in order to be part of the eHealth project teams, as well as help with the recruitment of both caregivers and coaches. In addition, other local services will be contacted, including nursing and mental health care services, as well as youth groups, professional training and apprenticeship schools, and hospitals.
4. *Regular eHealth project meetings:* Each municipality will have an eHealth project team, in addition to the municipality contact person. The contact person will be responsible for encouraging enthusiasm and increasing familiarity with the interventions and between team members. Members of the project team will include the municipality contact person, a representative from the research team, and the interested parties from the stakeholder and caregiver meetings.
5. *Promoting through online and offline campaigns:* In addition to the offline events, such as the stakeholder meetings, caregiver meetings, and eHealth project team meetings, municipalities will be encouraged to disseminate the interventions through any online channels they might have (such as websites, social media, newsletters, etc.).
6. *Emphasising name brand, evidence-based aspect:* All presentations and communication materials will emphasise the input of name-brand contributors, such as Maastricht University, Alzheimer Netherlands, ZonMW, the Alzheimer Center Limburg, INTERREG, and euPrevent.
7. *Collecting data to inform licensing models and ensure sustainability:* Describing the hours and financial resources needed during the project will help the municipalities decide whether the project will be sustainable in the future. This data will also help the research team and other future developers to budget for this need for continued,

personalised support to the implementing organisations, informing sustainable business models and implementation plans. In this regard, it is important to consult with a local health authorities to learn where their outcome priorities lie, so this can inform which data is collected.

8. *Tailoring more general strategies*: Each municipality's implementation plan also includes strategies specific to the local population and services, such as collaborations with local technology companies and recruitment of local experts-by-experience as coaches. Given the finding that the health care and municipality context varies widely between countries, and even regions, certain aspects of the more general strategies will have to be tailored to the differing local services. For example, the Public Centres for Societal Welfare (*Openbaar Centrum voor Maatschappelijk Welzijn*; OCMW) in Belgium are organised very differently and have different goals than the Dutch municipalities' Law for Societal Support (*Wet Maatschappelijke Ondersteuning*; WMO) services.

The proposed strategies can help researchers in two ways. First, based on the experiences of this project, the strategies could help future researchers achieve a more successful collaboration with implementing organisations outside of the academic trial context. Second, applying these strategies could result in more much-needed data on the dementia eHealth implementation context, which many stakeholders (such as health insurers) claim is necessary for the scaling-up of these interventions. More generally, increasing the rate of successful, sustainable implementation of evidence-based eHealth interventions for caregivers of people with dementia can have significant societal advantages, including more targeted and efficient research funding, the possibility for caregivers of people with dementia to gain access to the interventions developed for them, as well as the opportunity for health care systems to provide more targeted, cost-efficient, and evidence-based online dementia support<sup>42</sup>.

#### **4.4 Limitations**

To our knowledge, this is the first study that explores the views of municipality officials on implementing eHealth interventions in their local communities. However, this study does have a few important limitations. First, with the exception of the municipality that chose to discontinue the implementation and submitted the answers to the interview questions by email, all of the participating municipalities had already chosen to implement eHealth in their communities. This results in the study's sample being biased to look favourably on eHealth implementation, as it does not take into account the views of those municipalities that did not choose these interventions. Also, it is important to consider that this study interviewed municipalities that had signed up to be a part of the SFC project, and thus could have been more motivated to successfully implement the interventions than 'independent' municipalities might have been. Moreover, the SFC context limited the number of studied

municipalities to those that had signed up to implement Partner in Balance and Myinlife, which resulted in a relatively small sample size and made it difficult to assess whether data saturation had been reached. Nevertheless, this study provides a useful overview of why the municipalities that opted to adopt these eHealth interventions did so, and many common themes were observed in the interviews. Second, as some of the authors were involved with the research institute that had developed both interventions and were responsible for their implementation, it is possible that the respondents were influenced to provide socially desirable responses. However, doubts and concerns were also expressed and one municipality withdrew from the implementation, so there is reason to believe the municipalities still provided a nuanced and truthful account of their views. Additionally, the researchers had no advantage associated with municipalities choosing one eHealth intervention over the other, or instead of the other SFC activities. Finally, it is important to remember that all implementation plans were hypothetical at the time of interviewing, as they had not yet started implementing the interventions. While this approach made it possible to offer tailored implementation strategies, it also presumably made it difficult for the respondents to provide insight based on their experiences with the two specific eHealth interventions, although they did discuss their views on eHealth in general (Table 2, theme 4.2). Future research will evaluate the effectiveness of the proposed strategies.

## 5 CONCLUSIONS

This study helps fill the gap in the literature concerning the implementation context of eHealth interventions for caregivers of people with dementia. The interviews provided information on how municipality officials view eHealth for caregivers of people with dementia, and what they see as determinants of successful implementation. Proposed municipality implementation determinants included the enthusiasm from municipality officials to implement these interventions (despite a top-down push for them), the importance of face-to-face interviews in developing tailor-made implementation plans, regular face-to-face meetings with an eHealth project team, long-term sustainability planning by collecting data on required resources and benefits, and the facilitating effect of name brand recognition in adoption. Future research should collect data to inform pricing models to ensure long-term sustainability, as well as evaluate the efficacy of the various proposed implementation strategies.

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### **CONFLICTS OF INTEREST**

Authors Hannah Christie, Frans Verhey, and Marjolein de Vugt were involved in the development of the studied eHealth interventions (*Myinlife* and *Partner in Balance*). The authors declare no other conflicts of interest.

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# SUPPLEMENTARY DATA

## **Appendix. Interview guide for the semi-structured qualitative interviews**

### Theme 1: Background information

1. What is your job description within this municipality?
2. How did you come to be responsible for this intervention?
3. Who else is involved in implementing this intervention?
4. Do you have any experience with eHealth, dementia, caregiving, or implementation in general?
5. Yes = can you tell me something about that experience?

### Theme 2: Implementation strategy

6. Could you please describe how you intend to implement this intervention in the municipality? (recruitment, stakeholder meeting, caregiver meeting, organisational decisions, staff, ...). Do you have recommendation on how to do this?
7. How can we best reach the caregivers in this community?

### Theme 3: Thoughts on the implementation of the SFC eHealth intervention

8. Why/how did you choose [intervention]? What needs will this intervention meet that your community has?
9. What challenges do you foresee in implementing this intervention?
  - a. Concerning the intervention
  - b. Concerning the individuals involved
  - c. Concerning the organisation
  - d. Concerning the wider context
10. Is there enthusiasm in the municipality for this intervention?
  - a. From the municipality itself
  - b. From the community
11. Do you think caregivers will like and be helped by this intervention?
12. Where would you like to see this intervention in your municipality two years from now?

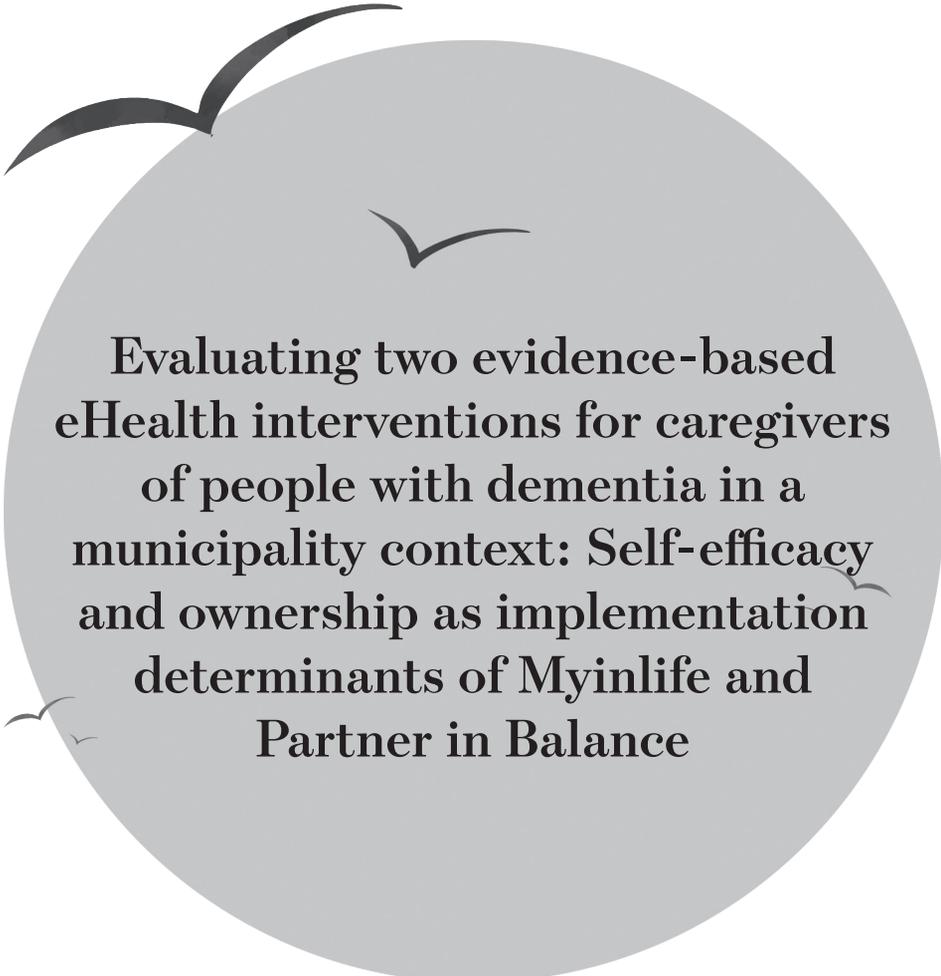
### Theme 4: Thoughts on eHealth in general

13. Where did you first hear about eHealth?
14. Do you have any examples of this?
15. Do you think eHealth has the potential to be successful in your municipality?

Summarise

16. So the main points I take away from this interview are [summary]. I appreciate the time you took for this interview. Is there anything else you think would be helpful for me to know?

8



**Evaluating two evidence-based  
eHealth interventions for caregivers  
of people with dementia in a  
municipality context: Self-efficacy  
and ownership as implementation  
determinants of Myinlife and  
Partner in Balance**

*Submitted*

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# ABSTRACT

**Background:** Very few evidence-based eHealth interventions for caregivers of people with dementia are implemented into practice. Municipalities are one promising context to implement these interventions, due to their available policy and innovation incentives regarding (dementia) caregiving and prevention. In this study, two evidence-based eHealth interventions for caregivers of people with dementia (Partner in Balance and Myinlife) were implemented in eight municipalities in the Euregion Meuse-Rhine. This study's aims were to (1.) evaluate this implementation and (2.) investigate determinants of successful implementation.

**Methods:** This study collected eHealth usage data, Partner in Balance coach evaluation questionnaires, and information on implementation determinants. This was done by conducting interviews with the municipality officials, based on the Measurement Instrument for Determinants of Implementation (MIDI). This data from multiple sources and perspectives was integrated and analysed to form a total picture of the municipality implementation process.

**Findings:** The municipality implementation of Partner in Balance and Myinlife showed varying levels of success. In the end, three municipalities planned to continue the implementation of Partner in Balance, while none planned to continue the implementation of Myinlife. The two Partner in Balance municipalities that did not consider the implementation to be successful, viewed the implementation as an external project. For Myinlife, it was clear that more face-to-face contact was needed to engage the implementing municipality and the target groups. Successful implementations were linked to implementer self-efficacy and sense of ownership, which seemed to be absent in unsuccessful implementations.

**Conclusions:** The experiences of implementing these interventions suggested that this implementation context was feasible regarding the required budget and infrastructure. The need to foster sense of ownership and self-efficacy in implementers will be integrated into future implementation protocols, as part of standard implementation materials for municipalities and organisations implementing Myinlife and Partner in Balance.

# 1 INTRODUCTION

Informal caregivers play an indispensable role in providing high-quality care for people with dementia<sup>1</sup>. Supporting informal carers of people with dementia is essential, as informal caregiving can potentially allow people with dementia to delay institutionalisation and result in positive effects on the person with dementia's physical and mental health<sup>2</sup>. Given the fact that there are currently 50 million people with dementia, and this number is set to triple by 2050<sup>3</sup>, the rising cost of dementia care and its reliance on informal care is a significant concern for many modern health care systems<sup>4</sup>. In part, because informal caregiving can have both positive<sup>5</sup> and negative<sup>6</sup> effects on the informal caregivers physical and mental well-being. Negative consequences of caregiving can include social isolation, depressive symptoms, stress and anxiety, financial issues, and sleep problems<sup>7,8</sup>.

eHealth interventions have been suggested as a means to meet both the demand for more cost-effective dementia health care<sup>9,10</sup>, and the need for effective informal caregiving support<sup>11</sup>. Many recent systematic reviews have shown evidence of the effectiveness of eHealth interventions for caregivers of people with dementia, with intervention studies reporting improvements in a variety of caregiver outcomes, including increased positive experiences with the caregiving process, self-efficacy, and confidence, in addition to the reduction of stress, experienced burden, and depressive symptoms and anxiety<sup>12-15</sup>.

Unfortunately, previous research has shown that very few of these eHealth interventions for caregivers of people with dementia are implemented into practice<sup>16</sup>. More generally, only 3% of evidence-based psychosocial interventions for dementia are translated into practice<sup>17</sup>. A lack of proven effects on health care outcomes, doubts from implementing health care staff, meagre implementation coordination and management, the fact that users are seldom involved in the eHealth development, and a lack of information on the implementation context have been cited as important barriers to the implementation of evidence-based interventions<sup>18-21</sup>.

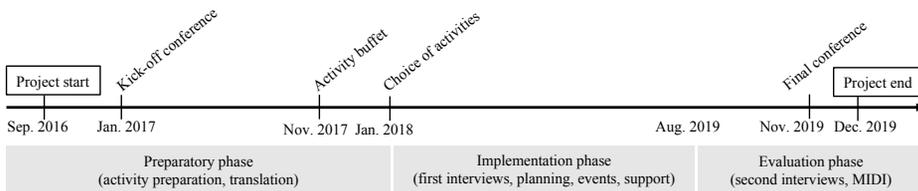
This study was designed to address the lack of information on the implementation context. One potentially important and well-suited implementation context for eHealth interventions for caregivers of people with dementia is the local municipality. This is because municipalities often have policy incentives and funds to tackle both dementia and caregiving challenges, as well as innovation budgets that are suitable to finance online solutions<sup>22,23</sup>. In this study, two evidence-based eHealth interventions for caregivers of people with dementia (Partner in Balance and Myinlife) were implemented in eight municipalities in the Euregion Meuse-Rhine (EMR). This study's aims were to (1.) evaluate the implementation in a municipality context and (2.) investigate determinants of successful implementation in this context.

## 2 METHODS

### 2.1 Study background

#### 2.1.1 euPrevent Senior Friendly Communities

This implementation study took place in the context of the euPrevent Senior Friendly Communities (SFC) project<sup>24</sup>, which is based on the World Health Organization's Active Ageing framework<sup>25</sup>. This project took place between September 2016 and December 2019, and data collection continued until March 2020 (see Figure 1 for a timeline of the project). In this project, 32 municipalities signed up on a *first come, first serve* basis, with the aim to become more senior-friendly. After a kick-off conference with the participating municipalities and other stakeholders, the project assessed what the municipalities were already doing for their ageing population and how they could improve. Informed by this assessment, municipalities selected activities from a so-called 'activity buffet', which consisted of 15 pre-existing activities. These activities were aimed at improving the mental health of the municipality's ageing population, by focusing on various aspects of dementia and age-related depression. These activities were to be implemented before a final conference with municipalities and stakeholders. Data collection took place parallel to the described activities and in three phases: A preparatory phase, an implementation phase, and an evaluation phase.



**Figure 1.** Timeline of eHealth implementation within SFC project

The activities of the 'activity buffet' included two eHealth interventions to support caregivers of people with dementia: 'Partner in Balance' and 'Myinlife'. Six municipalities opted to implement Partner in Balance in their municipalities (four in the Netherlands, one in Belgium, and one in Germany). Three opted for Myinlife (two in Belgium and one in Germany). Table 1 depicts some relevant characteristics of the SFC municipalities who chose to implement eHealth in their communities. A more detailed description of the municipalities' eHealth choice process is provided elsewhere<sup>23</sup>.

#### 2.1.2 The studied eHealth interventions

**2.1.2.1 Partner in Balance.** Partner in Balance is an evidence-based eHealth intervention, designed to aid caregivers of people with dementia in adapting to their new roles. It is a blended care, eight-week, self-management intervention, which consists of: (1.) an in-

person intake session with the coach, to acquaint the caregiver with Partner in Balance, select online modules, and set goals; (2.) tailored online thematic modules, including psychoeducation, behavioural modelling, videos of carers discussing their experiences with the chosen themes, change plans, and email feedback from the coach over eight weeks; and (3.) an in-person evaluation of the program with the coach, to assess the previously set goals. The requirements to be a Partner in Balance coach are that they have experience in (1.) health care and (2.) dementia care. All coaches take part in a two hour Partner in Balance training course, where the intervention is presented and exercises in coaching and self-management techniques are done. Detailed information about the program components and development is presented elsewhere<sup>27</sup>. Partner in Balance was shown to cause improvements in various caregiver outcomes, such as mastery, self-efficacy, and quality of life<sup>27,28</sup>.

**Table 1.** Characteristics of the participating municipalities

Characteristics	N
Number of municipalities that chose Partner in Balance	6
Number of municipalities that chose Myinlife	3
Municipality average general population	36376
Municipality average population age >65	7349
Municipality average estimated dementia population	1434

*Population statistics sourced from the Euprevent Senior Friendly Communities project<sup>23,24,26</sup>.*

**2.1.2.2 Myinlife.** Myinlife is an eHealth intervention designed to help caregivers of people with dementia utilise their social network to better organise care and to share positive (caregiving) experiences. Myinlife has been integrated into the Dutch Alzheimer's Association website, [www.dementie.nl](http://www.dementie.nl). In previous research, Myinlife has been shown to have the potential to make caregiving easier and help caregivers gain more control over their schedules<sup>29,30</sup>. Myinlife has the following functionalities: Profile, Circles, Timeline, Calendar, Helping, Personal Messages, Care book, and Compass.

## 2.2 Measures

### 2.2.1 Usage data

Implementation usage data was collected for the following measures: Number of municipalities choosing one of the two interventions, number of research team implementation hours (both face- to-face and remote), number of IT support hours, and number of accounts (caregivers and coaches). No data was collected on the effect of the intervention, or on the caregivers' experiences with the program, as this was assessed in previous research<sup>28</sup>.

### **2.2.2 Partner in Balance coach evaluation questionnaire**

Because Partner in Balance (but not Myinlife) makes use of a coach as part of its 'blended' approach, evaluation questionnaires were sent to all of the Partner in Balance coaches who took part in the coach training as part of the SFC project. An English translation of the coach evaluation questionnaire can be found in Appendix 1. The questionnaire asked the participants of the training to rate the usability and relevance of Partner in Balance for caregivers and coaches. It consisted of 11 multiple-choice items rated on a 5-point scale (1=completely disagree to 5=completely agree) and five open-ended items. A version of this questionnaire had previously been used in the Partner in Balance process evaluation<sup>31</sup>.

### **2.2.3 Determinants of implementation**

The Measurement Instrument for Determinants of Innovation (MIDI) is designed to assess which determinants may affect implementation, and can be applied both before or after the introduction of an innovation<sup>32</sup>. The MIDI groups determinants into four categories: Determinants associated with the innovation, determinants associated with the adopting person (user), determinants associated with the organisation, and determinants associated with the socio-political context. The MIDI was developed to be used in a research context, to explore the experiences of intermediary users ("*professionals whose actions determine the degree of exposure of end users to the innovation*") of the innovation<sup>33</sup>. To construct the MIDI, determinants were extracted from the results of eight empirical studies on the implementation of evidence-based innovations, and these were discussed with 22 implementation experts<sup>33</sup>. The instrument consists of 29 questions, each designed to explore a particular determinant. Responses consist of both a number on a one to five Likert scale, and an additional explanation with the reasoning behind the given score. However, in this study, due to the small sample size, no quantitative MIDI scores were collected, and the MIDI was rather used as an interview guide to ensure that various domains of implementation were discussed in the evaluation. Appendix 2 contains an English version of the MIDI, as it was used in these interviews as a semi-structured interview guide.

## **2.3 Data collection**

### **2.3.1 Usage data**

After each interaction with the municipality, implementation data was anonymously logged in a customised data collection platform, with separate entries for each municipality. The interactions included emails, telephone calls, and meetings. The dates and time required for these interactions were logged, including preparations and travel time. Data was logged by author HC from the start of the implementation in January 2018 until the end of implementation in December 2019. This was done for all municipalities that were using Myinlife and Partner in Balance.

### **2.3.2 Partner in Balance coach evaluation**

The coaches were sent the evaluation questionnaire via email and asked to reply via email. The emails were sent in December 2019, which was the end of the SFC project. Reminders were sent after six weeks and after twelve weeks. The email responses were stored on the described data collection platform.

### **2.3.3 Determinants of implementation**

Interviews with the municipality representatives responsible for the implementation of the chosen eHealth intervention were conducted to explore determinants of implementation. However, at the end of the project duration, not all municipalities had achieved the level of implementation necessary to appropriately evaluate implementation determinants using the MIDI questionnaire. The level of eHealth implementation was considered adequate to evaluate determinants if the municipalities had completed the implementation activities planned in the initial interviews. These differed per municipality<sup>23</sup> and included a minimum implementation threshold to be considered for determinant assessment. For Myinlife, municipalities had to at least have organised caregiver meetings around the intervention. For Partner in Balance, municipalities had to have completed a coach training and appointed an organisational Partner in Balance admin who oversaw the municipalities' coaches. The implementation level was assessed prior to the interview by phone call, by author HC. Five municipalities were assessed as having completed the minimum level implementation necessary to conduct an evaluation interview using the MIDI questionnaire as a semi-structured interview guide. These interviews were an average of 31 minutes long. For the remaining three municipalities, information was collected on the current level of implementation and what steps still needed to be taken in the future. This information was collected via email in one municipality (due to municipality time restraints), via face-to-face meeting in a second, and via telephone meeting in the final municipality.

The interviews took place between August 2019 and March 2020. All interviews were conducted by author HC, in Dutch, French, or English, according to municipality preferences. The MIDI interviews, face-to-face meeting, and telephone meetings were recorded and later transcribed verbatim. The written email evaluation was also stored on the data collection platform.

### **2.3.4 Informed consent and ethical approval**

All participants (municipality interviewees, Partner in Balance coaches, and experts) had received an information letter explaining the aims of the study, which also guaranteed the anonymous processing of their data and responses, in addition to the option of discontinuing study participation at any point. All participants signed an informed consent form. Ethical approval for the study was granted by Maastricht University's Medical Ethical Oversight Commission (METC), under approval number 2018-0489.

## **2.4 Data analysis**

### **2.4.1 Usage data**

After being logged into the online data collection platform by author HC, measures were automatically calculated across entries and subsequently exported.

### **2.4.2 Partner in Balance coach evaluations**

The responses were logged into the online data collection platform. Quantitative scores were calculated and qualitative responses were analysed inductively by author HC.

### **2.4.3 Determinants of implementation**

Authors HC and LB independently coded the semi-structured interviews using deductive thematic analysis<sup>34</sup>. The deductive codes used were the of the Consolidated Framework for Implementation Research (CFIR) constructs (Table 2). The CFIR is an established framework for mapping the implementation of evidence-based interventions, also for eHealth interventions<sup>35</sup>. It is comprised of five domains (Intervention characteristics, Outer setting, Inner setting, Characteristics of individuals, and Process), with 39 implementation constructs.

**Table 2.** Deductive CFIR codes

CFIR Domains	Deductive CFIR construct codes
I. Intervention characteristics	Intervention Source Evidence Strength & Quality Relative Advantage Adaptability Triability Complexity Design Quality & Packaging Cost
II. Outer setting	Patient Needs & Resources Cosmopolitanism Peer Pressure External Policy & Incentives
III. Inner setting	Structural Characteristics Networks & Communications Culture Implementation Climate Tension for Change Compatibility Relative Priority Organisational Incentives & Rewards Goals and Feedback Learning Climate Readiness for Implementation Leadership Engagement Available Resources Access to Knowledge & Information
IV. Characteristics of individuals	Knowledge & Beliefs about the Intervention Self-efficacy Individual Stage of Change Individual Identification with Organisation Other Personal Attributes
V. Process	Planning Engaging Opinion Leaders Formally Appointed Internal Implementation Leaders Champions External Change Agents Executing Reflecting & Evaluating

Adapted from Damschroder, et al. <sup>36</sup>.

## 3 RESULTS

### 3.1 Usage data

Table 3 shows the usage data for Partner in Balance and Myinlife (January 2018 - December 2019). The data shows that Myinlife was not chosen a single time in the Netherlands, and that Partner in Balance was a more popular choice, especially in the Netherlands. One of the six municipalities that initially chose to implement Partner in Balance (see Table 1), eventually chose to discontinue the implementation after the first meeting. This was due to a lack of information on future financing and pricing of Partner in Balance after the project end, and is discussed in depth elsewhere<sup>23</sup>. This municipality is therefore not represented in the table and the averages are calculated over the five municipalities that sustained the Partner in Balance implementation. Regarding the number of implementation hours, a total of 145 hours was spent on the implementation of Partner in Balance (an average 29 hours per municipality), while 54 hours were spent on the implementation of Myinlife (an average of 18 hours per municipality).

**Table 3. Usage data**

Measurement	Interventions	
	Partner in Balance	Myinlife
Number of times implemented by municipalities	5	3
<i>In the Netherlands</i>	3	0
<i>In Belgium</i>	1	2
<i>In Germany</i>	1	1
Total number of implementation hours (average)	145 (29)	54 (18)
<i>Total remote research team hours</i>	21 (4)	3 (1)
<i>Total in-person research team hours</i>	124 (25)	51 (17)
ICT support hours	48	5
Number of accounts made	22 caregivers 22 coaches	29 caregivers

### 3.2 Partner in Balance coach evaluations

In total, 26 coaches took part in the coach training, though only 22 coaches created Partner in Balance coach accounts. An average of five coaches were trained per Partner in Balance municipality. Across municipalities, the coaches recruited by the municipalities were dementia case managers (n=7), volunteers (n=3), nursing home personnel (n=6), municipality personnel responsible for caregiving (n=4), and dementia outreach nursing staff (n=6). Fourteen coaches filled in the coach evaluation questionnaire, resulting in a response rate of 64% (14/22). Eight coaches (six Dutch coaches and two Belgian coaches) replied that they had not been able to use Partner in

Balance in their work. Reasons for this were a lack of interest from the caregivers in their caseload (n=1), a lack of digital skills in caregivers in their caseload (n=1), a lack of time to implement the intervention (n=3), and a lack of dementia caregivers in their current caseload (n=1) (two respondents gave no reason). Two of these respondents spontaneously mentioned that they did find Partner in Balance a very useful and worthwhile tool, despite these barriers. Six completed questionnaires were received: Two from Dutch municipalities, two from the German municipality, and two from the Belgian municipality.

The results from the six completed questionnaires showed that coaches found Partner in Balance to be moderately useful (mean 3.7 [SD 0.8]) and moderately easy to integrate into their jobs (mean 3.3 [SD 0.8]). It was also perceived as a clear added value to the caregiver (mean 4.5 [SD 0.5]), and also to the coach, but to a lesser degree (mean 3.5 [SD 0.8]). In general, coaches found it moderately difficult to recruit suitable caregivers (mean 3.5 [SD 1.6]), though this question was not filled in by the two German coaches. Regarding its advantages for common practice, coaches reported an enriched contact with the caregiver (mean 4.1 [SD 1.0]). They expected the intervention to be time-efficient (mean 4.1 [SD 1.0]), but not cost-efficient (mean 2.8 [SD 1.0]) in the long run. Coaches would recommend Partner in Balance to other care professionals (mean 4.0 [SD 0.9]). Qualitative analysis of the open-ended questions interviews resulted in two main findings: (1.) the lack of digital literacy in the target population was perceived as a significant barrier, and (2.) the lack of necessary time for the trained coaches to recruit caregivers was perceived as a significant barrier.

### **3.3 Determinants of implementation**

#### **3.3.1 Characteristics of the intervention**

*3.3.1.1 Complexity.* In general, respondents described Myinlife as easy to use. However, one municipality official thought Myinlife was too complicated, as it focused on both online care coordination and positive engagement. This respondent recommended simplifying Myinlife to just the agenda function. Similarly, Partner in Balance was perceived as clear and easy to use. Municipalities found the intervention and coach training easy to understand. However, they would have preferred a more practical, hands-on training in smaller groups, as the training was too theory-focused and more implementation tips would have been welcome. Also, while Partner in Balance was easy to understand, there were a lot of tasks and organising involved in making it work (finding coaches, advertising, coordinating, etc.), which made it somewhat complex.

*3.3.1.2 Design quality and packaging.* For both interventions, it was reported that more face-to-face meetings and trainings were needed, as well as more advertising and promotional materials. In general, it was suggested that the packaging of the interventions needed to be expanded. For instance, several respondents mentioned that they would like an implementation guidebook. In the current form, coaches receive a guidebook during the training, but the suggested implementation guidebook would help management facilitate the adoption, implementation, and maintenance of the intervention. This would contain a general implementation package, consisting of an implementation protocol and premade templates for social media posts, posters, and flyers.

*3.3.1.3 Cost.* For Partner in Balance, municipalities confirmed that they thought the suggested price model of payment per client was reasonable in theory. The suggested financiers were municipalities and advertisers/sponsors. Regarding Myinlife, municipalities liked the idea of clients downloading the app from the App Store or Google Play, as this seemed to contain less liability for the municipality. In these cases, they suggested price points of 0, 5, and 10 euros.

*3.3.1.4 Relative advantage.* At the end of the implementation, some respondents still preferred face-to-face contact for discussing dementia case management issues. They said that typing sensitive issues on the Partner in Balance platform could be hard for caregivers and coaches, as meanings could be more easily be misconstrued than in face-to-face conversations. Myinlife was considered to be expensive in terms of necessary implementation time, compared to having a speaker give a lecture on the topic of dementia caregiving, especially as it is currently impossible for the municipality to see if people are actually using the Myinlife platform. They also wondered if Myinlife really posed an added value compared to other online solutions, such as WhatsApp and Facebook. Nevertheless, nine out of the 32 municipalities in the SFC project chose to implement these eHealth interventions in their communities, indicating that they perceived these interventions as having a relative advantage over the other activities on offer in this project.

### **3.3.2 Characteristics of individuals**

*3.3.2.1 Self-efficacy.* Self-efficacy was a recurring topic in the interviews, especially for Partner in Balance, where more guidance of the caregivers and coaches was needed. Both coaches and organisation coordinators were uncertain about whether they could fulfil their role and were scared to make mistakes. These fears eased once they started the coaching and they reported more confidence with increased experience. Municipality officials reported that successful coaches had confidence in the intervention and their own ability to use it to help their clients.

*3.3.2.2 Knowledge and beliefs about the intervention.* Municipality officials believed that the interventions would be effective at improving outcomes for caregivers, as this had been proven in previous research which they were familiar with. However, some officials wondered whether these effects would also be obtained outside the research context. For both interventions, there were significant privacy and liability concerns. There were also more general concerns regarding the timeliness and fit of the eHealth interventions in the current dementia health care setting. In particular, they wondered if there was sufficient digital literacy in caregivers, coaches, and in the municipality itself.

### **3.3.3 Inner setting**

*3.3.3.1 Structural characteristics & Networks and communication.* Municipality officials said that much more structural integration was needed. The implementation of the eHealth interventions was usually the sole responsibility of one person within the municipality. The municipality officials stressed that this was not enough, and that there should be a team to tackle the implementation together. As they recommended including this in the product itself, this is discussed in more detail under 'Characteristics of the Intervention'. Municipalities added that it was easy to set up the necessary meetings with the Partner in Balance team.

*3.3.3.2 Implementation climate.* For both interventions, there was not enough goal setting and feedback, the interventions had low relative priority, and there were no incentives or rewards to encourage the implementation into clinical practice. As management is primarily interested in concrete output, it is important to keep track of the output and use of the interventions. This is currently possible to track digitally for Partner in Balance, but not for Myinlife.

*3.3.3.3 Readiness for implementation.* Respondents indicated that there were few resources (especially in terms of available time) to spend on the implementation, as well as a lack of leadership engagement.

### **3.3.4 Outer setting**

*3.3.4.1 Cosmopolitanism.* Regarding how the implementing organisations are linked to other organisations, respondents stated that the interventions needed to be offered through an external party (not through the municipality) and cooperation with care providers would always be necessary, as they would have to agree to execute the interventions. Some municipalities reported that the SFC project had been a good chance to connect and strengthen their local dementia care networks.

3.3.4.2 *Patient needs and resources.* Myinlife and Partner in Balance were both perceived as fitting caregiver needs. However, for Myinlife, there was little enthusiasm from the local target population, as evidenced by the lack of attendance to the planned Myinlife caregiver meetings.

3.3.4.3 *External policy and incentives.* Partner in Balance was described as fitting well into initiatives around generalised services, current internal caregiver and prevention policies, as well as municipality innovation budgets. These budgets are facilitated by the outer setting, but their use is determined by the inner setting (municipality). The municipalities that had these innovation budgets mentioned that these budgets could potentially be used in the future to purchase licenses for the further implementation of Partner in Balance, if the experiences were positive.

### **3.3.5 Process**

3.3.5.1 *Engaging.* Municipalities implementing Myinlife indicated that a more hands-on demonstration and sale-pitch-like approach were needed to convince health care partners to cooperate in the dissemination of the intervention, and less of an academic presentation. There was not enough engagement of the target populations (both of Partner in Balance coaches and dementia caregivers), though two municipalities did involve local dementia groups in their activity choice and subsequent eHealth implementation. More opinion leaders and internal implementation leaders were needed.

3.3.5.2 *Executing.* The plans that were made at the beginning of the implementation<sup>23</sup> were followed. Nevertheless, these were in many cases insufficient and in several municipalities implementation plans are still being made for the future.

3.3.5.3 *Planning.* These new plans include involving more local health care groups (for Partner in Balance); more advertising and communications, which are more direct (for both Myinlife and Partner in Balance); and more structural goal setting and feedback (for Partner in Balance this pertains to coaching, for Myinlife this is tracking how many people use the intervention). Reflecting and evaluating was not a big part of this implementation, but was seen as important for the future implementation of both interventions.

## **3.4 Evaluation**

Integrating the usage data, coach questionnaires, and municipality interviews, it appears that the implementation of Partner in Balance and Myinlife showed varying levels of success in different municipalities. In the end, three municipalities planned to continue with their implementation of Partner in Balance, while no municipalities planned to continue with their implementation of Myinlife. What these three Partner in Balance

municipalities had in common, was that they considered the implementation of the intervention to be a success. These municipalities all appeared to have a sense of internal responsibility to facilitate the implementation of Partner in Balance and devise creative solutions. The two Partner in Balance municipalities that did not consider the implementation to be successful, seemed to see the implementation as more of an external project, where the municipalities role was more to facilitate than to execute. For Myinlife, it was clear from the municipality interviews and the usage data that more time was needed to successfully embed the intervention into the local health care landscape. Despite Myinlife not necessitating the recruitment of coaches, it was clear that more face-to-face contact was needed to engage the implementing municipality and the target group.

## 4 DISCUSSION

This study integrated usage data, coach questionnaires, and interviews to evaluate the implementations of Partner in Balance and Myinlife. These two eHealth interventions for caregivers of people with dementia were implemented in eight municipalities in the Euregion Meuse-Rhine (EMR). This study's aims were to (1.) evaluate the implementations in a municipality context and (2.) investigate determinants of successful implementation in this context.

### 4.1 Improvements for Partner in Balance coaches

A main finding from the interviews with municipality officials regarding the Partner in Balance implementation, was the need to increase the self-efficacy of the Partner in Balance coaches. Coaches reported that uncertainties about whether they were ready to coach, as well as insecurities about whether they could do a good job, were significant barriers to starting to coach caregivers. Hence, an important lesson from this study is that Partner in Balance cannot increase caregivers' self-efficacy, without ensuring that coaches already have a minimum level of self-efficacy to start the coaching. This is supported by previous research, which has described care professional self-efficacy as a major facilitator of successful intervention implementation in a variety of contexts<sup>37-39</sup>. Bandura, et al. 40 described four ways to increase self-efficacy: Mastery experiences, vicarious experiences, verbal persuasion, and monitoring physiological states. Subsequent research built on this by examining how self-efficacy can be enhanced through training in professional caregivers of people with dementia, which can potentially increase intervention adherence<sup>41</sup>. Discussing common barriers to implementation among the training participants, addressing barriers through role-playing, and providing constructive feedback on the role-play have been shown to increase dementia care professional self-efficacy<sup>42</sup>. In the future, Partner in Balance will incorporate these methods into coach trainings to help coaches develop the self-efficacy necessary to start coaching with Partner in Balance.

In their responses to the request to fill in the Partner in Balance coach evaluation questionnaire, several coaches mentioned that they were not able to offer Partner in Balance to any caregivers, as their clients did not possess sufficient digital literacy. These clients were often older, and previous research has indicated that advanced age is a barrier to adopting eHealth, due to related declines in motor, cognitive, and perceptive abilities, as well as the difficulties accompanying the rapidly changing technological market<sup>43-45</sup>. In general, studies regarding older adults' attitudes towards eHealth interventions have produced mixed results<sup>46-48</sup>. Additionally, many municipalities included in this study could be considered rural, and evidence has suggested that older adults in rural areas are less inclined to adopt eHealth interventions<sup>49</sup>. It is also important to consider health care

professionals' attitudes towards eHealth for dementia and their role as gatekeepers in deciding whether to offer eHealth interventions such as Partner in Balance to caregivers. In line with this research, a recent systematic literature review on the attitudes of health care professionals towards eHealth described workload concerns, lack of incentives, perceived threats to autonomy, liability concerns, and lack of organisational support and cooperation as important implementation barriers<sup>50</sup>. Here too, a possible remedy for these eHealth challenges experienced by health care professionals, is the embedding of improved eHealth education in their standard training<sup>51,52</sup>.

#### **4.2 Improvements for municipalities**

For both Myinlife and Partner in Balance, municipality officials reported that their municipality implementation teams were often understaffed. Previous research on municipal eHealth for home care<sup>53</sup> and for dementia care<sup>54</sup>, has underscored the importance of municipality-specific protocols when implementing eHealth in these contexts. Based on this study, these protocols should specify how to form municipality implementation teams, including suggestions to involve at least two people in the team and to schedule regular progress meetings within this team. These meetings should discuss new promotion ideas and opportunities, using templates for the promotion and advertising of the interventions. Additionally, these meetings should monitor the success of the interventions' implementation, as municipality officials reported that their management is most interested in demonstrable output. For Partner in Balance, it is possible for organisations to monitor the number of coaches and participating caregivers. However, there is currently no way to keep track of whether Myinlife is successfully being used in the community. Previous research on organisational learning as a method for eHealth benefit realisation in a municipal health care context emphasised the importance of reviewing and evaluating results and establishing potential for further benefits<sup>55</sup>. This makes it possible for the implementation teams to set and achieve goals around usage in the community. In this study, not doing so was counterproductive for both team motivation and the acceptability of the time spent on implementation to management. For both Partner in Balance and Myinlife, future implementation packages should include protocols on setting usage goals in the regularly scheduled team meetings, and the interventions should include functionalities to easily keep track of these statistics.

#### **4.3 Improvements for project management**

In order to recruit external health care organisations, the municipality is required to recruit coaches (for Partner in Balance) and integrate interventions into larger health care structures who can offer it as part of their services (for Partner in Balance and Myinlife). This requires regular meetings to follow up on coaches' experiences, where coaches can learn from each other, share tips and tricks, and discuss their progress. The involvement of the management

of these external health care organisations is crucial, as they can offer incentives for successful coaching and adapt structures to facilitate the integration of Partner in Balance into the coaches' tasks. For example, it is important that management ensures that time spent coaching can be declared to the health insurer as provided care. Previous research has reported this as a significant determinant of successful eHealth implementation for health care professionals<sup>56</sup>. Thus, future implementation packages should include protocols for these organisations on how to organise the suggested meetings, internal monitoring, and incentives, including the declaration of coached hours to health insurers. To facilitate this, future implementation packages should also suggest appointing an eHealth ambassador within the organisation, whose function is to ensure that these meetings take place, as well as to provide a reliable and continuous level of enthusiasm for the intervention. Previous research has advocated the use of ambassadors in implementing eHealth<sup>29,57-59</sup>.

#### **4.4 Sustainability measures**

Despite the relative ease of setting up the infrastructural aspects of this project, implementation was only successful in just over half of the municipalities. It is clear that successful implementation depends on more than merely setting the necessary structures in place. This study's interview findings indicated that successful implementation was tied to a sense of ownership and responsibility from the municipality officials. This is in line with previous research, which has pointed to a lack of eHealth ownership at both local and national levels as a considerable implementation barrier<sup>60,61</sup>. Therefore, future implementation packages for Myinlife and Partner in Balance will include suggestions on how to achieve sustainability by increasing sense of ownership and end-user adherence in general. An important element of this, is the reflection and feedback exercises that will also be part of new measures to monitor the interventions (described above), as they have been shown to improve eHealth ownership and adoption<sup>62</sup>. In addition to scheduling the described reflection and role-playing exercises, previous research on increasing the adherence of end-users to eHealth interventions recommends persuasive system design, which is used to aid the development of information systems to shape attitudes and behaviours<sup>63</sup>. This approach recommends that interventions incorporate on-the-spot reminders and feedback to increase end-user adherence. Hence, future implementations will incorporate more intervention monitoring and reflection moments, both for implementers and end-users.

Finally, it is also important to consider why Partner in Balance was more often successfully implemented in this municipality context than Myinlife. Previous research has indeed shown that blended eHealth interventions for caregivers of people with dementia are more effective at improving outcomes for caregivers of people with dementia than non-blended interventions<sup>2</sup>. One potential explanation for this increased success of Partner in Balance

in this particular context, is that its blended aspect (the human contact between caregiver and coach) not only increases effectiveness through improved caregiver outcomes, but also through a possible effect of increasing engagement among implementers. Here, Partner in Balance required more hours to implement in the municipality context than Myinlife. It is possible that these additional face-to-face hours required to implement Partner in Balance (but not Myinlife) increased implementers' sense of ownership of the successful implementation of the intervention. Of course, this study also shows that this blended aspect is more resource intensive. Future research could investigate the comparative cost-effectiveness of these interventions in order to weigh costs and benefits.

#### **4.5 Strengths and weaknesses**

This study had several important strengths. First, this study is one of few to examine the further implementation of eHealth interventions for caregivers of people with dementia, after the trial phase. This study uses various measures, from multiple perspectives, to construct a thorough evaluation of the implementation of these interventions in a municipality context. As a result, this study is able to shed novel light on the currently underexplored organisational and contextual implementation determinants. Second, by focusing on the municipality context specifically, and by taking the time to explore this context in depth, this study has successfully identified the municipality as a potential distributor with the financial means to further disseminate evidence-based eHealth interventions for caregivers of people with dementia.

This study also has several limitations. First, this study did not explore the experiences of caregivers using the Partner in Balance and Myinlife interventions. As a result, we have no information on actual eHealth usage and do not know how the caregiver target group used and evaluated the interventions in this context. This is because both Partner in Balance and Myinlife were previously assessed for usability and effectiveness by caregivers in a series of trials<sup>27,28,30,64</sup> informed by the Medical Research Council (MRC) framework<sup>65</sup>. The aim of this study was to gain information on their broader implementation contexts. Second, there was a moderate response rate to the request to fill in the Partner in Balance coach evaluation questionnaire (64%), with only six coaches submitting completed questionnaires (and eight providing details on why they had not yet started coaching). As a result, there is no information on how the non-responders experienced Partner in Balance, causing a potentially biased sample of coach responses, who might be more positively disposed towards the intervention. Next, this study was unable to take into account the views of those municipalities that chose not to implement Myinlife or Partner in Balance. While it was not this study's aim to generalise these qualitative findings to all municipalities, it is possible that this study represents a sample of municipalities that have more positive attitudes towards eHealth for dementia and its implementation than other municipalities.

Nevertheless, it is still useful to document and learn from these (potentially more engaged) municipalities, as they can provide valuable insight into the feasibility of eHealth for dementia in this context and into municipality needs. Finally, it must be acknowledged that all authors (with the exception of HT) were involved in the development of Myinlife and Partner in Balance and are therefore potentially not unbiased. However, the authors were also interested in differences between the two interventions, and were in this sense unbiased. Moreover, it is the authors' belief that this type of implementation research is essential for evidence-based interventions, and researchers should more often conduct longer-term implementation research on their own interventions.

## 5 CONCLUSIONS

This study provided a thorough exploration of the feasibility of the implementation of eHealth interventions to support caregivers of people with dementia in a municipality context. Future implementations can make use of protocols that provide municipalities and organisations with suggestions on how to tackle implementation challenges and realise improvements for the (Partner in Balance) coaches, the implementation team, and the external implementing organisations. In general, it is important to foster a sense of ownership of the success of the eHealth intervention in the municipality and dementia health care context, as this was seen as a main determinant of success in this implementation project. For Partner in Balance, an important finding was that the self-efficacy of coaches must be increased before they can be expected to help caregivers elevate their levels of self-efficacy regarding dementia caregiving. For Myinlife, it was necessary to involve more face-to-face contacts and integrate the intervention more into other local health services, despite it not being designed as a blended intervention. These insights will be integrated into future implementation protocols, that will become a standard part of the Myinlife and Partner in Balance implementation packages for municipalities and organisations.

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### **CONFLICTS OF INTEREST**

Authors HC, LB, MdV, and FV were involved in the previous development of Myinlife and Partner in Balance.

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# SUPPLEMENTARY DATA

## Appendix 1. Partner in Balance coach evaluation questionnaire

Some time ago you started as a coach for the online intervention Partner in Balance. We would like to hear from you how you felt about working with Partner in Balance.

This questionnaire consists of a number of closed questions and a number of open questions. You may always give an explanation of your answer, sometimes you will be asked to do so as well.

	Completely disagree	Disagree	Neutral	Agree	Completely agree
1. I think the intervention is useful for me as a coach.	1	2	3	4	5
2. I can integrate the intervention into my work.	1	2	3	4	5
3. I think the intervention has an added value for the caregiver.	1	2	3	4	5
4. I think the intervention has an added value for the coach.	1	2	3	4	5
5. On average I spend this many hours coaching for Partner in Balance:	.....				
6. It's hard to find suitable caregivers to participate in Partner in Balance.	1	2	3	4	
7. As a result of using Partner in Balance, I spend less time on caregiver support.	1	2	3	4	5
Additional question					
1. How many hours more/less?.....					
2. Why?					
8. Partner in Balance results in an enriched contact with the caregiver					
9. Partner in Balance saves time in the long Term.					
10. Partner in Balance saves costs in the long term.					
11. I would recommend Partner in balance to other care professionals.					
12. Did you completed the intervention as planned (within 9 weeks)? (1) no + Explanation / (2) yes					

13. What are the disadvantages to this intervention?

14. What are the advantages to this intervention?

15. What do you think is necessary to implement this intervention within your organisation in the future?

16. I would like to say this in order to improve Partner in Balance in the future:

## Appendix 2. Measurement instrument: Description and operationalisation of determinants (adapted from Fleuren et al.33)

### 1 DETERMINANTS ASSOCIATED WITH THE INNOVATION

#### **Determinant 1**      **Procedural clarity**

*Description*                      Extent to which the innovation is described in clear steps / procedures.

*Operationalisation*            The innovation clearly describes the activities I should perform and in which order.

Response scale:                (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

#### **Determinant 2**      **Correctness**

*Description*                      Degree to which the innovation is based on factually correct knowledge.

*Operationalisation*            The innovation is based on factually correct knowledge.

Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

<b>Determinant 3</b>	<b>Completeness</b>
<i>Description</i>	Degree to which the activities described in the innovation are complete.
<i>Operationalisation</i>	The innovation provides all the information and materials needed to work with it properly. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree
<b>Determinant 4</b>	<b>Complexity</b>
<i>Description</i>	Degree to which implementation of the innovation is complex.
<i>Operationalisation</i>	The innovation is too complex for me to use. Response scale: (5) totally disagree, (4) disagree, (3) neither agree nor disagree, (2) agree, (1) totally agree
<b>Determinant 5</b>	<b>Compatibility</b>
<i>Description</i>	Degree to which the innovation is compatible with the values and working method in place.
<i>Operationalisation</i>	The innovation is a good match for how I am used to working. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree
<b>Determinant 6</b>	<b>Observability</b>
<i>Description</i>	Visibility of the outcomes for the user, for example whether the outcomes of a particular treatment are clear to the user.
<i>Operationalisation</i>	The outcomes of using the innovation are clearly observable. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree
<b>Determinant 7</b>	<b>Relevance for client</b>
<i>Description</i>	Degree to which the user believes the innovation is relevant for his/her client.
<i>Operationalisation</i>	I think the innovation is relevant for my clients. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

## **2. DETERMINANTS ASSOCIATED WITH THE USER**

<b>Determinant 8</b>	<b>Personal benefits/drawbacks</b>
<i>Description</i>	Degree to which using the innovation has advantages or disadvantages for the users themselves.
<i>Operationalisation</i>	To what extent does using the innovation have personal benefits/drawbacks for you?

This question is asked for each concrete benefit or drawback that is expected to be salient for the particular user population.

Response scale advantages: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

Response scale disadvantages: (5) totally disagree, (4) disagree, (3) neither agree nor disagree, (2) agree, (1) totally agree

### **Determinant 9**

#### **Outcome expectations**

#### *Description*

Perceived probability and importance of achieving the client objectives as intended by the innovation

#### *Operationalisation*

Composite measure: the product of *importance* and *probability*

These questions about the importance and probability are asked for each objective separately.

#### *Importance*

I think it is important to achieve the following objectives for my client ...[state objectives].

Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

#### *Probability*

I expect that using the innovation will actually achieve the following objectives for my client ...[state objectives].

Response scale: (1) most definitely not, (2) definitely not, (3) perhaps not, perhaps, (4) definitely, (5) most definitely

### **Determinant 10**

#### **Professional obligation**

#### *Description*

Degree to which the innovation fits in with the tasks for which the user feels responsible when doing his/her work.

#### *Operationalisation*

I feel it is my responsibility as a professional to use this innovation.

This question is asked for each activity in the innovation.

Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

### **Determinant 11**

#### **Client satisfaction**

#### *Description*

Degree to which the user expects clients to be satisfied with the innovation.

#### *Operationalisation*

Clients will generally be satisfied if I use this innovation.

Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

<b>Determinant 12</b>	<b>Client cooperation</b>
<i>Description</i>	Degree to which the user expects clients to cooperate with the innovation.
<i>Operationalisation</i>	Clients will generally cooperate if I use this innovation. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree
<b>Determinant 13</b>	<b>Social support</b>
<i>Description</i>	Support experienced or expected by the user from important social referents relating to the use of the innovation (for example from colleagues, other professionals they work with, heads of department or management).
<i>Operationalisation</i>	I can count on adequate assistance from my colleagues if I need it to use the innovation. This question is asked for important social referent group or person inside or outside the organisation (colleagues, immediate hierarchical superior, management, professionals involved in the delivery of care etc.). Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree
<b>Determinant 14</b>	<b>Descriptive norm</b>
<i>Description</i>	Colleagues' observed behaviour; degree to which colleagues use the innovation.
<i>Operationalisation</i>	In your opinion, what proportion of the colleagues in your organisation for whom the innovation is intended actually use the innovation? Response scale: (1) not a single colleague (2) almost no colleagues (3) a minority (4) half (5) a majority (6) almost all colleagues (7) all colleagues.
<b>Determinant 15</b>	<b>Subjective norm</b>
<i>Description</i>	The influence of important others on the use of the innovation.
<i>Operationalisation</i>	Composite measure: the product of <i>normative beliefs</i> and <i>motivation to comply</i> These questions about normative beliefs and motivation to comply are asked for each referent person/group inside or outside the organisation (colleagues, heads of department, management, clients etc.).

*Normative beliefs*

To what extent do the following people [list people] expect you to use the innovation?

Response scale: (1) most definitely not (2) definitely not (3) perhaps not, perhaps (4) definitely (5) most definitely

*Motivation to comply*

When it comes to working in accordance with the innovation, to what extent do you comply with the opinions of the following people [list people]?

Response scale: (1) very little (2) little (3) not a little, not a lot (4) a lot (5) a great deal

**Determinant 16***Description***Self-efficacy**

Degree to which the user believes he or she is able to implement the activities involved in the innovation.

*Operationalisation*

Should you wish to do so, do you think you can put [state activity from the innovation] into practice?

This question is asked for each activity in the innovation.

Response scale: (1) most definitely not (2) definitely not (3) perhaps not, perhaps (4) definitely (5) most definitely

**Determinant 17***Description***Knowledge**

Degree to which the user has the knowledge needed to use the innovation.

*Operationalisation*

*Objective measurement* with a knowledge test including a range of questions.

*Subjective measurement* with one question:

I know enough to use the innovation.

Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

**Determinant 18***Description***Awareness of content of innovation**

Degree to which the user has learnt about the content of the innovation.

*Operationalisation*

To what extent are you informed about the content of the innovation?

Response scale: (1) I'm not familiar with the innovation (2) I'm familiar with the innovation, but I haven't read it through (yet)

(3) I'm familiar with the innovation and I've glanced through it (4) I'm familiar with the innovation and I have read through it thoroughly

### 3. DETERMINANTS ASSOCIATED WITH THE ORGANISATION

#### **Determinant 19      Formal ratification by management**

*Description*                      Formal ratification of the innovation by management, for example by including the use of the innovation in policy documents.

*Operationalisation*            Has the management set up formal arrangements in your organisation relating to the use of this innovation (in policy plans, work plans and so on)?  
Response scale: (1) no (2) yes

#### **Determinant 20      Replacement when staff leave**

*Description*                      Replacement of staff leaving the organisation

*Operationalisation*            In my organisation, there are arrangements in place so that staff who use the innovation and leave the organisation are replaced in good time by employees who are/will be adequately prepared to take over.  
Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

#### **Determinant 21      Staff capacity**

*Description*                      Adequate staffing in the department or in the organisation where the innovation is being used.

*Operationalisation*            There are enough people in our organisation to use the innovation as intended. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

#### **Determinant 22      Financial resources**

*Description*                      Availability of financial resources needed to use the innovation.

*Operationalisation*            There are enough financial resources available to use the innovation as intended. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

#### **Determinant 23 Time available**

*Description*                      Amount of time available to use the innovation.

*Operationalisation*            Our organisation provides me with enough time to include the innovation as intended in my day-to-day work.  
Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

<b>Determinant 24</b>	<b>Material resources and facilities</b>
<i>Description</i>	Presence of materials and other resources or facilities necessary for the use of the innovation as intended (such as equipment, materials or space).
<i>Operationalisation</i>	Our organisation provides me with enough materials and other resources or facilities necessary for the use of the innovation as intended. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree
<b>Determinant 25</b>	<b>Coordinator</b>
<i>Description</i>	The presence of one or more persons responsible for coordinating the implementation of the innovation in the organisation.
<i>Operationalisation</i>	In my organisation, one or more people have been designated to coordinate the process of implementing the innovation. Response scale: (1) no (2) yes
<b>Determinant 26</b>	<b>Unsettled organisation</b>
<i>Description</i>	Degree to which there are other changes in progress (organisational or otherwise) that represent obstacles to the process of implementing the innovation, such as re- organisations, mergers, cuts, staffing changes or the simultaneous implementation of different innovations.
<i>Operationalisation</i>	Are there, in addition to the implementation of [describe innovation], any other changes in the organisation affecting the implementation of the innovation now or in the foreseeable future (reorganisation, merger, cuts, staffing changes, other innovations)? Response scale: (2) no (1) yes
<b>Determinant 27</b>	<b>Information accessible about use of innovation</b>
<i>Description</i>	Accessibility of information about the use of the innovation.
<i>Operationalisation</i>	It is easy for me to find information in my organisation about using the innovation as intended. Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

**Determinant 28****Performance feedback***Description*

Feedback to the user about progress with the innovation process.

*Operationalisation*

In my organisation, feedback is regularly provided about progress with the implementation of the innovation.

Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree

**4. DETERMINANTS ASSOCIATED WITH THE SOCIO-POLITICAL CONTEXT****Determinant 29****Legislation and regulations***Description*

Degree to which the innovation fits in with existing legislation and regulations established by the competent authorities (examples being financial structures, or substantive legislation and supervision from the Dutch Health Care Inspectorate or the Dutch Care Authority).

*Operationalisation*

The activities listed in the innovation fit in well with existing legislation and regulations.

Response scale: (1) totally disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) totally agree.

**5. OTHER QUESTIONS**

Have we followed the implementation plan? Why (not)? Which parts of this plan worked, which parts did not work?

Have we forgotten anything in this plan / what could be improve?



9



## General discussion



# 1 INTRODUCTION

eHealth interventions show much promise regarding their potential to improve outcomes for caregivers of people with dementia<sup>1-3</sup> and tackle a growing societal challenge<sup>4,5</sup>. Unfortunately, very few psychosocial interventions for dementia are translated into practice<sup>6</sup>, and this is also the case for eHealth interventions<sup>7</sup>. Thus, the aim of this thesis was to shed light on the factors that influence the implementation of eHealth interventions for caregivers of people with dementia into practice.

In part 1, this thesis investigated what could be learned from examining previously developed interventions. In part 2, this thesis studied what could be learned from the continued implementation of two existing, evidence-based eHealth interventions for caregivers of people with dementia: Partner in Balance and Myinlife. This final chapter presents an overview of the main findings, as well as some methodological considerations. In addition, this research's implications and directions for future research are discussed.

## 2 MAIN FINDINGS

### 2.1 Part 1: Lessons from previous implementations

*What has previous research reported concerning the implementation of eHealth interventions for caregivers of people with dementia? (Chapter 2)*

As a first step, this thesis aimed to gain insight into what research had already been done on the topic of the implementation of eHealth interventions for caregivers of people with dementia. The resulting systematic literature review (Chapter 2) produced two main findings. First, only 46 out of the 122 identified studies about eHealth for dementia caregiving mentioned implementation, and a mere two of these were implementation studies. This demonstrated that implementation research on eHealth interventions for caregivers of people with dementia was still in its infancy. This review found that when previous research *had* mentioned the implementation of these interventions, this research was often limited to the characteristics of the eHealth intervention itself and the characteristics of the end users (the caregivers of people with dementia). As a result, the study of practical implementation issues and the mapping of organisational and contextual implementation determinants had largely been neglected.

Second, it appeared there was a mismatch between the focus of established implementation frameworks and the focus of current research into eHealth interventions for caregivers of people with dementia. On the one hand, available implementation frameworks were not suited to mapping the complexity of the available research findings concerning the specifics of the tested eHealth interventions and the characteristics of the individual end-users. On the other hand, it was clear that much could be learned from applying implementation frameworks to the field of eHealth interventions for caregivers of people with dementia, particularly regarding the mapping of implementation determinants associated with their process, organisation, and wider context.

The findings of this systematic literature study helped define the research direction of this thesis. Subsequent studies were aimed at building on the existing research concerning eHealth interventions and user characteristics, by identifying their process-related, organisational, and contextual implementation determinants.

*What can be learned from the current implementation status of previous, evidence-based eHealth interventions for caregivers of people with dementia? (Chapter 3)*

Next, this thesis aimed to gain insight into whether and how eHealth interventions for caregivers of people with dementia found their way from research into practice. By following up on 12 eHealth interventions for caregivers of people with dementia that had been included in a previous systematic review exploring their effectiveness in improving

caregiver outcomes', Chapter 3 was able to shed light on what has happened to promising, evidence-based eHealth interventions for caregivers of people with dementia, after their effectiveness trials. A first important finding was that 10 out of 12 included interventions were no longer available to use. The long-term implementation of the two available interventions was achieved through long-term aid from an external funding body. This underscored the fact that, in contrast to other industries (such as the pharmaceutical industry), there is no clear pathway to acquire the funding necessary to market and implement effective eHealth interventions for dementia caregivers into practice. To accomplish this, policy makers and funding bodies should dedicate more funding to the sustainable and long-term implementation of evidence-based eHealth interventions for dementia caregivers. In addition, researchers should consider more flexible and time-efficient research designs. These can include small studies with well-defined and significant research questions, quasi-experimental designs, the use of big data, and the continuous enhancement of interventions<sup>8</sup>.

*What can be learned from eHealth interventions for caregivers of people with dementia that are already used in practice? (Chapter 4)*

In Chapter 4, we aimed to view this topic from the opposite direction. Here, this thesis investigated eHealth interventions for caregivers of people with dementia that were already being used in practice, and explored how their implementation lessons could be applied to facilitate the implementation of their counterparts originating from the academic research context. Common characteristics of a sample of case studies were explored and a resulting core model of eHealth interventions for caregivers of people with dementia was proposed. This model's design was based on key factors that contributed to the desirability, feasibility, and viability of the case studies, based on the Business Model Canvas (BMC)<sup>9</sup>. It proposed the design of a core business model in which the eHealth intervention can be integrated into larger structures, which owns and supports content internally while outsourcing information and communication technology (ICT) services, and which offers fixed, low-level pricing. An additional important factor in these interventions achieving sustainability was the origin of the intervention, as case studies that had originated in an academic research context less often found their way to sustainable implementation. This chapter suggests this might be due to a lack of business modelling know-how in the academic implementation teams. As a result of these findings, forming and maintaining a community of intervention users, as well as more funding for implementation, more intersectoral cooperation, and business modelling research, were suggested to help future developers bring eHealth interventions for caregivers of people with dementia into practice.

## **2.2 Part 2: Lessons from continued implementation**

*Which factors influenced the implementation of Myinlife? (Chapter 5)*

In Chapter 5, a process evaluation was conducted to gain insight into the factors influencing the implementation of Myinlife, an online platform to help caregivers of people with dementia organise informal care. This was in line with the findings from part 1, which pointed to the need for more insight into the implementation of evidence-based eHealth interventions for caregivers of people with dementia. The main finding from this study was that this 'ready-made' eHealth intervention (meaning 'not-blended', or without a coach) required structural and organisational support to reach caregivers of people with dementia, as well as face-to-face contact, to ensure optimal use. From this process evaluation it was clear that Myinlife was not optimally used as a standalone platform, despite the positive experiences of its users. More face-to-face contact with the caregivers was needed to help them gain insight into their available social capital and eventually adopt Myinlife to organise dementia care within their networks.

*How can Partner in Balance be sustainably implemented in the future, and how can this facilitate the sustainable implementation of future eHealth interventions for caregivers of people with dementia? (Chapter 6)*

Chapter 6 was a case study of the implementation of Partner in Balance, a blended care intervention to support caregivers of people with dementia. This study used experiences from real-life pilots and qualitative interviews with national stakeholders to establish an implementation plan, consisting of implementation strategies and a business model. First, Chapter 6 showed that long-term implementation of Partner in Balance requires the formation of an 'innovation cluster'. It is important to form this innovation cluster at the beginning of the eHealth development. This cluster should consist of, at minimum, the eHealth supplier, the distributor, and the implementing organisation, and can include other necessary implementation parties. This allows developers to take into account the needs of the dementia organisations who will be implementing the eHealth intervention after the trial phase. Moreover, these parties can provide input on the type of data collected during the research phase, which they consider necessary to make decisions regarding long-term implementation. For instance, Partner in Balance stakeholders reported that cost-effectiveness data is very decisive in the question of whether to bring an effective eHealth intervention for caregivers of people with dementia into practice. This data is often not included in typical eHealth research designs, which largely follow the Medical Research Council Framework (MRC)<sup>10</sup>. In general, outcome measures for effectiveness trials of eHealth interventions are often psychological outcome measures. Implementation and cost-effectiveness data is unfortunately not routinely collected, or only at a later stage. This results in products that are less adapted to the market, as well as longer and less efficient development processes. Thus, the main finding from this Partner in Balance case study that

can be applied to future interventions, is the importance of forming innovation clusters early on, to facilitate organisational use, as well as timely and targeted data collection.

*What are the perspectives of municipality officials on the implementation of eHealth interventions for caregivers of people with dementia in their communities? (Chapter 7)*

In Chapter 7, interviews with municipality officials who chose to implement two eHealth interventions for caregivers of people with dementia (Myinlife and Partner in Balance) showed that municipalities were enthusiastic about implementing eHealth in their communities. Across municipalities, they devised similar strategies that centred around involving existing local services, organising face-to-face meetings, and regular project meetings. An important finding was that some municipalities experienced uncertainty about how long the eHealth interventions would continue to be available after the Senior Friendly Communities (SFC) project and how much these interventions would cost in the future. This was considered to be a significant barrier. This finding underscored the importance of considering business modelling and long-term financing of evidence-based eHealth interventions for caregivers of people with dementia, starting from early on in the research process.

*Was the implementation of eHealth interventions for caregivers of people with dementia successful in the municipality context, and why? (Chapter 8)*

Chapter 8 confirmed that there was willingness to implement eHealth interventions for caregivers of people with dementia in the municipality context. The experiences from implementing Myinlife and Partner in Balance suggested that this municipality implementation context was feasible regarding the required infrastructure. The implementation plans suggested in Chapter 7 were mostly carried out as planned. However, not all implementations could be considered successful, and some of the caregiver meetings had to be cancelled due to lack of participants. It seemed that unsuccessful implementations were linked to less implementer self-efficacy and ownership, while these issues seemed less present in successful implementations. Specifically, the findings indicated that there might be insufficient in-person interaction to foster a sense of ownership in the implementing municipalities for Myinlife. For Partner in Balance, implementers often reported a lack of self-efficacy concerning their implementation capabilities. It was decided that future implementations of similar eHealth interventions for caregivers of people with dementia should attempt to tackle these identified challenges with intervention-specific implementation protocols. These should be designed to realise successful implementation for the (Partner in Balance) coaches, the implementation team, and the broader implementing organisation. Important aspects of these new strategies were their emphasis on increasing implementer self-efficacy and providing implementers with tools to monitor and evaluate the implementation. Additionally, it was important to have an internal ambassador safeguard the implementation within the external organisation.

## 3 METHODOLOGICAL CONSIDERATIONS

### 3.1 Strengths

In its endeavour to help bring evidence-based eHealth interventions for caregivers of people with dementia into practice, this thesis boasts several important strengths. First, this research took into account the viewpoints of stakeholders from a broad range of sectors, such as clinicians, dementia case managers, policy makers, research funders, health care organisations managers, municipality officials, industry representatives, and health insurers, as well as people with dementia and their caregivers. Involving people with dementia and their caregivers was especially important, and the incorporation of their perspectives and opinions was safeguarded through regular in-person meetings with the European Working Group for People with Dementia (EWGPWD)<sup>11</sup>, and two consultations with dementia client panels, in Nottingham and in Maastricht.

This thesis also made use of frameworks, theories, and expert opinions from a number of different fields. These include implementation science (the Consolidated Framework for Implementation Research; CFIR)<sup>12</sup> and the Measurement Instrument for Determinants of Innovations (MIDI)<sup>13</sup>, psychological intervention development and evaluation methodologies (the MRC Framework<sup>10</sup>), and business (the BMC<sup>9</sup>). The use of the MRC framework helped this thesis address the need for more rigorous implementation data collection in the research context. The use of the CFIR helped gain insight into the organisational, contextual, and process characteristics of these evidence-based interventions. Finally, the BMC allowed us to examine what could be learned from interventions already being sustainably used in practice, to facilitate the implementation of evidence-based, academically developed eHealth interventions for caregivers of people with dementia.

In order to bring these intersectoral viewpoints to light, this thesis also made use of a variety of mainly qualitative research methodologies (though some quantitative, descriptive statistics were used in Chapters 3, 5, and 8). These included systematic literature review, qualitative surveys, semi-structured qualitative interviews, inductive and deductive thematic analysis, stakeholder analysis, multiple case study analysis, and business model analysis. Finally, the implication section of this chapter provides practical tips and lessons learned, which can help future eHealth developers in the sustainable implementation of their interventions for caregivers of people with dementia.

### 3.2 Limitations

This thesis also has a number of significant limitations. While this research was shaped and improved by its collaboration with the EWGPWD and the dementia client panels, it does not include any interviews with people with dementia or their caregivers. This is

because the aim of this thesis was to map the implementation context and shed light on how these interventions could best be adapted to organisational and contextual implementation needs. As such, we referred to previous research on the development and (process) evaluations of these interventions, as people with dementia and their caregivers were routinely consulted throughout the development and evaluation trajectory to fit the developed interventions to their needs.

This research has shed light on the perspectives of municipality officials on the implementation of eHealth interventions for caregivers of people with dementia in a municipality context. In addition, the implementation of two interventions, Myinlife and Partner in Balance, was evaluated on an organisational level. While this research did gain insight into how many users used the intervention in certain regions, it was not possible to gather more in-depth data on the user experiences, and whether the interventions, when used, achieved similar outcomes to the previous effectiveness studies. For Myinlife, municipalities reported wanting the option to evaluate whether their strategies were effective and the interventions were being used. In general, there was not much data on how the implementation was experienced by the users. This is a result of the fact that these studies took place in the context of the euPrevent SFC project, where data collection was limited to the experiences of municipality implementers. In the future, it would be beneficial to investigate the user experiences in this implementation context in a non-intrusive, low maintenance manner.

Another limitation of this thesis concerns the generalisability of its findings. First, it is possible that our recommendations for implementation are influenced by our own experiences with Myinlife, Partner in Balance, and other eHealth interventions developed at our Alzheimer Centre Limburg, potentially limiting the generalisability of these findings to other types of eHealth interventions for caregivers of people with dementia. Second, it is plausible that our recommendations are specific to the dementia health care context as experienced in the Euregion Meuse-Rhine, as this is where these studies took place. It is possible that these findings are not generalisable to other parts of the Netherlands, Belgium, and Germany (and broader), as the dementia health care context varies between these countries. Indeed, even within the Netherlands, the dementia case management systems differ between regions. Third, across studies, the studied sample size was rather small. This is because the sample size was often determined by the specificity of the studied context and the response rate of the participants. This could also have an effect on the generalisability of these findings.

On a related note, the possibility of a self-selection bias<sup>14</sup> of the participants of the various studies included in this thesis must be considered. The respondents who chose to participate in the surveys and interviews of these thesis, may have been included as a result of their own positive experiences with, or positive pre-existing attitudes towards,

eHealth. This thesis did not actively pursue the experiences of stakeholders who chose not to engage with eHealth. As a result, it is possible that this thesis is based on a sample of respondents who are positively biased towards eHealth and may not be representative of attitudes towards the implementation of eHealth for caregivers of people with dementia of the population at large.

Finally, while this thesis does make a concerted effort to include the perspectives of people with dementia and their caregivers through its collaboration with the EWGPWD and client panels, it must be noted that the education level of members of these groups tends to be high and the average age tends to be low, compared to the dementia (caregiving) population as a whole. As discussed in the following section 'Implications', it is crucial to offer eHealth as an expansion and improvement of existing dementia services, not as a replacement. As with other psychological interventions, the suitability of eHealth for improving outcomes in its clients remains a matter of *What works for whom*<sup>15</sup>. As such, eHealth cannot be expected to be a valid solution for all caregivers of people with dementia, though it is a very promising option to solve certain aspects of issues currently faced by individual caregivers, health care systems, and society as a whole.

## 4 IMPLICATIONS

### **4.1 Consider whether all effective eHealth interventions for caregivers of people with dementia should be implemented into practice**

Chapter 3 found that only 2 out of 12 eHealth interventions included in a systematic review on the effectiveness of eHealth interventions for caregivers of people with dementia were still available to use. This raises an important question: *Should* researchers endeavour to implement all effective eHealth interventions for caregivers of people with dementia into practice?

Previous research on the (lack of) implementation of evidence-based eHealth interventions has decried this failure to implement as a squandering of vast sums of public money, research resources, and a failure to achieve anticipated benefits for the intended users<sup>16</sup>. Indeed, the premise of this thesis seems based on the assumption that all evidence-based eHealth interventions should be implemented into practice.

However, some consideration is needed. A good product is not the same as good clinical practice. Some research has even pointed to adverse effects for users following unsuccessful eHealth implementations<sup>17</sup>. An intervention may be effective in a research context, but without additional information on whether it can sustainably be integrated into the broader health care organisation and policy context, it is very difficult for decision makers to know which interventions will not only be effective, but efficacious. It is also important to note that it is likely that at least some of the interventions studied in Chapter 3 were never meant to be implemented into practice, but rather to acquire knowledge on the topic of eHealth for caregivers of people with dementia. It is true that gathering evidence on the effectiveness of the interventions and their mechanisms is a worthwhile goal in itself, and perhaps not all effective interventions can or should be implemented.

Moreover, when considering whether all effective eHealth interventions for caregivers for people with dementia should be implemented, there are a number of ethical considerations that must be taken into account. First, there are indubitably important privacy and security concerns associated with eHealth<sup>16,18</sup>, and this has also been reported as a concern in dementia and caregiver populations<sup>19</sup>, as well as in Chapters 2, 5, 6, 7, and 8 of this thesis. Especially when examining eHealth interventions with commercial interests, this is an important consideration to weigh against potential benefits for caregivers. These benefits include the potential to alleviate social isolation and encourage the pursuit of meaningful activities<sup>20</sup>. Another possible consequence of eHealth is a potentially changed relationship between care provider, care professional, and caregiver. For this reason, implementation research is even more important, so we can gain insight

into how this could change care and whom these changes would affect. It has been claimed that some eHealth might unfairly benefit users of higher socio-economic status and perpetuate inequalities, as it requires advanced verbal and technological skills, informed access to care services, and specific hardware and software<sup>21</sup>. However, more recent research has pushed back at these claims, and pointed to the emergence and uptake of mobile phone interventions as a mediating factor in making eHealth more accessible throughout society<sup>22</sup>.

So, how will we know which effective eHealth interventions should be implemented, to best benefit those caregivers of people with dementia who wish to use these technologies? Incorporating checkpoints throughout the research process could be one way to assess whether continued implementation makes sense for the eHealth intervention in question. These checkpoints, installed at various crucial decision moments throughout the implementation process, should demarcate distinct *go* or *no-go* moments, where the utility of continuing with the implementation of the intervention is decided. As in this research, previous research has stressed the important of continuous monitoring of eHealth interventions<sup>6</sup>. The Centre for eHealth Research and Disease Management (CeHRes) roadmap also provides a relevant example of a suitable framework for the incorporation of regular checks with stakeholders and potential markets, to ensure optimally adapted eHealth implementation in dementia care<sup>23</sup>. In this regard, it is also important to consider what, exactly, constitutes successful implementation. From a research perspective, an eHealth intervention is successful if it makes a difference in caregiver outcomes. From a commercial perspective, an eHealth interventions is successful if it makes money. Moreover, commercially developed interventions often supply clients with what they like, while academically developed strive to offer clients what they need. These academically developed interventions are based on empirical research and supported with evidence, often both in terms of improving outcomes and in terms of cost-effectiveness. We advocate merging these perspectives and considering both kinds of success continuously throughout the development and implementation process at predefined checkpoints, incorporating perspectives from a variety of fields and backgrounds, and making use of alternative, flexible research designs. In the future, research should attempt to further incorporate these different intersectoral perspectives, as was the objective of this thesis, which took place in the context of the Interdisciplinary Network for Dementia Using Current Technology (INDUCT) project. This project is a relevant example of successful interdisciplinary cooperation and has resulted in many innovative research articles<sup>24-36</sup>, combining perspectives from a variety of backgrounds to improve dementia care through technology.

#### 4.2 Form 'innovation clusters' from the start

These checkpoints should be established from the very start, and the decision-making regarding these checkpoints should involve a carefully selected and expansive group of stakeholders. Recently, there has been more and more recognition of the importance involving people with dementia and their caregivers in the co-design of technology-based interventions<sup>37</sup>. Co-design entails "*the collective creativity as it is applied across the whole span of a design process*" and specifically refers to integrating the creativity of both designers and people not trained in design to cooperate on the design development process<sup>38</sup>. The benefits of involving people with dementia and caregivers in co-design include the development of technologies that are better suited to their needs and that facilitate the pursuit of meaningful activities after a dementia diagnosis<sup>39</sup>. In addition to this feasible and necessary involvement of people with dementia and their caregivers in co-design, previous research has also stressed the importance of involving representatives from the organisational health care context in the co-design of eHealth interventions for caregivers and older adults<sup>40</sup>. In this thesis, we have recommended forming so-called 'innovation clusters' from the start of eHealth interventions' development (Chapters 6 and 8), consisting of a technology developer, research team, intervention provider, and health insurer/other funder. The formation of this innovation cluster can also be seen as a part of co-design, in that it involves the perspectives of non-designers in the development process. Involving these different elements of an innovation cluster, as well as people with dementia and their caregivers, from the beginning through co-design, can inform a more efficient study design, geared at providing stakeholders with the data they need to make informed decisions on future long-term implementation. This thesis advocates the inclusion and utilisation of a range of intersectoral and interdisciplinary perspectives in the innovation cluster, who can collaborate in co-design and provide eHealth interventions for caregivers of people with dementia with crucial implementation information from the get-go.

This formation of innovation clusters also ensures the incorporation of the perspectives and needs of the existing health care implementers into the intervention's development and research designs. This allows for these eHealth interventions for caregivers of people with dementia to be adapted to both the dementia health care context, and the health care system in general. The stakeholder interviews in Chapter 6 underscored the importance of the thorough mapping of this health care implementation context, as the fit of the intervention to this context seems to be a crucial implementation determinant. Indeed, in the case of Partner in Balance, a recurring implementation barrier concerned the matter of whose responsibility it was to pay for the license. Many involved parties will agree that an eHealth intervention for caregivers of people with dementia is a useful and timely tool for an important societal challenge, though believe financing for such an intervention

does not fall under their mandate as an organisation. For instance, municipalities would often say Partner in Balance is considered *treatment* and therefore the health insurers responsibility. Conversely, health insurers would often say that Partner in Balance is considered *prevention*, which is the municipality's responsibility. This was also mentioned as an important barrier by the municipality officials interviewed in Chapter 7. Hence, intervention developers should carefully consider the most practical angle of approach, and make sure these interventions are carefully designed and targeted for the most suitable financiers.

Chapter 4 demonstrated that the creative construction of business models can provide a solution for these financing decision issues encountered in the implementation of eHealth interventions for caregivers of people with dementia. OZOverbindzorg was considered to be a good example of an independent business model for the sustainable implementation of these interventions, as it seems to have found a workable solution to this problem. One reason this model was successful is that it removed part of this financing decision barrier by financing the platform through a collaboration between the municipality and the health insurer, where both parties pay an equal, low price to make the platform available to all inhabitants of their region. However, it is important to note that this solution is specific to the Dutch dementia health care context. Chapter 7 discussed how dementia health care at the municipal level is organised differently in Belgium, the Netherlands, and Germany, and it is not certain that this model would work equally well in other contexts. For example, the Public Centres for Societal Welfare (*Openbare Centra voor Maatschappelijk Welzijn*; OCMWs) in Belgium are organised very differently and have different goals than the Dutch municipalities' Law for Societal Support (*Wet Maatschappelijke Ondersteuning*; WMO) services.

The examples of OZOverbindzorg and Partner in Balance emphasise the importance of using insights from the members of the innovation cluster early on to map preliminary business models for eHealth interventions of caregivers of people with dementia, that fit the local health care context.

### **4.3 Construct flexible and intersectoral research designs**

In eHealth research, the standard method of measuring an intervention's effectiveness has long been the Randomised Controlled Trial (RCT). While the RCT is an established and proven method to gain insight into eHealth effectiveness and mechanisms, they are time and resource intensive and often result in a lack of important, qualitative implementation data<sup>41</sup>. Conversely, this time and resource intensiveness makes it challenging for commercial enterprises to provide evidence of the effectiveness of their interventions. Moreover, eHealth technologies change quickly and eHealth research should not be years behind on

the market. Currently, staying up-to-date with technological advancements is difficult due to the expansive time frame of typical effectiveness studies. One way of developing eHealth interventions that are suitable to implementation when proven effective, is by using more flexible research designs<sup>8</sup>. In combination with the proposed input from co-design through innovation clusters, these novel research designs can result in technologically innovative eHealth interventions for caregivers of people with dementia that can be more easily be evaluated for specific dementia caregiving contexts, and adapted to these contextual needs<sup>8</sup>. Moreover, these alternative, flexible designs could facilitate the implementation of more technologically up-to-date interventions and avoid the longer duration of traditional evaluation methods. This aspect concerning whether the intervention is technologically up-to-date contributes to its desirability and thus affects the entire business model. Therefore, it is also something to be considered at the checkpoints for implementation, recommended above.

Inspiration for methods to evaluate the addition of new functionalities to the eHealth interventions can be gained from industry, where many commercial platforms use real-time evaluations to gain feedback from users. These can include pop-ups, which ask the user to rate their experiences, or the launch of different versions of the same functionality in order to assess which of the two versions is more successful. The inclusion of these methods into research designs can help achieve continuous monitoring and evaluation of eHealth interventions for caregivers of people with dementia.

#### **4.4 Create self-efficacy and ownership within implementing organisations**

This thesis has repeatedly stated that having an effective eHealth intervention for caregivers of people with dementia - even one that has the necessary infrastructural implementation components in place - is not sufficient to guarantee successful implementation (Chapters 3, 5, and 8). Much depends on the attitudes of the implementing organisations towards the eHealth intervention.

Chapter 8 proposed that a sense of ownership of the municipality implementers towards the successful implementation of the interventions was a determinant of successful implementation. It also suggested increasing the self-efficacy of the implementers, both within the municipality and the external implementing organisation, for instance through incorporating role play exercises into Partner in Balance coach trainings. As in previous sections of these implications, the importance of monitoring and evaluating the implementation was underscored for increasing implementer motivation and self-efficacy. This monitoring and evaluating of the interventions can be implemented in two ways. First, setting and achieving implementation goals by monitoring progress could increase motivation and self-efficacy in the organisation's implementing professionals.

Second, by building functionalities into the eHealth intervention for organisational management to evaluate implementation (such as local use statistics), the management of the implementing organisations can better justify the resources spent on the eHealth implementation and increase their ownership of implementation successes and failures.

#### **4.5 Even in eHealth, human interaction remains essential**

In line with these findings on the importance of increasing self-efficacy and ownership, the results of thesis contain the recurring theme of the necessity of continued human interactions in the implementation of eHealth interventions for caregivers of people with dementia. There is often an underlying assumption that eHealth implies a reduction of human contact and increased distance<sup>42</sup>. However, findings from the Myinlife process evaluation (Chapter 5) provided additional support to the existing literature asserting that blended eHealth interventions for caregivers of people with dementia are more effective at improving outcomes for caregivers of people with dementia than non-blended interventions. This was because this study showed that the caregivers required more guidance to optimally use Myinlife, despite it being a 'stand-alone' eHealth intervention. Furthermore, findings from the SFC evaluation study (Chapter 8) raised the question of whether the blended aspect of eHealth might not only result in increased effectiveness due to its effect on caregiver outcomes, but also due to its potential effect of increasing engagement among implementers through the human contact. In this study we saw that the Partner in Balance intervention required more hours to implement in the municipality context than Myinlife, but also that it was more often successfully implemented.

Hence, it is possible that including a blended aspect of the intervention increases ownership of the intervention in implementers. By necessitating the integration of the intervention into an organisational context, the implementers could become more familiar with the intervention, and more invested in its implementation. Moreover, this is in line with findings from the business model study (Chapter 4), where many of the successful eHealth interventions for caregivers of people with dementia reported community creation and management as one of their most important value propositions. This referred to forming and maintaining a community of intervention users, who are in contact with each other through the intervention, which was also mentioned as potentially promising digital implementation strategy for eHealth interventions for caregivers of people with dementia. Furthermore, in Chapter 6 (the Partner in Balance case study) stakeholders described the importance of creating a community around the implementing coaches. As a result, strategies were formulated to make sure that bonds were formed between coaches and structures were put in place for sustainability. Indeed, previous research has mentioned the potential of blended interventions to increase adherence in eHealth interventions<sup>43</sup>, further emphasising the need to keep incorporating human interaction into eHealth.

## 5 FUTURE RESEARCH DIRECTIONS

Overall, this thesis has helped fill the knowledge gap on organisational and contextual implementation determinants for eHealth interventions for caregivers of people with dementia. It also raises interesting questions concerning the continued implementation of these interventions and suggests promising avenues for future research.

### **5.1 Monitoring and evaluating the continued implementation of the interventions within the implementing organisation**

This thesis has shed light on various organisational implementation determinants in a number of contexts, and the needs of the professionals who implement them. However, it was clear that the implementations did not meet the organisations' own need to more comprehensively monitor and evaluate the implementation. In the future, research should investigate the effects of increased monitoring and evaluation of the implementation of the intervention, both through the design and introduction of implementation protocols, as well as through the incorporation of use statistics functionalities into the eHealth platforms.

### **5.2 Drawing inspiration from industry techniques for evaluation and implementation research**

Future research should investigate how methodologies from industry can be applied to the measurement of the efficacy of eHealth interventions for caregivers of people with dementia in the context of continued implementation, post effectiveness trial. This could result in novel, flexible ways of evaluating effectiveness and implementation, potentially providing an alternative to the restrictions and considerable cost of more traditional RCT designs.

### **5.3 Evaluating the relative effectiveness of implementation strategies**

Next, this thesis has proposed a number of promising strategies for the sustainable implementation of eHealth interventions for caregivers of people with dementia, including community creation (Chapter 4), monitoring and evaluating (Chapter 8), inspiration sessions (Chapter 6), and increasing self-efficacy by incorporating role play sessions (Chapter 8). It would be worthwhile to explore the relative effectiveness of these strategies, and compare which strategies are best suited to particular contexts. Using the RE-AIM framework<sup>44</sup>, previous research has compared implementation strategies in the context of an evidence-based, community health care intervention for diabetes<sup>44</sup>. Similar methodologies could be used to compare the effectiveness of the proposed implementation strategies for Partner in Balance, Myinlife, and other eHealth interventions for caregivers of people with dementia.

#### **5.4 Implementing implementation lessons**

Finally, it is important to continue to involve stakeholders in this continued implementation research. After all, these implementation lessons must, in turn, be implemented into practice. Findings on the effectiveness of the various evaluated implementation strategies and the monitoring of the interventions should be discussed, for example in focus groups, consisting of people with dementia, caregivers of people with dementia, policy makers, health insurers, industry representatives, dementia case managers, and other health care organisation implementers. Future research with the stakeholders included in these focus groups can give insight into the practical implications and feasibility of the proposed, evidence-based implementation strategies.

## 6 CONCLUSIONS

This research took an intersectoral approach to exploring the implementation of eHealth interventions for caregivers of people with dementia. In part 1, main findings from previous implementations included the fact that very few academically developed eHealth interventions for caregivers of people with dementia have been implemented into practice, and that early business modelling could facilitate sustainable intervention implementation. In part 2, the main finding from the continued implementations of Myinlife and Partner in Balance was the feasibility of the implementation of eHealth interventions for caregivers of people with dementia in a municipality context. The overarching implications of this thesis were that future developers of eHealth interventions for caregivers of people with dementia should aim to: (1.) consider whether all effective eHealth interventions for caregivers of people with dementia should be implemented into practice, with the use of checkpoints; (2.) form 'innovation clusters' from the start; (3.) construct flexible and intersectoral research designs; (4.) create self-efficacy and ownership within implementing organisations; and (5.) incorporate human interaction into the eHealth implementation. These findings are important, as they will help realise the development and implementation of evidence-based eHealth interventions for caregivers of people with dementia that are better adapted to their financial and organisational contexts. This can potentially lead to a more efficient spending of research resources, allowing these interventions to make a difference to individual caregivers and health care systems at large. In conclusion, there is goodwill from a variety of stakeholders to work together in an intersectoral manner to facilitate the implementation of eHealth interventions for caregivers of people with dementia into clinical practice. However, there is still work to be done in optimising research designs, methods, and measures. Future research should focus on monitoring and evaluating the continued implementation of the interventions within the implementing organisation, drawing inspiration from industry techniques for evaluation and implementation research, evaluating the relative effectiveness of implementation strategies, and implementing these implementation lessons.

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**Summary**

**Nederlandse samenvatting**

**Knowledge valorisation**

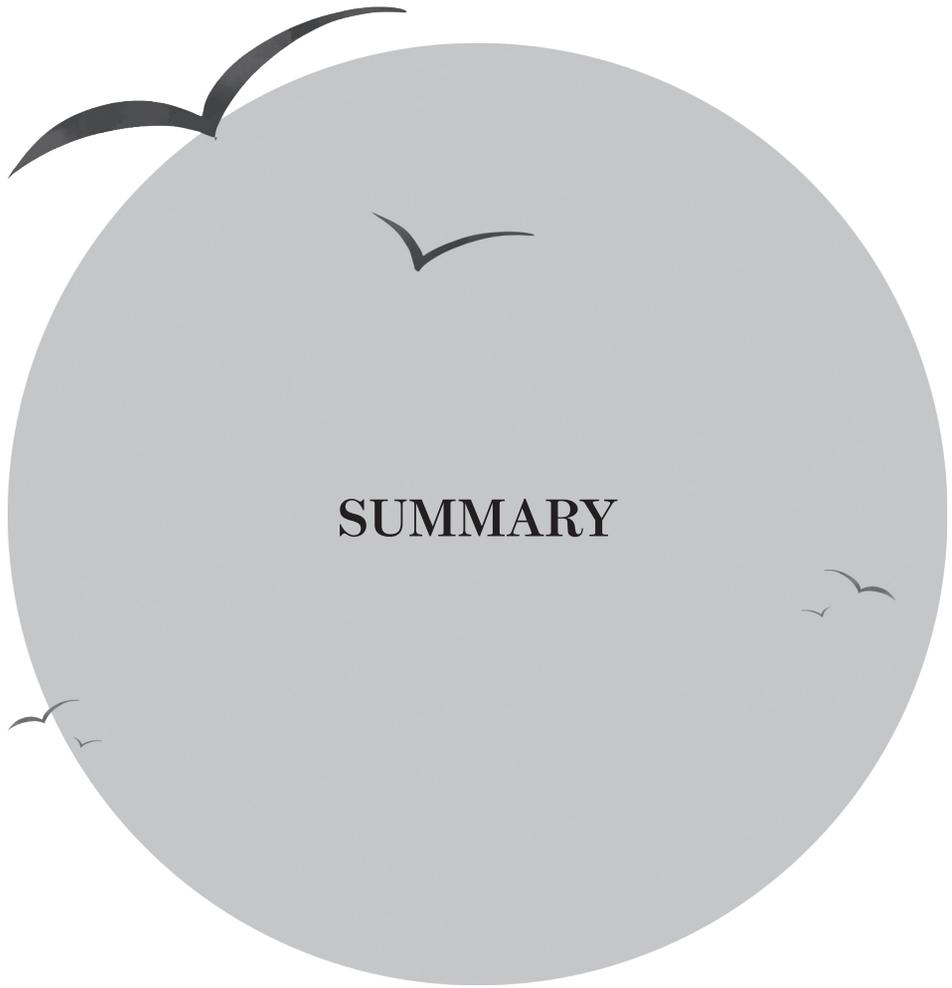
**List of publications**

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**Thesis defences from MHeNs**

**Author information**

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# SUMMARY



## SUMMARY

Informal caregivers play a crucial role in providing high-quality care for people with dementia. While informal caregiving has been shown to have positive effects for some caregivers, such as an enriched relationship with the person with dementia and increased sense of purpose, it has also been shown to pose a significant burden on caregivers' physical and mental well-being. eHealth has the potential to help tackle some of these challenges. Indeed, recent research has shown ample evidence of the effectiveness of eHealth interventions at improving a variety of outcomes for informal caregivers of people with dementia. Unfortunately, very few psychosocial interventions for dementia are translated into practice, and this is also the case for eHealth interventions. This is an important missed opportunity, as the successful implementation of eHealth for caregivers of people with dementia has the potential to improve the efficiency of dementia services, provide continuous care that can be adapted and personalised to the stages of dementia, and avoid the squandering of public money and research resources by realising the intended benefits of eHealth for dementia caregivers.

Hence, the main aim of this thesis was to gain insight into the factors that influence the implementation of eHealth interventions for caregivers of people with dementia. To accomplish this, this thesis explores this topic in two parts. A general introduction is provided in **Chapter 1**.

*The first part of this thesis describes the lessons learned from previous implementations of eHealth interventions for caregivers of people with dementia.*

The systematic literature review described in **Chapter 2** produced two main findings. First, implementation research on eHealth interventions for caregivers of people with dementia was still in its infancy. Second, it appeared there was a mismatch between the focus of established implementation frameworks and the focus of current research into eHealth interventions for caregivers of people with dementia.

In **Chapter 3**, the implementation trajectories of 12 eHealth interventions for caregivers of people with dementia that had been included in a previous systematic review were explored. A first important finding was that 10 out of 12 included interventions were no longer available to use. The long-term implementation of the two available interventions was achieved through long-term aid from an external funding body. This underscored the fact that there is no clear pathway to acquire the funding necessary to market and implement effective eHealth interventions for dementia caregivers into practice

**Chapter 4** explored how lessons from eHealth interventions for dementia caregiving that were already being used in practice, could be applied to facilitate the implementation of similar interventions from academia. This resulted in the proposal of a core model of eHealth interventions for caregivers of people with dementia. This model's design specified the value of integrating the eHealth intervention into larger structures, owning and supporting content internally while outsourcing information and communication technology (ICT) services, and which offering fixed, low-level pricing. This study also underscored the importance of the origin of the intervention, as case studies that had originated in an academic research context less often found their way to sustainable implementation.

*The second part of this thesis describes the lessons learned from the continued implementation of two eHealth interventions for caregivers of people with dementia: Myinlife and Partner in Balance*

In **Chapter 5**, a process evaluation was conducted to gain insight into the factors influencing the implementation of Myinlife, an online platform to help caregivers of people with dementia organise informal care. The main finding from this study was that this 'ready-made' eHealth intervention required more structural and organisational support to reach caregivers of people with dementia, as well as face-to-face contact, to ensure optimal use.

**Chapter 6** was a case study of the implementation of Partner in Balance, a blended care intervention to support caregivers of people with dementia. This study used experiences from real-life pilots and qualitative interviews with national stakeholders to establish an implementation plan, consisting of implementation strategies and a business model. The main finding from this Partner in Balance case study that can be applied to future interventions, is the importance of forming innovation clusters early on, to facilitate organisational use, as well as timely and targeted data collection.

In **Chapter 7**, interviews with municipality officials who chose to implement two eHealth interventions for caregivers of people with dementia (Myinlife and Partner in Balance) showed that municipalities were enthusiastic about implementing eHealth in their communities. An important finding was that some municipalities experienced the uncertainty around the continuing availability and future cost of the interventions as a significant barrier. This underscored the importance of considering business modelling and long-term financing of evidence-based eHealth interventions for caregivers of people with dementia, starting from early on in the research process.

**Chapter 8** was an evaluation of the implementation of Myinlife and Partner in Balance in the municipality context. The findings showed that not all implementations could be considered successful, and that unsuccessful implementations were linked to less implementer self-efficacy and ownership. Specifically, the findings indicated that there might have been insufficient in-person interaction to foster a sense of ownership in the implementing municipalities for Myinlife. For Partner in Balance, implementers often reported a lack of self- efficacy concerning their implementation capabilities. It was decided that future implementations of similar eHealth interventions for caregivers of people with dementia should attempt to tackle these identified challenges with intervention-specific implementation protocols.

In **Chapter 9**, the main findings are discussed, together with methodological considerations, implications, and recommendations for future research.

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SAMENVATTING**



# NEDERLANDSE SAMENVATTING

Mantelzorgers spelen een cruciale rol bij het verlenen van hoogwaardige zorg aan mensen met dementie. Hoewel is aangetoond dat informele zorgverlening voor sommige mantelzorgers positieve effecten heeft, zoals een verrijkte relatie met de persoon met dementie en een verhoogd betekenisgevoel, is ook aangetoond dat het een aanzienlijke belasting vormt voor het fysieke en mentale welzijn van de mantelzorgers. eHealth heeft het potentieel om een aantal van deze uitdagingen aan te pakken. Recent onderzoek heeft aangetoond dat eHealth-interventies de mogelijkheid hebben om verschillende uitkomsten voor mantelzorgers van mensen met dementie te verbeteren. Helaas worden zeer weinig psychosociale interventies voor dementie in de praktijk vertaald, en dit geldt ook voor eHealth-interventies. Dit is een belangrijke gemiste kans, aangezien de succesvolle implementatie van eHealth voor mantelzorgers van mensen met dementie het potentieel heeft om de efficiëntie van dementiediensten te verbeteren, continue zorg te bieden die kan worden aangepast en gepersonaliseerd naar het dementiestadium, en om verspilling van overheidsgeld en onderzoeksmiddelen te vermijden door de beoogde voordelen van eHealth voor mantelzorgers te realiseren.

Het hoofddoel van dit proefschrift was om inzicht te krijgen in de factoren die van invloed zijn op de implementatie van eHealth-interventies voor mantelzorgers van mensen met dementie. Om dit te bewerkstelligen, heeft dit proefschrift dit onderwerp onderzocht in twee delen. **Hoofdstuk 1** bevat een algemene inleiding.

*Het eerste deel van dit proefschrift beschrijft de lessen die zijn getrokken uit eerdere implementaties van eHealth-interventies voor mantelzorgers van mensen met dementie.*

Het systematische literatuuronderzoek beschreven in **Hoofdstuk 2** leverde twee belangrijke bevindingen op. Ten eerste stond implementatieonderzoek naar eHealth-interventies voor mantelzorgers van mensen met dementie nog in de kinderschoenen. Ten tweede bleek er een mismatch te zijn tussen de focus van gevestigde implementatiekaders en de focus van huidig onderzoek naar eHealth-interventies voor mantelzorgers van mensen met dementie.

In **Hoofdstuk 3** werden de implementatietrajecten van 12 eHealth-interventies voor mantelzorgers van mensen met dementie onderzocht die in een eerdere systematische review waren opgenomen. Een eerste belangrijke bevinding was dat 10 van de 12 opgenomen interventies niet meer beschikbaar waren voor gebruik. De uitvoering op lange termijn van de twee beschikbare interventies werd bereikt door middel van langdurige steun van een externe financieringsinstantie. Dit onderstreepte het feit dat er geen duidelijk pad is om de financiering te verwerven die nodig is om effectieve eHealth-interventies voor dementiemantelzorgers op de markt te brengen en in de praktijk te brengen.

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**Hoofdstuk 4** onderzocht hoe lessen over eHealth-interventies voor dementiezorg die al in de praktijk werden gebruikt, konden worden toegepast om de implementatie van vergelijkbare interventies van academische origine te vergemakkelijken. Dit resulteerde in het voorstel van een kernmodel van eHealth-interventies voor mantelzorgers van mensen met dementie. Het ontwerp van dit model specificeerde de waarde van het integreren van de eHealth-interventie in grotere structuren, het intern bezitten en ondersteunen van de inhoud, terwijl informatie- en communicatietechnologie (ICT)-diensten worden uitbesteed, en het bieden van vaste, lage prijzen. Deze studie onderstreepte ook het belang van de oorsprong van de interventie, aangezien case study's die hun oorsprong hadden in een academische onderzoekscontext minder vaak de weg vonden naar duurzame implementatie.

*Het tweede deel van dit proefschrift beschrijft de lessen die zijn getrokken uit de voortdurende implementatie van twee eHealth-interventies voor mantelzorgers van mensen met dementie: Myinlife en Partner in Balance*

In **Hoofdstuk 5** werd een procesevaluatie uitgevoerd om inzicht te krijgen in de factoren die van invloed zijn op de implementatie van Myinlife, een online platform om mantelzorgers van mensen met dementie informele zorg te helpen organiseren. De belangrijkste bevinding uit deze studie was dat deze 'kant-en-klare' eHealth-interventie meer structurele en organisatorische ondersteuning vereiste om mantelzorgers van mensen met dementie te bereiken, evenals persoonlijk contact, om een optimaal gebruik te garanderen.

**Hoofdstuk 6** was een case study van de implementatie van Partner in Balance, een 'blended care' interventie ter ondersteuning van mantelzorgers van mensen met dementie. In deze studie werd gebruik gemaakt van ervaringen van pilots en kwalitatieve interviews met nationale stakeholders om een implementatieplan op te stellen, bestaande uit implementatiestrategieën en een bedrijfsmodel. De belangrijkste bevinding van deze Partner in Balance case study die kan worden toegepast op toekomstige interventies, is het belang van het vroegtijdig vormen van innovatieclusters om het gebruik binnen de organisatie te vergemakkelijken, evenals tijdige en gerichte gegevensverzameling.

In **Hoofdstuk 7** lieten interviews met gemeente-ambtenaren die ervoor kozen twee eHealth-interventies te implementeren voor mantelzorgers van mensen met dementie (Myinlife en Partner in Balance), zien dat gemeenten enthousiast waren over het implementeren van eHealth in hun gemeentes. Een belangrijke bevinding was dat sommige gemeenten de onzekerheid rond de continue beschikbaarheid en toekomstige kosten van de interventies als een belangrijke barrière ervaarden. Dit onderstreepte het belang van het overwegen van bedrijfsmodellering en langetermijnfinanciering van evidence-based eHealth-interventies voor mantelzorgers van mensen met dementie, al vroeg in het onderzoeksproces.

**Hoofdstuk 8** was een evaluatie van de implementatie van Myinlife en Partner in Balance in de gemeentelijke context. De bevindingen toonden aan dat niet alle implementaties als succesvol konden worden beschouwd en dat niet-succesvolle implementaties verband hielden met minder zelfeffectiviteit en eigenaarschap van de implementeerder. De bevindingen gaven met name aan dat er mogelijk onvoldoende persoonlijke interactie is om een gevoel van eigenaarschap te bevorderen in de uitvoerende gemeenten voor Myinlife. Voor Partner in Balance rapporteerden implementeerders vaak een gebrek aan zelfeffectiviteit met betrekking tot hun implementatiemogelijkheden. Er werd besloten dat toekomstige implementaties van soortgelijke eHealth-interventies voor mantelzorgers van mensen met dementie zouden moeten proberen deze geïdentificeerde uitdagingen aan te pakken met interventiespecifieke implementatieprotocollen.

In **Hoofdstuk 9** worden de belangrijkste bevindingen besproken, samen met methodologische overwegingen, implicaties en aanbevelingen voor toekomstig onderzoek.

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**KNOWLEDGE  
VALORISATION**



# KNOWLEDGE VALORISATION

The main aim of this thesis was to gain insight into the factors that influence the implementation of eHealth interventions for caregivers of people with dementia. In this valorisation paragraph, we describe how the obtained knowledge from our research can be put into practice for clinical and societal use.

## **Societal relevance**

Approximately 9.1 million people are currently living with dementia in EU member states. The total number of people living with dementia in Europe has been predicted to rise by about 60%, and is expected to reach 14.3 million by the year 2040. The Council of the European Union has recognized that dementia is one of the major causes of disability and dependency among older adults, as well as its considerable impact on physical, psychological, social, and economic outcomes for people with dementia, their informal caregivers, and society at large. In particular, research has drawn attention to dementia care's reliance on informal care (also known as unpaid care or family care) and its effects on informal caregivers.

Recent research has shown that eHealth, can significantly improve outcomes for caregivers of people with dementia. In general, the advantages of eHealth interventions include easy personalisation, fast delivery, and real-time feedback. In the context of today's ageing population and society's increasing reliance on informal caregiving, eHealth is an especially suitable tool. In this regard, benefits include the potential of eHealth to widen service access to more remote areas, lower thresholds to participation, improve service efficiency, and reduce costs. eHealth interventions also offer dementia-specific advantages, as they can be personalised and adapted to the progressing stages of dementia, offer caregivers psychoeducation without requiring them to leave the person with dementia home alone, and provide support without facing the stigma often present with a dementia diagnosis.

Unfortunately, previous research has shown that only 3% of psychosocial interventions for caregivers of people with dementia are implemented into practice. This was confirmed to also be the case specifically for eHealth interventions for caregivers of people with dementia. The studies described in this thesis provide insight into the lessons that can be learned from previous successful and unsuccessful implementations of eHealth interventions to support caregivers of people with dementia. In addition, these studies describe lessons from the continued implementation of eHealth interventions for caregivers of people with dementia, providing relevant use cases and shedding light on the specific implementation context of the local municipality.

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### **Target audience**

The findings described in this thesis are relevant for caregivers of people with dementia, researchers, dementia health care professionals, health insurers, funders, and policy makers.

Insight into the factors that influence the implementation of eHealth interventions for caregivers of people with dementia can help increase the previously described low implementation rate in order to provide the intended benefits for caregivers of people with dementia. While often rewarding and enriching, the informal caregiving experience for a person with dementia has also been shown to have considerable negative effects on caregivers, such as chronic stress, caregiver overburdening, depression, anxiety, social isolation, financial burden, and disturbed sleep. Given eHealth's proven effects on caregiver self-efficacy and dementia caregiving knowledge, as well as the reduction of symptoms of depression and anxiety, the findings of this thesis are especially relevant for caregivers of people with dementia, as they stand to benefit the most from these interventions becoming sustainably available to them.

Next, this thesis described a number of important implications for the development and implementation of evidence-based eHealth interventions for caregivers of people with dementia, which are especially relevant to researchers in the field of eHealth (and dementia). These include the incorporation of checkpoints, innovation clusters, and flexible research designs into eHealth research.

Furthermore, dementia health care professionals will find this thesis' recommendations for organisational implementation relevant to them. In particular, the findings concerning the need to create self-efficacy and ownership, as well as the suggestions concerning continuous monitoring and feedback of the interventions within the health care organisations can be of added value in this setting.

Finally, health insurers, funders, and policy makers are included in the target audience of this thesis. This is because the included studies' insights concerning the most successful implementation trajectories and business models, protocols for optimal organisational implementation, perspectives on eHealth from a wide variety of intersectoral stakeholders, and the obtained process data can help inform a more efficient allocation of public money and health care resources.

### **Activities and products**

As a result of the thorough implementation research of this thesis, the eHealth interventions Partner in Balance and Myinlife were able to evolve from research projects to sustainable products. These research activities included stakeholder interviews, business modelling,

and context mapping. This research has resulted in the sustainable scaling-up of these interventions, and provided content for much-needed implementation protocols, which will now be a part of Myinlife and Partner in Balance's standard implementation packages for both municipalities and health care organisations.

The findings from this research were presented at several international scientific conferences and symposia, as well as at various dementia caregiver meetings, client panels, and Alzheimer Cafés. Moreover this project has been featured through several media channels, such as on UK Health Radio's dementia show 'The D-Word', the Alzheimer Europe twitter account, the Alzheimer Nederland website ([www.dementie.nl](http://www.dementie.nl)) and the Belgian young onset dementia website ([www.jongdementie.nl](http://www.jongdementie.nl)), RTZ Z television show '*De Barometer*', and as an enduring part of the euPrevent Senior Friendly Communities project.

### **Innovation and implementation**

This project's first study, the systematic review, indicated that there was an important knowledge gap concerning the implementation of eHealth interventions for caregivers of people with dementia. This thesis made use of an innovative combination of intersectoral frameworks (from implementation science, psychological interventions development, and business) and methods (systematic literature review, qualitative surveys, semi-structured qualitative interviews, inductive and deductive thematic analysis, stakeholder analysis, multiple case study analysis, and business model analysis) to help fill this gap with insights on the organisational and contextual implementation determinants of eHealth interventions for caregivers of people with dementia.

This project resulted in both the practical implementation of two eHealth interventions for caregivers of people with dementia (Partner in Balance and Myinlife) on a larger scale, as well as more generalisable eHealth implementation insights, which are useful for a variety of dementia stakeholders. The process findings from this implementation research are also proving valuable in providing more context to research funding applications for Partner in Balance, and constitute a more solid evidence base for these applications. Here, we would like to reiterate the importance of operationalising the implementation of these implementation lessons. Findings on the effectiveness of the implementation strategies and the monitoring of the interventions should be discussed further by stakeholders, for example in focus groups.

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**LIST OF  
PUBLICATIONS**



## LIST OF PUBLICATIONS

### Thesis

Christie, H. L., Boots, L. M. M., Peetoom, K., Tange, H. J., Verhey, F. R. J., & de Vugt, M. E. (2020). Developing a Plan for the Sustainable Implementation of an Electronic Health Intervention (Partner in Balance) to Support Caregivers of People With Dementia: Case Study. *JMIR Aging*, 3(1), e18624. <https://doi.org/10.2196/18624>

Christie, H. L., Schichel, M., Tange, H. J., Verhey, F. J., & de Vugt, M. E. (2020) Perspectives From Municipality Officials on the Adoption, Dissemination, and Implementation of Electronic Health Interventions to Support Caregivers of People With Dementia: Inductive Thematic Analysis. *JMIR Aging*, 3(1): e17255. <https://doi.org/10.2196/preprints.17255>

Christie, H. L., Martin, J. L., Connor, J., Tange, H. J., Verhey, F. R., de Vugt, M. E., & Orrell, M. (2019). eHealth interventions to support caregivers of people with dementia may be proven effective, but are they implementation-ready? *Internet Interventions*, 100260. <https://doi.org/10.1016/j.invent.2019.100260>

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Christie, H. L., Bartels, S. L., Boots, L. M., Tange, H. J., Verhey, F. J., & de Vugt, M. E. (2018). A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia. *Internet interventions*. 13, 51-59. <https://doi.org/10.1016/j.invent.2018.07.002>

### Other

Gruters, A. A. A., Christie, H. L., Ramakers, I. H., Verhey, F. R., Kessels, R. P., & de Vugt, M. E. (2020). Neuropsychological assessment and diagnostic disclosure at a memory clinic: A qualitative study of the experiences of patients and their family members. *The Clinical Neuropsychologist*, 1-17. <https://doi.org/10.1080/13854046.2020.1749936>

Christie, H.L. et al. (2020). "Results" in Veenstra M.Y. & van der Zanden, B. (ed.) *Building and sustaining a senior-friendly community movement*. p. 14-15. ISBN 978-94-6380-710-4.

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**DANKWOORD  
(ACKNOWLEDGEMENTS)**



## DANKWOORD (ACKNOWLEDGEMENTS)

*"The flower that blooms in adversity is the most rare and beautiful of all."*

To my parents: This PhD would never have been possible without the two of you. Mom, there aren't words to express how thankful I am for everything you've taught and given me. From you, I learned to be fearless about believing in myself and reaching for the stars. You have given me the self-confidence and skills to chase my dreams, and I am so grateful for everything you have done to support me. Dad, I could not have done this PhD without your support, be it in the form of our emotional eating, gin-tonic dashes, research talks, or car-crying sessions (mostly me). Thank you for understanding that we can't all be *acupuncturists*. To my siblings: Nelly, Cian, Oisín (and baby Ollie). Thank you all for putting up with my near-constant quoting of the all-time Disney classic masterpiece 'Mulan' (including the not-so-sneaky ones throughout this paragraph) and helping bring the family honour. Nelly, you are the best sister I ever could have asked for. Thanks for your creative direction, fashion advice, and sisterly affection. Our epic South-Korea adventure was one of the brightest highlights from this time and I'm ecstatic we were able to do this during my PhD. Cian and Oisín, thanks for being so Gucci. Fancy a pint, mates? Áine, thank you for the emotional support and for teaching me to not let the truth get in the way of a good story. Robert, thank you for the good talks, good wine, and very good times together.

*"Home is where the heart is"*

De drie vriendinnen waar ik opeenvolgend de laatste vier jaren een (t)huis mee heb mogen delen: Sara, Line en Louise.

Sara, where to begin? We have told the story of our forging a Hunger Games alliance at breakfast on the morning of our INDUCT interviews in London so many times, I'm sure it needs no repeating. If I had not had you as a fellow ESR, this PhD might not exist. From our first (slightly worried) fries in Maastricht, to watching the sun set on the beaches of Japan; from our single life shenanigans at home, to finding love away on secondment; from watching hours and hours of Netflix in the *Maagdenries*, to partying in Copenhagen, Cologne, Glasgow, Brussels, Madrid, Chicago, Tokyo and so many other places: You have been an integral and unmissable part of this PhD and I wouldn't trade these last four years with you for anything. Thank you for your unbelievable kindness, your unwavering willingness to help and support, your enormous heart, and your eternal optimism.

Line, je hebt met je stralende energie, plezier voor het leven, grenzeloze empathie en gevoel voor humor mijn leven helemaal opgefleurd. Ik voelde me nergens meer begrepen dan bij jou in onze tijd samen in de Mosalunet. Bedankt om er altijd voor me te zijn en me een beter persoon te maken door je mooie, authentieke zelf te zijn.

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Louise, ik ben zo blij dat we samen in Brussel wonen. Ons droomappartement in de Rue Marcq, de talloze RuPaul avonden, de vele *geravede* kilometers, onze gesprekken over eHealth, ongelijkheid, securitisation, late-stage capitalism, de vergrijzing, *Keeping up with the Kardashians* en het snijden van groenten, hebben afgelopen jaar echt een topjaar voor mij gemaakt. Bedankt voor al je lieve hulp met mijn doctoraat, je schitterende woordenschat en al de knuffels. Ik kijk zo uit naar onze komende avonturen samen in BXL.

*"Good friends are like stars - You don't always see them, but you know they are there."*

Mijn PhD is (relatief) stressloos kunnen verlopen omdat er zoveel mensen mij hebben doen lachen en plezier hebben. Mijn allerliefste rosies, Smannie, Pom, Jane, Trap, Eef, Sab en Lou (again). Mijn topvriendinnen, de Glasgow meisjes: Messie, Kaatie, Line (again) en Caro. De prachtige Sangria girls: Lena, Elissa, Sophie, Jolien en Marie. De Heel Straffe Klasuitstap Vriendjes: Anoes, Nick, Niels, Kobe en Daan. Diane, thank you for the beautiful emails, kind words, unwavering support, and fun times. Dank aan Ana en Liesl, topvriendinnen! Amira and Kamillah, thanks for the laughs, memes, parties, and good vibes. Quinten, thanks for introducing me to Amira and Kamillah (and also for being a true, smart, and hilarious friend).

*"I knew exactly what to do. But, in a much more real sense, I had no idea what to do."*

Graag wil ik ook alle collega's van het hele Alzheimer Centrum Limburg bedanken. De sfeer was altijd top en zo belangrijk in het me goed voelen op het werk. Er zijn zoveel mensen die deze Belg thuis hebben doen voelen. In het bijzonder wil ik mijn paranimf Linda bedanken. Wat hebben we gelachen en vooral gebabbeld. Angelique en Anouk, dank voor de superlieve sfeer in de kamer en de goede gesprekken. Olin, Leonie, Annemarie, Bert, Liselot: bedankt voor alle leuke momenten. Nikos, Niels, Mignon: Thanks for all the great coffee times. Aan het PiB team, Jeroen, Ela, Kirsten, Elles, Maud, Esther, Lizzy, Marjolein, Bram, Rob, en Liselot (again), bedankt om bij te dragen aan zo'n leuk groepsgevoel bij het implementeren van zoiets nieuws en uitdagends. Het was nooit een opgave, maar altijd een spannende uitdaging. Ik ben trots op ons. Dank aan mijn voorgangers: Joany, Rosalie, Alieske en Lizzy. Jullie harde werk heeft mijn PhD mede mogelijk gemaakt en ik ben zo dankbaar voor al jullie hulp en tips.

To my fellow INDUCT ESRs: Sara (again), Harleen, Martina, Aline, Sebastien, Yvette, Sophie, Sarah, Floriana, Angel, Joeke, Angie, Kate, Kim, Rose, and Annelien. We did it! This has been such a special experience, and being able to share it with such kind, smart, and interesting people from across the world is something I'll cherish and remember for the rest of my life. I also want to express my gratitude for the support of Inge, Fania, Deborah, Niels, and Orii, as well as to everyone who made INDUCT possible, including Professors Martin Orrell and Rose-Marie Dröes.

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*"The researcher's art is first of all to find himself a good boss"*

Lizzy, dankjewel voor de leuke babbels, je topbegeleiding en je altijd enthousiaste aanmoediging. Je bent een heel groot voorbeeld voor mij. Ik heb superveel gehad aan en jou en al je hulp bij mijn onderzoek. Daarnaast hebben we ook veel kunnen lachen samen. Mijn PhD zou zeker veel minder leuk geweest zijn zonder jou. Ik heb heel veel aan jou (en aan Partner in Balans) te danken. Ik kijk er heel erg naar uit om samen als postdocs te blijven genieten van het bespreken van onderzoek en Netflix (meestal door elkaar).

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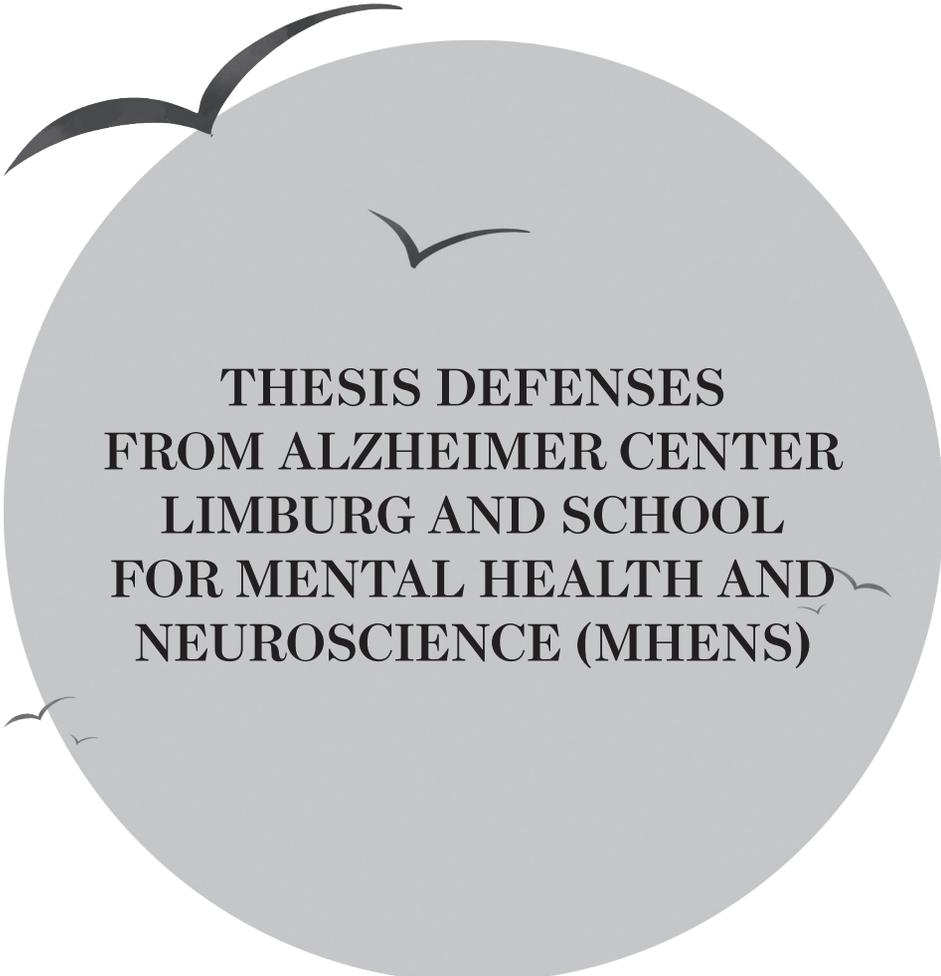
Frans, ik ben zo dankbaar voor alle kansen die je mij gegeven hebt. Bedankt om altijd in mij te geloven, en ook om het welbevinden van je PhDs altijd eerst te zetten. Ik heb het geluk gehad om mijn PhD in een heel ondersteunende, warme omgeving te kunnen doen, en dat is voor een groot deel dankzij de moeite die jij doet om het Alzheimer Centrum Limburg te vormen tot zo'n soort plek. Ik heb me bij jou altijd heel begrepen gevoeld, maar ook uitgedaagd en aangemoedigd om alles wat mij interesseerde te proberen doen. Dankjewel voor de uitstekende begeleiding, op onderzoeksvlak en op persoonlijk vlak.

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**THESIS DEFENSES  
FROM ALZHEIMER CENTER  
LIMBURG AND SCHOOL  
FOR MENTAL HEALTH AND  
NEUROSCIENCE (MHENS)**



# THESIS DEFENSES FROM ALZHEIMER CENTER LIMBURG AND SCHOOL FOR MENTAL HEALTH AND NEUROSCIENCE (MHENS)

2019

Jans van Ool. **Diagnostic and neuropsychiatric considerations in epilepsy and intellectual disability; Psychological perspectives.** Supervisor: Prof.dr. A. Aldenkamp. Co-supervisors: Dr. J. Hendriksen; Dr. H. Schelhaas, Kempenhaeghe.

Eveline Janssen. **Depression in the elderly: focus on high risk groups.** Supervisors: Prof.dr. F. Verhey; Prof.dr. M. de Vugt. Co-supervisor: Dr. M. Schram.

Cécile Kicken. **Extreme blood coagulation; investigating the influence of physiological extremes on thrombin generation and platelet activation.** Supervisor: Prof.dr. W. Buhre Co-supervisors: Dr. B. de Laet; Dr. M. Lancé, Qatar.

Martinus van Eerd. **Diagnosis and Interventional Pain Treatment of Cervical Facet Joint Pain.** Supervisor: Prof.dr. M. van Kleef. Co-supervisor; Dr. J. Patijn, Eindhoven; Dr. M. Sommer.

Chenxing E. Zhang. **Novel insights in the pathophysiology of cerebral small vessel disease – a study using advanced imaging techniques.** Supervisors: Prof. dr. R.J. van Oostenbrugge; Prof.dr.ir. W.H. Backes; Co-supervisor: dr. J. Staals.

Ivo Eijkenboom. **A zebrafish model of small-fiber neuropathy.** Supervisors: Prof.dr. H.J.M. Smeets; Prof.dr. C.G. Faber; Co-supervisor: dr. J. Vanoevelen.

Bianca de Greef. **Small fiber neuropathy: from underlying conditions to treatment.** Supervisor: Prof.dr. C.A. Faber; Co-supervisor: Dr. I.S.J. Merkies; Dr. J.G.J. Hoeijmakers.

Lotte Berk. **MINDFULNESS AND AGING: Exploring Mechanisms and Interventions.** Supervisors: Prof.dr. J. van Os; Prof.dr. M.W. de Vugt; Co-supervisor: dr. M.P.J. van Boxtel.

Mor Dickman. **Practice patterns and outcomes of corneal transplantation.** Supervisor: Prof.dr. R.M.M.A. Nuijts; Co-supervisors: Dr. T.J.M. Berendschot; dr. F.J.H.M. van den Biggelaar.

Thyagi Ponnampereuma. **Mental Health Problems in Sri Lankan Adolescents Exposed to the Tsunami and Other Traumatic Events.** Supervisor: Prof.dr. M.W. De Vries; Co-supervisor: Dr. N.A. Nicolson.

Robbert C. Maatman. **Anterior cutaneous nerve entrapment syndrome (acnes): an analysis of various subtypes and**

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**alternative treatment modalities.**

Supervisor: Prof.dr. M. van Kleef; Co-supervisors: Dr. R.M.H. Roumen, dr. M.R.M. Scheltinga.

**Mari Elshout. Neovascular Age-Related Macular Degeneration in the Era of Value-Based Health Care.**

Supervisor: Prof.dr. C.A.B. Webers; Co-supervisor: Dr. J.S.A.G. Schouten.

**Jeroen Deenik. Thinking inside the box; Changing lifestyle to improve the health status of inpatients with severe mental illness.**

Supervisor: Prof.dr. P.N. Harten; Co-supervisors: Dr. D.E. Tenback; dr. I.J.M. Hendriksen.

**Thomas Draak. Peripheral Neuropathy outcome measures Standardisation (PeriNomS) study part 3: Capturing the Patient's Voice.**

Supervisor: Prof.dr. C.G. Faber; Co-supervisor: Dr. I.S.J. Merckies.

**Ana Luisa Gil Martínez. Neuroprotection in neurodegenerative processes associated with Parkinsonism and aging. Correlation between dopaminergic neuronal death and glial activation.**

Supervisor: Prof.dr. H.W.M. Steinbusch, Prof.dr. Maria-Trinidad Herrero Ezquerro, University of Murcia.

**Bernice J.A. Gulpers. Anxiety in older adults; Correlates, comorbidities and prognosis with lifespan perspectives.**

Supervisor: Prof.dr. F.R.J. Verhey, Prof.dr. R.C. Oude Voshaar; Co-supervisor: Dr. S. Köhler.

**Elke Devocht. Combining a cochlear implant and a hearing aid in opposite ears: The best of both worlds.**

Supervisor: prof.dr. H. Kingma; co-supervisor: dr. E.I.J. George.

**Gillian Townend. Rett Syndrome: Recognising the Communication Challenges, Needs and Potential of Individuals Living with a Rare Disease.**

Supervisor: Prof.dr. L.M.G. Curfs; co-supervisor: Dr. P.B. Marschik, Med. University of Graz, Austria.

**Takashi Koizumi. Genetic and neuroinflammatory components of familial and sporadic cerebral Small Vessel Disease.**

Supervisor: Prof.dr. H. Steinbusch, Prof.dr. T. Mizuno, Japan; co-supervisor: Dr. S. Foulquier.

**Muhammad Ali. Integrative network-based approaches for modelling Human disease.**

Supervisor: Prof.dr. J. Kleinjans; co-supervisor: Dr. D. van den Hove; Dr. E. Pishva.

**Guillaume Durand. The adaptive side of psychopathy. Investigating adaptive characteristics associated with the psychopathic personality.**

Supervisor: Prof.dr. B. Rutten; co-supervisor: Dr J. Lobbestael.

**Darius C. Henatsch. Honey: A Novel Treatment in Chronic Ear Infections.**

Supervisor: Prof.dr. R.J. Stokroos; UMC Utrecht/UM; co-supervisor: Dr. J.J. Briedé.

Reinhilde J. Melles. **Vaginal penetration: pain or pleasure? The role of fear and sexual arousal.** Supervisor: Prof.dr. M.L. Peters; co-supervisor: Dr. M. ter Kuile, LUMC, Dr. M. Dewitte.

Raul Felipe Abella Antón. **Cardiac Surgery Biochemical Monitoring in Congenital Heart Diseases Infants.** Supervisors: Prof. dr. D. Gazzolo, Prof. dr. L.J.I. Zimmermann, Prof. dr. J.S.H. Vles, co-supervisor; Dr. A.W.D. Gavilanes.

Francesca M. Snoeijen-Schouwenaars. **Diagnostic, neuropsychiatric and therapeutic considerations in epilepsy and intellectual disability – medical perspectives –.** Supervisor: prof.dr. A.P. Aldenkamp, co-supervisors: Dr. H.J. Schelhaas, SEIN Zwolle; dr. J.G.M. Hendriksen, Kempnaheghe, Heeze.

Mariëlle H.J. Pruppers. **Peripheral Neuropathies: Standardizing Functional Assessment.** Supervisors: prof.dr. C.G. Faber; prof.dr. N.C. Notermans, UU; Dr. I.S.J. Merkies, ius promovendi.

Shenghua Zong. Autoantibodies in disorders of the brain: expanding the spectrum. Supervisor: prof.dr. P. Marinez; co-supervisor: dr. M. Losen; dr. R. Rouhl.

Jan-Willem Kallewaard. **Diagnosis and minimally invasive treatment of chronic discogenic low back pain.** Supervisor: prof.dr. M. van Kleef; co-supervisors: prof. dr. H. van Santbrink; dr. P. Willems.

Simone M. Crivelli. **Sphingolipid metabolism in the pathophysiology and treatment of Alzheimer's disease.** Supervisors: prof.dr. P. Martinez-Martinez; prof.dr. E. de Vries, VUmc. Co-supervisors: dr. M. Losen; dr. M. Mulder, Rotterdam.

Natasha Pahuja. **Etiopathogenesis, advanced imaging and treatment outcomes in Asian Indians with keratoconus.** Supervisor: prof.dr. R. Nuijts, co-supervisor: dr. R. Shetty, Bengaluru.

Pooja Khamar Mayur Raksha. **Clinical, Molecular and Biomechanical outcomes of SMILE (small incision lenticule extraction) and other refractive surgery techniques.** Supervisor: prof.dr. R. Nuijts, co-supervisor: dr. R. Shetty, Bengaluru.

Niels Janssen. **Patterns and pathways. Indicators for potential improvements of dementia care.** Supervisors: prof.dr. F. Verhey; prof.dr.mr. S. Evers; Co-supervisor: dr. R. Handels.

Giovanni Mansueto. **Childhood adversities and Psychosis: investigation of the potential aetio-pathogenetic mechanisms.** Supervisor: prof.dr. K. Schruers; co-supervisors: prof.dr. F. Cosci, University of Florence, It; prof.dr. R. van Winkel, KU Leuven.

Joke Debruyne. **Cochlear implantation in adults with early-onset deafness.** Supervisors: prof.dr. B. Kremer; prof.dr.ir. T. Francart, KU Leuven; Co-supervisor: dr.ir. J. Brokx.

Koenraad Meuwissen, **Burst Spinal Cord Stimulation in a Rat Model of Chronic Neuropathic Pain: Spinal and Supraspinal Mechanisms**. Supervisors: prof. dr. E.A.J. Joosten; prof. dr. M. van Kleef.

Lisa Schmiedek, **Episodic memory in ageing and AD: a possible target for electrical stimulation ?** Supervisors: prof. dr. F.R.J. Verhey; prof. dr. A.T. Sack; co-supervisor: dr. H.I.L. Jacobs

Paolo Maino, **Implantable Intrathecal Drug Delivery in Treatment of Chronic Intractable Pain and Spasticity: Improvement of Safety and the Use of Imaging Techniques**. Supervisors: prof. dr. E.A. Joosten; prof. dr. M. van Kleef.

José Geurts, **Chronic Pain; Impact of Chronic Pain on a Societal, Personal, and Treatment Level**. Supervisors: prof. dr. C.D. Dirksen; prof. dr. M. van Kleef; co-supervisor: dr. P.C. Willems.

Brigitte Brouwer, **Painful Small Fiber Neuropathy; Symptoms, assessments and interventions**. Supervisor: prof. dr. C.F. Faber; co-supervisors: dr. I.S.J. Merkies, Willemstad, Curaçao; dr. J.G.J. Hoeijmakers.

Ruth Gussenhoven, **Antenatal inflammatory insults and preterm brain injury: Pathophysiology and therapeutic strategies**. Supervisors: prof. dr. B.W. Kramer; prof. dr. L.J.I. Zimmermann; Dr. T.G.A.M. Wolffs.

Adriana (Janine) Collet, **Specific Care on the Interface of Mental health and Nursing home "SpeCIMeN"**. Supervisors: prof. dr. M.E. de Vugt; prof. dr. J.M.G.A. Schols; Prof. dr. F.R.J. Verhey.

Fares Nigim, **Glioblastoma and Meningioma Biology, Targeted Therapy and Oncolytic Virus Therapy**. Supervisors: prof. dr. Y. Temel; prof. dr. S.D. Rabkin, Harvard; co-supervisors: dr. H. Wakimoto, Harvard; dr. L. Ackermans.

Leonie Banning, **Neuropsychiatric symptoms in Alzheimer's disease; Associations with biomarkers**. Supervisor: prof. dr. F.R.J. Verhey; co-supervisors: dr. P. Aalten; Dr. I.H.G.B. Ramakers.

Johan Haumann, **Prevalence and pharmacological treatment of pain in patients with cancer; The role of opioids with and without NMDA receptor affinity**. Supervisor: prof. dr. E.A. Joosten; co-supervisors: Prof. dr. M.H.J. van den Beuken-van Everdingen; dr.

S.M.J. Van Kuijk, Joost Riphagen, **Vascular matters in aging and dementia**. Supervisor: prof. dr. F.R.J. Verhey; co-supervisor: Dr. H.I.L. Jacobs.

Nikos Priovoulos, **Structural and functional imaging of the locus coeruleus at 7T: from methodological to clinical application**. Supervisor: prof. dr. F.R.J. Verhey; co-supervisors: Dr. H.I.L. Jacobs; dr. B.A. Poser.

Simone Verhagen, **The power of individual landscapes; A clinical exploration of personal experience sampling and new horizons.** Supervisors: prof.dr. P.A.E.G. Delespaul; prof.dr. J.J. van Os, UM/UU; co-supervisor: dr. C.J.P. Simons.

Nagy Youssef, **Epigenetics, resilience and brain stimulation: advances in the mechanistic and therapeutic utility in patients with affective (PTSD and mood) disorders.** Supervisor: Prof.dr. B.P.F. Rutten; co-supervisor: Prof. dr. P. Sienaert, KU Leuven.

Abhishek Appaji, **Retinal vascular features as a biomarker for psychiatric disorders.** Supervisor: Prof. Dr. C.A.B. Webers; co-supervisor: Dr. T.T.J.M. Berendschot, Dr. Naren P. Rao.

Koos Hovinga, **Angiogenesis Inhibition in Glioblastoma.** Supervisor: prof. dr. Y. Temel; co-supervisor: Prof. V. Tabar, New York, USA.

Gerhard Drenthen, **Myelin and networks, Magnetic Resonance Imaging in Epilepsy.** Supervisors: prof.dr.ir. W.H. Backes; Prof.dr. A.P. Aldenkamp; co-supervisor: dr. J.F.A. Jansen.

Anna Gorlova, **Understanding the Molecular Mechanisms of Aggression in BALB/C and TPH2-Deficient Mice.** Supervisor: prof.dr. K. Lesch, Universitätsklinikum Würzburg, co-supervisors: dr. T. Strekalova; prof.dr. L. Bettendorff, University of Liège.

Ekaterina Veniaminova, **The impact of the 'Western Diet' on Emotional, Social and Cognitive Behaviours as revealed by a study on conventional and serotonin Transporter-Deficient Mice.** Supervisor: prof.dr. K. Lesch, Universitätsklinikum Würzburg, co-supervisors: dr. T. Strekalova; prof. D.C. Anthony, Oxford.

Dmitrii Pavlov, **The contribution of CNS inflammation and Glycogen Synthase Kinase-3 (GSK-3)-cascades on adverse memory learning on mouse models of emotional stress.** Supervisor: prof.dr. K. Lesch, Universitätsklinikum Würzburg, co-supervisors: dr. T. Strekalova; prof.dr. L. Bettendorff, University of Liège.

Eric Fonseca Wald, **Absence Epilepsy and Panayiotopoulos Syndrome: Neurocognition and Brain Development.** Supervisor: prof.dr. R.J. Vermeulen; co-supervisors: Dr. S. Klinkenberg; dr. M.J.A. Debeij-van Hall; Dr. J.G.M. Hendriksen, Epilepsiecentrum Kempenhaeghe.

Kimberley S. Noij, **Cervical vestibular evoked myogenic potentials; Toward optimizing clinical use.** Supervisors: prof.dr. H. Kingma; prof. S.D. Rauch, MD,Massachusetts Eye and Ear, Harvard; co-supervisor: Dr. R. van de Berg.

Mark J. van Tilburg, **Advancement in cVEMP's.** Supervisors: prof.dr. H. Kingma; prof.dr. S. Rauch, Harvard; co-supervisors: dr. R. van de Berg; dr. B. Herrmann, Boston.

Nalini Atcharayam, **Duchenne Muscular Dystrophy: The NIMHANS Experience.**  
Supervisors: prof.dr. T. Delhaas; prof.dr. B.W. Kramer.

Murat L Atagün, **Cognitive neurophysiology and neurochemistry in bipolar disorder.** Supervisor: Prof. Dr.

Therese van Amelsvoort; co-supervisors: Dr. Sinan Guloksuz; Dr. Marian Drukker.

**Thesis defences from MHeNs from previous years can be found via the following link:** <https://mhens.mumc.maastrichtuniversity.nl/node/14680>



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**AUTHOR  
INFORMATION**



## AUTHOR INFORMATION



Hannah Christie was born on 17 May 1993 in Newark, Delaware (U.S.A.) to British-Belgian parents. At the age of nine she moved to Leuven, Belgium, where she entered the Belgian school system. In 2011 she graduated from the Heilig Hartinstituut in Heverlee and started her Bachelor's degree in Psychology at the KU Leuven. In her third year she participated in an Erasmus exchange program to the University of Glasgow in Scotland.

Hannah completed this bachelor's degree (Cum Laude) in 2014 and subsequently commenced a two-year Master's degree in Clinical and Health Psychology, which she completed in 2016 (Magna Cum Laude). In the final year of her Master's degree, Hannah carried out a year-long clinical internship in the Old-Age Psychiatry Department at the University Psychiatric Centre KU Leuven, where she also conducted a research project on late-onset psychosis. Additionally, Hannah wrote a Master's thesis on the relationship between congenital prosopagnosia and facing bias. In 2016 she moved to the Netherlands, to start her PhD at the department of Psychiatry and Neuropsychology at Maastricht University. This PhD took place as part of INDUCT (Interdisciplinary Network for Dementia Using Current Technology) H2020 Marie Skłodowska-Curie Innovative Training Networks, and as such included two secondments. The first secondment was to Mindtech at the University of Nottingham (United Kingdom, while the second was to the SME Betawerk (Heerlen, the Netherlands). Hannah currently lives in Brussels, Belgium.

Hannah Christie werd geboren op 17 mei 1993 in Newark, Delaware (VS), als dochter van Brits-Belgische ouders. Op negenjarige leeftijd verhuisde ze naar Leuven, België, waar ze het Belgische schoolsysteem intrad. In 2011 studeerde ze af aan het Heilig Hartinstituut in Heverlee en begon ze haar bachelor studie in de Psychologie aan de KU Leuven. In haar derde jaar nam ze deel aan een Erasmus-uitwisselingsprogramma naar de Universiteit van Glasgow in Schotland. Hannah voltooide deze bacheloropleiding (Cum Laude) in 2014 en begon vervolgens aan een tweejarige master in de Klinische en Gezondheidspsychologie, die ze in 2016 voltooide (Magna Cum Laude). In het laatste jaar van haar Masteropleiding heeft Hannah een jaar lang klinische stage gelopen bij de afdeling Ouderenspsychiatrie aan het Universitair Psychiatrisch Centrum KU Leuven, waar ze ook een onderzoeksproject heeft uitgevoerd rond laat-ontstane psychose. Daarnaast schreef Hannah een masterscriptie over de relatie tussen aangeboren prosopagnosie en *facing bias* werd onderzocht. In 2016 verhuisde ze naar Nederland om te promoveren op de afdeling Psychiatrie en Neuropsychologie aan de Universiteit Maastricht. Deze PhD vond plaats als onderdeel van INDUCT (*Interdisciplinary Network*

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*for Dementia Using Current Technology*) H2020 Marie Skłodowska-Curie Innovative Training Networks en omvatte daarom twee *secondments*. De eerste *secondment* was vond plaats bij Mindtech aan de Universiteit van Nottingham (Verenigd Koninkrijk), de tweede bij Betawerk (Heerlen, Nederland). Hannah woont momenteel in Brussel, België.