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Dissertation submitted in fulfilment of the requirements to obtain the degree of PhD in  
Medical Sciences

# **SUPPORTING PEOPLE WITH DEMENTIA AND THEIR FAMILY IN ADVANCE CARE PLANNING:**

## **THE INNOVATIVE USE OF TECHNOLOGY**

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**MEMENTO MORI.**



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## **LIST OF ABBREVIATIONS**

ACP = Advance Care Planning

EMA = Ecological Monetary Assessment

ICT = Information And Communication Technology

MRC = Medical Research Council

PPI = Patient and Public Involvement

## LIST OF CHAPTERS

Chapters 1-6 in parts one and two of this thesis are based on the following publications:

### *Chapter 1*

**Dupont C**, Smets T, Monnet F, Pivodic L, De Vleminck A, Van Audenhove C, Van den Block L. Publicly Available, Interactive Web-Based Tools to Support Advance Care Planning: Systematic Review. *J Med Internet Res* 2022 Apr 20;24(4):e33320. doi: 10.2196/33320

### *Chapter 2*

**Dupont C**, Smets T, Monnet F, Pivodic L, De Vleminck A, Van Audenhove C, Van Den Block L. Defining the content of a website on advance care planning in dementia: a focus group study with family and health professionals. *BMC Med Inform Decis Mak* 2023 Nov 8;23(1):254. doi: 10.1186/s12911-023-02359-1

### *Chapter 3*

**Dupont C**, Smets T, Monnet F, Eneslätt M, Tishelman C, Van den Block L. The cultural adaptation of the go wish card game for use in Flanders, Belgium: a public health tool to identify and discuss end-of-life preferences. *BMC Public Health* 2022 Nov 17;22(1):2110. doi: 10.1186/s12889-022-14523-9

### *Chapter 4*

**Dupont C**, Monnet F, Pivodic L, Vleminck AD, Audenhove CV, Van Den Block L, Smets T. Evaluating an advance care planning website for people with dementia and their caregivers: Protocol for a mixed method study. *DIGITAL HEALTH* 2023 Jan;9:20552076231197021. doi: 10.1177/20552076231197021

### *Chapter 5*

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### *Chapter 6*

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## **PART 1      GENERAL INTRODUCTION**



# GENERAL INTRODUCTION

*General background, aims and study objectives, and outline of the dissertation.*

## 1. GENERAL BACKGROUND

### 1.1 DEMENTIA

Dementia is a syndrome referring to a progressive cognitive decline (1). It is an overarching term to describe symptoms affecting memory, thinking, and social abilities that are severe enough to affect daily life and independence that are not part of normal ageing (1,2). Dementia is anticipated to become the leading cause of serious health-related suffering, with an expected 264% increase between 2016 and 2060 (3). It is estimated that at the moment, 55 million people live with dementia, which will probably double every 20 years, reaching 150 million by 2050 (4). In 2019, the global societal costs of dementia were 1313.4 billion dollars, including direct medical costs like medication or diagnostics tests and the cost of family members caring for the person with dementia, e.g. informal care (5). Currently, there is no cure for dementia, but medications and treatment can help to slow down or manage dementia symptoms (6). Globally, dementia is the seventh leading cause of death and has become one of the leading causes of death in Belgium (7).

Dementia is caused by changes in or damage to the brain, and the clinical presentation varies (8). Common symptoms are (short-term) memory loss, difficulties in speaking or communicating thoughts, hallucinating, acting impulsively, taking longer to complete daily tasks, or getting lost in familiar areas (8,9). Dementia is an overarching term to describe a set of symptoms, with Alzheimer's being the most known and common cause of dementia (60-80%), followed by vascular dementia (9). Though age is the most prominent recognised risk factor for dementia, it does not exclusively affect older people, with 3.9 million people between 30 and 64 years living with young or early-onset dementia (9). Over the last decade, many more risk factors have been identified, like family history, gender, and ethnicity. Nevertheless, most identified risk factors for dementia can be reduced by not smoking, eating a healthy diet, being physically active, and maintaining a healthy blood pressure (6).

Given the progressive nature of dementia, dementia is often classified into three main stages: early, moderate, and severe. To better understand the various stages of dementia, there are also scales with a more comprehensive description of the progressive impact of dementia on

cognitive and physical abilities. The “Reisberg Scale” or “Global Deterioration Scale for Assessment of Primary Degenerative Dementia” (GDS) is one of the most well-known scales (10–12). In the GDS, dementia is classified into seven stages based on a patient's cognitive decline. In stage 1, there is no cognitive decline. Stage 2 is very mild cognitive decline, for example, forgetting names and misplacing objectives. In the third stage, there is mild cognitive decline – not yet dementia - with difficulties concentrating, a decrease in work performance and getting lost more frequently. In stage 4 – early stage dementia – symptoms may be difficulties travelling alone to new places, managing finances, and completing tasks. Stage 5 is mid-stage with moderately severe cognitive decline, for example, not knowing the time and date, and stage 6 is severe cognitive decline where patients forget recent events and experience incontinence. The last stage, stage 7, is a very severe cognitive decline or late dementia, where patients need help with most daily activities like eating and personal hygiene (11,12).

### ***Dying with dementia***

Though dementia is a progressive, life-limiting disease and patients with dementia have complex needs, not every patient with dementia dies from dementia. The course of dementia is difficult to predict, and the median survival period after diagnosis considerably varies across studies, from one to twelve years (13,14). The trajectory of dementia is progressive, with acute events impacting the health of the person with dementia (15). People with dementia may experience infections, falls, or deliriums, which can cause a rapid decline in their health (16). Some people with dementia spend a significant amount of time in the advanced stage of dementia (17). However, many people with dementia do not experience an advanced stage of dementia and die earlier from other diseases (18,19)

## **1.2 PALLIATIVE CARE IN DEMENTIA**

The World Health Organization defines palliative care as: *“an approach that improves the quality of life of patients (adults and children) and their families facing problems associated with a life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”* (20). Palliative care, recognised as a human right, focuses on relieving pain and symptoms and improving the quality of life of patients and families (20,21). According to the 2014 resolution of the World Health Organization, palliative care should be integrated into primary, secondary, tertiary, and quaternary levels of care (20).

Research has suggested that palliative care benefits patients with serious illness, including people with dementia and their families (22–24). It improves the quality of life for patients and their families, lowers the burden on family caregivers and can help to manage or reduce mental and physical distress (22–24). Furthermore, pain, depression, and spiritual suffering can be managed more effectively, and patients and their families experience greater happiness (25–27). A propensity-matched decedent cohort study on nationwide administrative databases in Belgium (2010-2015) showed that early implementation of palliative home care improved the quality of end-of-life care for people with dementia and reduced the risk of inappropriate treatments, surgeries, and hospitalisations (28). Additionally, it showed potential cost savings, reflecting reduced direct medical costs in the last month of life (28).

Despite accumulating evidence suggesting its potential benefits in improving outcomes, people with dementia are still an underserved group when it comes to receiving palliative care (29). A nationwide administrative database study in Belgium (2010-2015) revealed that 23.8% received palliative home care support during the last two years of life. Of those, 30.5% were initiated within 14 days before death (28).

### 1.3 ADVANCE CARE PLANNING

Advance care planning (ACP) has been identified as a central domain of optimal palliative care in dementia (30). It has been defined in multiple ways over the past decades. In 2017, supported by the European Association for Palliative Care, ACP was defined as a process that: *“enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals’ concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences so that their preferences can be taken into account should they, at some point, be unable to make their own decisions”* (31). ACP can serve as a vital tool to identify the patient's preferences and goals, ensuring that the care provided is in accordance with their values throughout the illness journey and facilitate timely access to palliative care (32,33).

First mentioned by Luis Kutner in 1969, the concept of ACP has changed considerably over the last 50 decades (34–36). The concept of ACP emerged from developing laws regulating end-of-life treatments via advance directives (36). In the 1960s, such advance directives aimed to allow people to state their wishes for medical treatment and care in advance if they could not communicate their needs at a certain moment (36). Though introduced to empower patients' rights, it became clear that advance directives alone had little impact on end-of-life decision-making and the quality of end-of-life care (36). The SUPPORT trial, a large-scale controlled trial conducted between 1989 and 1994 to improve care for seriously ill hospitalised patients, showed the advance directives did not enhance communication between the physician and patient or decision-making about resuscitation (37). Hence, from that time onwards, the importance of advance care planning as an ongoing communication process has been emphasised (34–36). It has been repeated ever since, stressing that ACP is an ongoing communication process between the patient, family, and healthcare professional. Nevertheless, it appears challenging to implement in practice, and many information campaigns, websites or leaflets about ACP still focus on written documentation (i.e., advance directives). A recent study evaluating the information on the websites of dementia Associations in Europe showed that, if the information on ACP was available, it mainly focused on legal, financial, and medical topics, stressing the completing advance directives (38).

### ***New approaches to ACP: need for supporting patients and families beyond the medical context***

A recent systematic review of the public knowledge on ACP showed that ACP is often misunderstood, with misconceptions about its scope and purpose (39). The review found a lack of knowledge, low awareness, and ongoing confusion in the general population about ACP and a reluctance to discuss ACP because of the fear of discussing topics related to death and dying (39). Interestingly, despite their limited knowledge of ACP, individuals tend to discuss ACP with their family and friends. Some studies observed that some individuals had more conversations with their families about ACP than with healthcare professionals (39). This underscores that ACP goes beyond the medical context, an idea also recognised by the public health or health-promoting approaches to palliative care and ACP.

Authors advocating for a public health approach to ACP stress the importance of normalising conversations about end-of-life preferences, death, and dying and underline the need to support conversations in the family context (40,41). They also highlight the need to change

and normalise how we make decisions by reframing ACP as a health-promoting activity through public education and engagement (40). Abel et al. (2020) argue that ACP should shift more toward a social focus on “what matters most to people” rather than the current emphasis on end-of-life decision-making and treatments (41). Instead of solely discussing end-of-life decisions or the location of death – as is often done within the medical context – ACP should start by exploring values and the broader aspects of life. According to the authors, the choice to receive care and die at home or in a familiar setting is driven by the significance of relationships and places (41). These important aspects should be at the core of ACP conversations, focusing on the positive impact of relationships with family and friends and the importance of familiar surroundings (41). Such fundamental discussions could create a foundation that could lead to other important considerations, such as treatment preferences and preferred places of death within the professional context (41). Moreover, by beginning with discussions about values, other aspects of ACP can be approached more naturally and openly, creating more accessible and more relevant ACP conversations, and improving ACP uptake (41). These ideas are congruent with recent studies among people with dementia and their families. People with young-onset dementia and their family caregivers underlined, in a recent qualitative study by Rickstal (2022), the importance of discussing “*what matters now and in the future*”, including non-medical aspects of care within ACP (42).

The most recent definitions of ACP also emphasise the importance of engaging in conversations about values and personal preferences. In the ACP definition supported by the European Association for Palliative Care, it is recommended that ACP is “*person-centred*”, can be initiated “*within or outside of health-care settings*”, and includes “*the exploration of the individual’s health-related experiences, knowledge, concerns, and personal values across the physical, psychological, social, and spiritual domains*” and “*exploring goals for future care*”. This need for a holistic, flexible, and relational communication process is also emphasised by people with dementia and their families (42).

Important to mention is that, in our view, the public health approach to ACP is not a matter of choosing between “ACP within the medical context – versus ACP in the family context”, as both are complementary. However, it is notable that a significant proportion of the existing literature focuses on supporting ACP in the medical context (43–46). At the same time, there is relatively limited guidance in supporting ACP in the family context. In this dissertation, we

aim to address this gap by explicitly aiming to support people with dementia and their family caregivers in the ACP process i.e. by providing information, resources, and guidance in ACP.

### ***Regulatory context of advance care planning in Belgium***

In Belgium, ACP occurs in a regulatory and medical context (47). In 2002, Belgium enacted three laws providing a legal foundation for ACP: legislation to enhance patients' rights, the right to palliative care, and the regulations governing euthanasia (47,48). These laws give patients the right to receive quality care that meets their needs, to be informed about their health condition and its likely progression, regardless of potential treatments, and to consent to or refuse treatment, even if it could be life-saving (47,48). Several advance directives have been established, including an instructional advance directive that allows people to legally refuse treatment or medical interventions. In addition, to request euthanasia, Belgian law permits the use of an advance directive in cases of irreversible coma. The law also foresees a cascade procedure concerning the proxy decision maker in ACP (47,48). The cascade establishes an order of precedence regarding representation. If no representative is present at the higher level, can or wants to be the proxy, the representation shifts to a “lower level”. The cascade arrangement consists of the following levels: the cohabiting partner (factual - does not need to be registered), an adult child, a parent, or an adult sibling. If there is no representative or in case of conflict, the physician acts as the patient's proxy (47,48).

In recent years, policy efforts have been made to promote ACP. In nursing homes, quality indicators have been implemented to improve the quality of palliative care. One of the quality indicators is related to ACP, e.g., the number of residents with an “up-to-date plan for end-of-life care” (49). Additionally, since September 2022, a reimbursement regulation has been implemented to compensate family physicians for the time they spend on ACP. This initiative seeks to enable family physicians to discuss ACP with their patients and share the preferences expressed by the patient with other health professionals involved in the patient's care (47,48). The extent to which these recent developments will positively impact ACP in practice remains to be studied.

## **1.4 ADVANCE CARE PLANNING IN DEMENTIA**

In dementia, the pace of cognitive decline can vary significantly (1). Initiating discussions about future care, treatment, and end-of-life preferences early in the dementia trajectory seems crucial considering the gradual cognitive deterioration (50–52). While dementia progresses slowly over the years and can entail a relatively long trajectory of cognitive



decline, there comes a point when people with dementia may lose their capacity to make decisions (53). This often leaves family caregivers in the position of making (medical) decisions on their behalf, mainly when the person with dementia is in a more advanced stage (29). Therefore, early initiation of ACP in dementia is strongly encouraged. ACP is intended to help prepare for the unpredictable course of the disease and support family caregivers for their crucial role in the decision-making process (54).

An umbrella review (2020) summarising quantitative and qualitative evidence on ACP in dementia concluded that ACP interventions were associated with increased completion of ACP documentation and improved concordance between care and formulated wishes of the person with dementia (52). The review also highlighted reductions in hospitalisation rates and increased satisfaction with care, both from the perspective of person with dementia and their family caregiver (52).

Despite most academics and practitioners agreeing on the importance of ACP in dementia, the uptake of ACP in dementia is still relatively low, as it is estimated that less than 40% of people with dementia engage in ACP (55,56). According to a systematic review examining the adoption of ACP in various life-limiting illnesses, people with dementia are considerably less likely to have engaged in ACP compared to those with conditions such as cancer (57). In a 2012 nationwide study involving GPs in Belgium, 10.8% of patients with dementia who died had been assigned a proxy decision maker. In 7.8% of cases, the GP knew of the treatment preferences of the patients with dementia who passed away (58). A 2017 cross-sectional retrospective survey of GPs in Belgium, Italy, and Spain that examined patients aged 65 and older who passed away (2009-2011) and had dementia (according to the GP) found that knowledge of patient preferences for end-of-life care was limited (59). A more recent study (2022) in The Netherlands found that, based on 15,493 electronic records of people with dementia, ACP was initiated 22 times per 1,000 person-years of follow-up, i.e. only in 801 persons, ACP conversations were recorded during 26,809 person-years (60). 80,3% of the time, it was a one-time conversation (60).

### ***Barriers to advance care planning in dementia***

Research has identified various challenges associated with advance care planning in dementia. Qualitative research found that people with dementia often struggle to acknowledge the end of life and their possible future needs. Planning for the future concerning property and financial affairs was viewed as straightforward by people with

dementia and their families. However, discussing topics related to the end of life was found to be more challenging (42,56,61). People with dementia and their family caregivers were often reluctant to “think in advance” because of the complexity and uncertainty of the future (52,56,62). In Sellars et al. (2019) systematic review, it was found that people with dementia and their families felt that they had not been given enough information about the course of dementia and treatment options and emphasised the need for education (56). While some people with dementia and their families actively choose not to participate in ACP because they find the deterioration caused by dementia too frightening (56), others wanted to engage in ACP but felt they did not find the right time to start ACP (56). Although participants were uncertain about “the right time,” they generally believed that immediately after the diagnosis was inappropriate. They felt they needed time to come to terms with the diagnosis before introducing ACP (56). Another barrier people with dementia and family caregivers experienced was the lack of knowledge (56). Their concerns included an insufficient understanding of available ACP resources, uncertainty about who should initiate ACP, and how to start conversations about ACP (56,63).

### ***Facilitators to advance care planning in dementia***

Three reviews have identified the most cited facilitators to initiate ACP in the dementia (52,56,64). The need to tailor the approach and timing of ACP discussions to suit the unique needs of people with dementia and their caregivers is stressed in these reviews (52,56,64). Supporting the perceived lack of knowledge on ACP and what it can achieve can facilitate ACP. Moreover, training and education in ACP for healthcare professionals, people with dementia and family caregivers was perceived as very important (52,56,64).

Flexibility in recognising the appropriate moment for ACP discussions is crucial, considering factors like understanding the diagnosis and the decision-making capacity (52,56,64). The willingness of people with dementia and their family carers to engage in ACP is unique, as well as between couples. According to the authors of the reviews, understanding these differences is vital to successfully initiate ACP (52,56,64). Regarding who initiates ACP, healthcare professionals were commonly seen by people with dementia and their families as the most suitable initiators of ACP conversations (52,56,64). Conversations at home are an underestimated facilitator in ACP, as they provide insight into lifelong wishes and preferences, guiding the decision-making process (65).

### 1.5 THE USE OF ICT IN DEMENTIA AND ADVANCE CARE PLANNING

It has been argued that interactive web-based tools such as websites or apps can help support ACP within families (66). Web-based tools can be accessed at any time and location and can offer tailored content to meet the specific needs of users. This can be particularly helpful for people with dementia and their caregivers as their circumstances change throughout the disease (56).

The introduction of information and communication technology (ICT) has revolutionised our daily lives. ICT tools like computers, tablets, smartphones, and smartwatches aim to provide safety, services, comfort, and entertainment. Especially in dementia, such tools may help them to live independently, monitor symptoms, train memory or can be used just for leisure. ICT has been described as:

*“a diverse set of technological tools and resources used to transmit, store, create, share or exchange information. These technological tools and resources include computers, the Internet (websites, blogs and emails), live broadcasting technologies (radio, television and webcasting), recorded broadcasting technologies (podcasting, audio and video players, and storage devices) and telephony (fixed or mobile, satellite, video-conferencing, etc.) (67).”*

Electronic health or eHealth refers to the adoption of ICT in healthcare. eHealth has many benefits, such as facilitating information exchange through electronic patient records, enhancing access to care, potentially reducing costs, and improving patient awareness of their conditions, fostering their involvement in their own care (68–76).

Recent research has shown that eHealth can aid in disease management by monitoring disease progression, personalised medicine, and social and leisure activity support, leading to improved health outcomes (68–76). ICT tools can support communication and prompt conversations by serving as “ice breakers” to initiate conversations between the person with dementia and their family (77–79). A recent systematic review by Hoel et al. (2021) on technology-driven tools, such as web-based tools or robots for people with dementia, found that these tools can facilitate interactions and increase the frequency of these interactions (79). According to family caregivers, these tools can help to understand the person with dementia better and enhance the connection between people with dementia and their families. (79). ICT tools can also benefit a better understanding of the person with dementia by sharing memories to strengthen connectedness and help to trigger memories that can

enhance communication (80,81). Lastly, ICT tools to promote communication can also support family caregivers. The stress and feelings of disconnection caregivers may experience because of the progressive decline in communication can be reduced by tools that prompt topics to be discussed (79,82).

### ***Barriers and facilitators to uptake of ICT in dementia***

ICT can benefit people with dementia and their caregivers; however, their uptake and optimal use are sometimes complex because of several barriers. For example, people may experience stress and anxiety when using new technology, causing avoidance of usage (83). Moreover, digital literacy, or the competence to use technology, can challenge technology uptake (84). Another barrier is the timing of implementation. Preferably, tools should be introduced in the earliest stages of dementia and sometimes even before the diagnosis of dementia (83). In a study by Arntzen et al. on assistive technology use with people living with young-onset dementia, the introduction of tools was most successful when they were introduced early and corresponded with daily routines (83).

These barriers may lead to digital exclusion, which is particularly pertinent in the context of dementia. Digital exclusion refers to the lack of access to or ability of using technology (84). In the case of dementia, people may face additional challenges due to cognitive impairments that affect their ability to understand and use technology (84). Memory loss, problems with orientation, and difficulty in learning new skills can further contribute to digital exclusion among people with dementia. Addressing these barriers through tailored support, education, and an accessible design of the web-based tool can help minimize digital exclusion (83).

Moreover, to improve the inclusion, uptake and implementation of new ICT tools, the involvement of stakeholders is essential (85). Not only people living with dementia and their family caregivers but also healthcare professionals, IT professionals, management of services, and other support staff, such as cleaning staff, are stakeholders that impact implementation (86). Another significant facilitator is the ease of use of the tools themselves. Overly complex technology seems to be the least successful in incorporating technology into people's lives (86). Additionally, cultural relevance influences perceived usefulness, and acceptance may differ based on nationality, spiritual and religious beliefs, language, and setting (87).

To support the usage of ICT, tools should be personalised and tailored to the needs of people with dementia and their families (88–90). Involving people with dementia and their family caregivers with a user-centred approach can lead to a better understanding of the target group, supporting the development of more meaningful and appropriate ICT tools (91,92). A user-centred approach aims to build tools to meet the needs and requirements of the envisaged users (93). The users and their usability feedback are at the core of the development. The users will see, try, and evaluate the prototype of the tool. The feedback is used to modify the tool, and the subsequent testing rounds are organised until the tool is ready (94). However, co-designing research with people living with dementia, where they are equal collaborators rather than just research participants, is still relatively rare (95).

### ***ICT tools to support advance care planning***

ICT can play a valuable role in facilitating and supporting ACP. In the late nineties, Dexter et al. evaluated computer-generated prompts to remind physicians to increase completion rates of advance directives (66,96). Later, research showed that these reminders alone were not increasing completion rates, but when patients were also reminded of ACP via email, completion rates rose (97). Advances in ICT have led to the development of secure electronic databases that enable people to store, retrieve and send advance directives from any location. These electronic databases often allow people to complete a basic advance directive and include information about the legal status of advance directives and the possibilities of a proxy (66,98).

More recently, these places to store or create advance directives have been broadened to prepare people's decisions about future care, treatment and end-of-life wishes, as ACP involves much more than focusing on advance directives alone. Websites and applications provide educational material about ACP, including the legal frameworks, a description of what ACP is, its benefits and how to complete advance directives (98). Though most of these websites are developed by hospitals and non-profit organisations like patient associations, some commercial sites also entered "the market". These sites provide information on ACP and legal frameworks and often include interactive tools to develop an advance directive. Some websites charge a monthly or one-time fee to continue access to the created files. However, it is often unclear what these websites do with the data generated by the users (98).

More ICT tools to support ACP have been developed in the last decade. The common denominator these tools have is they can be used without support by the healthcare professional to discuss ACP in the family context. A recent scoping review of the published peer-reviewed studies assessed the feasibility and effectiveness of such tools (98). They identified 11 tools, most developed in the United States. The way the tools addressed ACP, their functionalities and accessibility differed (98). Though all these tools could be found in peer-reviewed literature, only six were evaluated. The most studied ACP tool is the “PREPARE for your care” tool (99–107).; this tool, developed in the United States, has five steps: choose a decision maker, decide what matters most, choose flexibility, tell others your wishes, and ask doctors questions. Several studies have shown that the “*PREPARE for your care*” increased ACP engagement (99,108). Two other tools identified in peer-reviewed literature are the *MyDirectives* and *Plan Your Life Span*, also developed in the United States (109–112). Both address important elements of ACP and aim to activate the user to start ACP communication (98). Recently, an ACP tool, the “Explore Your Preferences for Treatment and Care” tool, has been developed in the Netherlands, dividing ACP into three steps: thinking, discussing, and recording (113).

#### 1.4 RESEARCH GAPS IN ACP SUPPORT TOOLS FOR PEOPLE WITH DEMENTIA AND THEIR FAMILY CAREGIVERS

Compared to people with other illnesses, people with dementia and their families require specific support for ACP. This is because dementia often leads to cognitive decline, and in later stages, family caregivers have to take up decision-making responsibilities (50–52). In several studies, people with dementia have emphasised their wish to discuss ACP within the family context (56,63). Research that examines the specific needs of people with dementia and their families and **how to support ACP within the family context is currently limited**. Moreover, research has not yet uncovered how to meet the recently expressed needs of people with dementia and their families for more accessible and understandable information about ACP and for support to discuss such sensitive topics within the family context.

As ICT has proven effective in other domains (98) and as some ICT tools have demonstrated potential in supporting ACP in non-dementia populations (98), **it is noteworthy that there are no evidence-based tools available and explicitly tailored to people with dementia and their families**.

**Importantly, existing ACP tools have often not been developed using a comprehensive co-design approach with the target group.** In the domain of dementia, ample studies have shown positive outcomes when ICT tools are developed with the involvement of people with dementia and their families through co-design approaches, including Patient and Public Involvement (114,115). Dementia organisations also emphasise the importance of such a user-centred approach (116–118). Nevertheless, the majority of ICT in dementia is still developed **for** people with dementia and their families rather than **with their active participation** (95). To promote user-centric development, iterative approaches can be employed to ensure that the needs and preferences of people with dementia and their families are at the forefront of the development process. This seems particularly relevant in the sensitive and complex field of ACP.

Furthermore, as emphasised in the scoping review by van der Smissen, the current landscape of web-based ACP support tools often lacks a comprehensive evaluation (98). **There is an urgent need for in-depth assessments of web-based ACP support tools to better understand how people use these tools, their potential benefits, and their limits.** For example, the evaluations of ACP tools that are conducted lack real-time assessments, which hinders the ability to understand how such tools are used and how people navigate them. **This real-time evaluation is crucial for a more accurate and deeper understanding of their practical impact on supporting ACP.** Traditionally, social scientists use interviews, focus groups and surveys to test and evaluate ICT. However, when developing web-based interventions, studying user behaviour using these methods may not provide the necessary results to understand how users engage with ICT, which features are being used and potential differences between how users use ICT. Self-reported behavioural measurements of usage have limited reliability as they are often assessed retrospectively, which requires much cognitive work that may be difficult for people with dementia (119). With web log data or digital traces of in-the-moment usage, human behaviour can be collected with high precision (120). In other fields, using log data shows promising results in evaluating and improving ICT (121,122). However, this method is hardly used in medical social sciences.

## 2 AIMS AND STUDY OBJECTIVES OF THE DISSERTATION

The overarching aim of the dissertation is **to develop and evaluate a website to support people with dementia and family caregivers in the advance care planning process**. More specifically, two aims with each three objectives are addressed:

The first aim: To **inform the development of the content and features of the website with people with dementia, family caregivers and healthcare professionals to support advance care planning in the family context**.

Objective 1: To identify existing web-based ACP support tools to describe their content characteristics, readability, and quality and investigate whether and how they have been evaluated (CHAPTER 1).

Objective 2: To define the content of the website to support ACP in the family context and to assess the barriers and facilitators to finding and using the website (CHAPTER 2).

Objective 3: To develop a card game that initiates and supports ACP discussions to identify values and preferences about end-of-life issues (CHAPTER 3).

The second aim: To **evaluate the website with people with dementia and family caregivers to support advance care planning in the family context**.

Objective 1: To describe the study protocol of an evaluation study to evaluate the usage, usability, acceptability, and feasibility (i.e. uptake) of the website, the experiences of people with dementia and their family caregivers in using the website and the effects on ACP readiness, knowledge, self-efficacy, skills, and perceived barriers to start ACP (CHAPTER 4).

Objective 2: To evaluate the usability, acceptability, and feasibility (i.e. uptake) of the website, the experiences of people with dementia and their family caregivers in using the website and its effects (CHAPTER 5).

Objective 3: To explore to what extent and how the website was used by people with dementia and their family caregivers, identify the type of users and visualise how these types of users navigated the website. (CHAPTER 6).



## 1. METHODS

### **METHODS TO ANSWER RESEARCH AIM 1**

#### 1.1 SYSTEMATIC GREY LITERATURE REVIEW

*To identify existing web-based ACP support tools to describe content characteristics, readability, and quality and investigate whether and how they have been evaluated*, we systematically reviewed grey literature to identify existing web-based ACP support tools to describe content characteristics, readability, and quality and investigate whether and how they are evaluated (123). We followed Godin et al.'s four search strategies for online grey literature (124). Before the search, the protocol was registered in PROSPERO (CRD42020184112).

To systematically search ACP tools, we used the four search strategies recommended by Godin et al. First, we searched online grey literature databases: OpenGrey, Clinicaltrials.gov, ProQuest, British Library, GLIN, and Health Services Research Projects in Progress. We searched ACP tools via Google Search Engine, the Google Play Store, and Apple App Stores. Two researchers (CD and FM) conducted the first three search strategies. Because search results can differ based on the search history, both used the same search combinations on different computers with 'clean' (deleted cookies and history) browsers without logging into a Google account. Also, because search engines have their own algorithm for showing relevant results, we used several different search combinations to minimise the risk of omitting relevant sources. Because a search engine can give an overwhelming amount of "hits", we screened each search combination's first fifteen pages (i.e., the first 150 hits). After the last search strategy was conducted, experts on ACP were consulted. Experts were identified via frequently listed and cited authors of relevant literature, known stakeholders and suggestions from other key informants. Experts were consulted by e-mail and were provided with a list of the found tools via the first search strategies (123).

To describe the content characteristics, we developed four data extraction tables to summarise the characteristics, functionalities, and key elements of ACP addressed. To evaluate the readability of the included tools, we used the Flesch-Kincaid Grade Level and the Common European Framework of Reference for Languages (CEFR) levels to assess the readability. The quality of the ACP tools assessed by using the QUality Evaluation Scoring Tool (QUEST) to assess online health content. To assess if the ACP tools had been evaluated, we

searched the grey literature databases OpenGrey, Clinicaltrials.gov, ProQuest, British Library, GLIN, Health Services Research Projects in Progress, and we searched for publications of primary peer-reviewed studies in PubMed, Web of Science, PsycINFO and CINAHL (123).

## 1.2 FOCUS GROUP STUDY

We performed a focus group study *to define the content of an interactive website to support ACP in the family context and assess the barriers and facilitators to finding and using such a website*. Focus groups were conducted with family caregivers of people with dementia and healthcare professionals separately (125). Due to the COVID-19 restrictions during data collection, the focus groups were conducted online.

Family caregivers had to be the primary caregivers of a person diagnosed with dementia. Healthcare professionals had to be professional caregivers in the Flemish dementia care field and have frequent (> four times a week) interactions with people with dementia and their family caregivers. Moreover, all participants had to have access to the internet on the day of the focus group, a certain degree of computer literacy and comfortable discussing topics online, an interest in and willingness to talk about ACP, be 18 years of age and older and be fluent in Dutch. The study received Ethics approval via the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (BUN: 1432020000277) (125).

Family caregivers were recruited via the peer support groups for family members of persons with dementia in Flanders, accommodated within the Flemish Alzheimer's League (Alzheimer Liga Vlaanderen). Healthcare professionals were recruited via the researchers' professional networks and The Flanders Centre of Expertise on Dementia (Expertisecentrum Dementie Vlaanderen). All participants who gave consent received, from the researcher, a link to participate in an online focus group. The focus groups were conducted using a semi-structured topic guide and PowerPoint with possible relevant content topics for the website to support ACP in the family context (125).

The data analysis followed a thematic framework analysis approach involving the following stages: data familiarisation, thematic framework development, indexing of study data based on this framework, data summarisation through charting, and final mapping and interpretation. The researchers reviewed the identified themes, and a consensus was reached

to establish the framework. Subsequently, all transcripts were analysed using this framework, and the results were organised and discussed with all authors for interpretation (125).

### 3.1 DEVELOPMENT OF A CARD GAME: A CULTURAL ADAPTATION PROCESS

*To develop a card game that initiates and supports ACP discussions to identify values and preferences about end-of-life issues*, we performed an extensive, systematic, negotiated cultural adaptation with various community stakeholders and potential end-users (126). We culturally adopted the original English-language Go Wish card game (127). Afterwards, this card game was digitalised as part of the ACP website.

The evidence-based Go Wish cards, containing 36 cards, were identified in the systematic review on existing web-based ACP support tools. These cards feature statements illustrating behavioral choices or situations, with 35 of them based on research by Steinhäuser et al. (128). We followed the structured, multistep process for cultural adaptation used by McGreevy et al. (2014) (129). Each of the steps in this process is complementary to the others, intending to extract factors of cultural and linguistic significance. First, we performed a forward translation. Afterwards, we discussed the translated card game with representatives from various organisations (dementia, cancer, family caregivers, end-of-life care, people with structural vulnerabilities, senior citizens, Christianity, Judaism, and Islam) and negotiated consensus on the translation and adaptations. In step 3, we evaluated the translated and adapted cards by surveying various healthcare professionals with experience in end-of-life care. We calculated the content validity index (CVI) to measure inter-rater agreement per card for four criteria: linguistic equivalence to the original version, applicability, comprehensibility, and relevance based on the scores derived in Step 3. As the last step, we tested the card game with potential end-users (126).

We used the feedback from steps 3 and 5 to list suggested card changes. This list was emailed to representatives of step 2 with a request to approve or dismiss suggested adaptations per card and/or suggest other changes. When consensus was reached on all adaptations, the translation and adaptation of the card game were finalised (126).

## METHODS TO ANSWER RESEARCH AIM 2

### 1.3 MIXED-METHOD EVALUATION STUDY

*To evaluate the usage, usability, acceptability, and feasibility (i.e. uptake) of the website, the experiences of people with dementia and their family caregivers in using the website and its effects*, we performed an eight-week evaluation study using a convergent parallel mixed methods pretest-posttest design (130). During the eight-week study period, web log data or digital traces of in-the-moment usage were collected, and participants were shown in-the-moment pop-up questions (i.e. ecological momentary assessment) while using the website, facilitating real-time evaluations. The study was conducted in Flanders, the Dutch-speaking part of Belgium. We recruited people with mild to moderate dementia (both early and late onset) and their family caregivers as dyads or the family caregiver alone. The participants used the ACP in their own homes or another place of their preference, and participants used their own devices (e.g., computers, tablets, phones, etc.) to access the website (130).

Participants were recruited via organisations involved in dementia (care), neurologists working in memory clinics, and individual GPs. To achieve variability in age, gender, dementia type, and dyad composition (i.e. partners, parents(in law) and a child), we estimated to need 30 participants, i.e., thirty eligible dyads of people with mild to moderate dementia (both early and late onset) and/or their family caregivers used the website in their everyday life for eight weeks.

We conducted both an interview and surveys at the start of the 8-week intervention period (baseline at T0) and after the 8-week intervention period (follow-up at T1). Interviews and surveys were conducted separately (i.e., interviews were conducted individual with the person with dementia and the family caregiver), but the participants could choose to have the interview together. During the eight weeks, there was continuous data collection via logging user activity and the pop-up, in-the-moment questions (130).

All interviews were transcribed and analysed using framework analysis. Initially, two researchers coded 20% of the transcripts using a combination of deductive and inductive approaches. Predetermined codes were derived from the interview guide and research protocol, and new codes were created as needed. The themes established through this process were reviewed with the involved researchers, aiming for consensus in constructing the framework. Afterwards, the remaining transcripts underwent analysis using the

framework, with the two researchers comparing their coding, resolving discrepancies through discussion, and achieving consensus. Descriptive statistics were used for the quantitative data (surveys) and analysed using SPSS. The answers to the pop-up questions were analysed using RStudio. Quantitative and qualitative data were independently analysed, integrated, and summarised to interpret to what extent the results related to, converged with, or diverged from each other and how they related to, converged with, or diverged from each other.

During the evaluation study, data on usage, i.e. log data, was collected. This data was used *to explore how people with dementia and their family caregivers use the ACP support website, whether and which user behaviour clusters can be typified based on the engagement of people with dementia and their family caregivers and explore and visualise user pathways of the identified user behaviour clusters*. Usage is the interactions of people with dementia and family caregivers with the website. Log data recorded various aspects, including visited pages, time spent on each page, content interactions, visit frequency, and search queries. During the evaluation study, log data was collected in three separate databases:

1. Application logs. These were interactions with the website when users entered their study ID, who was using the website. In these logs, the used search terms were also collected.
2. Access logs. These were all other interactions with the website
3. A unique log for all interactions with the interactive communication tools. These were, for example, when people typed in their wishes or used the cards.

Log data was analysed using R (version 4.2.3) in RStudio. First, the databases with logs were cleaned. The application logs were filtered to include only valid study IDs used by the participants. Study IDs were then added to the access logs based on cross-matching with IP addresses. The access and application logs were combined, and the additional information from the third dataset regarding the completion of interactive tools was incorporated by matching IP addresses to the study IDs.

First, usage was summarised, i.e. all interactions with the website, including time spent on the website and pages visited. The data underwent K-means clustering to identify the user behavioural clusters, which was applied to discover patterns typifying user engagement. Six features derived from the summary data were used for clustering: total interactions, unique days, duration of use, total clicks on communication, information, and documentation pages.

Normalisation using min-max normalisation and the "caret" package was performed, converting variables to a range between 0 and 1 (131). The "NbClust" package determined the optimal number of clusters (k) between 2 and 10 (132). The k-means algorithm, along with PCA for data visualisation, was employed. Kruskal-Wallis rank sum and chi-squared tests were conducted to assess significant differences between features for each cluster.

AI-driven process mining and data visualisation were employed to explore and visualise user pathways of the identified user behaviour clusters (133). Log data underwent filtering to eliminate redundant information, such as usage of the website by changes in font size, contrast, privacy policy and using the text-to-speech option. First, a process matrix was generated to visualise the entire log dataset, providing insights into sequential patterns of user navigation (134). Next, individual process maps were created for each study ID, displaying the specific paths participants took. After, these paths were compared with the IDs per cluster to identify similarities and differences between and within each cluster.

#### 4 DISSERTATION OUTLINE

Following the introduction, the second part of this thesis describes the work to inform the development of the content and format of the website with people with dementia, family caregivers and healthcare professionals to support ACP in the family context. **Chapter 1** presents the results of existing online ACP support tools, their content characteristics, readability, and quality, and whether and how they are evaluated. **Chapter 2** describes the needs and preferences of family caregivers and healthcare professionals regarding the content of the interactive website to support ACP and the barriers and facilitators to finding and using it. **Chapter 3** presents the development of a card game that initiates and supports discussions about “*what matters most*” and end-of-life preferences.

Together, the results from the work outlined in Chapters 1 to 3 were used to develop the ACP support website using a user-centred design. This design and the evaluation study following the development are described in the third part of the thesis.

The third part describes the developed website to support ACP, the protocol, and the results of an evaluation study with people with dementia and family caregivers. **Chapter 4** describes the website to support ACP and outlines the study protocol of the mixed-method evaluation study of the website. The results of the evaluation study, i.e. the usability, acceptability, and feasibility and the experiences of people with dementia and their family caregivers in using the website and the effects on self-efficacy, skills, and perceived barriers to starting ACP, are described in **Chapter 5**. **Chapter 6** explores how people with dementia and their family caregivers used the website, identifies the type of users, and visualises how these types of users navigated the website

The last part consists of a summary of the main findings, the strengths and limitations of the methodologies used, a general discussion of the main findings and recommendations for research, practice, and policymakers.

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## **PART 2 TO INFORM THE DEVELOPMENT OF THE CONTENT AND FEATURES OF THE WEBSITE**



# **CHAPTER 1**

## **PUBLICLY AVAILABLE INTERACTIVE WEB-BASED TOOLS TO SUPPORT ADVANCE CARE PLANNING: A SYSTEMATIC REVIEW**

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## ABSTRACT

*Background:* There is an increasing number of interactive web-based advance care planning (ACP) support tools, which are web-based aids in any format encouraging reflection, communication, and processing of publicly available information, most of which cannot be found in the peer-reviewed literature.

*Objective:* This study aims to conduct a systematic review of web-based ACP support tools to describe the characteristics, readability, and quality of content and investigate whether and how they are evaluated.

*Methods:* We systematically searched the web-based gray literature databases OpenGrey, ClinicalTrials.gov, ProQuest, British Library, Grey Literature in the Netherlands, and Health Services Research Projects in Progress, as well as Google and app stores, and consulted experts using the following eligibility criteria: web-based, designed for the general population, accessible to everyone, interactive (encouraging reflection, communication, and processing of information), and in English or Dutch. The quality of content was evaluated using the Quality Evaluation Scoring Tool (score 0-28-a higher score indicates better quality). To synthesize the characteristics of the ACP tools, readability and quality of content, and whether and how they were evaluated, we used 4 data extraction tables.

*Results:* A total of 30 tools met the eligibility criteria, including 15 (50%) websites, 10 (33%) web-based portals, 3 (10%) apps, and 2 (7%) with a combination of formats. Of the 30 tools, 24 (80%) mentioned a clear aim, including 7 (23%) that supported reflection or communication, 8 (27%) that supported people in making decisions, 7 (23%) that provided support to document decisions, and 2 (7%) that aimed to achieve all these aims. Of the 30 tools, 7 (23%) provided information on the development, all of which were developed in collaboration with health care professionals, and 3 (10%) with end users. Quality scores ranged between 11 and 28, with most of the lower-scoring tools not referring to information sources.

*Conclusions:* A variety of ACP support tools are available on the web, varying in the quality of content. In the future, users should be involved in the development process of ACP support tools, and the content should be substantiated by scientific evidence.

## INTRODUCTION

Via a European consensus process, advance care planning (ACP) has been defined as a process that enables individuals to define goals and preferences for future medical care, to discuss these preferences with family and healthcare providers, and to record these preferences and choices [1,2]. In recent decades, the concept of ACP has changed considerably, shifting from a clinician-led and documentation-focused process that emphasizes the need for advance directives to a broader concept of ongoing communication about various aspects of future care and treatment planning [3,4]. In recent public health literature, the concept has been broadened further by emphasising the opportunities that ACP conversations offer for the normalizing and reshaping of how we think, talk, and make decisions about the last chapters of our lives [5,6].

To support people in having such conversations, a wide variety of ACP support tools have been developed in several formats such as print or websites. They exist in different kinds of modalities, (guides, card games, videos) and for different target groups: people with specific diseases and/or their families, family caregivers or for the general public [7,8]. With the growing use of the internet and international efforts to promote ACP [9], more *web-based* ACP support tools are becoming publicly available [10]. An advantage of these web-based tools is that they are easily accessible to a large audience and are often interactive and can thus be tailored to the needs of the user. Interactive elements include, for example, questions or exercises to encourage reflection and communication and to process the information provided [10–12].

A recent review of published peer-reviewed studies assessed the feasibility and effectiveness of interactive web-based ACP support tools for adult patients, relatives, and/or healthy individuals, and found that users considered the tools easy to use and not burdensome. It also demonstrated that they can improve a user's knowledge of ACP, ACP communication with relatives and health care professionals, and ACP documentation [8]. However, this review was not able to include all ACP support tools available to the general public as many exist only online and have not been published in academic journals [7,8]. Reviewing these web-based tools is important because the quality of online content could vary widely or be based on personal opinions and experiences rather than on scientific evidence [13–16]. This can be particularly problematic with regard to ACP, as content may be biased in favour of or against certain medical interventions [15], while the primary purpose of ACP should be to promote choice based on individual values and preferences [1,2].



Currently, there is no comprehensive overview of these interactive ACP tools available on the world wide web. Therefore, this systematic review aims to answer the following research questions:

1. What are the characteristics and functionalities of interactive web-based ACP support tools?
2. How is ACP addressed in these tools?
3. What is the readability and quality of their content and have they been evaluated in a study, and if so, what is their level of evidence?

## **METHODS**

### *Review design and protocol registration*

We conducted a systematic review of web-based, interactive ACP support tools (hereafter called tools) following the four search strategies for online grey literature of Godin et al [17]. The search, selection and data synthesis were performed between September 2020 and January 2021. The protocol of this systematic review is registered in PROSPERO (CRD42020184112).

### *Eligibility criteria*

We searched for tools that met the following inclusion criteria:

- 1) designed to support the general population, that is; people with or without serious illness and/or their families;
- 2) available on the internet;
- 3) accessible to whoever visits the tool and can be used by anyone;
- 4) interactive, that is; encourages the user to reflect, communicate, formulate decisions and/or to document wishes [10–12];
- 5) in English or Dutch.

Tools that aim exclusively to support the health care professional in the ACP process were excluded.

### *Search strategies*

We systematically searched for tools, using the four search strategies recommended by Godin et al: [1] online grey literature databases, [2], search engine, [3] app stores and [4] expert consultation [17]. The first three search strategies were conducted separately by two researchers (CD and FM) who both used the same search combinations (appendix 1-3), on different computers with 'clean' (deleted cookies and history) browsers without being logged

into a Google account. Because, as with peer-reviewed databases, every search database (grey literature databases, search engines and app stores) has its own search functionalities and filters, we adapted the search terms to fit into the search fields of each database. Furthermore, because search engines have their own algorithm for showing relevant results, we used several different search combinations that is, combining the search terms, their permutations, and trending keywords, in search strategy two to minimize the risk of omitting relevant sources (appendix 2). Because a search engine can give an overwhelming amount of 'hits', we screened the first fifteen pages (first 150 hits) of each search combination.

We screened the available content of the results such as executive summaries, the webpage 'about', or the explanation of the tool - when available - until we could answer the following question: *'is this tool potentially a web-based ACP support tool for the general population?'*. If the answer was yes, we included the tool for full screening, and transferred the results to an Excel file (with the name of the tool, or the website if there was no specific name for the tool).

For the first search strategy (grey literature databases), we used the following databases: *OpenGrey, Clinicaltrials.gov, ProQuest, British Library, Grey Literature in the Netherlands (GLIN), and Health Services Research Projects in Progress*. For the second search strategy, we used the *Google Search Engine* and for the search in app stores we used the *Google Play Store* and *Apple App Store*.

The fourth search strategy entailed a consultation of experts on ACP. We identified experts via frequently listed and cited authors of relevant literature, known stakeholders and suggestions from other key informants. We consulted these experts by e-mail and, in order to achieve saturation, asked them whether they knew any other tools that we had not found using the first three search strategies. Responses were added to the Excel file and saved for final selection.

#### *Selection of web-based ACP support tools*

For the final selection, the two researchers (CD and FM) separately screened all the available content of each potentially relevant tool against the eligibility criteria. In cases of disagreement about whether to include a tool, a third reviewer (TS) screened it and made the final decision on including it. We used Archive.is to archive the homepage or first page of the tools.

### *Evaluation of the readability and quality of the content of the included tools*

Readability was evaluated using online readability analysis tools. These readability tools calculate several readability scores based on characteristics of the text such as number of syllables per word and the number of words per sentence. Since the online readability analysis tools were exclusively for one language, we used two tools: One for the English tools [18] and one for the Dutch ones [19]. To determine the readability, we used the Common European Framework of Reference for Languages (CEFR) levels [20,21]. The CEFR levels can be used to determine both English and Dutch readability and is calculated by the algorithm of the online readability analysis tools and looks beside the number of words per sentence, also at number of pronouns and prepositions in a sentence and the number of simple words [22]. CEFR consists of six reading levels (A1, A2, B1, B2, C1, and C2), with A1 as the easiest level, and C2 as the most difficult one. The recommended readability standard for the CEFR is B1 [22].

To evaluate the quality of the content of the tools, we used the validated *QUality Evaluation Scoring Tool (QUEST)* [23]. This quality assessment tool can be used to assess online health content by evaluating seven items each assigned with a weighted score. Six items have a possible score between 0-1 or 0-2 and weight between 1 and 3: Authorship (score 0-2x1), conflict of interest (score 0-2x3), complementarity (whether they support the patient-physician relationship – score 0-1x1), currency (if the content is frequently updated – score 0-2x1) and the tone of the content (whether the content was “*fully supported*” using strong vocabulary such as “cure”, “guarantee”, and “easy”, “*mainly supported*” where the authors mainly support their claims but with more cautious vocabulary or “*balanced/cautious support*” with statements of limitations and/or contrasting findings - score 0-2x3). The seventh item is attribution (whether and what kind of sources are used to create the content) and is measured using two steps, firstly identifying the presence of references to scientific studies (score 0-3x3) and, second when scored >1, identifying the type of studies referred to in vitro, observational studies or meta-analyses/clinical trials – score 0-2x1 [23,24]. Each tool was evaluated for each of these seven items. The scores on each item were summed to create a total quality score ranging between 0 and 28, with higher scores indicating better quality of the content in the tool.

The readability was evaluated by two researchers (CD and FM) who copy-pasted the text of a full webpage into the text fields of online readability score calculator tools. The same two researchers assessed the content in the tools to determine the QUEST score for each tool.

Any disagreements on the readability and/or QUEST scores were discussed to find consensus. If no consensus was found, the third researcher (TS) made the final decision.

#### *Evaluation of the level of evidence of the included tools*

To assess whether the included tools had been evaluated as part of a research study, we [1] screened each one for any information on evaluation, [2] we searched the grey literature databases OpenGrey, Clinicaltrials.gov, ProQuest, British Library, GLIN, Health Services Research Projects in Progress, and [3] we searched for publications of primary peer-reviewed studies in PubMed, Web of Science, PsycINFO and CINAHL. Search terms in the database included the name of the tools, the name of the website and/or the name of the persons/organizations involved in the development of the tool.

We screened the available content (for scientific article abstracts or, when needed, full-texts) to check whether the result was a primary study on one of the included tools. If it was, where possible, we determined the level of evidence using the Hierarchy of Evidence from the National Health and Medical Research Council [25,26], in order to determine how the tools were evaluated.

Two researchers (CD and FM) independently assessed full texts of the peer-reviewed studies to determine the level of evidence and to assess what was evaluated (usability and/or effectiveness). Any disagreements were discussed to find consensus. If no consensus was found, a third researcher (TS) made the final decision.

#### *Data synthesis and outcomes of interest*

In order to answer the research questions, we developed four data extraction tables. For the first three extraction tables, the two researchers (CD and FM) independently assessed the content of the tools to summarize the characteristics, functionalities and the key elements of ACP addressed. Any disagreements were discussed to find consensus. If no consensus was found, a third researcher (TS) made the final decision.

The first extraction table we used to assess the aim, target group, available languages, format and where, by whom and how the tools were developed. We evaluated which functionalities were used by developing a second extraction table based on the review of peer-reviewed studies by van der Smitten et al (2020) [8]. We slightly changed the 12 assessed functionalities by removing 'can be used without assistance' since in our review we only

included tools that are designed to be used by the general population and we added the functionalities “*pre-determined path*” and ‘*possibility to save input and return*’ as this allows the user to conduct the ACP process at their own pace and “*input can be printed*” as this functionality can increase the accessibility of websites [27]. In this review we therefore extracted the following data with regards to the functionalities of the ACP tools:

- The tool is free of charge;
- Registration is needed;
- There is a save and return option;
- It is possible for the user to give input;
- The tool is tailored to the user;
- The tools provide feedback based on input of the user;
- The input from the user can be printed;
- The tool suggests a pre-determined ACP path;
- The tool gives an indication of the progress of the user;
- Videos are used, hyperlinks to other web pages;
- There is a text to speech option;
- A privacy policy is mentioned and
- Data log analysis is mentioned.

How ACP is addressed in the tools was extracted by using 14 ACP key elements (the third extraction table) as analytic framework. The 14 key elements are self-developed and based on the recommendations of Rietjens et al. (2017), the consensus definition of ACP of Sudore et al. (2017) and the review by van der Smits et al (2020) [1,2,8]. From these definitions, we aimed to extract all relevant elements that can be part of ACP, that is, the following elements:

- Providing information on ACP;
- Providing information on legal frameworks;
- Address readiness, and timing for ACP;
- Stimulates to explore personal values and goals;
- Stimulates to explore preferences regarding future care;
- Stimulates to explore uncertainties and consequences;
- Stimulates to explore preferences regarding last days of life;
- Stimulates to explore preferences on a possible a proxy decision-maker;
- Encourages to appoint proxy decision-maker;
- Encourages to discuss ACP with family;

- Encourages to discuss ACP with health care professionals;
- Encourages to document ACP;
- Encourages to generate that document (in the tool) and
- Encourages to share that document.

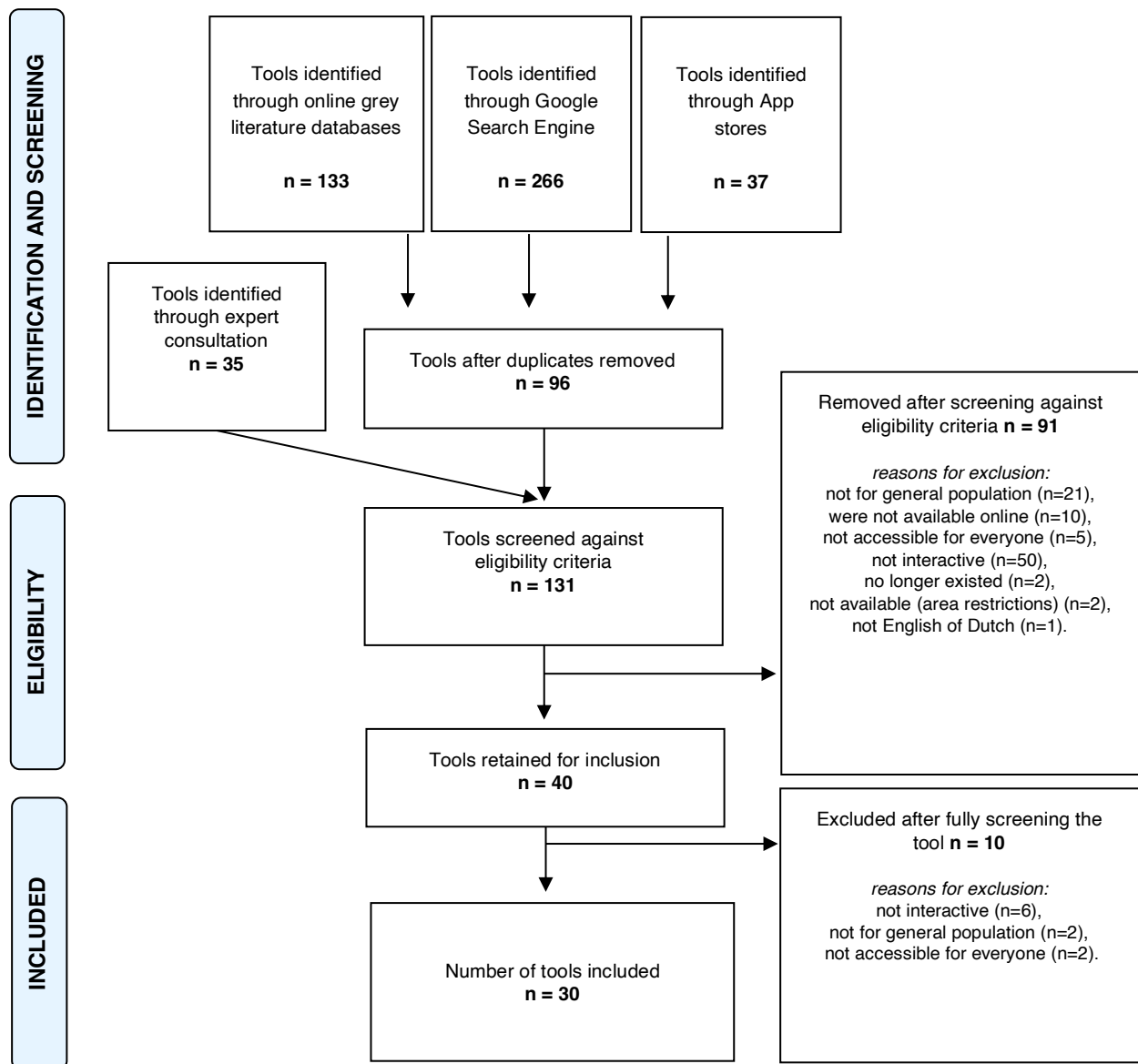
The readability, the quality of the content, information about the evaluation of the tools , as well as their level of evidence were summarised in the fourth extraction table.

## **RESULTS**

### *Selection and inclusion of the tools*

We found 436 tools using the first three search strategies. After removing duplicates (the tools retrieved and the removed duplicates per search strategy can be found in appendix 4), a list of 96 potential interactive, web-based ACP support tools for the general population was sent to 15 experts on ACP. Fourteen replied and together they identified 35 additional tools. Two researchers (CD and FM) subsequently screened the 131 tools against the eligibility criteria. A total of 91 were excluded (figure 1) and there were no conflicts to solve regarding exclusion. The remaining 40 tools were fully screened, that is all text available in the tool for data extraction, and we ended up excluding ten more in agreement between both researchers. The total number of included tools is thus 30. An overview of the screening, selection and reasons for exclusion and inclusion is shown in Figure 1.

Figure 1 – PRISMA flowchart of selection process



### *Characteristics of the tools*

Twenty-four tools (80%) target the general population although six (20%) also aim to target healthcare professionals (Table 1). For instance, the app *ACD* (Advance Care Directive) *Care* can be used by patients to make an advance care directive which can be uploaded to their health record, to which the healthcare professional has access [28]. The tools *Mydirectives*, *Be My Voice*, *My Living Will*, *Speak Up* and *Considering your own future health care* not only support the general population in ACP, but also provide information on ACP for healthcare professionals [29–33]. Twenty-four tools (80%) do mention a clear aim; seven (23%) support reflection and/or communication, eight (27%) support people in making decisions, seven (23%) support to document decisions, and two (7%) aimed to achieve all these aims. Fifteen (50%) tools are websites, ten (33%) are online portals with a possibility to login and return to personal information, three (10%) are apps and two (7%) have a combination of formats. For example, *PREPARE for Your Care* (*PREPARE*) can be used via the website, or by logging in to an online portal [34].

Twelve tools (40%) have been developed in the United States, six (20%) in Canada, four (13%) in Australia, three (10%) in the Netherlands, three (10%) in the United Kingdom, one (3%) in New Zealand and one (3%). Twenty-five tools (83%) are owned by non-profit organizations. Seven tools (23%) provide information on their development; all have been developed in collaboration with healthcare professionals and three (10%) also with end-users.



Table 1 – Characteristics of included interactive, web-based ACP support tools

| Nr | Name of the tool                                                              | Aim of the tool                                                                                                                                                                                                               | Target group(s)               | Language(s) | Format  | Country of development | Developed by (in year, (non-)profit)      | Description on development |
|----|-------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------|-------------|---------|------------------------|-------------------------------------------|----------------------------|
| 1  | ACDCare [28]                                                                  | "The app guides you through the process to <b>fill out the ACD and then generates the official document</b> for South Australia and Northern Territory that you can carry with you and upload to MyHealthRecord."             | Individuals and professionals | English     | App     | Australia              | GP Partners Australia (non-profit)        | No description available   |
| 2  | Advance Care Planning: Should I Have Artificial Hydration and Nutrition? [35] | "This <b>decision aid</b> is for patients considering artificial hydration and nutrition if or when they are no longer able to take food or fluids by mouth."                                                                 | Individuals                   | English     | Website | Canada                 | Healthwise and Alberta (2019, non-profit) | No description available   |
| 3  | Advance Care Planning: Should I Receive CPR and Life Support? [36]            | "This <b>decision aid</b> helps patients with serious or advanced illness decide whether or not to receive CPR and be put on a ventilator if heart or breathing stops."                                                       | Individuals                   | English     | Website | Canada                 | Healthwise and Alberta (2019, non-profit) | No description available   |
| 4  | Advance Care Planning: Should I Stop Kidney Dialysis? [37]                    | "This <b>decision aid</b> helps patients with kidney failure who have been undergoing dialysis, and for whom kidney transplantation is not possible, decide whether to continue kidney dialysis, which will allow you to live | Individuals                   | English     | Website | Canada                 | Healthwise and Alberta (2019, non-profit) | No description available   |

|   |                                                                            |                                                                                                                                                                                                                      |                               |                   |               |               |                                                                   |                          |
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|   |                                                                            | longer, or stop kidney dialysis, which will allow death to occur naturally.”                                                                                                                                         |                               |                   |               |               |                                                                   |                          |
| 5 | Advance Care Planning: Should I Stop Treatment That Prolongs My Life? [38] | "This <b>decision aid</b> helps patients with serious or advanced illness decide whether to stop treatment that prolongs life and instead receive only hospice care, or to continue treatment that prolongs life.”   | Individuals                   | English           | Website       | Canada        | Healthwise and Alberta (2019, non-profit)                         | No description available |
| 6 | Be my voice [30]                                                           | No description about aim on the website                                                                                                                                                                              | Individuals and professionals | English           | Website       | Australia     | Capital Health Network (non-profit)                               | No description available |
| 7 | Beslischulp - Vroegtijdige zorgplanning [39]                               | No description about aim on the website                                                                                                                                                                              | Individuals                   | Dutch             | Website       | Belgium       | Centrum voor Evidence-Based Medicine (non-profit)                 | No description available |
| 8 | Cake [40]                                                                  | "Our goal is to empower people to live in accordance with their <b>values</b> all the way to the end. This can only happen if we <b>know our end-of-life preferences</b> and <b>share</b> them with our loved ones." | Individuals                   | English           | Online portal | United States | Cake (2015, profit)                                               | No description available |
| 9 | Considering your own future health care [33]                               | No description about aim on the website                                                                                                                                                                              | Individuals and professionals | English and Maori | Website       | New Zealand   | Health Quality & Safety Commission New Zealand (2018, non-profit) | No description available |

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| 10 | Dementia Values and Priorities Tool [41] | No description about aim on the website                                                                                                                                                                  | Individuals | English | Website       | United States  | Compassion & Choices (non-profit)               | No description available                                                                                                       |
| 11 | Dying to Talk [42]                       | "Dying to Talk encourages all Australians <b>to talk</b> about dying no matter your age, background or current health."                                                                                  | Individuals | English | Online portal | Australia      | Palliative Care Australia (non-profit)          | No description available                                                                                                       |
| 12 | Everplans [43]                           | "Your Everplan helps you take control of your End-of-Life <b>planning process</b> ."                                                                                                                     | Individuals | English | Online portal | United States  | Everplans (2012, profit)                        | No description available                                                                                                       |
| 13 | Five Wishes [44]                         | " <b>Completing</b> the Five Wishes <b>advance directive</b> can help you and your loved ones gain peace of mind around these difficult decisions."                                                      | Individuals | English | Online portal | United States  | Aging with Dignity (1996, non-profit)           | "Aging with Dignity founder J. Towey created Five Wishes with doctors, nurses, lawyers and other experts in end-of-life care." |
| 14 | Go Wish card game [45]                   | "The goal of the tool is <b>to facilitate discussions</b> , and for the end result of getting people to <b>think and talk</b> about positive values and goals for having the best end of life possible." | Individuals | English | Website       | United States  | CODA Alliance (2018, non-profit)                | No description available                                                                                                       |
| 15 | Lets Think Ahead – My ACP [46]           | "This App will help you <b>develop your plan</b> , think about what's important to you and help you be in control of your future"                                                                        | Individuals | English | App           | United Kingdom | University of the West of Scotland (non-profit) | No description available                                                                                                       |

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| 16 | My decisions [47]    | "MyDecisions is a website which helps you plan ahead for your future treatment and care. This online service guides you through questions and scenarios <b>to help you think about the things</b> that are important to you." | Individuals                   | English | Online portal | United Kingdom | Compassion in Dying charity (non-profit) | No description available                                                                                                                      |
| 17 | My living voice [48] | No description about aim on the website                                                                                                                                                                                       | Individuals                   | English | Online portal | United States  | Vital Decisions (profit)                 | No description available                                                                                                                      |
| 18 | My Living Will [31]  | "My Living Will aims to help individuals and professionals <b>understand and take decisions</b> about care towards the end of life."                                                                                          | Individuals and professionals | English | Website       | United Kingdom | My Living Will Charity (non-profit)      | "A diverse group of senior healthcare professionals, senior lawyers and an ethicist have overseen My Living Will's creation of this website." |
| 19 | My Values [49]       | "We specifically designed MyValues <b>to help address</b> an important problem – that we generally don't know what people would want when confronted by difficult life-and-death <b>decisions</b> ."                          | Individuals                   | English | Online portal | Australia      | Barwon Health (non-profit)               | "This version of MyValues was created with valuable input from Sharyn Milnes, Nick Simpson, Jonathan                                          |

|    |                   |                                                                                                                                                                                                                                                             |             |                               |                       |                |                                                       |                                                                                                                                       |
|----|-------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|-------------------------------|-----------------------|----------------|-------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------|
|    |                   |                                                                                                                                                                                                                                                             |             |                               |                       |                |                                                       | Silverman and Julian Savulecu. The process was facilitated by Deb Porter with critical feedback from the Camperdown community group." |
| 20 | MyDirectives [29] | "MyDirectives helps you <b>create your own digital advance care plan</b> or upload any advance directive, advance care plan or portable medical order you already have."                                                                                    | Individuals | English                       | Online portal and App | United States  | ADVault (non-profit)                                  | No description available                                                                                                              |
| 21 | MyWishes [50]     | "We will help you; <b>write your last will &amp; testament</b> , leave goodbye messages to be released after your death, make plans for your future health care, safeguard your digital legacy, publish your bucket list and document your funeral wishes." | Individuals | English                       | Online portal         | United Kingdom | MyWishes (profit)                                     | No description available                                                                                                              |
| 22 | NVLivingWill [51] | NVLivingWill.com guides you in <b>completing your Living Will</b> , which is also known as an <b>Advance Directive</b> ".                                                                                                                                   | Individuals | English, Spanish and Filipino | Online portal         | United States  | Nevada Center for Ethics & Health Policy (non-profit) | No description available                                                                                                              |

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| 23 | Oog in Oog [52]               | "The Oog in Oog app has been developed <b>to provide guidance in the conversation</b> about the final phase of life"                                                                                                  | Individuals and professionals | Dutch               | App                       | The Netherlands | Bureau MORBidee (profit)                    | No description available                                                                                                                                                                      |
| 24 | Plan your Life Span [53]      | "This website will help you <b>plan</b> for health events such as hospitalizations, falls, and memory loss that may happen as people get older. This <b>planning</b> differs from end of life care and wills."        | Individuals                   | English             | Website                   | United States   | Northwestern University (non-profit)        | No description available                                                                                                                                                                      |
| 25 | Planning for Your Future [54] | No description about aim on the website                                                                                                                                                                               | Individuals                   | English             | Website                   | Canada          | People's Law School (non-profit)            | No description available                                                                                                                                                                      |
| 26 | PREPARE [34]                  | "PREPARE is a step-by-step program with video stories to help you: <b>have a voice</b> in YOUR medical care, <b>talk</b> with your doctors, <b>fill out an advance directive</b> form to put your wishes in writing." | Individuals                   | English and Spanish | Website and Online portal | United States   | University of California (2008, non-profit) | "PREPARE is the result of a collaboration of broad and talented group of people and organizations" and "Conducted <b>studies with diverse populations to further understand patients' and</b> |

|    |                                              |                                                                                                                                                                                                                  |                                     |                       |                  |                    |                                                                       |                                                                                                                                                                                                                                           |
|----|----------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|-----------------------|------------------|--------------------|-----------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|    |                                              |                                                                                                                                                                                                                  |                                     |                       |                  |                    |                                                                       | <b>caregivers'</b><br>needs for advance<br>care planning".                                                                                                                                                                                |
| 27 | Speak up [32]                                | "We provide a repository of resources and tools developed for professionals and patients/individuals to <b>assist them in making the appropriate decision</b> regarding their end of life care."                 | Individuals<br>and<br>professionals | English and<br>French | Website          | Canada             | Canadian<br>Hospice<br>Palliative Care<br>Association<br>(non-profit) | No description<br>available                                                                                                                                                                                                               |
| 28 | The Letter project<br>Advance Directive [55] | "To help, <b>empower and support</b> all adults to prepare for their future and take the initiative <b>to talk</b> to their doctors and their friends and family about what matters most to them at life's end." | Individuals                         | English               | Website          | United States      | Stanford<br>Medicine (2015,<br>non-profit)                            | "We conducted<br>interviews and<br>focus groups in<br>multiple<br>languages with<br>people in the<br>community <b>and<br/>talked to<br/>numerous<br/>patients and<br/>their family<br/>members</b> as well<br>as health<br>professionals" |
| 29 | Tijdig nadenken over het<br>levenseinde [56] | "The digital <b>decision aid</b> helps you to form an opinion about your wishes regarding the last phase of your life.                                                                                           | Individuals                         | Dutch                 | Online<br>portal | The<br>Netherlands | NPV Zorg (non-<br>profit)                                             | No description<br>available                                                                                                                                                                                                               |

|    |                                                |                                                                                                                                                                                                                                        |             |       |         |                 |                                                                                                                                                                                                                                                                                       |
|----|------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|-------|---------|-----------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 30 | Verken uw wensen voor zorg en behandeling [57] | <p>"This <b>decision aid</b> helps you to <b>think</b> about wishes for care and treatment, and <b>to discuss</b> and <b>record them</b>. You can start this when you are still healthy, but also when you get older or get sick."</p> | Individuals | Dutch | Website | The Netherlands | <p>Dutch College of General Practitioners, Erasmus MC and thuisarts.nl (2020, non-profit)</p> <p>of General Practitioners, Kidney Patients Association, Netherlands NPVzorg.nl, Agora, LEVEL, University of Twente, and a sounding <b>board group of patients and relatives.</b>"</p> |
|----|------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|-------|---------|-----------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|



### *Functionalities of the tools*

Twenty-seven tools (90%) are free of charge and seventeen (57%) are available without registration (Table 2). Twenty-nine tools (97%) offer users the option to provide input by responding to a question or statement, for example by asking them to write in an empty box. With regard to the flow of the tool (the steps or path a user has to take to go through it), twenty-nine (97%) use a predetermined path [28–56]. For example, there are x number of steps in a tool, the user needs to go through these steps to ‘finish’ the ACP process provided in the tool. One tool (Go Wish card game) does not have a set path but uses a mechanism in which users can sort cards on particular wishes and preferences to stimulate reflection or/and communication [57]. Five (17%) use the input of the user to tailor information, redirect them to a specific webpage with more information or ask for clarification on the input. For example, in *My Values*, when identifying ‘*not wanting to be a burden*’ as important, a screen pops up asking them to explain briefly (by typing) what ‘*becoming a burden*’ means to them [48]. One also uses input to give feedback (Table 2): PREPARE not only tailors provided information based on input but also provides tips when for example the user indicates ‘*not ready to choose a proxy decision-maker*’ [34].

Table 2 – Functionalities of included interactive, web-based ACP support tools

|   | Name of the tool                                                              | Free of charge <sup>a</sup> | No registration needed <sup>b</sup> | Save and return <sup>c</sup> | Possible to give input <sup>d</sup> | Tailored <sup>e</sup> | Feedback based on input <sup>f</sup> | Input can be printed <sup>g</sup> | Pre-determined path <sup>h</sup> | Shows progress <sup>i</sup> | Use of Video's | Hyperlinks to other web pages | Text to speech option | Privacy policy mentioned | Data log analysis mentioned <sup>j</sup> | Total |
|---|-------------------------------------------------------------------------------|-----------------------------|-------------------------------------|------------------------------|-------------------------------------|-----------------------|--------------------------------------|-----------------------------------|----------------------------------|-----------------------------|----------------|-------------------------------|-----------------------|--------------------------|------------------------------------------|-------|
| 1 | ACDCare [28]                                                                  | x                           |                                     | x                            | x                                   |                       |                                      | x                                 | x                                | x                           |                |                               |                       | x                        | x                                        | 8     |
| 2 | Advance Care Planning: Should I Have Artificial Hydration and Nutrition? [35] | x                           | x                                   |                              | x                                   |                       |                                      | x                                 | x                                | x                           |                | x                             |                       | x                        | x                                        | 9     |
| 3 | Advance Care Planning: Should I Receive CPR and Life Support? [36]            | x                           | x                                   |                              | x                                   |                       |                                      | x                                 | x                                | x                           |                | x                             |                       | x                        | x                                        | 9     |
| 4 | Advance Care Planning: Should I Stop Kidney Dialysis? [37]                    | x                           | x                                   |                              | x                                   |                       |                                      | x                                 | x                                | x                           |                | x                             |                       | x                        | x                                        | 9     |
| 5 | Advance Care Planning: Should I Stop Treatment That Prolongs My Life? [38]    | x                           | x                                   |                              | x                                   |                       |                                      | x                                 | x                                | x                           |                | x                             |                       | x                        | x                                        | 9     |
| 6 | Be my voice [30]                                                              | x                           | x                                   |                              | x                                   | x                     |                                      |                                   | x                                | x                           | x              | x                             |                       | x                        | x                                        | 10    |
| 7 | Beslischulp - Vroegtijdige zorgplanning [39]                                  | x                           | x                                   |                              | x                                   | x                     |                                      | x                                 | x                                | x                           |                | x                             |                       |                          | x                                        | 9     |
| 8 | Cake [40]                                                                     | x                           |                                     | x                            | x                                   |                       |                                      | x                                 | x                                | x                           |                | x                             |                       | x                        | x                                        | 8     |
| 9 | Considering your own future health care [33]                                  | x                           | x                                   |                              | x                                   |                       |                                      | x                                 | x                                | x                           |                | x                             |                       | x                        | x                                        | 9     |

|    |                                           |   |   |   |   |   |   |   |   |   |   |   |   |   |   |    |
|----|-------------------------------------------|---|---|---|---|---|---|---|---|---|---|---|---|---|---|----|
| 10 | Dementia Values and Priorities Tool [41]  | x | x |   | x |   |   | x | x |   |   | x |   |   |   | 6  |
| 11 | Dying to Talk [42]                        | x | x | x | x |   |   | x | x | x |   | x |   | x | x | 10 |
| 12 | Everplans [43]                            |   |   | x | x |   |   | x | x | x |   | x |   | x | x | 8  |
| 13 | Five Wishes [44]                          |   |   | x | x |   |   | x | x | x |   |   |   | x | x | 7  |
| 14 | Go Wish card game [45]                    | x | x | x |   |   |   | x |   |   |   |   | x | x | x | 7  |
| 15 | Lets Think Ahead – My ACP [46]            | x |   | x | x |   |   | x | x |   |   |   |   | x | x | 7  |
| 16 | My decisions [47]                         | x |   | x | x |   |   | x | x | x |   |   |   | x | x | 8  |
| 17 | My living voice [48]                      | x |   | x | x |   |   | x | x | x |   |   |   | x | x | 8  |
| 18 | My Living Will [31]                       | x | x | x | x |   |   | x | x | x | x |   |   | x | x | 10 |
| 19 | My Values [49]                            | x |   | x | x | x |   | x | x | x |   |   |   | x | x | 9  |
| 20 | MyDirectives [29]                         | x |   | x | x | x |   | x | x | x | x | x |   | x | x | 11 |
| 21 | MyWishes [50]                             | x |   | x | x |   |   | x | x |   | x | x |   | x | x | 9  |
| 22 | NVLivingWill [51]                         | x |   | x | x |   |   | x | x | x |   | x |   | x | x | 9  |
| 23 | Oog in Oog [52]                           |   |   | x | x |   |   | x | x | x |   |   |   | x | x | 6  |
| 24 | Plan your Life Span [53]                  | x | x | x | x |   |   | x | x | x | x | x |   |   |   | 9  |
| 25 | Planning for Your Future [54]             | x | x |   | x |   |   |   | x |   | x | x |   | x | x | 8  |
| 26 | PREPARE [34]                              | x | x | x | x | x | x | x | x | x | x |   | x | x | x | 13 |
| 27 | Speak up [32]                             | x | x | x | x |   |   | x | x | x |   | x |   | x | x | 10 |
| 28 | The Letter project Advance Directive [55] | x | x |   | x |   |   | x | x |   |   |   |   | x | x | 7  |

|    |                                                   |   |   |   |   |  |  |   |   |   |   |   |   |   |   |    |
|----|---------------------------------------------------|---|---|---|---|--|--|---|---|---|---|---|---|---|---|----|
| 29 | Tijdig nadenken over het<br>levenseinde [56]      | x |   | x | x |  |  | x | x | x | x | x |   |   |   | 8  |
| 30 | Verken uw wensen voor zorg<br>en behandeling [57] | x | x |   | x |  |  | x | x | x | x | x | x | x | x | 11 |

- <sup>a</sup> Tool can be used without payment
- <sup>b</sup> Tool can be used without the need of registration or being logging in (using a personal logging and password)
- <sup>c</sup> People can save their process and return to continue their ACP process (via personal code/login system)
- <sup>d</sup> Responding to a question or statement in the tool for example via multiple-choice or typing text in an empty field
- <sup>e</sup> Content in the tool (ie information, questions, video’s etc.) are tailored based on the input of the user
- <sup>f</sup> Feedback such as to do’s or clarification on the impact of a choice are provided based on the input of the user
- <sup>g</sup> Generates document with input given by user
- <sup>h</sup> A “pre-determined path” was considered present if tools directed the user to follow a specific order. For example, when texts such as "you start at xx, and then move on to" or when indicators of such order were used such as numbers or steps (step 1, step 2, etc.)
- <sup>i</sup> The different steps that the user follows in the process, are shown in the tool itself
- <sup>j</sup> Tracking behaviour of the users in the tool is mentioned

### *ACP elements addressed in the tools*

All tools contain at least seven of the 14 ACP key elements we identified in our analytical framework; six (20%) comprised all (Table 3). With regard to the information available, 12 (40%) provide both information on ACP and on the legal frameworks of ACP. Readiness and timing of ACP is addressed in 15 (50%), encourage people to explore personal values and goals in 28 (93%), and preferences regarding future care in 29 (97%). Uncertainties and consequences of hypothetical serious illness scenarios is addressed in 25 (83%), preferences regarding the last days of life in 27 (90%), and the possibility of appointing a proxy decision-maker in 21 (70%). Twenty tools (67%) encourage appointing a proxy decision-maker and 27 (90%) encourage discussing ACP with family or a health care professional and documenting ACP outcomes (for example using an advance directive). In 27 tools (90%), it is possible to document one's wishes and preferences within the tool itself and share this document with others (by printing, via email or via a direct link) (Table 3).



[illegible]

|    |                                                      |   |   |   |   |   |   |   |   |   |   |   |   |   |   |    |
|----|------------------------------------------------------|---|---|---|---|---|---|---|---|---|---|---|---|---|---|----|
| 30 | Verken uw wensen voor<br>zorg en behandeling<br>[57] | x | x | x | x | x | x | x | x | x | x | x | x | x | x | 14 |
|----|------------------------------------------------------|---|---|---|---|---|---|---|---|---|---|---|---|---|---|----|

AD: advance directives

HCP: health care professional

PMD: proxy decision-maker, or health care representative, legal representative

<sup>a</sup> Explanation what is ACP, why ACP, what are the goals, and limitations

<sup>b</sup> Applicable law and regulatory framework w.r.t. ACP (including AD)

<sup>c</sup> Preferences and goals regarding future (medical) care, future treatments and/or site of care excl. last days of life

<sup>d</sup> Uncertainties and consequences of (hypothetical) serious illness scenarios

<sup>e</sup> ACP communication such as what are preferences and goals regarding future (medical) care, future treatments and/or site of care, last days of life

<sup>f</sup> To record and document ACP for example using an advance directive

<sup>g</sup> Documentation of wishes, preferences and needs based on input of the user in the tool (not necessarily an AD, can also be a summary of the input of the user)



### *Readability and quality of the content*

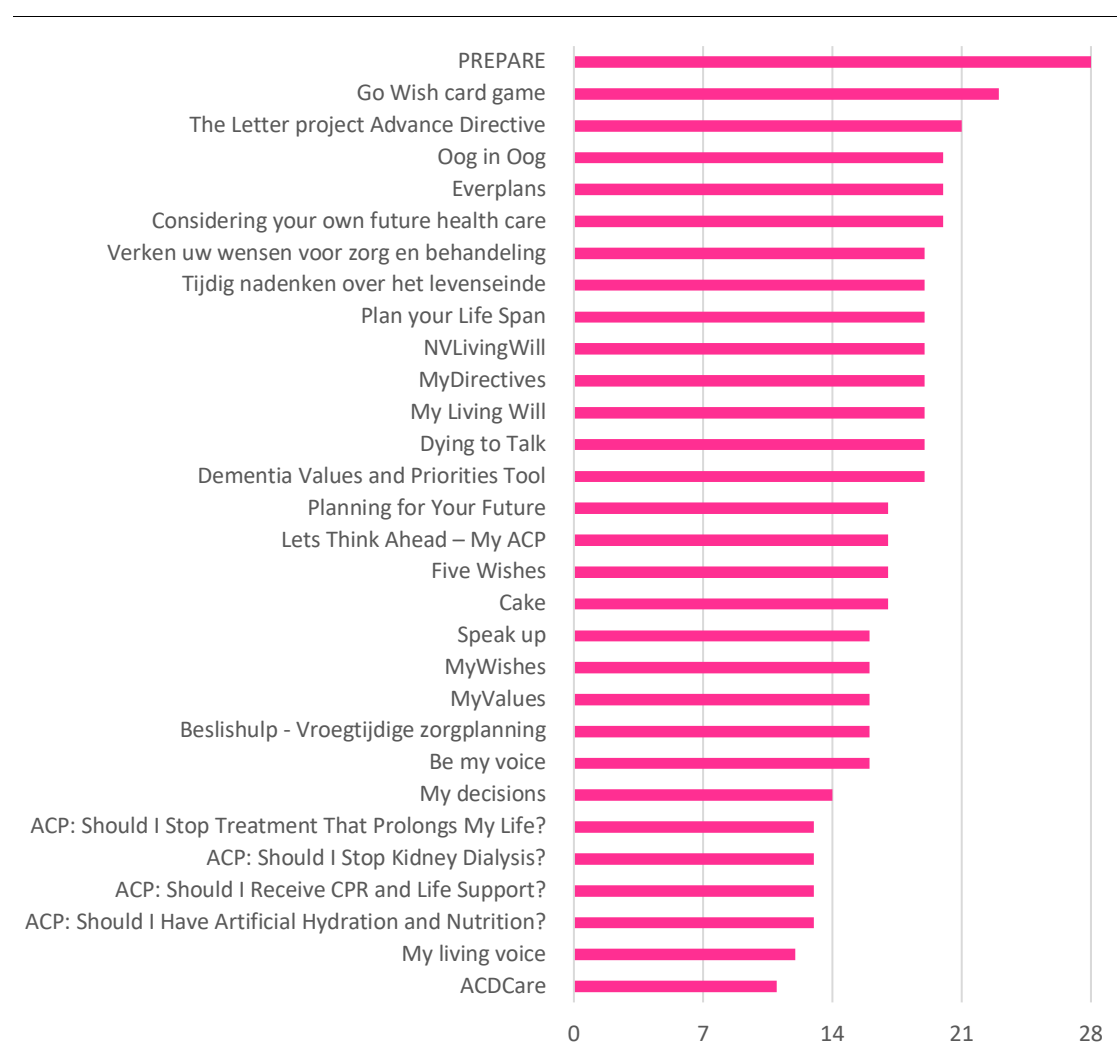
The readability of the ACP tools varied (table 4), but 25/30 ACP tools (83%) have a B1 or lower CEFR level. The QUEST scores of the tools vary between 11 and 28 (theoretical scale score between 0 and 28) (figure 2). Most of the lower scoring tools do not refer to any sources to support the information they contain, were not current. that is; not updated in the past five years, or did not provide any information on authorship. The ones which scored 21 or higher all used at least one reference to a scientific study to support the information in the tool.

*Table 4 – Readability scores of the interactive, web-based ACP support tools*

| <b>Name of the tool</b>                                                  | <b>CEFR Scale</b> |
|--------------------------------------------------------------------------|-------------------|
| My decisions                                                             | A1                |
| My living voice                                                          | A1                |
| Speak up                                                                 | A1                |
| PREPARE                                                                  | A2                |
| Go Wish card game                                                        | A2                |
| MyDirectives                                                             | A2                |
| Plan your Life Span                                                      | A2                |
| Lets Think Ahead – My ACP                                                | A2                |
| Advance Care Planning: Should I Stop Treatment That Prolongs My Life?    | B1                |
| The Letter project Advance Directive                                     | B1                |
| Advance Care Planning: Should I Receive CPR and Life Support?            | B1                |
| MyWishes                                                                 | B1                |
| My Living Will                                                           | B1                |
| Everplans                                                                | B1                |
| Considering your own future health care                                  | B1                |
| Tijdig nadenken over het levenseinde                                     | B1                |
| Oog in Oog                                                               | B1                |
| Verken uw wensen voor zorg en behandeling                                | B1                |
| Dying to Talk                                                            | B1                |
| Be my voice                                                              | B1                |
| ACDCare                                                                  | B1                |
| Five Wishes                                                              | B1                |
| MyValues                                                                 | B1                |
| Dementia Values and Priorities Tool                                      | B1                |
| Advance Care Planning: Should I Have Artificial Hydration and Nutrition? | B2                |
| Planning for Your Future                                                 | B2                |
| Beslishulp - Vroegtijdige zorgplanning                                   | B2                |
| Cake                                                                     | B2                |
| NVLivingWill                                                             | B2                |
| Advance Care Planning: Should I Stop Kidney Dialysis?                    | C1                |

*Ranked from lowest (A1) to highest score (C2) possible*

Figure 2 – QUEST scores of the interactive, web-based ACP support tools



Ranked from lowest to highest based on QUEST score

#### Evaluated tools and their level of evidence

Five of the thirty (16%) included tools had been evaluated in a study, all of which were published in peer-reviewed literature (Table 5). *Verken uw wensen voor zorg en behandeling* (49) is under evaluation but these results are not yet published. *MyDirectives* and *NVLivingWill* were studied using a post-test design [58–60] and the *PREPARE*, *Plan Your Life Span* and *The Letter project Advance Directive* were studied in at least one properly designed randomized controlled trial [61–71]. The study on *NVLivingWill* evaluated the ease of use of the tool [58], the studies on *PREPARE* evaluated ease of use, effectiveness, acceptability and understandability (information in the tool was easy to read) [63–71], *Plan your Life Span* evaluated effectiveness [61] and the study on *The Letter project Advance Directive* evaluated understandability [72].

*Table 5 – Level of evidence of the interactive, web-based ACP support tools*

| Nr | Name of the tool         | Authors, year                 | Title study                                                                                                                                           | The hierarchy of evidence                                                         |
|----|--------------------------|-------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|
| 20 | MyDirectives [29]        | Holland, et al (2017)         | Nurse-Led Patient-Centered Advance Care Planning in Primary Care (52)                                                                                 | Evidence obtained from a post-test                                                |
|    |                          | Fine, et al (2016)            | Early experience with digital advance care planning and directives, a novel consumer-driven program (53)                                              |                                                                                   |
| 22 | NVLivingWill [50]        | Klugman and Usatine (2012)    | An evaluation of 2 online advance directive programs (51)                                                                                             | Evidence obtained from a post-test                                                |
| 24 | Plan your Life Span [52] | Ramirez-Zohfeld, et al (2020) | Longitudinal Follow-Up of Long-Term Care Planning Using PlanYourLifespan.org (55)                                                                     | Evidence obtained from at least one properly designed randomised controlled trial |
|    |                          | Lindquist (2017)              | PlanYourLifeSpan.org – an intervention to help seniors make choices for their fourth quarter of life: results from the randomized clinical trial (54) |                                                                                   |
| 26 | PREPARE [34]             | Howard, et al (2020)          | Effect of an Interactive Website to Engage Patients in Advance Care Planning in Outpatient Settings (64)                                              | Evidence obtained from at least one properly designed randomised controlled trial |
|    |                          | Freytag, et al (2020)         | Empowering Older Adults to Discuss Advance Care Planning During Clinical Visits: The PREPARE Randomized Trial (63)                                    |                                                                                   |
|    |                          | Lum, et al (2018)             | Improving A Full Range of Advance Care Planning Behaviour Change and Action Domains: the PREPARE Randomized Trial (62)                                |                                                                                   |
|    |                          | Zapata, et al (2018)          | Feasibility of a Video-Based Advance Care Planning Website to Facilitate Group Visits among Diverse Adults from a Safety-Net Health System (61)       |                                                                                   |
|    |                          | Sudore, et al (2018)          | Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial (60)                      |                                                                                   |
|    |                          | Sudore, et al (2017)          | Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans (59)          |                                                                                   |
|    |                          | Cresswell, et al (2017)       | Evaluation of an advance care planning web-based resource: applicability for cancer treatment patients (58)                                           |                                                                                   |
|    |                          | Ouchi, et al (2017)           | Preparing Older Adults with Serious Illness To Formulate Their Goals for Medical Care in the Emergency Department (57)                                |                                                                                   |
|    |                          | Sudore, et al (2014)          | A Novel Website to Prepare Diverse Older Adults for Decision Making and Advance Care Planning: A Pilot Study (56)                                     |                                                                                   |

|    |                                           |                          |                                                                                                                    |                                                                                   |
|----|-------------------------------------------|--------------------------|--------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|
| 28 | The Letter project Advance Directive (47) | Periyakoil, et al (2017) | A Randomized Controlled Trial Comparing the Letter Project Advance Directive to Traditional Advance Directive (65) | Evidence obtained from at least one properly designed randomised controlled trial |
|----|-------------------------------------------|--------------------------|--------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|

<sup>a</sup> The Hierarchy of Evidence from the National Health and Medical Research Council. [I] evidence obtained from a systematic review of all relevant randomised controlled trials, [II] evidence obtained from at least one properly designed randomised controlled trial, [III-1] evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method), [III-2] evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case- control studies, or interrupted time series with a control group, [III-3] evidence obtained from comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group, [IV] evidence obtained from case series, either post-test or pre-test and post-test (20)

## DISCUSSION

### *Principal Findings*

This review included thirty ACP tools, which were developed in North America, Europe, or Oceania. Most tools mention a clear aim, that is to support reflection and/or communication, to support people in making decisions and/or to support to document decisions, but only two (7%) aimed to achieve all three aims. Seven of the tools (23%) were developed in collaboration with healthcare professionals but just three (10%) also involved end-users. All tools except one encourage users to follow steps in a predetermined order to go through the ACP process. With regard to the ACP elements, almost all tools stimulate the user to explore personal values and goals and preferences regarding future care; 12 (40%) provide both information on ACP and its legal frameworks. Two out of three tools also encourage the user to appoint a proxy decision-maker. Most of the ACP tools had a good readability score, but the quality of the content varied between 11 and 28 on the QUEST scale. Most of the included ACP tools had not been evaluated in a study.

We found great variety among tools available online in terms of their aims, functionalities, approaches to addressing ACP and quality. However, the included tools also share important commonalities.

First, we found that many tools do not provide information on their development process. If they do, they involved healthcare professionals like physicians, experts on end-of-life care, ethicists and/or lawyers. End-users were only involved in three tools (10%) development, even though this is highly recommended in the literature on developing web-based technologies [73–75]. Research on developing new technologies shows that the involvement of end-users inevitably yields improvement in usability and quality, and ensures the tool is tailored to the needs of prospective end-users [73–75].

Second, most tools did stimulate the user to explore personal values and goals and preferences regarding future care and the last days of life, which is the primary purpose of ACP [1,2], and most also encouraged the appointing of a proxy decision-maker and discussion with family and a health care professional. However, all but one tool in this review use an approach in which all users are encouraged to follow a pre-determined path or steps to go through the ACP process. ACP is a process of exploration, discussion and recording preferences, wishes and decisions. How and when to best perform these parts of ACP depends, among other things, on personal barriers, needs, preferences and readiness [76,77]. Using steps in a predetermined order suggests that ACP is a linear instead of an iterative process [1]. Moreover, using predetermined steps may not be appropriate for all users, as some may just want to explore possibilities without making decisions, while others, for instance because of their illness, prefer to focus on anticipatory decision-making [76,78].

Third, with regards to the quality of the content of the included tools as rated by the QUEST score, we found that six scored 20 or above, of which one (PREPARE) scored the maximum of 28 points. All other tools have a medium to low quality score because they did not refer to any information sources and were not up to date, that is; had not been updated in at least five years. Especially with regards to ACP, having evidence-based information that can be verified by the user is important as people use this information to plan and make health-related care decisions [79,80]. We also found that most included tools had not been evaluated in a study. Only the PREPARE tool has been evaluated for ease of use, effectiveness, acceptability, and understandability. When people look for support in ACP, they may use tools that have a low or even non-existent level of evidence regarding their usability and effectiveness [13–16,81].

#### *Strengths, limitations, and future research*

This is the first systematic review to provide an overview of interactive, web-based ACP support tools that are available on the internet for a general population. Previous reviews have given an overview of web-based ACP support tools that could be found in peer-reviewed literature and emphasized the absence of an overview of those available in the grey literature [7,8]. Furthermore, our review is the first to assess the quality of the content of web-based ACP support tools [7,8]. It also has some limitations. First, because we limited our third search strategy, that is; search engine to 150 ‘hits’ per search combination, there is a possibility that some existing tools were not included in our review. However, we consider this unlikely, as our search was conducted systematically by two researchers using a broad

range of search terms and we searched more 'hits' than recommended (recommended a 100) by Godin et al [17]. We also consulted experts and asked them whether they knew any other tools that we had not yet found. Furthermore, though we did archive the tools when performing the data synthesis using Archive.is, there is a possibility that new content or functionalities have been added to the tools included in our review or that new tools have been released since the search was carried out.

For future developments, users should be involved in order to align the preferences and needs of the user with the content and functionalities of the tools. Involving users early in the development process can improve the usability of tools and increase their uptake [82]. Additionally, we would recommend following a thorough design process using existing roadmaps when developing new ACP tools, rigorously evaluating through usability and effectiveness testing prior to deployment and transparently reporting on development and evaluation. Second, ACP content provided to users should be regularly updated and supported by sources and hence we recommend that content in ACP tools should be substantiated with the most recent scientific literature. Moreover, future research should focus on how these ACP tools are used by the general population and how they can support ACP in the medical context, that is; between patient and healthcare professional. Lastly, it would be interesting to know how the general population would assess the tools.

## **Conclusion**

There are numerous interactive web-based ACP support tools publicly available, varying in terms of their characteristics, functionalities, readability, quality of content, and level of evidence. Most tools were not co-developed with end-users, were of low or medium quality and, with a few exceptions, have not been evaluated in research. For the future, users should be involved in the development of ACP support tools and their content should be substantiated by scientific evidence. Additionally, we recommend developers should follow a rigorous design process and evaluate the usability and effectiveness of tools prior to their deployment. Future research should focus on how tools are used by the general population and how they can support ACP in the medical context, that is; between patient and healthcare professional.

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## Appendix 1 – search terms for online grey literature databases

|    |                                                                                                                                                                                                           |
|----|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1  | "Advance care planning" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")         |
| 2  | "Advance directive" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")             |
| 3  | "Advance health care directive" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid") |
| 4  | "End of life care" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")              |
| 5  | "Shared decision making" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")        |
| 6  | "Question prompts list" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")         |
| 7  | "Living will" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")                   |
| 8  | "Personal directive" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")            |
| 9  | "Advance decision" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")              |
| 10 | "ACP" AND ("Patient support tool" OR Tool OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Website OR App OR application OR "Decision aid" OR "Conversation aid")                           |

## Appendix 2 – search terms for search engine Google

|    |                                                                                                                                                                                                                                                                |
|----|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1  | "Advance care planning" AND ("Patient support tool" OR Tool OR Aid OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Help OR Intervention OR Document OR Guide OR support OR "Decision aid" OR "Conversation aid")                                |
| 2  | "Advance directive" OR "Advance health care directive" AND ("Patient support tool" OR Tool OR Aid OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Help OR Intervention OR Document OR Guide OR support OR "Decision aid" OR "Conversation aid") |
| 3  | "Shared decision making" AND ("Patient support tool" OR Tool OR Aid OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Help OR Intervention OR Document OR Guide OR support OR "Decision aid" OR "Conversation aid")                               |
| 4  | "Question prompts list" AND ("Patient support tool" OR Tool OR Aid OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Help OR Intervention OR Document OR Guide OR support OR "Decision aid" OR "Conversation aid")                                |
| 5  | "Living will" OR "Advance decision" AND ("Patient support tool" OR Tool OR Aid OR "Conversation prompts" OR "Question Guide" OR "Tool kit" OR Help OR Intervention OR Document OR Guide OR support OR "Decision aid" OR "Conversation aid")                    |
| 6  | "Advance care planning" AND start conversation with family OR start talk with family                                                                                                                                                                           |
| 7  | "Advance care planning" AND start conversation with partner OR start talk with partner                                                                                                                                                                         |
| 8  | "Advance care planning" AND help to talk                                                                                                                                                                                                                       |
| 9  | "Advance care planning" AND how to start                                                                                                                                                                                                                       |
| 10 | "Advance care planning" AND how to document OR how to do                                                                                                                                                                                                       |

### Appendix 3 – search terms for app stores

|    |                                 |
|----|---------------------------------|
| 1  | "Advance care planning"         |
| 2  | "Advance directive"             |
| 3  | "Advance health care directive" |
| 4  | "End of life care"              |
| 5  | "Shared decision making"        |
| 6  | "Personal directive"            |
| 7  | "Care for the future"           |
| 8  | "End-of-life care planning"     |
| 9  | "Decision aid"                  |
| 10 | "Conversation aid"              |



**Appendix 4 – tools retrieved per search strategy**

|                | Tools found | After removing duplicates |
|----------------|-------------|---------------------------|
| Grey databases | 133         | 27                        |
| App stores     | 37          | 7                         |
| Google         | 266         | 62                        |
| Total          | 436         | 96                        |



## **CHAPTER 2**

### **DEFINING THE CONTENT OF A WEBSITE ON ADVANCE CARE PLANNING IN DEMENTIA: A FOCUS GROUP STUDY WITH FAMILY AND HEALTH PROFESSIONALS**

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## ABSTRACT

*Background:* Advance care planning (ACP) is a process that enables individuals to define goals and preferences for their future care. It is particularly relevant for people with dementia and their family. Interactive tools, such as websites, that encourage reflection, communication and/or documentation, may support this group in the ACP process. However, considering the specific needs of people with dementia, it is important to develop adapted tools for this population. This study was conducted to define the content of an interactive website for people with dementia and their family caregivers to support them in ACP and to assess the barriers and facilitators for potential users in finding and using such a website from the perspective of family caregivers and healthcare professionals.

*Methods:* Online focus groups with family caregivers (serving both as potential users and proxies for people with dementia) and healthcare professionals caring for people with dementia, using a semi-structured topic guide. To analyse the data, we used thematic framework analysis with a combination of deductive and inductive approaches to coding.

*Results:* We conducted 4 focus groups with family caregivers of people with dementia (n=18) and 3 with healthcare professionals (n=17). Regarding the content of the website, participants highlighted that information on ACP (what and why) and guidance on how to start talking about ACP throughout the dementia trajectory should be included on the website. To increase the usability of the website, most participants considered a text-to-speech and a print option as important functionalities. A lack of computer literacy was found to be the most significant barrier to finding and using the website.

*Conclusion:* A website for people with dementia and their family caregivers to support them in ACP should focus on comprehensive content on ACP, peer testimonials, and interactive communication tools. Moreover, there should be certain flexibility in navigating through the website so people with dementia and their family caregivers can use it at their own pace. As the next step, we will include people with dementia in developing the website.

## INTRODUCTION

Advance care planning (ACP) has been defined as a process that enables individuals to define goals and preferences for future care, to discuss these preferences with family and healthcare providers, and to record these preferences and choices [1, 2]. In recent literature the concept of ACP has been broadened from a clinician-led process that stresses the need to complete advance directives to an ongoing process of communication between patients, their family, and healthcare professionals [3, 4].

While ACP might be important for all patient groups, it has particular relevance in dementia. Because of the cognitive and functional decline in dementia and the disease's difficult-to-predict course, it has been advocated that ACP should be initiated in the early stages of dementia. This allows the patient to be actively involved in decision-making about their future care [5]. Furthermore, when initiating ACP early on in dementia, people with dementia can be fully involved and family caregivers can gain a better understanding of the care and treatment preferences of the person with dementia and, hence, they may experience less doubt and stress when making proxy-decisions on behalf of the person with dementia [6, 7].

However, people with dementia and their family caregivers often indicate that they lack ACP knowledge and, although they want to, they cannot find the right time to start the conversation [8]. In the last few years, many new interventions have been developed to support people with dementia and their families in ACP. However, most of these interventions focus on ACP between the patient/family caregivers and healthcare professionals [9–12], while studies show that people with dementia and family caregivers also want to discuss future care and preferences in the family context—outside of the professional care settings [8, 13, 14].

To support such conversations, using interactive, web-based ACP support tools (e.g., websites and apps) can be beneficial. These web-based tools offer many advantages – including the possibility to access them at any preferred time and location [15] – and often contain interactive elements that allow the content to be tailored to the user's needs [15]. This can be an advantage for people with dementia, as their abilities and the needs of their family caregivers change during the disease trajectory [5]. Web-based ACP tools can also facilitate the initiation of conversations, which has been identified as an important barrier in ACP [14, 16, 17]. However, despite their potential, the currently available web-based ACP support tools are not specifically developed for people with dementia and their family

caregivers [18]. Considering the specific trajectory of the disease and the need to initiate ACP early [8, 19, 20], it is important to develop web-based tools that are adapted to the needs and preferences of this population.

To ensure usability and future uptake of web-based tools, understanding people with dementia and their families' needs and preferences is essential. This study is part of a larger study in which we developed an interactive, web-based ACP tool for people with dementia and their families [21]. As a first step, we conducted the present qualitative study to identify what should be included as content, the mode of delivery, and what may influence using and finding such an ACP support tool in this population. We have involved family caregivers acting as users and proxies for people with dementia, and professionals working with people with dementia. The specific aims of this study are to identify:

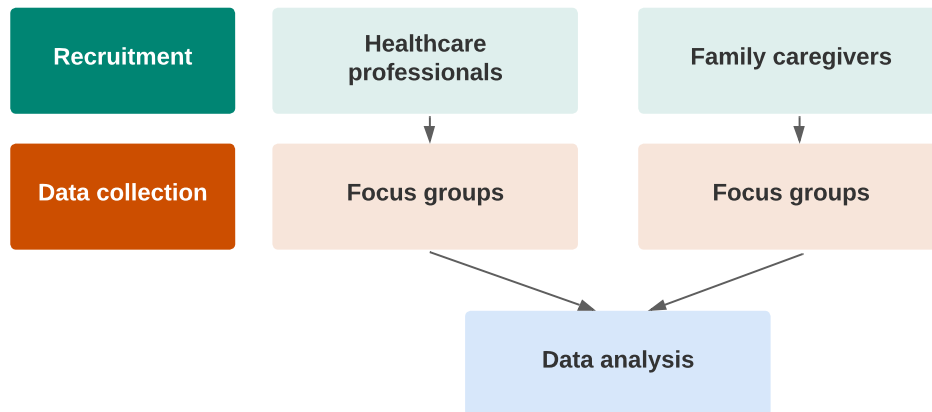
1. the content of the interactive ACP tool;
2. the delivery of the content (i.e., functionalities) of the interactive ACP tool;
3. the perceived barriers and facilitators for finding and using the interactive ACP tool.

## **METHODS**

### *Study design*

Recruitment and focus groups were conducted with family caregivers and healthcare professionals of people with dementia separately. For data analysis, the focus groups' data were combined (Figure 1). Focus groups were considered the most appropriate method for this study because they can help generate individual perspectives while also creating collective interaction. This interaction between participants often results in rich discussions and can lead to the emergence of diverse perspectives, shared experiences, and group dynamics (1). Due to the COVID-19 restrictions during data collection, the focus groups were held online. We limited the number of participants per focus group because it is recommended to have fewer participants (4-6 participants) in online focus groups to manage the discussion and facilitate interaction among the participants. Based on earlier qualitative research, we aimed to include 15 healthcare professionals and 15 family caregivers [22–25]. The findings of our study are reported following the Standards for Reporting Qualitative Research (SRQR) guideline [26]. Because the web-based ACP support tool will be the format of a website, we call it hereafter 'interactive ACP website'.

Figure 1 - an overview of the study procedures



#### *Participants and recruitment*

Participants were recruited using 2 strategies: [1] Family caregivers were recruited via peer support groups for family members of persons with dementia in Flanders, also accommodated within the Alzheimer Liga Flanders; [2] Healthcare professionals were recruited via the researchers' professional networks of individuals working in the Flemish dementia care field and the Expertise Centrum Dementia Flanders. Inclusion criteria (Table 1) were self-assessed (i.e., these inclusion criteria were mentioned in the recruitment call) and were checked by the researcher (CD) before sending the invitation to the participants.

A recruitment call was distributed by the researchers and the recruitment channels (i.e., Alzheimer Liga Flanders and the Expertise Centrum Dementia Flanders) via e-mail, newsletters, and social media. Family caregivers and healthcare professionals who were interested in participating were asked to express their interest in an e-mail to the researcher (CD). Interested participants received an information letter and an online informed consent form by e-mail and were asked to sign the online form using (the Open Source software) Limesurvey.



*Table 1 - Participant inclusion criteria*

| <b>Family caregivers</b>                                                                                                        | <b>Healthcare professionals of people with dementia</b>                                              |
|---------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------|
| Being a primary caregiver of a person diagnosed with dementia;                                                                  | Professional caregiver in Flemish dementia care field;                                               |
| Having participated (>3 times) in one of the family groups dementia and/or early-onset dementia of the Alzheimer Liga Flanders; | Having frequent (>4 times a week) interaction with people with dementia and their family caregivers; |
| Having access to the internet on the day of the focus group;                                                                    |                                                                                                      |
| Having a certain degree of computer-literacy and feeling comfortable discussing topics online;                                  |                                                                                                      |
| Having an interest in, and being willing to talk about, the topic of the focus groups;                                          |                                                                                                      |
| 18 years of age and older;                                                                                                      |                                                                                                      |
| Fluent in Dutch.                                                                                                                |                                                                                                      |

### *Data collection*

All participants who gave consent received, directly from the researcher, a personal meeting link to participate in an online focus group. Each online focus group was led by an experienced moderator (CD or LVdB) and an observer (CD, TS, or FM), who also assisted when technical problems occurred, moderated the chat, and took notes. Family caregivers were asked to respond from their own perspective as a caregiver as well as from that of their relative with dementia. We asked healthcare professionals to give us their views on what they thought would be important for people with dementia and their family.

The focus groups were conducted using a semi-structured topic guide and PowerPoint with possible relevant content topics for the ACP website to guide the discussion. The following topics were shown to the participants during the online meeting: [1] information on ACP, [2] information on legal frameworks, [3] reflecting on readiness for and timing of ACP, [4] reflecting on personal values and goals, [5] reflecting on preferences regarding future care, [6] reflecting on uncertainties and consequences, [7] reflecting on preferences regarding last days of life, [8] reflecting about a proxy decision-maker, [9] appointing a proxy decision-maker, [10] communication with family, [11] communication with healthcare professionals, [12] and documentation of ACP [1, 2]. Before showing these topics to the participants, we explained and showed them the broad definition of ACP by Rietjens et al. (2017) [1]. Preferences regarding functionalities – how the content is delivered (e.g., video), options for a larger font, text-to-speech option, etc. – and the possible barriers and facilitators to finding and using the website were assessed using open questions. Moreover, we also asked about

the need for separate sections within the ACP website for people with dementia, family caregivers and dyads.

Each focus group was scheduled for 1.5 hours. If this timeframe was not enough, we sent the questions about the barriers and facilitators for using and finding the interactive ACP website via e-mail. The focus groups were held between January and April 2021.

### *Data analysis*

The focus groups were recorded and transcribed verbatim. All transcripts were pseudonymised by the researcher (CD), who was involved in all focus groups. To analyse the data, we used framework analysis. The framework analysis approach in thematic analysis involves several stages, including data familiarisation, thematic framework development, indexing all study data against the framework, charting to summarise this data, and lastly mapping and interpretation. First, two researchers (CD and FM) coded 30% of the transcripts in NVivo (version 1.4.1) using both deductive and inductive approaches to qualitative data analysis. We started with predetermined codes and analysed the transcripts to find excerpts that fit these codes (deductive approach). For the data that did not fit pre-determined codes, we created new codes (indicative approach). The coding tree with codes for the deductive approach was built on the content topics presented during the focus groups (i.e., a content topic was a theme). Participants' responses to questions about the barriers and facilitators to finding and using the ACP website received via e-mail were added to the transcript of the focus group and analysed simultaneously. The identified themes were reviewed with the researchers involved and consensus was sought to build the framework. After, all transcripts were analysed using the build framework. Finally, the results were ordered and discussed with all authors of this article for interpretation.

### *Ethics*

The study was carried out in accordance with relevant guidelines and regulations and received Ethics approval via the Ethical Review Board of UZ Brussels, Belgium (BUN: 1432020000277).

## RESULTS

We performed 4 focus groups with family caregivers (n=18); 10 persons were family caregivers for their partner and 8 for their parent(s). Most of the family caregivers were female (n=14). We conducted 3 focus groups with healthcare professionals (n=17 (of which n=11 were female); occupational therapist n=4, physician n=3, reference person dementia n=3, employee of dementia organization n=3, nurse n=2, speech therapist n=1, and director of nursing home n=1). Afterwards, participants of 3 focus groups (1 with family caregivers and 2 with healthcare professionals) received (via e-mail) the questions about the barriers and facilitators to finding and using the ACP website.

After the first focus group, we slightly adjusted the focus group guide and PowerPoint slides by adding 3 topics that the participants mentioned as important topics: [13] What if my loved one does not communicate (much), [14] what if there are difficult end-of-life decisions to be made, and [15] what if there is a disagreement in the family. We deleted the division within the ACP website of possible target groups (i.e., people with dementia, family caregivers, and the dyad).

### *Needs and preferences for the content of the ACP website*

Both family caregivers and healthcare professionals addressed comparable content needs. They considered content on information and guidance in ACP as important. Based on our findings, we identified 3 main topics regarding the content of the website:

#### *1. Information about Advance Care Planning*

Most participants valued the topics 'information on ACP' and 'legal frameworks' for the content of the website. Especially information on 'what is ACP' and 'why should one perform ACP' was deemed as important to be included. Several participants stressed the importance of straightforward and realistic information on ACP, including a precise but clear explanation of existing ACP legal frameworks. Additionally, most participants thought the information on ACP on the website should be adjusted to the trajectory of dementia. Family caregivers, in particular, indicated that they think it is important that the information on the website take the declining cognitive capacities in the different stages of dementia into consideration and should include tips on how to do ACP throughout the trajectory.

*Family caregiver 3 (partner): "It is important to actually look at it in terms of the stage of the dementia, that it is very important to build on that. People with dementia who are still able to*

*start those conversations themselves or indicate to the family caregiver that they want to talk about it – so the stage of dementia, and how the person with dementia deals with it, all play a role in the story of ACP."*

Also, according to most participants, ACP readiness can differ within a dyad, and this should be mentioned on the website. For example, a family caregiver could be ready to discuss possibilities for future care, while the person with dementia only wants to discuss her/his preferences around social care. This should be clear in the information about what ACP is, when and how to conduct ACP, what possible barriers to expect, and how to deal with them. Lastly, most participants agreed that the additional topics added after the first focus group – i.e., what if my loved one does not communicate (much), what if there are difficult end-of-life decisions to be made, and what if there is a disagreement in the family – are very relevant and should be mentioned on the website.

## *2. Guidance on how to start and conduct an ACP conversation:*

Most participants mentioned that they found talking about ACP – and, more specifically, starting an ACP conversation – to be the most difficult. Especially family caregivers said they had difficulties bringing up the topic, both with the person with dementia, and with a healthcare professional. Most participants indicated that they would like to see content on the website about *'how do I start?'* and preferably with an interactive aid that can function as a conversation starter:

Family caregiver 2 (parent has dementia): *"You can find a lot of information about advance directives and what it is, but how do you start it [ACP], which tool can you use? That's something that is not easy to find, or you have to ask services or organizations about it, but I haven't found many tools to support us, and that's something that can be very useful."*

Moreover, most healthcare professionals and family caregivers said that it would be important to distinguish between different kinds of family caregivers. For example, a family caregiver who is a child may have different needs regarding ACP communication than a family caregiver who is a partner, as their relationship with the person with dementia is different. Most family caregivers also stressed that, when they would be able to talk about ACP among each other (person with dementia and the family caregiver), it would be easier to discuss ACP with a healthcare professional:

Family caregiver 6 (parent): *"I think it should mostly be done between the family and maybe they (i.e., the person with dementia and their family) will start talking to their caregiver more easily."*

### 3. Information about the disease and dementia care

Although family caregivers found information about dementia, its prognosis, and possibilities for (future) care important, they did not necessarily want it to be available on the ACP website. They are aware that such information is already available on the internet, though they thought that it would be important to refer to other websites about dementia for specific information on the disease and care because the information is, according to them, needed to be able to discuss ACP. Several healthcare professionals also suggested referrals to other websites on dementia (e.g., hyperlinks) because it is important to know more about the trajectory of dementia when conducting ACP.

### Needs and preferences for delivery of the content

All participants were very clear about how the content should be delivered. The content on the website should be easy to understand, convenient to look up, and relatable. Participants highlighted several ways to deliver the content, which we categorized in 4 ways:

- a. Presenting ACP as a process: According to the participants, the ACP website should consider the need for flexibility and should be tailored to the different needs of persons regarding the timing and their readiness to engage in ACP. Therefore, it should be possible to use the ACP website in every phase of readiness – i.e., users can start and quit when and wherever they want. Family caregiver 7 (partner): *"I think showing that it is a process is very important. You can't do that [ACP] all at once, it only hits you in pieces – and now after [I have done] everything, I can see it [ACP] in its entirety, whereas at the time I couldn't see it that way."*
- b. A section with frequently asked questions (FAQ): Participants would like to see a section where they can easily search and find information that they are looking for. According to family caregivers and the healthcare professionals, people often have the same kinds of questions, and a place for them to easily search and find what they need would be convenient.
- c. A glossary: All participants valued an overview and explanation of important ACP terms, as this is, according to the participants, not easy to find on the internet.
- d. Testimonials: Participants considered testimonials and peer support to be helpful content in supporting ACP. They would value stories on experiences about how others

conducted ACP, what they struggled with, and what helped them to start an ACP conversation.

Family caregiver 16 (partner): *"It would help when you hear others about how they conducted ACP; what did they experience with their partner who did not accept their diagnosis, and what did they do so they were able to talk anyway."*

Physician 2: "You can also use testimonials of peers so people can see others also find it difficult."

For their part, healthcare professionals mentioned that testimonials about how they also sometimes struggle with starting an ACP conversation with their patients could lower the threshold for patients and family caregivers to start an ACP conversation with the healthcare professional.

#### *Needs and preferences for the functionalities of the ACP website*

Family caregivers and healthcare professionals addressed similar needs and preferences with regard to the use of functionalities on the ACP website. According to participants, when adding functionalities to the ACP website, they should benefit usability (i.e., they should support the user in easily using the ACP website). Four functionalities were mentioned that might facilitate the ease of use of the ACP website:

- a. Provide clear navigation: the navigation of the ACP website should be clear, so that it is easy for the user to navigate and find the content they are searching for. For example, the navigation in the ACP website should always be visible, and it should be easy to return to the homepage.
- b. Provide a print option: on every page of the ACP website, a print option should be available so that the user can print the content and read it on paper.
- c. Use a text-to-speech option: just like the print option, on every page there should be an option to transform the text into speech. This way, people who have reading problems can visit and use (listen to) the ACP website.
- d. Provide an option to increase the font size: it should be possible to increase the font size of every paragraph individually. This way, people can read the part they want without everything in the whole ACP website getting bigger.

## *Barriers and facilitators to finding and using the ACP website*

### *1. Barriers to, and facilitators for, finding the ACP website*

According to healthcare professionals and family caregivers, the biggest barrier will be that people most probably will not find the ACP website ‘spontaneously’ and they will need some kind of introduction via an organization or healthcare professional. Also, because there is still a large taboo concerning ACP, and people think it is only about dying, they may not search for the ACP website on their own.

Participants suggested promoting the ACP website via dementia organizations, insurance funds and healthcare professionals. This would help people find the ACP website, as these parties could refer people with dementia and family caregivers to the ACP website. Participants also mentioned using a variety of media to promote the ACP website, including: social media, other websites, videos in healthcare professionals’ waiting rooms, and the use of print media like brochures. Especially in healthcare settings like hospitals, brochures can be useful because people often spend time in a waiting room.

### *2. Barriers and facilitators to using the ACP website*

According to the participants, the most important barrier to using the ACP website is that people with dementia, especially those with late-onset dementia, but also their family caregivers, may lack the necessary computer skills. Moreover, many people with dementia have reduced ability for abstract thinking. Healthcare professional 8 (nurse): *“Digital literacy can be a problem in addition to impaired abstract thinking skills.”* However, participants did believe the population of people with dementia and family caregivers is changing, since the use of computers and tablets have become far more widely used in recent years. Many people with young-onset dementia, in particular, have been working most of their life with a computer, and this will soon also apply for people with late-onset dementia.

Furthermore, according to some participants, the ACP website would be difficult for the person with dementia to use by her/himself because of their deteriorating cognitive abilities. However, the use of functionalities to adjust the delivery of the content (i.e., text-to-speech, larger font size) could support people in the earlier stages of dementia when using the ACP website.

Another facilitator, according to participants, is the possibility of using the ACP website at the person's own pace in terms of timing and readiness. Family caregiver 3 (partner): *"At that time, we did not get any help from anyone to talk about it [ACP] and I found it difficult to start talking about it with the two of us. At one point it was vaguely mentioned, but not in detail. And indeed, it is a very good way to start a conversation and maybe it is also necessary to let it rest for a while and say I'll come back to it. Yes, I think that is important to give the person with dementia some space and time to prepare."*

A possibility for using the ACP website and returning to the same page (saving the user time) is a login system. Participants thought this would be interesting because it would give users the opportunity to stop and return when they want. Nevertheless, the use of a login system would be a big barrier, because users would have to remember their login codes.

## **DISCUSSION**

Participants in this study considered information on ACP – including legal frameworks and guidance on thinking and talking about ACP – to be important content for the interactive website to support ACP. To support the accessibility and usability of the website, participants recommended the use of a text-to-speech option, a print option, and the possibility of increasing the font size. Participants suggested that healthcare professionals should be involved in guiding people with dementia and their family caregiver to the website since people may not find the website on their own.

Family caregivers and healthcare professionals addressed the importance of the content of ACP information, which should go further than explanations of advanced directives, and should provide guidance on how to initiate an ACP. They also considered it to be important to refer to other websites for information on dementia. Family caregivers need for information on ACP, dementia and the expected disease trajectory was also mentioned in Van Rickstal et al. (2019) exploratory interview study among people with young-onset dementia [27]. Providing information on ACP and dementia is crucial in assisting people with dementia and their family in ACP [28]. It could support them in actually starting to think about ACP [29, 30]. Moreover, the participants in our study suggested that the inclusion on the website of an interactive conversation starter would be useful in supporting people with dementia and their family caregivers to start talking about ACP. The use of interactive conversation starters to support discussions between a person with dementia and their family caregivers has already



been used successfully in other domains (such as reminiscence therapy) and might stimulate meaningful conversations [31, 32].

Moreover, most participants in this focus group study stressed that whether or not someone engages in ACP depends on their readiness to think and talk about these difficult topics. Some people may not be ready to start an ACP discussion, and this readiness to engage in ACP can differ between the person with dementia and their family caregiver. The various needs in the timing of ACP – where some people with dementia only want to focus on day-to-day challenges and others want to start planning as soon as possible – is also shown in earlier studies [8, 20, 33, 34]. Therefore, information on the website should emphasise the possible differences in readiness, and the structure of the ACP website should allow users to access all parts of the website without having to follow a predefined chronological structure. This means that the users should have certain flexibility in navigating through the ACP website and should be able to use it at their own pace. However, existing ACP tools often use a predetermined path or step structure to go through the tool [18]. Although these existing ACP tools use a login system to try to provide flexibility by offering the option to ‘leave and return’ [18], participants in this study did not recommend using this functionality as it was deemed too difficult to use. These findings again show the importance of considering the end-user when developing new web-based tools.

Most of the participants in our study were convinced that functionalities should only be used if they benefit the accessibility and usability of the website. Three important functionalities were mentioned: a text-to-speech option, a print option, and the possibility of increasing the font size. Two of these functionalities (the print option and the option to increase the font size) are also recommended by the Alzheimer Association as important functionalities to consider when developing technology for people with dementia [35]. However, the use of text-to-speech is relatively uncommon on ACP websites. A recent systematic review that identified 30 ACP support tools that are publicly available for anyone to use and found that only 3 used a text-to-speech option [18]. However, using text-to-speech could increase the accessibility of a website for people with cognitive disabilities, as content can be presented in multiple modalities and be altered to the needs of the user [36].

Lastly, many participants indicated that people with dementia and family caregivers who want to conduct ACP conversations might, in many cases, not search for the website. [8, 13, 14]. For this reason, healthcare professionals’ organisations should be stimulated to guide people

to the website during consultations or via various media. This finding aligns with the known barriers for the initiation of ACP in dementia [37].

### *Strengths and limitations*

This study contributes to the limited research on the needs of people with dementia and their family caregivers regarding ACP [27], and this study is the first to assess the needs and preferences regarding a website to support people with dementia and their family caregiver(s) in ACP. In this focus group study, we included family caregivers of various ages and with varying relationships to the person with dementia and healthcare professionals from different disciplines involved in dementia care. We also evaluated barriers to, and facilitators for, finding and using the ACP website to anticipate possible barriers to implementation. From previous research, we know implementation of web-based tools in ageing populations is difficult [38]; and a recent systematic review of implementation of eHealth interventions for informal caregivers of people with dementia showed again the importance of thinking ahead about implementation in the real world [39]. This study also has some limitations. Because we did not have a prototype of the website yet and this study was a first abstract exploration of possible needs to support ACP via a web-based tool in a family context, we did not include people with dementia [21]. Our aim was first to get a general impression of the possible contents of the website to develop a prototype after. This is also recommended in literature on technology developed for people with dementia [21]. We included people with dementia in the development of the website prototype, and we used their valuable feedback to adapt content and functionalities of the website [21]. For the developed we utilised an agile development approach, including a user-centred design [21]. This way, the input of people with dementia and their family caregivers was central in the developed process of the website. Second, although we considered focus groups the most appropriate method for this study, the fact that we had to conduct them online may have influenced the interaction between participants.

## **CONCLUSION**

This study provides valuable insights from family caregivers and healthcare professionals regarding the content of an interactive website for people with dementia and their family caregivers, its delivery, potential barriers and facilitators for findings, and the use of the website to support ACP. Participants stressed the importance of comprehensive ACP information, testimonials, and interactive conversation starters. Flexibility in navigating through the website was deemed crucial so users could use the website at their own pace.

Moreover, healthcare professionals are important in guiding potential users to the website. While the study lacked direct input from people with dementia, their perspectives will be taken into account in the development phase of the website. In conclusion, this study provides a framework for an ACP website tailored to the needs of people with dementia and caregivers.

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## **CHAPTER 3**

### **THE CULTURAL ADAPTATION OF THE GO WISH CARD GAME FOR USE IN FLANDERS, BELGIUM: A PUBLIC HEALTH TOOL TO IDENTIFY AND DISCUSS END- OF-LIFE PREFERENCES.**

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## ABSTRACT

*Background:* Public health tools like the Go Wish card game from the US, have been found useful to support people in reflecting on their end-of-life preferences, but a cultural adaptation is essential for their success. In the present study, we explore the necessary cultural adaptations to the Go Wish cards by applying an extensive, systematic, and community-engaging negotiating procedure to facilitate the use of the cards in the general population of Flanders, Belgium.

*Methods:* We used an iterative cultural adaptation process with repeated discussions with various community organizations and representatives of minority and religious groups. After that, the cards were evaluated by 12 healthcare professionals in relation to: linguistic equivalence to the original version, applicability, comprehensibility, and relevance per card. Additional testing with potential users preceded final adjustments.

*Results:* We found that stakeholders were keen to engage throughout the process of cultural adaptation and we were able to make a range of cultural adaptations for the use of the cards in Flanders. All original statements were rephrased from passive to more active statements. Sixteen out of 36 cards were adjusted to make them more culturally appropriate for use in Flanders, e.g., “to meet with clergy or a chaplain” to “having a spiritual counselor as support.” Three new cards were added: two with statements appropriate to the Belgian patient rights and euthanasia legislation and one extra Wild Card. Potential users (n=33) felt that the cards supported conversations about end-of-life preferences.

*Conclusion:* By making community engagement a cornerstone of our adaption process, we developed a card set that potential end-users considered a supportive public health tool for reflecting and discussing end-of-life values and preferences. The described process is particularly valuable for culturally adapt interventions, especially given that community engagement in adapting interventions is essential to creating grounded interventions.

## INTRODUCTION

The European Association for Palliative Care defined advance care planning (ACP) as a process that enables individuals to define goals and preferences for their future medical treatment and care (1). As noted in this definition, the focus of ACP is shifting from completing advance directives to an ongoing communication and decision-making process (1). Stimulating individuals to identify end-of-life preferences and wishes have been found to be beneficial for both the patient and their relatives (2–4). Recent systematic reviews found that individuals who discussed and documented their wishes were more likely to receive their desired end-of-life care (3,5), and relatives who served as surrogate decision-maker felt it was easier to make decisions since relevant issues had been discussed (4).

Games have been shown to lower reluctance and resistance when discussing potentially uncomfortable topics such as death, dying, and end-of-life care (6) and can thus be helpful in supporting individuals in thinking and talking about ACP and end-of-life values and preferences. One card game that has shown positive results in stimulating discussion in various studies is the American Go Wish card game (developed the mid 90s by Coda Alliance, a U.S.-based non-profit organization) (7–18). The card game consists of preformulated statements to initiate and support ACP discussions by identifying values and preferences about end-of-life issues and death and dying. The Go Wish cards have been tested in the United States, e.g., with patients on inpatient services (13) and with patients with mild cognitive impairment (11). Moreover, the Go Wish game has been translated and adapted from its source context to use in other groups, e.g., with parents of children with a life-threatening illness (14), as a teaching tool with medical students (10) and in other cultures, e.g., in Sweden, France, China (7,8,15–17,19–24).

The cultural adaptation of public health tools like the Go Wish card game is likely to be vital for their success (7,20,25), as topics like end-of-life care and death and dying are strongly linked to culture and context (26,27). Research indicates that culture affects perceptions of health conditions, appropriate treatments, and responses to illness and death (28), aspects of particular importance when thinking and talking about ACP and end-of-life values and preferences. Furthermore, legal contexts can influence people's thoughts about end-of-life care and death and dying. For instance, in countries where euthanasia was introduced, such as Belgium, there is a substantial relative increase in euthanasia acceptance (29).

Although the literature suggests that cultural adaptation rather than a direct linguistic translation alone is necessary (7,25), adaptations have not always been performed as comprehensively as might be desired (30). The target population of the intervention is not always actively involved. However, this has been found to yield improvement in usability and ensure that the adapted version is tailored to the needs of prospective end-users (31–33). Moreover, it is essential to consider the way researchers, healthcare professionals, and representatives of community organizations are biased in perceptions of how people may think and talk about topics like ACP and end-of-life values and preferences (34,35). Therefore, community engagement, where critical actors like individuals, healthcare professionals, and other relevant stakeholders are closely involved throughout the adaptation process, is important for the future success of the adapted intervention (36–38).

In the present study, we explore cultural adaptations to the Go Wish cards determined through an extensive, systematic, negotiated procedure with a wide variety of community stakeholders and pretesting with potential end-users to facilitate the use of the cards in the general population of Flanders, Belgium.

## **METHODS AND MATERIALS**

### *Study context*

Belgium is a federal state consisting of three culturally different communities: Flanders, the Dutch-speaking northern part of the country which makes up 56% of the population; Wallonia, the southern French-speaking part of the country with 43.5% of the Belgian population and the German-speaking community in the east where 0.5% of the population lives (39). In the past years, the Federal authorities have delegated some forms of autonomous responsibility to these communities, e.g. care for older people who are older or disabled, mental health care, primary care, rehabilitation, health promotion, and disease prevention. While we have made three versions of the Go Wish cards, a Dutch, Walloon, and German one, for use in Belgium, we only discuss the Flemish adaptation here because the lessons learned from this adaptation process provided a model for the other translation processes.

### *Materials*

The original English-language *Go Wish card game* contains 36 cards with 35 single statements that illustrate a behavioral choice or situation based on Steinhauser et al.'s seminal study (40). The remaining card is a blank 'wild' card with no pre-printed statement to

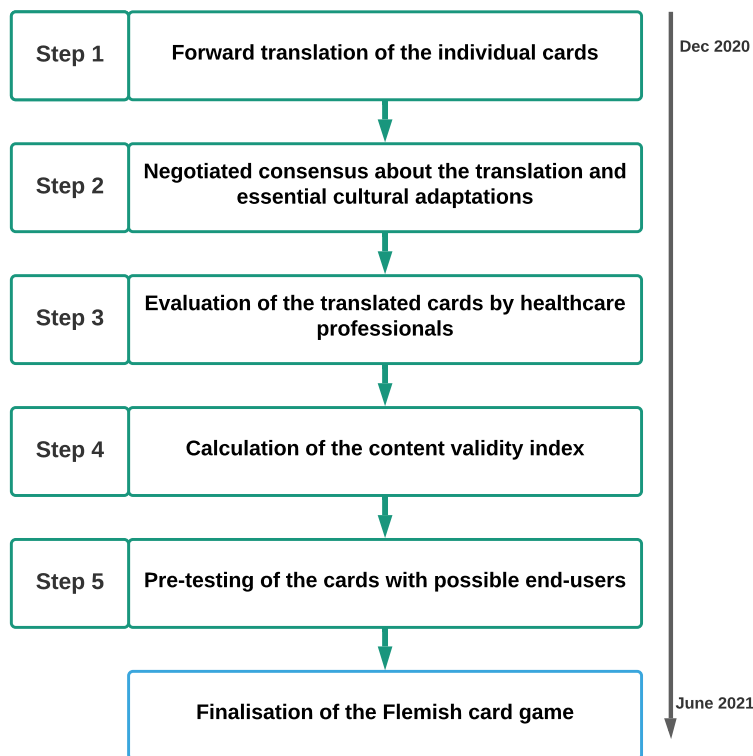
allow for other possible issues of importance. The cards can be used in various ways, but original instructions ask users to read through the cards and sort them into three piles: very important, somewhat important, and not important. After that, users are asked to re-examine their “very important” pile, choose their 10 most important cards and rank these from one to 10, with 1 being the most important.

### *Study design and procedure*

We followed the structured, multistep process for cultural adaptation used by McGreevy et al (2014) (41). Each of the five steps in this process is complementary to the others with the aim of eliciting factors of cultural and linguistic significance through discussion with various stakeholders (Figure 1).

Additionally, because we aimed to develop a community-based card game for the large and heterogeneous population of all adult individuals with or without life-threatening illness in Flanders, we wanted to ensure that as many perspectives as possible were represented in the cultural adaptation process. To assure inclusion of community perspectives, we formed a reference group consisting of researchers, representatives of the fund Landsbond der Christelijke Mutualiteiten (non-profit health insurance), and representatives of Flemish organizations working with dementia, cancer, family caregivers, end-of-life care, and senior citizens. Representatives were identified via the researchers’ professional networks based on the following criteria: 18 years or above, fluent in Dutch, have a good understanding of English, and have an interest in ACP. This reference group was consulted during steps 2 and after step 5 (Figure 1) of the cultural adaptation process.

Figure 1 – overview of the cultural adaptation process (41).



#### *Step 1: Forward translation*

Four researchers each individually completed a preliminary forward translation of all Go Wish cards. Three of these researchers have Dutch as native language, are educated in Flanders, and are fluent in English, while one is a native American English speaker with Dutch as second language. After the translation, one of the four researchers (CD) summarized and compared all four translations and differences were discussed card-by-card by the four researchers in an online meeting until consensus for all cards was reached.

#### *Step 2: Negotiated consensus about the translation and essential cultural adaptations*

In this step, we involved the reference group as well as other strategically selected groups in the process of negotiating consensus on the translation and adaptations. Firstly, the original English-language and Flemish cards translations were sent by email to the members of the reference group. They were asked to comment via email on the translation, the linguistic equivalence of the translated cards to the original cards, the proposed Flemish card game name and to suggest cultural adaptations that they considered essential for use of the cards in Flanders. Cards receiving one or more comments on the translation or on essential cultural adaptations, as well as the proposed Flemish card game name were deliberated upon in

online Zoom meetings with the reference group until consensus was reached. After reaching consensus within the reference group as described above, we asked representatives of organisations of people affected by structural vulnerabilities (e.g. ethnic minorities, immigrants, poverty) and representatives of Christianity, Judaism, Islam, the three major religions in Flanders to reflect on the cultural appropriateness of the cards to ensure that the phrases on the cards were open enough, did not exclude or were offensive to minority groups, and avoided systematic bias in relation to particular groups or communities. Representatives were asked to comment on both the translation and cultural appropriateness of each card in one-on-one online meetings with the researcher (CD). This feedback was used to adapt the preliminary version of the Flemish card deck.

#### *Step 3: Evaluation of the translated cards by healthcare professionals*

We evaluated the translated and adapted cards by surveying a variety of healthcare professionals with experience in end-of-life care. Healthcare professionals were recruited by a call via email and social media through the professional networks of the researchers and reference group members, requesting active volunteering with the following inclusion criteria: 18 years or above, fluent in Flemish, good understanding of English, and interest in ACP. When healthcare professionals responded to the recruitment call, the researcher (CD) sent them an email with an information letter and a link to an online consent form and online questionnaire. After consenting, the healthcare professionals could access the questionnaire (example in appendix 1) and were asked to evaluate the card deck, its linguistic equivalence to the original version, as well as applicability, comprehensibility, and relevance per card on a four-point score (for example for relevance: 1= Not relevant; 2 = Somewhat relevant; 3 = Quite relevant; 4 = Highly relevant) and through open responses to comment on their scores.

#### *Step 4: Calculation of the content validity index*

We calculated the content validity index (CVI) to measure inter-rater agreement per card for four criteria: linguistic equivalence to the original version, applicability, comprehensibility, and relevance based on the scores derived in Step 3. We calculated the item CVI (I-CVI) for each criterion per card based on the evaluation of the healthcare professionals in Step 3. The I-CVI is the number of healthcare professionals rating a criteria as 3 or 4 on the four-point scale (thus for relevance: 3 = quite relevant; 4 = very relevant) and therefore the proportion of experts giving a positive rating (41–43). The number of recommended experts to complete the questionnaire is approximately 8 to 12, because when the number of experts grows larger, the probability of chance agreement diminishes (41–43). The minimum recommended

I-CVI is 0.78, with 0.90 or higher being considered as an excellent score (41–43). We calculated the I-CVI scores in Excel by dividing the number of healthcare professionals who rated a card positively, i.e. as quite or highly equivalent, relevant, applicable, or comprehensible by the total number of healthcare professionals who evaluated the card.

#### *Step 5: Pre-testing of the card game with potential end-users*

We assessed and pre-tested the preliminary negotiated Flemish version of the card game with potential end-users. We recruited participants through the networks of the reference group who disseminated a recruitment call via email, their member magazines, newsletters, websites, and social media, using the following inclusion criteria: 18 years or older, fluent in Dutch, able to give informed consent to participate in the study and adequate computer-literacy to participate in an online group discussion. Those interested in participating were asked to send an email to the researcher (CD), who sent further information about the study after verifying participant's eligibility, and asked them to confirm participation by signing an online informed consent form.

Because of the COVID-19 restrictions, we organized both online and in-person group discussions and participants were given the choice of how they wanted to participate. Participants received an invitation to one of the group discussions which were arranged based on homogeneity within groups (e.g. participant being a family caregiver, patient, being retired, etc.). Participants were invited to the (online) group discussion after providing informed consent. Each participant received the preliminary version of the card game by postal mail and was asked to try the card game before joining the group discussion. During the group discussions, the moderator asked participants to comment on the language used in the cards, give feedback and suggest adaptations when relevant. Participants were also asked to share which cards they considered most important for themselves. At the end of each group discussion, the moderator presented the cards that had an I-CVI score of  $<0,78$  (based on the feedback of healthcare professionals in step 4) and asked the participants if and how these cards should be adapted. All group discussions were recorded and took place between April and May 2021. Recruitment of participants continued until data saturation was reached, defined as the point at which no remarks emerged.

For each group discussion, participant feedback was summarized both question-by-question and card-by-card, and in relation to the cards each participant considered most important for themselves. Additionally, the observer made detailed notes of participants' answers,

comments, and body language. These detailed notes were analysed inductively to derive suggestions to improve the cards.

#### *Finalisation of the Flemish card game*

We used the feedback from steps 3 and 5 to make a list of suggested changes to the cards. All cards with a I-CVI <0,78 (Step 4) were added to the list with the comment that the cards scored relatively low on inter-rater agreement along with the participants' comments for these cards. This list was sent via email to the reference group with a request to approve or dismiss suggested adaptations per card, and/or suggest other changes. When consensus was reached on all adaptations, the translation and adaptation of the card game was finalized.

#### *Ethics*

Research ethics approval was granted via the Ethical Review Board of Brussels University Hospital of the Vrije Universiteit Brussel (BUN: 1432020000317). All methods were carried out in accordance with relevant guidelines and regulations in the declaration. Informed consent was obtained without coercion and only participants who signed an informed consent were included in the study. The cultural adaptation was carried out through a collaboration between the End-of-life Care Research Group of the Vrije Universiteit Brussel and the Landsbond der Christelijke Mutualiteiten (non-profit health insurance).

## **RESULTS**

As Step 1 entailed the original translation only, we present the results of each step, beginning with Step 2

#### *Step 2: Negotiated consensus about the translation and essential cultural adaptations*

After the four researchers reached consensus, the reference group members (n=11) evaluated the preliminary translation. Fourteen of the 36 cards were accepted as they were, without comments (Table 1). The other 22 cards were discussed one-by-one in the first reference group meeting to seek consensus on the translation and wording, leading to acceptance of the suggested translation of an additional eight cards. For four cards, the reference group proposed slight adaptations to better suit the Dutch way of speaking in Flanders. Ten cards were adjusted for cultural reasons (See Table 1). For example, "to be able to share my accomplishments" was changed to "being able to share my memories" since members of the reference group believed people tend to share memories instead of what they have achieved (Card 9). Also, members of the reference group thought funeral



("uitvaart" in Dutch) was a difficult term, and they therefore changed the card "to have my funeral arrangements made" to "arrange my burial (in Dutch "begravenis") in advance" (Card 34). In Flanders the term "begravenis", while literally translated as burial, is often colloquially used even for related ceremonies. Lastly, a general comment was that the translation of "to be" into Dutch was too passive and there was consensus in the group to formulate all statements more actively (Table 1).

In the second reference group meeting, we discussed the possibility of adding or removing cards. It was unanimously decided to add a statement related to the legal framework for end-of-life care in Belgium (i.e. the right to choose one's own end of life, including euthanasia). Although some members wanted to explicitly mention the word 'euthanasia', others preferred a more general formulation. Consensus was reached to add two cards: "A self-chosen end-of-life" (card 36) and "being able to record my choices" (card 37). Furthermore, members suggested adding a second "wild card" to give users the opportunity to formulate their own wishes (Table 1). Cards 24 and 27 "to be in peace with god" and "to pray" led to discussions as to whether their religious-focus was appropriate or not. It was decided to keep these cards in the deck, as religion is important for some people when talking about and considering end-of-life preferences. No cards were removed from the deck because all original cards were considered relevant in Flanders. The reference group also decided the card game would be called "*Levenswensen kaartspel*" (In English: "Life Wishes card game").

Based on feedback from representatives of organizations of people who might be affected by structural vulnerabilities and various religions, translations of six card were revised (see Table 1). Most comments here were related to the use of specific words and formulations. For example, Card 34 had been changed by the reference group as described above, but one religion's representative opposed the change from 'uitvaart' to 'begravenis', arguing that it was less inclusive, as it could be interpreted as excluding cremation. This comment was supported by representatives of organizations of people affected by structural vulnerabilities who often use the term "uitvaart" as funeral insurance is often important to avoid their next of kin having to pay for the funeral. Also, the reference group proposed to write the word "god" in Card 27 without a capital letter to indicate any kind of "God". However, one representative of a religion disagreed, saying that "God" should be written with a capital letter since in this context it functions as a name. Moreover, whereas the reference group suggested reformulating Card 9, two representatives of people affected by structural vulnerabilities emphasized the importance of accomplishments for people affected by

structural vulnerabilities. They suggested that both words (i.e. memories and accomplishments) be included (see Table 1). The representatives of people affected by structural vulnerabilities and various religious groups concluded that the other cards were inclusive enough and would not be offensive for anyone. This feedback was presented to members of the reference group, who agreed with the suggested adjustments and this new version of the deck was accepted.

*Table 1 – Overview of adaptations by card and step*

|           | Ordinal cards                                                        | Adaptation after Step 2<br>(reference group)                                  | Adaptation after Step 2<br>(organizations structural<br>vulnerabilities and religions) | Adaptations before<br>final version |
|-----------|----------------------------------------------------------------------|-------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|-------------------------------------|
| <b>1</b>  | To be free of pain                                                   | Not being in pain*                                                            |                                                                                        |                                     |
| <b>2</b>  | Not being short of<br>breath                                         | Not being short of<br>breath*                                                 |                                                                                        |                                     |
| <b>3</b>  | To be kept clean                                                     | Being neat and clean                                                          |                                                                                        | Being neat and tidy                 |
| <b>4</b>  | To be free of anxiety                                                | Not being afraid                                                              |                                                                                        |                                     |
| <b>5</b>  | To have human touch                                                  | Having physical<br>contact                                                    |                                                                                        |                                     |
| <b>6</b>  | To have my family<br>prepared for my death                           | That my family is<br>prepared for my death*                                   |                                                                                        |                                     |
| <b>7</b>  | To die at home                                                       | Dying at home*                                                                |                                                                                        |                                     |
| <b>8</b>  | To say goodbye to<br>important people in<br>my life                  | Being able to say<br>goodbye to my loved<br>ones                              |                                                                                        |                                     |
| <b>9</b>  | To remember<br>personal<br>accomplishments                           | Sharing my memories<br>with others                                            | Being able to share my<br>memories and<br>accomplishments with others                  |                                     |
| <b>10</b> | To take care of<br>unfinished business<br>with family and<br>friends | Being able to take care<br>of unfinished business<br>with family and friends* |                                                                                        |                                     |
| <b>11</b> | To be treated the way<br>I want                                      | Being treated the way I<br>would want to be<br>treated*                       | Being treated the way I wish to<br>be treated                                          |                                     |
| <b>12</b> | To maintain my<br>dignity                                            | Keeping my dignity*                                                           |                                                                                        |                                     |
| <b>13</b> | To keep my sense of<br>humour                                        | Keeping my sense of<br>humor*                                                 |                                                                                        |                                     |
| <b>14</b> | To have close friends<br>near                                        | Being surrounded by<br>good friends*                                          |                                                                                        |                                     |

|    |                                                                 |                                                           |                                             |                                                          |
|----|-----------------------------------------------------------------|-----------------------------------------------------------|---------------------------------------------|----------------------------------------------------------|
| 15 | To have someone who will listen to me                           | Having someone who listens to me*                         |                                             |                                                          |
| 16 | Not being a burden to my family                                 | Not being a burden to my family*                          |                                             |                                                          |
| 17 | To be able to help others                                       | Being able to mean something for someone else             | Being able to do something for someone else |                                                          |
| 18 | To be able to talk about what scares me                         | Being able to talk about what scares me*                  |                                             |                                                          |
| 19 | To have my family with me                                       | Being surrounded by my family*                            |                                             |                                                          |
| 20 | To feel that my life is complete                                | Feeling that my life is complete*                         |                                             |                                                          |
| 21 | To have a doctor who knows me as a whole person                 | That the doctor sees me as a whole person*                |                                             |                                                          |
| 22 | Not dying alone                                                 | Not dying alone*                                          |                                             |                                                          |
| 23 | To be mentally aware                                            | Be clear-headed                                           |                                             |                                                          |
| 24 | To pray                                                         | Being able to pray*                                       |                                             |                                                          |
| 25 | To meet with clergy or a chaplain                               | Having a philosophical counsellor                         | Having a spiritual counselor as support     |                                                          |
| 26 | To be able to talk about what death means                       | Being able to talk about death*                           |                                             |                                                          |
| 27 | To be at peace with God                                         | Be at peace with god                                      | Be at peace with God                        |                                                          |
| 28 | To have my financial affairs in order                           | Getting my financial affairs in order*                    |                                             |                                                          |
| 29 | To know how my body will change                                 | Knowing how my body will change*                          |                                             | Knowing how my body and mind will change                 |
| 30 | To prevent arguments by making sure my family knows what I want | Avoid discussions by ensuring my family knows what I want |                                             |                                                          |
| 31 | To have an advocate who knows my values and priorities          | Having someone to represent my values and priorities      |                                             | Having someone to speak up for what I think is important |
| 32 | To trust my doctor                                              | Being able to trust my doctor*                            |                                             |                                                          |

|    |                                         |                                                          |                               |                                                  |
|----|-----------------------------------------|----------------------------------------------------------|-------------------------------|--------------------------------------------------|
| 33 | To have a nurse I feel comfortable with | Having a healthcare professional I feel comfortable with |                               |                                                  |
| 34 | To have my funeral arrangements made    | Arrange my burial in advance                             | Arrange my funeral in advance |                                                  |
| 35 | Not being connected to machines         | Not being dependent on machines*                         |                               | Not being dependent on machines to keep me alive |
| 36 |                                         | A self-chosen end of life                                |                               | Being able to choose when and how I die          |
| 37 |                                         | Being able to record my choices                          |                               |                                                  |
| 38 | Wild Card                               | Joker                                                    |                               |                                                  |
| 39 |                                         | Joker <sup>a</sup>                                       |                               |                                                  |

1: Approximated translation to English for this article only. English translation is a forward translation of the final Flemish cards. Appendix 3 elaborates on this Table to include details about reasoning underlying changes

\* was accepted as it was (translation in Step 1), with no comments by the reference group on the translation

A = card was added

B = extra wild card next to the original one

C = wording has been slightly adapted to better suit the Dutch way of speaking in Flanders.

### *Step 3: Evaluation of the translated cards by healthcare professionals*

The card deck was reviewed by 12 healthcare professionals (General Practitioner n=2, psychologist n=2, social worker n=2, psychotherapist n=1, coordinator of local end-of-lifecare center n=1, head nurse palliative care unit n=1, care developer n=1, occupational therapist n=1, and employee of dementia organization n=1). All 12 healthcare professionals completed the questionnaire and made suggestions for improvements. For example, seven healthcare professionals commented the word “proper” (which can be translated to “clean”) in Card 3. In Flanders the word “proper” (English “clean”) is more used for an object rather than for personal hygiene. They therefore suggested to adjust it to “verzorgd” (“tidy” or “well-groomed”) since reference is made to being orderly in appearance. Six healthcare professionals found item on Card 9 too long and would have formulated it differently themselves (e.g. reflect on my achievements in life). Also, the new Card 36, “a self-chosen end of life”, was unclear to five healthcare professionals who also indicated that this wording may give an incorrect impression as a self-chosen end-of-life may not always be possible. The adaptations made in this step will be presented under 'finalization of the cards'

#### Step 4: Content validity index

Twenty-eight of the 38 cards had a CVI score of >0.78 on all four criteria (e.g. linguistic equivalence to the original version, applicability, comprehensibility, and relevance), of which 20/28 scored >0.90 on all four criteria (Table 2). Three cards scored <0,78 on linguistic equivalence, eight cards scored <0,78 on understandability, five cards scored <0,78 on relevance and six cards scored <0,78 on applicability in context. Only Card 9 scored <0,78 on all four criteria.

Table 2 – Overview of four I-CVI<sup>a</sup> scores per card

| Card Nr. | Step 2 adapted cards                                                   | Linguistic equivalence | Understandability | Relevance | Applicability in context |
|----------|------------------------------------------------------------------------|------------------------|-------------------|-----------|--------------------------|
| 1        | Not being in pain                                                      | 0,92                   | 0,92              | 0,92      | 0,92                     |
| 2        | Not being short of breath                                              | 1,00                   | 1,00              | 0,91      | 0,92                     |
| 3        | Being neat and proper                                                  | 0,75*                  | 0,58*             | 0,83      | 0,58*                    |
| 4        | Not being afraid                                                       | 1,00                   | 1,00              | 0,92      | 0,91                     |
| 5        | Having physical contact                                                | 0,92                   | 0,92              | 0,83      | 0,75                     |
| 6        | That my family is prepared for my death                                | 1,00                   | 0,92              | 0,91      | 0,83                     |
| 7        | Dying at home                                                          | 1,00                   | 1,00              | 1,00      | 1,00                     |
| 8        | Being able to say goodbye to my loved ones                             | 1,00                   | 1,00              | 1,00      | 1,00                     |
| 9        | Being able to share my memories and accomplishments with others        | 0,67*                  | 0,58*             | 0,75*     | 0,75*                    |
| 10       | Being able to take care of unfinished business with family and friends | 0,83                   | 0,82              | 0,83      | 1,00                     |
| 11       | Being treated the way I wish to be treated                             | 0,92                   | 0,92              | 1,00      | 1,00                     |
| 12       | Keeping my dignity                                                     | 1,00                   | 0,91              | 1,00      | 1,00                     |
| 13       | Keeping my sense of humor                                              | 1,00                   | 1,00              | 0,92      | 0,83                     |
| 14       | Being surrounded by good friends                                       | 0,92                   | 0,92              | 1,00      | 1,00                     |
| 15       | Having someone who listens to me                                       | 1,00                   | 1,00              | 1,00      | 1,00                     |
| 16       | Not being a burden to my family                                        | 0,92                   | 1,00              | 0,91      | 1,00                     |
| 17       | Being able to do something for someone else                            | 0,75*                  | 0,83              | 0,92      | 0,83                     |
| 18       | Being able to talk about what scares me                                | 0,91                   | 0,92              | 1,00      | 1,00                     |
| 19       | Being surrounded by my family                                          | 1,00                   | 0,92              | 1,00      | 1,00                     |
| 20       | Feeling that my life is complete                                       | 0,83                   | 0,92              | 1,00      | 1,00                     |
| 21       | That the doctor sees me as a whole person                              | 0,83                   | 0,83              | 0,92      | 0,92                     |
| 22       | Not dying alone                                                        | 1,00                   | 0,92              | 1,00      | 1,00                     |

|       |                                                           |      |       |       |       |
|-------|-----------------------------------------------------------|------|-------|-------|-------|
| 23    | Be clear-headed                                           | 1,00 | 1,00  | 1,00  | 1,00  |
| 24    | Being able to pray                                        | 1,00 | 1,00  | 0,75* | 0,75* |
| 25    | Having a spiritual counselor as support                   | 0,92 | 0,75* | 1,00  | 0,83  |
| 26    | Being able to talk about death                            | 1,00 | 1,00  | 1,00  | 1,00  |
| 27    | Be at peace with God                                      | 1,00 | 0,92  | 0,67* | 0,50* |
| 28    | Getting my financial affairs in order                     | 1,00 | 0,92  | 1,00  | 1,00  |
| 29    | Knowing how my body will change                           | 1,00 | 0,75* | 0,75* | 0,75* |
| 30    | Avoid discussions by ensuring my family knows what I want | 0,92 | 1,00  | 0,92  | 1,00  |
| 31    | Having someone to represent my values and priorities      | 0,83 | 0,67* | 1,00  | 0,92  |
| 32    | Being able to trust my doctor                             | 1,00 | 1,00  | 1,00  | 1,00  |
| 33    | Having a healthcare professional I feel comfortable with  | 1,00 | 1,00  | 0,83  | 0,92  |
| 34    | Arrange my funeral in advance                             | 1,00 | 1,00  | 1,00  | 1,00  |
| 35    | Not being dependent on machines                           | 0,83 | 0,75* | 0,92  | 0,92  |
| 36    | A self-chosen end of life                                 | n/a  | 0,67* | 0,91  | 0,83  |
| 37    | Being able to record my choices                           | n/a  | 0,67* | 1,00  | 0,83  |
| 38/39 | Joker                                                     | 0,92 | 1,00  | 1,00  | 1,00  |

Item Content Validity Index: the inter-rater agreement per card for the four criteria: linguistic equivalence to the original version, applicability, comprehensibility, and relevance

\* scored below the minimum recommended I-CVI score of 0.78

### Step 5: Pre-testing

In total, 33 individuals between the ages of 35 and 92 participated in the pre-testing of the cards in this step. These individuals received and tested the adapted card set derived from Step 2. Nineteen people participated in six online group discussions: two group discussions were held with cancer survivors (n=4), two with family caregivers (n=6), two with retirees (n=9). Fourteen people participated in four in-person group discussion: two with people from two community centers for people affected by structural vulnerabilities (n=6) and two with nursing home residents (n=8). Four participants in this last group had mild or moderate dementia.

All participants in pre-testing indicated that the cards were user-friendly and assisted them in thinking and talking about end-of-life values and preferences. Twenty-nine of the 33 participants were able to sort the cards into three piles (i.e. very important, important, not important), and choose their top 10 priorities. Only the participants with dementia found ranking the cards into a top 10 list of their priorities too difficult.

The 12 cards with an I-CVI <0,78 score were discussed in all groups excepting those with nursing home residents. Participants said Cards 31 (n=9), 35 (n=7) and 36 (n=7) were unclear and suggested rephrasing and simplifying them, but considered them important to include in the deck because of the legal framework in Belgium. For example, several participants said they would want to be connected to machines (Card 35), but not to be kept alive when without prospect of improvement. They therefore suggested rewording Card 35 to “not being dependent on machines that keep me alive”. Moreover, six people affected by structural vulnerabilities said the cards regarding religion and God were the most important cards for them and they were pleased that these cards were in the deck. Two family caregivers of people with dementia and two nursing home residents suggested adding “and mind” to Card 29 as they considered this an important addition for people with cognitive diseases. Sixteen participants mentioned that when testing the card game, they used the wild card to add statements, for example the statement “*my animals are taken care of*”. All participants found that the card set was complete without suggestions for adding or omitting cards. Twelve participants did however suggest revising the name of the card deck “*Levenswensen kaartspel*” (Life Wishes Card Game) to *Levenswensen kaarten* (Life Wishes Cards) as the word “game” was considered inappropriate.

#### *Finalisation of the Flemish card game*

Based on the feedback of the healthcare professionals in Step 3 and the feedback of participants in Step 5, we made suggestions for adjustments of the 12 cards with an I-CVI score of <0,78 on one of the four criteria (table 3). The suggestions for adjustments were submitted to the reference group (via email), who in consensus decided to accept five adaptations. Reasons for the suggested adaptations are summarized in table 3. An overview of the final version of the Flemish cards can be found in Appendix 3

*Table 3 – Overview feedback Step 3 and Step 5 and the finalization of the Flemish card game.*

| Card Nr. | Cards                     | Summery feedback step 3                                                      | Summery feedback step 5                                                                                                           | Suggested changed   | Accepted/ not accepted |
|----------|---------------------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------|---------------------|------------------------|
| 1        | Not being in pain         |                                                                              |                                                                                                                                   |                     |                        |
| 2        | Not being short of breath |                                                                              |                                                                                                                                   |                     |                        |
| 3        | Being neat and proper*    | can be understood as "keeping an object clean" rather than personal hygiene. | Proper is a word used in a “having a clean house” context. Suggest to change to something to underline it is about person hygiene | Being neat and tidy | Accepted               |

|    |                                                                        |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
|----|------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|--|
| 4  | Not being afraid                                                       |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 5  | Having physical contact*                                               | Unclear what kind of physical touch and if users would understand, but there were no problems about if the card was clear.                                                                        | No comments. Card was perceived as very clear and important. | No changes were suggested since the card was perceived as straightforward and essential by potential users.                                  |  |
| 6  | That my family is prepared for my death                                |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 7  | Dying at home                                                          |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 8  | Being able to say goodbye to my loved ones                             |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 9  | Being able to share my memories and accomplishments with others*       | Need for rewriting this card according to some health professionals as it should be more about “sharing life stories with others” as sharing “accomplishments” is not that important in Flanders. | No comments. Participants choose this card regularly.        | No changes were suggested since the card was perceived as essential. Moreover, “share accomplishments” was perceived as important in step 2. |  |
| 10 | Being able to take care of unfinished business with family and friends |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 11 | Being treated the way I wish to be treated                             |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 12 | Keeping my dignity                                                     |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 13 | Keeping my sense of humor                                              |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 14 | Being surrounded by good friends                                       |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 15 | Having someone who listens to me                                       |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 16 | Not being a burden to my family                                        |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 17 | Being able to do something for someone else*                           | Some healthcare professionals had comments about the translation since they felt this card was about “helping” and found “do something” too vague.                                                | No comments.                                                 | No changes were suggested since the card was perceived as clear.                                                                             |  |
| 18 | Being able to talk about what scares me                                |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 19 | Being surrounded by my family                                          |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |
| 20 | Feeling that my life is complete                                       |                                                                                                                                                                                                   |                                                              |                                                                                                                                              |  |



|    |                                                           |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
|----|-----------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------|-----------|
| 21 | That the doctor sees me as a whole person                 |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 22 | Not dying alone                                           |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 23 | Be clear-headed                                           |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 24 | Being able to pray*                                       | Health professionals considered this card as not relevant for the context and suggested to widen the formulation of this card to "spirituality" | Potential users found this card very important.                                                                           | No changes were suggested since the card was perceived as important.                                                |           |
| 25 | Having a spiritual counselor as support*                  | Some healthcare professionals suggested to use another term for "spiritual counselor" as they thought this term was unclear.                    | Potential users found this card clear                                                                                     | Since the term "spiritual counselor" is accepted and used by the all involved religions, no changes were suggested. |           |
| 26 | Being able to talk about death                            |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 27 | Be at peace with God                                      |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 28 | Getting my financial affairs in order                     |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 29 | Knowing how my body will change*                          | Unclear if it is about during or after life.                                                                                                    | For people living with dementia and their family caregivers it was also important to understand how the mind will change. | Knowing how my body and mind will change                                                                            | Accepted  |
| 30 | Avoid discussions by ensuring my family knows what I want |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 31 | Having someone to represent my values and priorities*     | Priorities could be a difficult word to use. Suggestion to change it to important things, values or preferences.                                | Potential users found the word priorities difficult and suggested to change this card.                                    | Having someone to speak up for what I think is important                                                            | Accepted. |
| 32 | Being able to trust my doctor                             |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 33 | Having a healthcare professional I feel comfortable with  |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 34 | Arrange my funeral in advance                             |                                                                                                                                                 |                                                                                                                           |                                                                                                                     |           |
| 35 | Not being dependent on machines*                          | Unclear what kind of machines. Suggestion to specify that kind of machines.                                                                     | Unclear what kind of machines. Some potential users said they wanted a machine for comfort but not to keep them alive.    | Not being dependent on machines to keep me alive                                                                    | Accepted  |

|       |                                  |                                                                                                                                                                                                                 |                                                                                                   |                                                                  |          |
|-------|----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------|------------------------------------------------------------------|----------|
| 36    | A self-chosen end of life*       | Though all healthcare professionals perceived this card as important, they found the formulation difficult. Some suggested to use the word “euthanasia” of “palliative sedation” as an example in the sentence. | Potential users found this sentence difficult. They suggested to reformulate it in a simpler way. | Being able to choose when and how I die                          | Accepted |
| 37    | Being able to record my choices* | Suggestion for more clarification for example “for the end of life”.                                                                                                                                            | No comments. Card was perceived as very clear and important.                                      | No changes were suggested since the card was perceived as clear. |          |
| 38/39 | Joker                            |                                                                                                                                                                                                                 |                                                                                                   |                                                                  |          |

\* scored on one of the criteria below the minimum recommended I-CVI score of 0.78

## DISCUSSION

We found that stakeholders were keen to engage throughout the cultural adaptation process, with no difficulties finding healthcare professionals and potential end-users to evaluate the cards. We were able to make a range of cultural adaptations for using the cards in Flanders through the involvement of various community stakeholders. As a result of this collaborative cultural adaptation process, all original Go Wish card statements were rephrased from passive statements (eg “to be” or “to have”) to more active statements. Sixteen cards were adjusted to make them more culturally appropriate for use in Flanders, two new cards were added with statements appropriate to the Belgian legal context in relation to patient rights and euthanasia, and an additional Wild Card was added. The card deck was named *Levenswensen kaarten* (Life Wishes cards).

We found differences among various stakeholder groups to be particularly noteworthy; some cards were found less applicable and relevant by members of the reference group, for example, “to pray”, “to be in peace with God” and “to share my accomplishments”, though these were found very important by representatives of people affected by structural vulnerabilities and various religious groups. This highlights the importance of a cultural adaptation process that involves different perspectives and considers contextual factors in developing interventions (7,25). However, there was consensus among members of the reference group from the onset that the Belgian euthanasia law and the right to record one’s own choices should be addressed in the cards. A previous similar cultural adaptation process of the Go Wish cards in Sweden, where euthanasia is not legal, showed that people who described euthanasia as important chose a wild card to formulate a statement on this

(7,8,16). In Belgium, the taboo on euthanasia is relatively low and the topic is often part of ACP conversations with physicians (29,44). However, the formulation and the terminology have been shown to influence an individual's preferences (30). A similar argument was made by the reference group, healthcare professionals, and potential end-users, which led to a decision to formulate the card more broadly than about euthanasia alone.

Most participants in Step 5's pre-testing of the cards were able to use them with little or no problems with the instructions; however people with dementia found it difficult to prioritize the cards. This is in line with Tishelman et al's finding that users with cognitive impairment found it difficult to rank "top 10" preferences from their "most important" card choices (7). Prioritizing preferences requires a high level of abstract reasoning, which may be difficult at times for people with dementia (45). However, people with dementia have been found to be able to express preferences and wishes, even at a more advanced stage (46,47) and the use of cards with preformulated statements can support them in this (48) .

Furthermore, this study shows community engagement as a fundamental component in the development of interventions (49,50). Throughout the cultural adaptation process we encountered several opposing arguments about possible adaptations but through repeated discussions with various stakeholders like community organizations and citizens, we managed to develop a card set which potential end-users considered a supportive public health tool for reflection and discussion about ACP and end-of-life values and preferences. Hence, in order to normalise conversations about death, dying, and end-of-life care in the community, it is important to involve a wide range of actors like individuals, healthcare professionals and other relevant stakeholders (36,37). Community engagement can lead to more grounded interventions that have the potential to be picked up more quickly by the community than interventions developed top-down (36–38). Moreover, community engagement may increase the capacity to talk about death, dying and end-of-life care which may set the stage to achieve a wider acknowledgement of palliative and end-of-life care as everyone's responsibility (39–41).

### *Strengths and limitations*

This study has several strengths. First, from the start of this adaptation process we strived to have strong community engagement which allowed us to include many perspectives using different methods throughout the adaptation process along with a negotiation process used to reach consensus. Second, we used the in-depth multistep process of cultural adaptation

developed by McGreevy et al (2014) that was originally developed to translate a taste and smell survey, but has been successfully used in other domains like cardiology (51) and palliative care (52,53), as well as to adapt the Go Wish cards in Sweden (7). This process of cultural adaptation including the community engagement can be replicated by others to successfully translate and adapt the Go Wish cards or other culturally-sensitive interventions to their own context. Based on the lessons learned from this adaptation process, we were able to develop a French (*Mes souhaits de vie*) and German (*Meine lebenswünsche*) version of the card game for use in the French and German speaking parts of Belgium, respectively.

This study also has some weaknesses. While collaboration with the “Landsbond der Christelijke Mutualiteiten” allowed us to ensure good community engagement, it should be noted that because residents of Belgium are free to choose a non-profit health insurance provider, we may have not reached all potential interested parties. Moreover, even though we used an open sampling strategy to reach many sub-groups in the community, it is difficult to include all possible perspectives in the large and heterogeneous Flemish population. Finally, it is important to recognize that this study does not evaluate the actual use of the card deck. Further research on how people use the cards and whether and what kind of support people need after using the cards is needed.

## **CONCLUSION**

Through a collaborative process with strong community engagement in which representatives of Flemish organizations working with dementia, cancer patients, family caregivers, end-of-life care and seniors, a health insurance fund, healthcare professionals and possible end-users were actively involved, we have adapted the English language Go Wish card game for use in Flanders. Sixteen cards from the original card deck were adapted for cultural reasons. Two cards and an extra wild card were added, resulting in a Flemish version with 39 cards. Possible end-users who tested the cards found them to be user-friendly and felt that the cards supported them in thinking and talking about their end-of-life preferences. To normalize thinking and talking about death, dying, and end-of-life care, community engagement in the adaption of interventions is important and can lead to more grounded interventions. Further research on how people use the cards and whether and what kind of support people need after using the cards is needed.

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## APPENDIX 1 – OVERVIEW OF REASONS FOR CULTURAL ADAPTATIONS

|   | Ordinal cards                                 | Final Flemish version (English translation)                     | Reason for adaptation                                                                                                                                                                                                                                                                                 |
|---|-----------------------------------------------|-----------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | To be free of pain                            | Not being in pain                                               | formulated without the expression “to be”                                                                                                                                                                                                                                                             |
| 2 | Not being short of breath                     | Not being short of breath                                       | formulated without the expression “to be”                                                                                                                                                                                                                                                             |
| 3 | To be kept clean                              | Being neat and tidy                                             | By the reference group (Step 2a), it was suggested that "kept" should be modified to "being" (in the moment) and to change the care depended aspect in "to be kept clean". Changed clean to tidy because clean can in Flemish also be interpreted an object being clean, or cleaning something.       |
| 4 | To be free of anxiety                         | Not being afraid                                                | wording has been slightly adapted to better suit the Flemish way of speaking                                                                                                                                                                                                                          |
| 5 | To have human touch                           | Having physical contact                                         | wording has been slightly adapted to better suit the Flemish way of speaking                                                                                                                                                                                                                          |
| 6 | To have my family prepared for my death       | That my family is prepared for my death                         | formulated without the expression “to be”                                                                                                                                                                                                                                                             |
| 7 | To die at home                                | Dying at home                                                   | formulated without the expression “to be”                                                                                                                                                                                                                                                             |
| 8 | To say goodbye to important people in my life | Being able to say goodbye to my loved ones                      | formulated without the expression “to be”                                                                                                                                                                                                                                                             |
| 9 | To remember personal accomplishments          | Being able to share my memories and accomplishments with others | The choice (by reference group in Step 2) has been made to drop achievements and use memories regardless of whether they are something one has achieved because its more about share your life story with others. However, the organizations working around structural vulnerabilities indicated that |

|    |                                                             |                                                                   |                                                                                                                                                                                                     |
|----|-------------------------------------------------------------|-------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|    |                                                             |                                                                   | "achievements" are actually very important to people because they are proud of them and like to share them. We therefore choose to use both words                                                   |
| 10 | To take care of unfinished business with family and friends | To be able to settle unfinished business with family and friends* | formulated without the expression "to be"                                                                                                                                                           |
| 11 | To be treated the way I want                                | Being treated the way I wish to be treated                        | The reference group (Step 2) wanted to reformulate this card to be less forcing. Suggestion for organizations working around minorities: "like to have" to "wish to have. its easier to understand. |
| 12 | To maintain my dignity                                      | Keeping my dignity                                                | formulated without the expression "to be"                                                                                                                                                           |
| 13 | To keep my sense of humour                                  | Keeping my sense of humor                                         | formulated without the expression "to be"                                                                                                                                                           |
| 14 | To have close friends near                                  | Being surrounded by good friends                                  | formulated without the expression "to be"                                                                                                                                                           |
| 15 | To have someone who will listen to me                       | Having someone who listens to me                                  | formulated without the expression "to be"                                                                                                                                                           |
| 16 | Not being a burden to my family                             | Not being a burden to my family                                   | formulated without the expression "to be"                                                                                                                                                           |
| 17 | To be able to help others                                   | Being able to do something for someone else                       | Suggestion by organizations working around minorities (Step 2): this card sounds too much like "hands on" but sometimes people cannot be "hands on" though they can be there for someone else       |
| 18 | To be able to talk about what scares me                     | Being able to talk about what scares me                           | formulated without the expression "to be"                                                                                                                                                           |
| 19 | To have my family with me                                   | Being surrounded by my family                                     | formulated without the expression "to be"                                                                                                                                                           |
| 20 | To feel that my life is complete                            | Feeling that my life is complete                                  | formulated without the expression "to be"                                                                                                                                                           |
| 21 | To have a doctor who knows me as a whole person             | That the doctor sees me as a whole person                         | formulated without the expression "to be"                                                                                                                                                           |

|    |                                                                 |                                                           |                                                                                                                                                                                                                                                                                |
|----|-----------------------------------------------------------------|-----------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 22 | Not dying alone                                                 | Not dying alone                                           | formulated without the expression "to be"                                                                                                                                                                                                                                      |
| 23 | To be mentally aware                                            | Be clear-headed                                           | wording has been slightly adapted to better suit the Flemish way of speaking                                                                                                                                                                                                   |
| 24 | To pray                                                         | Being able to pray                                        | formulated without the expression "to be"                                                                                                                                                                                                                                      |
| 25 | To meet with clergy or a chaplain                               | Having a spiritual counselor as support                   | Suggestion by the consulted religions (Step 2): spiritual counselor is umbrella term used by multiple religions                                                                                                                                                                |
| 26 | To be able to talk about what death means                       | Being able to talk about death                            | formulated without the expression "to be"                                                                                                                                                                                                                                      |
| 27 | To be at peace with God                                         | Be at peace with God                                      | The reference group proposed to write the word "god" without a capital letter because then it could mean any kind of "God". However, a representative of a religion said that all religions will write "God" with a capital letter since it is about the reverence of sanctity |
| 28 | To have my financial affairs in order                           | Getting my financial affairs in order                     | formulated without the expression "to be"                                                                                                                                                                                                                                      |
| 29 | To know how my body will change                                 | Knowing how my body and mind will change                  | The mind was suggested by family caregivers of people with dementia (Step 5) because according to them this is also something to consider because it is not only the body that can change.                                                                                     |
| 30 | To prevent arguments by making sure my family knows what I want | Avoid discussions by ensuring my family knows what I want | wording has been slightly adapted to better suit the Flemish way of speaking                                                                                                                                                                                                   |
| 31 | To have an advocate who knows my values and priorities          | Having someone to speak up for what I think is important  | Removing specification who because the words "lawyer or representative" have a legal connotation in Belgium and the reference group (Step 2) wanted to avoid this                                                                                                              |

|    |                                         |                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|----|-----------------------------------------|----------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|    |                                         |                                                          | connotation. Also, changed priorities to “what I think is important” because according to organizations working with people in structural vulnerabilities priorities is a difficult word                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
| 32 | To trust my doctor                      | Being able to trust my doctor                            | formulated without the expression “to be”                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |
| 33 | To have a nurse I feel comfortable with | Having a healthcare professional I feel comfortable with | To be more inclusive nurse was adjusted to caregivers because patients interact with many types of caregivers                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| 34 | To have my funeral arrangements made    | Arrange my funeral in advance                            | The reference group though funeral (“uitvaart” In Dutch) was a difficult term and changed the card to “arrange my burial (in Dutch “begravenis”) in advance”. In Flanders we often use the term “begravenis” for a funeral, though when people use this term (which can be translated to “burial”), they also mean the related ceremonies (thus not only the interment or entombment). But a representative of a religion said that a “burial” is not an inclusive term and according to and representatives of people affected by structural vulnerabilities said the word “funeral” (in Dutch “uitvaart”) is often known by people because they associate it with their insurance. |
| 35 | Not being connected to machines         | Not being dependent on machines to keep me alive         | Unclear for some healthcare professionals and participants in the pre-testing what exactly those machines                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |

|           |           |                                         |                                                                                                                                                                                                                    |
|-----------|-----------|-----------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|           |           |                                         | are (Step 3, 4 and 5). Added the clarification.                                                                                                                                                                    |
| <b>36</b> | Wild Card | Being able to choose when and how I die | Added because of the legislation in Belgium. Only the initial wording (self-chosen end of life) was not clear to healthcare professionals and participants in the pre-testing so clarified and made wording easier |
| <b>37</b> |           | Being able to record my choices         |                                                                                                                                                                                                                    |
| <b>38</b> | Wild Card |                                         |                                                                                                                                                                                                                    |
| <b>39</b> |           | Extra Wild Card                         |                                                                                                                                                                                                                    |

## APPENDIX 2 – OVERVIEW FLEMISH CARDS

|    | Go Wish card game                                               | Levenswensen kaarten                                                 |
|----|-----------------------------------------------------------------|----------------------------------------------------------------------|
| 1  | To be free of pain                                              | Geen pijn hebben                                                     |
| 2  | Not being short of breath                                       | Niet kortademig zijn                                                 |
| 3  | To be kept clean                                                | Netjes en verzorgd zijn                                              |
| 4  | To be free of anxiety                                           | Geen angst hebben                                                    |
| 5  | To have human touch                                             | Lichamelijk contact hebben                                           |
| 6  | To have my family prepared for my death                         | Dat mijn familie voorbereid is op mijn dood                          |
| 7  | To die at home                                                  | Thuis sterven                                                        |
| 8  | To say goodbye to important people in my life                   | Afscheid kunnen nemen van mijn dierbaren                             |
| 9  | To remember personal accomplishments                            | Mijn herinneringen en verwezenlijkingen kunnen delen met anderen     |
| 10 | To take care of unfinished business with family and friends     | Onafgeronde zaken met familie en vrienden kunnen bespreken           |
| 11 | To be treated the way I want                                    | Dat er met mij wordt omgegaan zoals ik dat wens                      |
| 12 | To maintain my dignity                                          | Mijn waardigheid kunnen behouden                                     |
| 13 | To keep my sense of humour                                      | Mijn gevoel voor humor kunnen bewaren                                |
| 14 | To have close friends near                                      | Omringd zijn door goede vrienden                                     |
| 15 | To have someone who will listen to me                           | Iemand hebben die naar mij luistert                                  |
| 16 | Not being a burden to my family                                 | Mijn familie niet tot last zijn                                      |
| 17 | To be able to help others                                       | Nog iets voor iemand anders kunnen betekenen                         |
| 18 | To be able to talk about what scares me                         | Kunnen praten over wat mij bang maakt                                |
| 19 | To have my family with me                                       | Omringd zijn door mijn familie                                       |
| 20 | To feel that my life is complete                                | Het gevoel hebben dat mijn leven compleet is                         |
| 21 | To have a doctor who knows me as a whole person                 | Een arts hebben die mij goed kent als persoon                        |
| 22 | Not dying alone                                                 | Niet alleen sterven                                                  |
| 23 | To be mentally aware                                            | Helder van geest zijn                                                |
| 24 | To pray                                                         | Kunnen bidden                                                        |
| 25 | To meet with clergy or a chaplain                               | Een spiritueel begeleider als steun hebben                           |
| 26 | To be able to talk about what death means                       | Kunnen praten over de dood                                           |
| 27 | To be at peace with God                                         | Vrede hebben met God                                                 |
| 28 | To have my financial affairs in order                           | Mijn financiële zaken op orde hebben                                 |
| 29 | To know how my body will change                                 | Weten hoe mijn lichaam en geest zullen veranderen                    |
| 30 | To prevent arguments by making sure my family knows what I want | Discussies voorkomen door te zorgen dat mijn familie weet wat ik wil |
| 31 | To have an advocate who knows my values and priorities          | Iemand hebben die opkomt voor wat ik belangrijk vind                 |
| 32 | To trust my doctor                                              | Mijn arts kunnen vertrouwen                                          |
| 33 | To have a nurse I feel comfortable with                         | Zorgverleners hebben bij wie ik mij op mijn gemak voel               |
| 34 | To have my funeral arrangements made                            | Mijn uitvaart op voorhand regelen                                    |

|           |                                 |                                                            |
|-----------|---------------------------------|------------------------------------------------------------|
| <b>35</b> | Not being connected to machines | Niet afhankelijk zijn van machines die mij in leven houden |
| <b>36</b> |                                 | Zelf kunnen kiezen wanneer en hoe ik sterf                 |
| <b>37</b> |                                 | Mijn keuzes kunnen vastleggen                              |
| <b>38</b> | Wild Card                       | Joker                                                      |
| <b>39</b> |                                 | Joker                                                      |

### APPENDIX 3 – EXAMPLE QUESTIONS IN QUESTIONNAIRE STEP 3 AND 4

|                                                                                    |                                          |                                               |                                            |                                             |
|------------------------------------------------------------------------------------|------------------------------------------|-----------------------------------------------|--------------------------------------------|---------------------------------------------|
| Card 1 - To be free of pain                                                        |                                          |                                               |                                            |                                             |
| Does this Dutch translation for Flanders mean the same thing as the original card? | <input type="radio"/> Not equivalent     | <input type="radio"/> Somewhat equivalent     | <input type="radio"/> Quite equivalent     | <input type="radio"/> Highly equivalent     |
| Do you find this card comprehensible?                                              | <input type="radio"/> Not comprehensible | <input type="radio"/> Somewhat comprehensible | <input type="radio"/> Quite comprehensible | <input type="radio"/> Highly comprehensible |
| Do you find this card is applicable to the Flemish context?                        | <input type="radio"/> Not applicable     | <input type="radio"/> Somewhat applicable     | <input type="radio"/> Quite applicable     | <input type="radio"/> Highly applicable     |
| Do you find this card relevant to the card set?                                    | <input type="radio"/> Not relevant       | <input type="radio"/> Somewhat relevant       | <input type="radio"/> Quite relevant       | <input type="radio"/> Highly relevant       |
| Do you have any comments or concerns about this card?                              |                                          |                                               |                                            |                                             |



## **PART 3 TO EVALUATE THE WEBSITE TO SUPPORT ADVANCE CARE PLANNING**



## **CHAPTER 4**

### **EVALUATING AN ADVANCE CARE PLANNING WEBSITE FOR PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS: PROTOCOL FOR A MIXED METHOD STUDY**

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## ABSTRACT

*Background:* Web-based tools (e.g., websites, apps) for people with dementia and their family caregivers may be useful in supporting advance care planning (ACP). Using a user-centred design approach, we developed an ACP website for people with dementia and their families. This protocol describes how we will test and evaluate the ACP website. Publishing a study protocol can guide others who want to evaluate web-based tools. Moreover, the data collection methods used in this study are very innovative since they aim to involve people living with dementia without overburdening them.

*Methods:* We will conduct an evaluation study of the ACP website in Flanders, Belgium, using a convergent parallel mixed methods pre-post-test design with continuous follow-up. Thirty eligible dyads of people with mild to moderate dementia (both early and late onset) and their family caregivers will use the website in their everyday life for 8 weeks. We will evaluate the usage, usability, acceptability, and feasibility of the website, as well as the experiences of users. Additionally, we evaluate the effects of using the website on ACP readiness, ACP knowledge, attitudes, perceived barriers to engage in ACP, self-efficacy and skills to engage in ACP.

*Results:* Recruitment and data collection is foreseen between end of 2022 and 2023.

*Conclusion:* This evaluation study of an ACP website for people with dementia and their family caregivers will be the first to evaluate how a web-based tool can support people living with dementia and their families in ACP. The strength of this study lies in the combination of interviews, surveys, and ongoing data logging, which provide insights into the use of support tools in people's daily context. We expect that recruiting people with dementia and their families will be difficult so we have set up a thorough strategy to reach the anticipated sample size.

## **BACKGROUND**

Because of the progressive cognitive and functional decline in dementia, considering and engaging in discussions about potential health changes that may occur is very important (1–3). The process of thinking and talking about wishes and goals when one's health changes is called advance care planning (ACP). ACP enables people to identify their values, define goals and preferences for future medical treatment and care, and discuss this with healthcare professionals and family (4). The concept of ACP has transitioned from a physician-driven process focused on documentation and advance directives to a broader concept of ongoing communication about future care and treatment preferences. Recently, ACP has been broadened further by reframing ACP as a health promoting activity through public education and engagement. This public health approach to ACP underlines the importance of having conversations about future care and end-of-life preferences within the medical context but also within the family context (5–7). Though, most interventions to facilitate ACP are aimed at supporting healthcare professionals (8,9). Research has shown that people with dementia and family caregivers also want to discuss their values and preferences for future care outside of the professional context with their family (10–13). Web-based tools may help support people with dementia and their families to engage in ACP in the family context, but this has not yet been explored (14,15).

The number of web-based tools for people with dementia, such as websites and apps, has increased considerably over the years. Such tools offer promising solutions for meeting several of their needs (16,17) – for instance, supporting reminiscence or aiding daily activities like managing time (18). Generally, people with dementia and their families are enthusiastic and optimistic about using technologies to facilitate their independence and support their care needs (19). Most web-based tools have interactive features that allow tailoring of content to user needs (20), which is an advantage for people with dementia – as their abilities and needs, and their family caregivers' needs, change constantly during the disease trajectory (21,22).

We have developed an evidence-based, theory-informed, and user-centred ACP website for people with dementia and their families. First, we identified existing evidence on web-based ACP tools and defined the content of the ACP website with family caregivers and dementia experts (23). Next, we developed the ACP website using the SCRUM method, which emphasises the role of feedback loops (24). To improve the ultimate uptake of new interventions – such as our ACP website – by end-users, it is essential to systematically

evaluate them before they are implemented. In the evaluation study of the ACP website, we aim to evaluate the usage, usability, acceptability, feasibility (i.e., uptake), and effects of the website, explore the experiences of people with dementia and their family caregivers in using the website, and explore the similarities and differences among people with dementia and family caregivers regarding usage, usability, feasibility, acceptability, experiences, and effects.

In this article, we describe the protocol of the evaluation study. Publishing a study protocol improves transparency in conducting and reporting research studies (25). Moreover, it helps readers understand the conducted study better, allows the possibility of replicating the study, and facilitates applying the results in practice (25). More specifically, the combination of data collection methods used for this study is innovative. We will use log data, online pop-up in-the-moment questions, surveys, and interviews. Our approach enables the involvement of people living with dementia without asking them to recall or document their usage throughout the study. This is particularly important considering the challenges associated with memory recall for people with dementia and the potential burden of maintaining a detailed usage diary (26). This protocol is written using the “SPIRIT” (Standard Protocol Items: Recommendations for Interventional Trials) checklist for reporting protocols (27).

## **METHODS**

### *Study design*

We will perform an evaluation study, using a convergent parallel mixed methods pretest-post-test design, with additional data collection that is done continuously. Our design will simultaneously collect quantitative and qualitative data. We will conduct quantitative and qualitative research concurrently (i.e., convergent mixed methods design) to address all research questions. In this design, quantitative and qualitative data are analysed independently, and integrated at the point of interpretation. Previous research among family caregivers and health professionals (23), and studies on web-based ACP interventions (28–30), have shown that people with dementia and their families wish to engage in ACP at their own pace (23). Hence, we estimated that an 8-week period would be a long enough time frame to allow participants to use the website.

At the start of the study, participants were given the link to the website so that they can use it at home. We will conduct an interview and survey prior to the 8-week intervention period

for the baseline pre-test data collection (T0), and another survey and interview after the 8-weeks for the follow-up post-test data collection (T1).

### *Setting and Participants*

The study will take place in Flanders, the Dutch-speaking part of Belgium. Several types of advance directives are established in Belgium, and policy efforts have been made to promote ACP. Although ACP has been advocated in Belgium for over 20 years, there are no up-to-date numbers on the prevalence of ACP in dementia. Moreover, there have been evidence-informed initiatives to promote ACP for nursing home residents, including people with dementia (31–35), but not for people with dementia living at home. We will recruit people with mild to moderate dementia (both early and late onset) and their family caregiver as dyads, or the family caregiver alone. This study will be carried out in the participants' homes or another place of their preference, and participants can use their own devices (e.g., computers, tablets, phones, etc.) to access the website. We used the following eligibility criteria:

- For people with dementia and family caregivers:
  - Having an interest in and being willing to test the ACP website
  - Being able to consent to study participation
  - Speaking and understanding Dutch
  - Having a device (laptop, iPad, mobile phone, etc.)
  - Did not participate in the cognitive testing of study materials
- Person living with dementia: is being diagnosed with young- or late-onset dementia
- Family caregiver: takes active care (physical, emotional, social, etc.) for the person with dementia
- Dyads: Although the website has a text-to-speech option, to be able to use the website and text-to-speech, one of the participants needs to be able to navigate the website (e.g. the person with dementia and the family caregiver cannot both have visual impairments or other disabilities that prevent them from interacting with the ACP website)

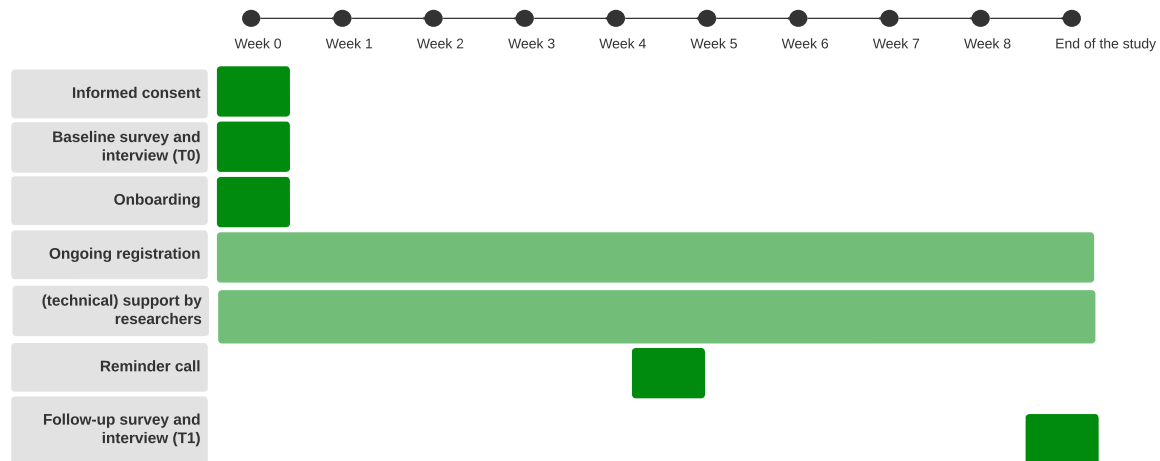
### *General procedures for the evaluation study*

A timeline for the participants is shown in Figure 1. Prior to the 8 weeks, participants will receive an information letter. All data collection happened individual e.g., per dyad or family caregiver in the participants' homes (or whatever location the participant preferred) so participants did not have to travel. When a participant indicates that they wish to participate in the study, the researcher will schedule an appointment to conduct the informed consent, T0 interview, survey, and onboarding. During the 8 weeks, there is an ongoing activity



registration of the ACP website's use (logging), a reminder call at 4 weeks and ongoing (technical) support when needed. After the 8 weeks, participation in the study is concluded with a T1 survey and interview.

*Figure 1 - Participant timeline*



### *The ACP website*

The ACP website is designed to inform people with dementia and their family caregivers about ACP, and to support them in the ACP process. The website was iteratively developed using a user-centered design. First, the content of the website was defined by a user-needs assessment. Afterwards, 4 prototypes were presented to people with dementia, their families, and a patient and Patient and Public Involvement (PPI) group. The website was continually adjusted according to the feedback received. The website aims to improve people's knowledge of ACP, attitudes toward ACP, self-efficacy to start ACP, and skills for engaging in ACP. The ACP website contains several parts: a part about what ACP is and its legal frameworks, a part focused on providing support for people on how to talk about ACP, and a part about the existing possibilities to document ACP decisions. The website contains 2 tools to support people in thinking and talking about their wishes and preferences (including a digital version of the GoWish cards adapted for use in Flanders(36)), a glossary, a frequently asked questions (FAQ) page, a search functionality, a resource and contact page, and a page with information on the website developers and the aim of the website. The website includes special functionalities, such as an option to adjust the text size, choose a different colour contrast, read the text out loud (i.e., speech-to-text function), and the possibility to print (sections of) the content.

### *Informed consent procedure*

Informed consent will be obtained before including potential participants in the study. We will follow the recommendation of the Alzheimer's Association National Board of Directors (2004) by using a double-consent method: consent for the patients' participation is signed by both themselves and their caregiver (who functions as 'witness') (37). Therefore, we will ask the family caregiver to sign the consent form with the participant with dementia. Moreover, the researcher, a nurse with experience working with people with dementia, will explain the research and procedures and will ensure that participants with dementia understand the study and their rights by discussing the statements formulated in the informed consent form with them and the family caregiver. Individuals interested in participating in this study will receive an information letter and an informed consent form. Potential participants are asked to indicate interest if they want to participate in the study. When people indicate they want to participate, an onboarding session will be planned in which informed consent will be obtained, and the website and the study are introduced.

### *Onboarding session*

After receiving informed consent, the researcher will start the onboarding. This consists of introducing the website and giving the participants access. Since the website is not yet publicly available, participants will be able to access the website through a personal link and a participant number. During the onboarding, participants are shown how they can find and access the website and what is on it, and the researcher will ask them to use the website as they see fit. Moreover, the participants will be informed that they can use the website alone or with their family caregiver. Every time the participants visit the website, they are asked to enter their unique participant number and indicate who is using it (person with dementia, caregiver, dyad). In week 4, the research team will call the participants and ask whether they have been using the website and/or need help, schedule the follow-up session and underline that they have the flexibility to cancel or reschedule if the person with dementia is not feeling well or has a challenging day. The ACP website is in a beta phase of development (i.e., testing with target audience before dissemination/release), there will be technical support available from the research team. This support is active throughout the study and can be reached via e-mail or phone. The study number, website name, and technical support contact details are summarised on a small support note.

### *Sample size*

The number of participants in the study was chosen based on the sample sizes in previous similar evaluation studies of interactive, web-based tools with heterogeneous (non-stratified) populations aimed at evaluating usability and feasibility (28,38–40). For a full understanding of the usability and feasibility of our website, we aimed mainly to include a sample with sufficient variabilities, i.e. to have people from different age groups, gender, type of dementia, and dyad composition. To achieve this variability, we have estimated needing 30 participants, of which 80% are dyads.

### *Recruitment*

Participants will be recruited via organisations involved in dementia (care), neurologists working in memory clinics, and individual GPs. We will ask the health professionals to select potential participants who might be interested and eligible for this study. Additionally, we will launch a recruitment call, allowing potential participants to contact the researchers directly if they want to participate in the study.

To announce the study, we will ask different organizations, such as the Flemish Alzheimer Liga, day centers, dementia cafes, Belgian health insurers, and individual healthcare professionals and GPs to help recruit via their networks by, for example, contacting patients/clients (e.g., people who have said they want to be involved in studies such as these), e-mail, their member magazines, newsletters, brochures, and/or their websites. The researchers will provide the organisations involved and individual healthcare professionals with a template for a call for participation. Additionally, we will also recruit, via memory clinics, neurologists who will introduce the study to dyads they think are eligible to be included in this evaluation. When dyads are interested in the study, the neurologist will ask the potential participants to contact the researcher or see the researcher directly when s/he is in the hospital. Interested potential participants will receive an information letter and consent form. If one still wants to participate after reading, the researcher will make an appointment with the participant(s) for inclusion.

### *Outcome measures*

#### *Socio-demographic and clinical variables*

Socio-demographic data (age, gender, education level, marital status, occupational status), computer literacy, and clinical factors (type of diagnosis, time since diagnosis, co-morbidities) will be collected using a study-specific questionnaire (Appendix 5). We will also

assess the quality of the dyad relationships utilizing the quality of caregiver-patient relationships (QCPR) scale (41). Moreover, post-intervention we will ask the participants if, and how often, they have contacted their healthcare professionals about ACP.

### *Usage*

Usage is defined as the way people with dementia and family caregivers use the ACP website, which will be measured using log data. The results of the participants' usage within and across each usage session over the 8 weeks of home use will be described in detail to examine usage patterns – and more precisely:

- What pages do the people with dementia and the family caregivers visit, what content or functions do they watch or use, how often do they visit each page, and what do they look for when using the search bar?
- Do they use the interactive elements of the website?
- Do they use the 3 accessibility features (i.e., text-to-speech feature, option to enlarge the text, and contrast option), and how often do they use them?

### *Usability, acceptability, and feasibility of the website*

Usability in this study is the participants' evaluation of the user interface. Usability is evaluated by [1] the System Usability Scale (SUS) questionnaire, [2] a semi-structured interview on their evaluation of the website interface, and [3] pop-up, in-the-moment questions (42,43).

Acceptability is defined as the perceptions of the people with dementia and their family caregivers of the appropriateness of the content, its delivery, and the format of the ACP website (44). Acceptability will also be assessed through a post-intervention interview. The website is deemed acceptable if the majority (>70%) of participants evaluate the use of the website as an overall acceptable and positive experience (44). The interview will address the following 7 constructs of the Theoretical Framework of Acceptability (44): affective attitude (i.e., how the participants feel about the website), burden (the perceived amount of effort that is required to use the website), ethicality (the extent to which the intervention has a good fit with the participants' value system), intervention coherence (the extent to which the participants understand the ACP website and how it works), opportunity costs (the extent to which benefits or values must be given up to use the website), perceived effectiveness (the extent to which the ACP website is perceived to achieve its purpose), and self-efficacy (the participants' confidence that they can use the ACP website) (44). The participants will also

be shown 2 pop-up, in-the-moment questions to assess acceptability – (1) *“I find the website easy to use”*, and (2) *“I find the information on this website clear”* – with answer options on a 5-point rating scale, with 1 = totally agree and 5 = totally disagree. The EMA questions will also include an open-ended item – “can you explain why you have given this score?” – asking for suggested improvements. These questions pop up after 30 seconds when using the website, and are displayed every time the website is re-opened.

Finally, feasibility in this study is defined as uptake: i.e., whether people used the website or not, and why. Feasibility will be evaluated using log data and a semi-structured interview with the people living with dementia and their family caregivers.

#### *Experiences using the website*

The ‘experience’ is the way using the website goes/happens, and how it makes the participants feel. To evaluate user experiences, the participants will be asked to rate the following pop-up, in-the-moment question: *“My experience with this website so far is”* on a 5-point rating scale (from very positive, slightly positive, neutral, slightly negative, to very negative), and they will be asked to explain why they gave this rating. Moreover, the participants will be asked post-intervention how using the website made them feel. If the participants indicate that they did not use the ACP website, the reason for not using the website will be evaluated, including how we can improve the website to make it more useable. Furthermore, we will consider any technical issues interfering with the use of the ACP website, because they can be considered barriers to using the website. The calls the participants make to the helpdesk, and the issues discussed, will be recorded in a logbook. The entries in the helpdesk logbook will be evaluated based on the type of issue encountered and if and how the problem can be solved.

#### *Effects on ACP readiness, ACP knowledge, attitudes, perceived barriers to engage in ACP and self-efficacy, skills to engage in ACP*

Effect will be the changes in selected outcomes as a result of using the ACP website. To assess the potential effects of the ACP website, we will investigate any possible changes in readiness for ACP engagement via the Dutch 4-item ACP engagement survey. The survey will be administered to the people with dementia and family caregivers at both time points (T0 & T1) (45). Moreover, we will assess: knowledge (i.e., the range of one’s understanding or information); attitude (i.e., a person’s positive or negative evaluation of performing a particular action); perceived barriers (i.e., a person’s beliefs regarding the potential negative aspects of a particular action); self-efficacy (i.e., subjective probability that a person is capable of

executing a certain course of action); and skills (i.e., an ability or proficiency acquired through training and practice).

We will ask the participants before and after using the ACP website what they think ACP is and their experiences with ACP. The interview will address the following points: (1) what do they think ACP is, and what do they think ACP can achieve; (2) have they ever considered discussing the different elements of ACP with a member of their family (or other close relationship); (3) have they ever discussed ACP, and how, with their family caregiver or with a healthcare professional; (4) the researcher will also ask them to elaborate on their experiences with conversations about ACP.

#### *Data collection methods*

We will conduct both an interview and surveys at the start of the 8-week intervention period (pre-test data collection T0) and after the 8-week intervention period (post-test data collection T1). The results from the study are expected at the end of 2023. During the 8 weeks, there will be continuous data collection via logging of user activity on the website, recording technical issues addressed via phone, and the pop-up, in-the-moment questions hereafter called ecological momentary assessment (EMA) questions (Table 1).

Table 1 - Overview of research questions and data collection methods

| Research questions                                              | Pre-test (T0)                                | Continuous collection   | data      | Post-test (T1)                               |          |
|-----------------------------------------------------------------|----------------------------------------------|-------------------------|-----------|----------------------------------------------|----------|
| Evaluating the usage, usability, acceptability, and feasibility |                                              | Quantitative collection | data      | Qualitative collection                       | data     |
| Usage                                                           |                                              | Log data                |           |                                              |          |
| Usability                                                       |                                              | EMA questions           |           | Semi-structured interview                    |          |
| Acceptability                                                   |                                              | EMA questions           |           |                                              |          |
| Feasibility                                                     |                                              |                         |           |                                              |          |
| Exploring experiences                                           |                                              | Quantitative collection | data      | Qualitative collection                       | data     |
| Experiences                                                     |                                              | EMA questions           |           | Semi-structured interview                    |          |
|                                                                 |                                              | Logbook issues          | technical |                                              |          |
| Evaluating effects of the ACP website                           | Qualitative and Quantitative data collection |                         |           | Qualitative and Quantitative data collection |          |
| Readiness for ACP engagement                                    | Structured survey                            |                         |           | Structured survey                            |          |
| ACP knowledge                                                   | Semi-structured interview                    |                         |           | Semi-structured interview                    |          |
| Self-efficacy to potentially start an ACP conversation          |                                              |                         |           |                                              |          |
| Skills (have the intention) to engage in ACP.                   |                                              |                         |           |                                              |          |
| Perceived barriers to engaging in ACP                           |                                              |                         |           |                                              |          |
| Attitudes towards ACP                                           |                                              |                         |           |                                              |          |
| Exploring similarities and differences                          |                                              | Quantitative collection | data      | Qualitative collection                       | and data |

### *Baseline interview (T0)*

We will conduct the baseline interview during the onboarding session. In this interview, we will ask the participants about their previous experience with ACP: e.g., what they think ACP is and whether they have engaged in ACP before; and if yes, with whom. Interviews will be conducted using a semi-structured interview guide (Appendix 6) and will last about 30 minutes. Interviews will be held separately (i.e., the person with dementia and the family caregiver are interviewed by themselves), but the participants could also choose to have the interview together.

### *Baseline survey (T0)*

Directly after the interview, we will ask each participant individually to fill in the baseline survey, consisting of questions on [1] socio-demographic data, clinical factors, the quality of the dyad relationship (5), and [2] their ACP engagement using the ACP engagement survey (45). Each participant (i.e., the person with dementia or the family caregiver) will complete their own surveys.

### *Ongoing log data registration and EMA questions*

When the participants use the website, log data (i.e., records of the website usage) are collected. Collecting log data can provide information (via log files) on the interaction between the user and the website (46). It can reveal the patterns regarding how many sections of the website are being used and how often and in which way the website is being used. During the use of the website, questions will pop up in the moment (pop-up, in-the-moment questions) of usage. These so-called Ecological Momentary Assessments (EMA) (or experience sampling methods (ESM)) questions will capture real-time data to capture the participants' behaviour, mood, and activities (42,43). In EMA, participants are asked to respond to 'in the moment' questions, which avoids recall bias, making this a valuable tool for people with dementia. The ACP website holds a logging facility for the following events:

1. Entry – who is using the website (i.e., study ID and the person with dementia, family caregiver, or dyad);
2. Usage – the way people with dementia and family caregivers use the ACP website – for example, watching a video, visiting a webpage, using interactive tools;
3. Evaluation – 'in the moment' information on their website evaluation using EMA. The EMA question for feasibility will be related to the page the user is on, shown 30 seconds after they enter the page. The EMA question for experiences is shown 3 minutes after the participants start using the website.

### *Post-intervention interview and survey (T1)*

T1 will proceed in the same way as T0. First, an interview will be conducted, which will also ask about experiences with the website. After that, the questionnaires will again be administered individually.

### *Testing of data collection instruments*

We cognitively tested all data collection instruments (the EMA questions, surveys, and interviews) with people with dementia (n=2) and family caregivers (n=4). We presented the



instruments to the people with dementia and family caregivers to understand how potential participants interpret the questions and the instructions used in the evaluation study. We asked them if the questions were clear, understandable, not too difficult, and if the instruments are easy to use. Only some minor details were adjusted, such as the use of words and making sentences shorter. Based on this feedback, the instruments were slightly modified.

### *Data analysis and reporting*

#### *Qualitative data*

All interviews will be recorded and transcribed verbatim. All transcriptions will be pseudonymized and analysed via thematic framework analysis on the qualitative analysis software NVivo. First, 2 researchers (independent coding) will familiarize themselves with the data. Next, they will generate initial codes, identify recurrent patterns and define and name themes (47). After independent coding, the 2 researchers will compare their coding, and differences will be resolved in a small group meeting with a third researcher until a consensus is reached for all themes. Subsequently, the 2 researchers who did the independent coding will separately group all similar or related themes to form thematic categories. This grouping of thematic categories will again be compared and discussed with a third researcher until a consensus for all thematic categories is reached.

#### *Quantitative data*

All of the data from the surveys will be analysed using SPSS. Descriptive statistics will be used for participant characteristics, general evaluation, and ACP engagement. We will use linear mixed models to test for differences between pre- and post-intervention outcomes and to identify differences within and across the dyads and between and across people with dementia and family caregivers in general. Log data and responses to the EMA questions will be analysed using RStudio. Logs will comprise a time stamp, a unique ID (based on the user's IP address), and what the interaction with the website was (e.g., watching a video, or visiting a page). The EMA responses consist of unique ID (IP address), the proposed question, and the user's given response.

#### *Integrating qualitative and quantitative results*

Because of this study's convergent parallel mixed method design, we will combine the qualitative and quantitative results (48). In this study, quantitative and qualitative data will be analysed independently and integrated at the point of interpretation to obtain a complete

evaluation of the ACP website. If, for example, the qualitative and quantitative results contradict, we will take further steps to try to explain the differences by re-examining the results (48).

#### *Data reporting*

When reporting the study's results, we will follow the Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) statement.

#### Ethical considerations

The research protocol was submitted to the Ethical Committee of the University Hospital (UZ) Brussels before the start of the research, and positive advice to start the study was granted by the Ethical Committee (B.U.N. 1432022000179). Several measures will be taken to protect the research participants and ensure ethical research practices. Thinking and talking about ACP can raise questions or might be distressing. The researcher will monitor the participants' reactions during all in-person data collection activities and remind them that they can stop at any time. To ensure that the participants can raise questions after the researcher has left, or reach out in case of distress, they will have the option to contact the researchers. The researchers' contact details will be made available on the ACP website, in the support note, and in the information letter.

## **DISCUSSION**

In this article, we have described the protocol for a study in which we will test and evaluate an ACP website for and with people with dementia and their family caregivers. This evaluation study will provide a detailed understanding of the usage, usability, acceptability, and feasibility (i.e., uptake) of the website and the experiences of people with dementia and their family caregivers in using the website. Moreover, it will provide knowledge on the potential effects of using the website on ACP readiness, knowledge of ACP, attitudes towards ACP, perceived barriers to engage in ACP, self-efficacy and skills to potentially start an ACP conversation.

Through this study, we aim to better understand how the ACP website can support people with dementia and their families in ACP. We will do this by extensively evaluating the effects of the website on people with dementia and their family caregivers' knowledge of ACP, their attitudes towards ACP, perceived barriers to engaging in ACP, their self-efficacy, and skills to start an ACP conversation, and their intention to engage in ACP. The concept of ACP has

changed significantly over time. While initially focused on completing advance directives, the focus has shifted towards an ongoing communication and decision-making process (4). This process has been highlighted as very important for people living with dementia and their families (1–3).

However, conducting ACP in dementia is challenging (21). People with dementia and their families experience difficulties in talking about ACP (12). Because of dementia, they may have difficulties comprehending the concepts involved in ACP (21). Moreover, though insufficient knowledge about ACP is a big barrier to engaging in ACP (12,49), a recent study on online ACP information for people living with dementia showed online ACP information is often incomplete or even missing (50). Hence, it is very useful to understand whether and how technology – such as a website and the online information provided – can help support them in the ACP process.

The described methods of this study will also deepen the knowledge of how new interventions, such as ours, can be evaluated for people with dementia and their families. Evaluating new interventions helps one understand what works and needs to be changed to advance uptake in the long run (51). While necessary for all new interventions, it is especially important for ACP interventions in dementia since only a handful of interventions have been developed for this population, and even fewer have been systematically evaluated. As far as we know, this is the first study to evaluate a web-based ACP intervention for people with dementia and their families in the family context.

This study has several strengths. First, our research methods were specifically adapted for people with dementia and their families, which is crucial in order to collect high-quality data. We will use a combination of interviews, surveys, and ongoing data logging. The latter allows us to retrospectively examine usage and evaluate in-the-moment experiences without burdening people with dementia to recollect memories. Moreover, when using web log data, we request less data collection, which enables us to collect data more efficiently and ethically. In addition, combining interviews, surveys, and web log data can give a complete and accurate picture of how people use the ACP website, which can help us optimise it (46).

At the same time, this study also has some challenges. First, we expect to have some difficulties recruiting people with dementia and family caregivers and reaching the anticipated sample size. Previous research shows that recruiting people with dementia and their families

can be challenging, especially in studies about end-of-life care communication (52). In the past, recruiting people living with dementia and their families has been difficult because they do not want to discuss their future and do not have time to participate in research (52). Moreover, since people living with dementia have relatively low care needs in the early stages of the disease, the population cannot be recruited via a single site, such as a hospital. Therefore, we chose various recruitment strategies to reach as many participants as possible. In this study, we did not calculate a sample size. We thoroughly considered and decided on our sample size and consulted similar studies, we did not calculate a sample size. We aim to evaluate the website, not find differences between groups. Moreover, to facilitate participation, we have tried to eliminate known barriers to participation in research studies, such as the travel distance to the study site (52,53). Furthermore, it is important to note that potential participants may have been unintentionally omitted due to the inclusion criteria requiring of owning a device. Introducing a new device can present challenges and impose additional barriers to participation. Additionally, there may be exclusion of people due to the requirement of digital literacy. Because the use of the ACP website requires a certain computer proficiency, we may have unintentionally missed valuable perspectives from people who lack digital skills or access to digital devices. Therefore, the findings of our evaluation study may not fully capture the experiences of those with limited digital literacy.

## **CONCLUSION**

This evaluation study of an ACP website for people with dementia and their family caregivers will be the first to systematically evaluate how a web-based tool can support people living with dementia and their families in ACP. This study will add considerably to the evidence on ACP in dementia and the use of web-based tools to support ACP in the daily family context. Considering the growing number of people with dementia and family caregivers of people with dementia, websites such as the one that we have developed can be a promising way to support them in thinking and talking, in a timely manner, about their wishes and goals for future health and end-of-life care.

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## **CHAPTER 5**

### **A WEBSITE TO SUPPORT PEOPLE WITH DEMENTIA AND THEIR FAMILY CAREGIVERS IN ADVANCE CARE PLANNING: RESULTS OF A MIXED-METHOD EVALUATION STUDY**

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[Submitted]



## ABSTRACT

*Background:* Advance care planning (ACP) can be important for people living with dementia as it gives them the opportunity to consider preferences for future care and treatment. We developed a theory-based website to support people with dementia and their families in the ACP process using a user-centred design. This study evaluates the website's usability, acceptability, feasibility, experiences, and effects.

*Methods:* We conducted an eight-week evaluation study with a convergent parallel mixed-methods design involving people with mild to moderate dementia and their family caregivers who used the website at their convenience. Interviews were conducted at baseline and after eight weeks to evaluate usability, acceptability, feasibility, experiences, and effects on ACP knowledge, attitudes, perceived barriers to engaging in ACP, self-efficacy and skills to engage in ACP. Surveys assessed readiness to ACP and usability (System Usability Scale) of the website. While participants used the website, pop-up questions were included to evaluate usability, acceptability, and user experiences in the moment.

*Results:* We included 52 participants (21 people with dementia and 31 family caregivers). In the interviews, all participants considered the website useful and valued the ACP content, with people with dementia rating usability via the System Usability Scale as above average (68%) and family caregivers rating it excellent (80%). In the interviews, dyadic participants reported that the family caregivers mostly used the website alone or with the person with dementia, while people with dementia rarely used it alone. Participants' ACP knowledge, self-efficacy, and skills improved after eight weeks compared to the beginning of the study. They reported fewer barriers to engaging in ACP, and attitudes toward ACP and the website remained positive.

*Conclusion:* The website may support ACP, providing user-friendly content and features for initiating and exploring ACP in the family context. As people with dementia perceived the website as less user-friendly than family caregivers, and given that family caregivers often introduced the website to people with dementia after using it first themselves, family caregivers seem to play a crucial role in adopting the website and initiating ACP.

## Introduction

ACP has been defined as a communication process between patients, families, and healthcare professionals to enable people to define goals and preferences for future care and treatment (1). It has been advocated as particularly relevant in dementia, giving people with dementia the possibility to express preferences for future care and treatment in advance (2–4) and helping family caregivers understand the values and preferences for future care of the person with dementia (5,6).

While several aspects of ACP can concern medical end-of-life topics, recent studies have shown that people with dementia and their family caregivers want to discuss their values and preferences for future care in a holistic and relational manner focused on what matters most to them (7,8). Recent work with the European Working Group of People with Dementia additionally confirmed that ACP should be a medical and social process focussing on daily activities, psychosocial needs, and place of residence (8). This corresponds well to the public health approaches in palliative care, emphasising the importance of having conversations about what matters most to people, not solely in the medical but also within the family context and underlining the importance of normalising conversations about end-of-life care, death, and dying (9–11).

Previous research showed that people with dementia and their family caregivers could use support in the ACP process. They find it difficult to start thinking and talking about ACP and feel they are not informed about what ACP is and when and how to start the process (7,12,13). In recent years, the Internet has played a crucial role in supporting this part of ACP (14). For example, web-based tools can provide essential information and empower people to enhance their engagement in ACP (15–17). However, there is currently no web-based tool for or adapted to the specific needs of people with dementia and their families. For these reasons, we developed a website to support people with dementia and their families in ACP. Using an iterative user-centred design, we developed the website, from colours and fonts to the content and interactive elements, together with people with dementia and their families (18).

Comprehensive evaluations of new developments are crucial to enhance future uptake, promote acceptability, and optimise user experience (19,20). The present study aims to evaluate the ACP support website developed with and for people with dementia and their families. The aims of this study are:

1. To evaluate the usability, acceptability, and feasibility of the ACP support website;
2. To explore the experiences of people with dementia and their family caregivers with the use of the website;
3. To evaluate the effects of using the website on people with dementia and family caregivers' ACP readiness, knowledge, attitudes, perceived barriers to engage in ACP, self-efficacy, and skills to engage in ACP.

The results of this study will be used to optimise the website before further implementation and dissemination.

## **METHODS**

### *Study design*

We performed an eight-week evaluation study using a convergent parallel mixed-methods design. We conducted individual interviews and administered questionnaires with people with dementia and family caregivers before the 8-week intervention period (i.e. baseline data collection T0). After eight weeks, we performed post-intervention interviews and administered surveys with each participant (i.e. post-intervention data collection T1). During the eight-week study period, participants were shown pop-up questions when they used the website to evaluate the website in-the-moment (i.e. ecological momentary assessment). Quantitative and qualitative data were analysed independently and integrated at the point of interpretation. A more detailed description of the research methodology is published in a separate research protocol (21).

### *Setting and Participants*

We recruited people with mild to moderate dementia (both early and late onset) and their family caregivers as dyads or the family caregiver alone. We used the following eligibility criteria:

- For both people with dementia and their family caregivers:
  - Having an interest in and being willing to test the ACP website
  - Being able to consent to study participation
  - Speaking and understanding Dutch
  - Having a device (laptop, tablet, mobile phone, etc.)
  - Did not participate in the cognitive testing of study materials
- For people with dementia: is diagnosed with mild to moderate young- or late-onset dementia
- For the family caregiver: takes active care (physical, emotional, social, etc.) of the

person with dementia

- For participants recruited as dyads: At least one of the participants needs to be able to navigate the website (e.g. the person with dementia and the family caregiver cannot both have visual impairments or other disabilities that prevent them from interacting with the ACP website)

The study took place in Flanders, the Dutch-speaking part of Belgium.

#### *Recruitment and procedures of the evaluation study*

Participants were recruited via organisations involved in dementia (care) and neurologists working in memory clinics. We asked the (health) professionals to identify and approach potential participants who met the eligibility criteria and might be interested and eligible for this study. When potential participants were interested in the study, they were asked to contact or meet the researcher directly when s/he was in the hospital. Potential participants who contacted the researcher received an information letter and a consent form. If the person was still interested in participating after receiving the study information, the researcher made an appointment with the participant(s) to do the eligibility screening and ask for informed consent (i.e. onboarding meeting).

#### *The website to support advance care planning*

The website was developed using a user-centred design involving persons with dementia and family caregivers in each development step. The ACP support website was designed to inform people with dementia and their family caregivers about ACP and to support them in the process of ACP, more specifically to improve people's knowledge of ACP, their attitudes towards ACP, and their self-efficacy and skills to engage in the ACP process (21). The corresponding theoretical change methods to support the outcomes were grounded in theory (18). An overview of theoretical methods and their practical applications on the ACP website is reported elsewhere (18). The website contains:

- The flexibility to navigate according to the preferences of the user, allowing a non-linear approach, i.e. people with dementia and their families can use the website based on their needs and ACP readiness levels (17,22,23).
- Information about what ACP is and its legal frameworks, why ACP is important, and reasons to discuss ACP with the healthcare profession supported by videos.
- Support for communication by tips and videos on how to start talking about ACP and how to introduce the topic with the healthcare professional.
- Information about the documentation of ACP and referral to healthcare professionals



- Two interactive communication support tools to support reflection and communication about what matters most and social aspects of future care and treatment and end-of-life preferences: the digitalised *Levenswensen* cards with preformulated statements (24) and a fill-in tool (*Thinking Now About Later*), to help users think and talk about and write down their preferences for the present and future.
- Several functionalities support the website's accessibility, e.g. text-to-speech, enlarge-the-text and contrast options (appendix 1 and 2 for screenshots of the website and the interactive tools and summary overview of all pages ).

### *Sample size*

We aimed to include a diverse group of participants, including people of different ages, genders, types of dementia (Alzheimer's, Lewy-Body, Vascular, etc.) and relationships between the family caregiver and person with dementia (e.g. partners, child-parent). To ensure sufficient variations, we aimed to include 30 participants, with 80% of them being dyads. This sample size was considered sufficient to fully evaluate the study objectives (21).

### *Outcomes, data collection methods and procedures*

The timeline for the participants is shown in Figure 1, and an overview of the outcome measures is shown in Table 1. An extensive description of the outcome, data collection methods and procedures is published in the research protocol (21).

#### *Onboarding and baseline data collection (T0)*

The timeline for the participants is shown in Figure 1, and an overview of the outcome measures is shown in Table 1. An extensive description of the outcome, data collection methods and procedures is published in the research protocol (21).

#### *Onboarding and baseline data collection (T0)*

The onboarding meeting took place in the participants' homes to start the study period. During this visit, the researcher explained the study and obtained informed consent (21). The researcher then performed an interview and administered a questionnaire (T0). In the interview, participants were asked about their prior knowledge of and involvement with ACP, e.g., what they believe ACP was, whether they have participated in ACP previously, and, if so, with whom (21). For participants recruited as dyads, we aimed to interview the persons with dementia and the family caregivers separately, though participants could opt to conduct the interviews jointly. The baseline questionnaires were administered individually and

included questions on sociodemographic information, computer literacy, clinical characteristics, and their ACP engagement, which was assessed via the Dutch 4-item ACP engagement survey (16).

Afterwards, participants were shown the website and received a study ID. Every time the participants visited the website, they were asked to enter this unique study ID and indicate who was using the website (person with dementia, caregiver, dyad). Participants were told they could use the website for eight weeks, how and whenever they wanted. When visiting the website during the eight-week study period, pop-up questions or ecological momentary assessments were used, asking the participants to evaluate the website in the moment (25,26).

#### *Follow-up call at four weeks*

Four weeks after the start of the study period, a researcher called participants via phone, asking if any problems occurred or if they needed extra support. During this call, the researcher also made an appointment with the participants to collect the post-intervention data (T1).

#### *Follow-up data collection after eight weeks*

Post-intervention data collection (T1) proceeded in the same manner as the data collection at baseline (T0). First, an interview was conducted, asking participants about their experiences with ACP and using the website. After the interview, participants were asked to individually fill in the T1 questionnaire, including the usability of the website (System Usability Scale).

Figure 1 - participant timeline

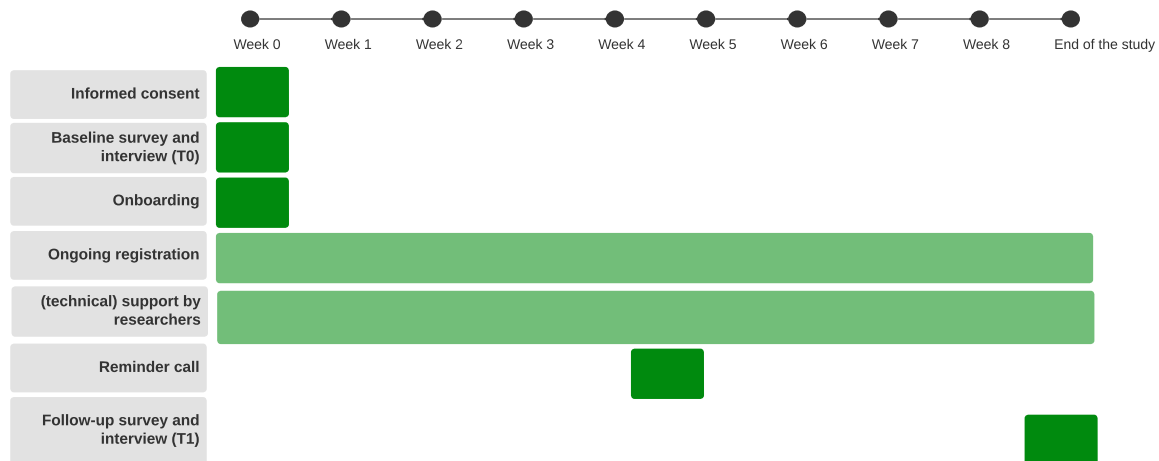


Table 1 - overview of the outcome measures

| Outcome                               | Definition of the outcome                                                                                                 | Measurement instruments                                | When        |                  |             |
|---------------------------------------|---------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------|-------------|------------------|-------------|
|                                       |                                                                                                                           |                                                        | Week 0 (T0) | Week 4 Follow up | Week 8 (T1) |
| Personal and clinical characteristics |                                                                                                                           |                                                        |             |                  |             |
| Sociodemographic data                 | age, gender, education level, marital status, occupational status                                                         | Survey                                                 | X           |                  |             |
| Computer literacy                     | Self-assessment of ability to use the computer                                                                            |                                                        | X           |                  |             |
| Clinical factors                      | type of diagnosis, time since diagnosis, comorbidities                                                                    |                                                        | X           |                  |             |
|                                       |                                                                                                                           |                                                        |             |                  |             |
| Usability                             | Participants' evaluation of the user interface                                                                            | Survey (the System Usability Scale (SUS))              |             |                  | X           |
|                                       |                                                                                                                           | Interview                                              |             |                  | X           |
|                                       |                                                                                                                           | EMA* question                                          |             | X                |             |
| Feasibility                           | Uptake, i.e. whether people used the website or not and why.                                                              | Interview                                              |             |                  | X           |
|                                       |                                                                                                                           |                                                        |             |                  |             |
| Acceptability                         | The majority (>70%) of participants evaluate the use of the website as an overall acceptable and positive experience (27) | Interview (Theoretical Framework of Acceptability)(27) |             |                  | X           |
|                                       |                                                                                                                           | EMA* question                                          |             | X                |             |
|                                       |                                                                                                                           |                                                        |             |                  |             |
| Experiences of participants (users)   | The way using the website goes/happens and how it makes participants feel                                                 | Interview                                              |             |                  | X           |
|                                       |                                                                                                                           | Technical issues addressed (week 4 phone call)         |             | X                |             |
|                                       |                                                                                                                           | EMA* question                                          |             | X                |             |
|                                       |                                                                                                                           |                                                        |             |                  |             |
| readiness for ACP engagement          | any possible changes in readiness for ACP engagement                                                                      | survey (ACP engagement survey (16))                    | X           |                  | X           |
| ACP knowledge                         | the range of one's understanding of information                                                                           | Interview                                              | X           |                  | X           |
| attitudes                             | person's positive or negative evaluation of performing a particular action                                                |                                                        | X           |                  | X           |
| perceived barriers to engage in ACP   | a person's beliefs regarding potential negative aspects of a particular action                                            |                                                        | X           |                  | X           |

|                      |                                                                                                    |  |   |  |   |
|----------------------|----------------------------------------------------------------------------------------------------|--|---|--|---|
| <i>self-efficacy</i> | subjective probability that a person is capable of executing a certain course of action and skills |  | X |  | X |
| <i>ACP skills</i>    | an ability or proficiency acquired through training and practice                                   |  | X |  | X |

*\* ecological momentary assessment. The usability and acceptability questions were displayed on each page after the user spent 30 seconds there, while the experiences question appeared if the user remained on the website for 5 minutes. If the user chose to 'end' the session, e.g. close the browser, the same questions would be presented again in the subsequent session.*

## *Data analysis*

### *Qualitative data*

All interviews were recorded and transcribed verbatim. The qualitative analysis program NVivo was used to conduct framework analysis (28). The framework analysis process within thematic analysis comprises multiple stages, encompassing data familiarisation, development of the thematic framework, indexing of all study data based on the framework, charting for data summarisation, and ultimately, mapping and interpretation (28). First, two researchers (CD and FM) familiarised themselves with the data and coded 20% of pre- and post-study transcripts using a deductive and inductive approach. The predefined codes were derived from the interview guide, which can be found in the study protocol (21), and the outcome was defined during the website's development (18). New codes were established for data that did not fit the predetermined codes (inductive approach). The identified themes were reviewed with the researchers involved, aiming for consensus to construct the framework. Subsequently, the remaining transcripts underwent analysis, with the two researchers comparing their coding, addressing discrepancies through discussion, and finding consensus. Lastly, the results were structured and discussed with all the authors of this article for interpretation.

### *Quantitative data*

Descriptive statistics were used to analyse participant characteristics, ACP engagement and the SUS survey. All data from the surveys was analysed using SPSS. To analyse the ecological momentary assessment answers and suggested improvements via the open-text boxes of the ecological momentary assessment questions, we used RStudio. The data was summarised per ecological momentary assessment questions using descriptive analysis.

### *Integrating qualitative and quantitative results*

Quantitative and qualitative data were analysed independently and integrated at the point of interpretation to obtain a complete evaluation of the ACP website. First, we generated an overview of the results for each research method and outcome measure, ensuring a clear understanding of individual findings. Second, we created a matrix to summarise the outcomes of quantitative and qualitative analyses, allowing us to discern patterns, correlations, and discrepancies between the two data sets. When results deviated partially or completely, we examined the results and considered the implications for our overall understanding of the ACP website. This approach ensured a robust integration process, enriching the depth and validity of our study findings.

### *Ethical considerations*

The research protocol was submitted to the Medical Ethics Committee of Brussels University Hospital (UZ Brussel and received ethical approval (BUN 1432022000179).

## **RESULTS**

Sixty-three participants initially expressed their interest in participating in the study. After contact with the researcher, four dyads indicated the person with dementia was not ready for ACP, and three family caregivers did not have the time to participate. A total of 52 participants were included in the study, comprising 21 dyads consisting of persons with dementia and their family caregivers and ten family caregivers participated alone because the person with dementia was unable to provide informed consent ( $n=6$ ) or did not want to participate ( $n=4$ ). Five participants with dementia did not complete the follow-up data collection (T1) due to a nursing home placement ( $n=1$ ) because they chose not to participate in ACP any longer, believing that their partner would make the decisions, saying things like, 's/he will handle that' ( $n=2$ ), or because they did not feel like seeing anyone ( $n=2$ ).

The average age of the persons with dementia was  $62.8 \pm 10.4$  years, with 42.8% being female. Of family caregivers, 68% were female and had an average age of  $62.1 \pm 10.9$  years. Most family caregivers were a partner of the person with dementia ( $n=25$ ). Most people with dementia had been diagnosed with Alzheimer's disease ( $n=25$ ). Family caregivers had an average computer literacy score of 7,5 (on a scale from 1 to 10, with higher scores indicating higher self-reported computer literacy). In contrast, people with dementia had an average score of four.

Table 1 – Description of the study population

| Variables          |                           | Person with dementia<br>(n=21) | Family caregiver<br>(n=31) |
|--------------------|---------------------------|--------------------------------|----------------------------|
| Gender             | Female n                  | 9                              | 21                         |
| Age                | Mean±SD                   | 62.1±10.9                      | 62.8±10.4                  |
| Relationship       | Partners                  | 18                             | 25                         |
|                    | Parent (in law)-child     | 3                              | 6                          |
|                    | Alone                     | 0                              | 5                          |
| Living situation   | With partner              | 17                             | 22                         |
|                    | With children and partner | 3                              | 4                          |
|                    | In a nursing home         | 1                              | 0                          |
| Education          | Primary school            | 6                              | 3                          |
|                    | High school               | 5                              | 5                          |
|                    | Applied sciences          | 7                              | 14                         |
|                    | University                | 3                              | 15                         |
| Profession         | Employed                  | 1                              | 16                         |
|                    | Retired                   | 20                             | 15                         |
| Computer literacy  | Between 0 – 10 (mean±SD)  | 4,2±3.1                        | 7,5±2.1                    |
| Date of diagnosis  |                           | 01/2013 – 12/2022              |                            |
| Dementia diagnosis | Alzheimer's disease       | 15                             | 20                         |
|                    | Vascular dementia         | 1                              | 3                          |
|                    | Frontotemporal dementia   | 3                              | 3                          |
|                    | Lewy body dementia        | 1                              | 1                          |
|                    | Parkinson's dementia      | 0                              | 1                          |
|                    | I do not know             | 1                              | 3                          |
| Comorbidities      | No                        | 18                             | 29                         |
|                    | Yes                       | 3                              | 2                          |
|                    | Cardiovascular disease(s) | 2                              | 1                          |
|                    | Insomnia                  | 1                              | 1                          |

a: Married, living together or being in a romantic relationship. b: 6 of the retired persons with dementia were forced to take early retirement because of their diagnoses. c: One person with dementia moved to a nursing home during the study d: self-evaluation on a scale from 1 (no computer skills) to 10 (excellent computer skills). e: comorbidity of the person with dementia/comorbidity of the family caregivers.

### Evaluation of the website's usability, acceptability, and feasibility

#### *Usability*

In the interviews, certain features of the website, like its interface's colours, easy-to-read content, and accessibility features, were praised by most participants. However, younger participants noted during the interviews that the website appeared outdated and suggested adding more colours to enhance its visual appeal. Via the Ecological Momentary Assessment question, participants indicated that they found the website very useful (mean score:  $1.23 \pm 0.66$  on a 1 to 5 scale, lower score = higher usability). No suggestions for improvement were made in the ecological momentary assessment open-ended text box. Similar findings were echoed in the interviews, where participants had no suggestions for enhancing usability. In the System Usability survey, people with dementia rated the website usability as above average (68%), while family caregivers found it excellent (80%). Of people with dementia, 75% found it easy to use, but 38% indicated needing support (Table 3). The interviews yield the same, as people with dementia, whether using the website alone or with their family

caregivers, found it easy to use. However, those who used it with family caregivers expressed they needed assistance if they would use it alone.

*Table 3 – overview of the scores on the system usability scale*

| System Usability Scale                                  | Person with dementia (n=16) N (%) |         |          | Family caregiver (n=31) N (%) |         |          |
|---------------------------------------------------------|-----------------------------------|---------|----------|-------------------------------|---------|----------|
|                                                         | Agree                             | Neutral | Disagree | Agree                         | Neutral | Disagree |
| Would like to use the website regularly                 | 12 (75)                           | 4 (25)  | 0        | 23 (74)                       | 7 (23)  | 1 (3)    |
| Website too complex                                     | 0                                 | 3 (19)  | 13 (81)  | 1 (3)                         | 20 (64) | 18 (58)  |
| Website easy to use                                     | 12 (75)                           | 3 (19)  | 1 (6)    | 29 (94)                       | 1 (3)   | 1 (3)    |
| Need support to use the website                         | 6 (38)                            | 1 (6)   | 9 (56)   | 1 (3)                         | 1 (3)   | 29 (94)  |
| Functions of the website are very well integrated       | 8 (50)                            | 8 (50)  | 0        | 25 (81)                       | 5 (16)  | 1 (3)    |
| Too much inconsistency on the website                   | 0                                 | 6 (38)  | 10 (62)  | 0                             | 3 (10)  | 28 (90)  |
| People can learn to use the website in a quick way      | 10 (62)                           | 5 (31)  | 1 (6)    | 25 (81)                       | 5 (16)  | 1 (3)    |
| Website is very cumbersome to use                       | 4 (25)                            | 4 (25)  | 8 (50)   | 0                             | 2 (6)   | 29 (94)  |
| Felt familiar using the website                         | 11 (68)                           | 5 (31)  | 0        | 25 (81)                       | 7 (23)  | 0        |
| Had to learn many things before I could use the website | 2 (12)                            | 6 (38)  | 8        | 2 (6)                         | 1 (3)   | 28 (90)  |
| Overall score                                           | <b>68,1%</b>                      |         |          | <b>80,1%</b>                  |         |          |

*\*Based on the System Usability survey with a scale of 1 or 2 = totally agree or Agree, 3 = Neutral, and 4 or 5 = Disagree or completely disagree. The total SUS score was computed using the scoring formula. The SUS score is derived from a user's responses to the 10-item questionnaire. For odd-numbered items, one is subtracted from the user's response, while for even-numbered items, the user's response is subtracted from 5. The adjusted scores for all ten items are then summed. To normalise the score, this sum is multiplied by 2.5 to normalise the score, resulting in a final SUS score that falls within the range of 0 to 100. A higher SUS score indicates better-perceived usability, with an average SUS score typically around 68.*

### *Feasibility*

Regarding the feasibility or uptake of the website, participants indicated in the interviews that they mostly used the website together. In six out of 21 dyads, the family caregivers used the website only on their own. These family caregivers pointed out that the person with dementia was no longer able to use websites. Hence, according to them, early access is important. Three people with dementia used the website without their family caregiver.

### *Acceptability*

In the Ecological Momentary Assessment acceptability question, participants rated acceptability with an average of  $1,31 \pm 0,7$  on a scale from 1 to 5, with a lower score indicating higher acceptability. In the interviews, the same was found, with most participants (>70%) perceiving the website as easy to navigate, intuitive, and having added value to support ACP in dementia. However, family caregivers of people with more moderate dementia thought it was too difficult for their family members with dementia.

Family caregiver (female, 62 years): *'For me, the website is very clear and easy to use, but for [name of the person with dementia], that is not possible anymore; together would be possible, maybe, but I am not sure. I think it is too late now.'*

Person with mild dementia (man, 55 years): *'I haven't actually experienced any difficulties. It's extensive and a lot, of course, but that's not a bad thing [laughs]. As I said before, it is well structured and was easy to use.'*

#### Experiences of participants with using the website

Participants rated their experiences with the ACP website via the Ecological Momentary Assessment question as very positive (mean 1,16±0,63 - on a scale from 1 to 5, with a lower score indicating better experience). Family caregivers and people with dementia indicated the same in the interviews, as they felt at ease when using the website but did mention the emotional nature of ACP conversations, leading them to occasionally stop using the website and return later. Moreover, family caregivers indicated in the interviews they missed some information on financial affairs, the progression of dementia and information on possibilities for future care. Also, some of the younger family caregivers suggested including videos of people with early-onset dementia because they may have different difficulties (e.g. working partners, young children, etc.). No technical issues were mentioned.

#### Evaluation of the effects of the ACP website on ACP readiness, knowledge, attitudes, perceived barriers to engage in ACP, self-efficacy, and skills to engage in ACP

##### *ACP readiness*

The proportion of persons with dementia who indicated in the ACP readiness survey that they wanted or discussed possibilities with family about future care and treatment increased from 57% at baseline to 67% after the study period. For family caregivers, this increased from 68% to 77% (Table 5).



Table 5 - Readiness for ACP engagement

| Readiness for ACP engagement*                                                                              | Person with dementia (n=21) N (%) |                        | Family caregiver (n=31) N (%) |           |
|------------------------------------------------------------------------------------------------------------|-----------------------------------|------------------------|-------------------------------|-----------|
|                                                                                                            | Baseline (T0)                     | Post (T1) <sup>a</sup> | Baseline (T0)                 | Post (T1) |
| Wants to or documented who is the proxy decision maker n (%)                                               | 14 (67)                           | 18 (86)                | 25 (81)                       | 29 (93)   |
| Wants to or discussed possibilities with family/person with dementia about future care and treatment n (%) | 12 (57)                           | 14 (67)                | 19 (61)                       | 27 (87)   |
| Wants to or discussed possibilities with healthcare professional about future care and treatment n (%)     | 10 (57)                           | 15 (71)                | 21 (68)                       | 24 (77)   |
| Wants to or documented possibilities for future care and treatment n (%)                                   | 8 (38)                            | 15 (71)                | 21 (68)                       | 25 (81)   |

\* Participants who wanted to document/discuss answered they wanted to do it within six months

<sup>a</sup> Five people with dementia were not able to fill in this questionnaire at T1

### ACP knowledge

At baseline, some participants (n=12) mentioned in the interviews they did not know what ACP was, but most participants (n=40) indicated they had some knowledge about ACP. Participants (n=25) often mentioned euthanasia and documentation as the main topic of ACP. Thirteen of these participants mentioned that, concerning ACP, ‘everything was taken care of’. However, when asked what was ‘taken care of’, these participants mainly mentioned financial affairs (n=13). After the study, most participants (n=31) said they better understood ACP even though they indicated they already knew the topic, while others (n=16) mentioned their knowledge did not change much because of their prior knowledge.

Family caregiver (female, 58): *‘Actually, I did not get a different image [about ACP], but some things that come with it are clearer now. Appointing a proxy and why, for example, that's an element I hadn't thought of yet.’*

Person with mild dementia (man, 67 years): *Yeah, it changed a little. I think now that it [ACP] is about that, I already think about what I would want, and that I would already express that [what you want] and share it with important people like my wife and children so that they know what I want.*

### Attitudes towards the website and towards ACP

At baseline, all participants had positive attitudes towards ACP, with some participants mentioning during the interviews that they had not yet thought about or discussed preferences for future care or treatment (n=26) or wishes around the end of life (n=31). Only a few wanted to or had previously discussed ACP with their healthcare professional (n=11).

In the follow-up interviews, all participants expressed again positive attitudes towards using the website and engaging in ACP and thought the website may be helpful in facilitating the ACP process. After eight weeks, more people (n=36) said they discussed preferences for future care and treatment or wishes around the end of life (n=24). Also, after eight weeks, more people discussed or wanted to discuss ACP with their healthcare professionals (n=21). However, after using the website, five family caregivers felt it was too late to discuss ACP with the person with dementia because the person with dementia was unable, according to them, to think or discuss ACP because of the moderate stage of dementia. They felt ACP was important, especially to talk about what is important, and they had some regrets about not starting earlier.

Family caregiver (female, 72 years): *Yes, we now have that feeling like we know what we want now. Or 'We have it mapped out. Mapped.' That's kind of it, or we have mapped it out, so now we can discuss it with someone else more easily.*

Person with mild dementia (female, 61 years): *'You should not wait to discuss these topics [ACP] until there is a care emergency or something like that. You should say to yourself, 'I'll stop for a moment, and I'll try to discuss this with the people who care about me.'*

#### *Perceived barriers to engage in ACP*

At baseline, the most mentioned barrier to engaging in ACP expressed by people with dementia (n=15) during the interviews was the desire to live in the present and consider themselves too healthy to think about ACP. Family caregivers (n=23) often mentioned the business of everyday life as a reason not to start with ACP. Family caregivers (n=15) also found it challenging to anticipate the changes associated with dementia and needed support to start the conversation. After the eight weeks, participants mentioned the same barriers, but particularly, family caregivers felt the ACP website could support overcoming some of these barriers. The interactive communication tools and testimonial videos on the website were valued as helpful in this area. Family caregivers underlined they found the tip *'talk together, rather than solely focusing on the person with dementia'* useful. However, people with dementia (n=3) and family caregivers (n=10) perceived anticipating and formulating wishes in advance as challenging because of the uncertainties associated with dementia. Three family caregivers and three people with dementia still perceived the same barriers (business of everyday life and being too healthy to think about ACP) as they did at baseline and did not see how to overcome them.

Family caregiver (female, 58 years): *'Yes, the tips helped to start a conversation with her family. You don't want to say anything wrong, of course. The problem is that you do not want to push her [the person with dementia] in a certain direction. And that ... I don't want that. I want to do what I think is right.'*

Person with dementia (man, 67 years): *'Ah yes, that's [support to start ACP] exactly the added value of that website, isn't it. You have a tool that you don't have to start inventing things yourself or think, what we are going to talk about next.'*

#### *Self-efficacy to use the website and to start ACP*

At baseline, all family caregivers and 17 people with dementia believed they could use the website independently without assistance. In the interviews, over half of the participants said they had initiated ACP together before the start of the study, which aligns with what participants indicated in the ACP readiness survey. In follow-up interviews, all family caregivers reported they used the website alone, while six people with dementia required assistance from their partners. Overall, after eight weeks, 34 participants indicated that they used the website to start thinking about potential future care preferences. Some of them (n=14) made an appointment with their physician to discuss these thoughts and/or indicated they (n=16) downloaded or got an advance directive, which they wanted to discuss with family and a healthcare professional. All participants who used the website would recommend it to others, highlighting they felt it could benefit others. Moreover, those who started thinking and talking about ACP during the eight weeks through the website expressed a desire to continue using it, including reconsidering past conversations, and exploring additional ACP topics they were not ready to discuss, like nursing home placement.

#### *Skills to engage in ACP*

At baseline, some participants (n=27) indicated they did not know how to start thinking and discussing ACP – besides filling in advance directives. Others felt they could find their way if they searched the Internet or would ask their healthcare professional (n=25). When participants had already discussed or documented ACP before their participation in this study, a healthcare professional (n=10) or a notary (n=20) was involved in most cases. After the eight-week study period, all participants indicated in the interview that the website could help them to develop skills to reflect on and have conversations about what is important for them and potential future care preferences, for example, by using communication tips or

interactive communication tools. Family caregivers of dyads indicated they first used the website alone – to learn what ACP is and how to start discussing the future – and then involved the person with dementia. This way, twenty-eight participants discussed potential future care needs and what they would or would not want. For example, some dyads used the interactive communication card tool to start a conversation about potential future care and care possibilities. For instance, in one couple, the cards ‘dying at home’ and ‘being surrounded by family and friends’ triggered a conversation about future care and potential placement in a nursing home.

Family caregiver (female, 54 years): *‘My idea was to try to do that [involving the person with dementia] every time when using the website and also using the cards [interactive communication tool] to discuss ACP. By using those, how to talk about ACP becomes more concrete. First, [name person with dementia] watched those videos, which I found very useful. And then using them to try to go into things a bit deeper.’*

## **DISCUSSION**

This evaluation study showed that people with dementia and family caregivers considered the website useful and valued the ACP content. They felt that the website supported them in ACP. The website improved participants' ACP knowledge, self-efficacy, and skills and reported fewer barriers to engaging in ACP after 8 weeks compared to the beginning of the study. Participant attitudes toward ACP and the website remained positive throughout the study. Participants expressed a desire to continue using the website and would recommend using it to others. However, people with dementia found the website less user-friendly than family caregivers, and family caregivers mostly used the website alone or with the person with dementia, with only three people with dementia indicating they used the website alone.

Both people with dementia and their family caregivers emphasised the website's potential to support ACP in dementia. This evaluation study observed increased ACP readiness, improved knowledge of ACP, and decreased reported barriers to engaging in ACP. The measured outcomes in this study were aligned with the two primary website objectives: informing users about ACP and encouraging users to engage in ACP conversations, which were identified as critical needs addressed by people with dementia and their families themselves (8,12,22). Our results point to the importance of theory-based interventions, underscoring the need to select theoretical change methods that align with user needs. This approach is consistent with the recognised necessity for outcome measures that specifically

reflect the needs of people with dementia and their families, as highlighted in a recent umbrella review (2020) summarising quantitative and qualitative evidence on ACP in dementia (4).

In this study, the website to support ACP was mostly used by family caregivers, with only a few people with dementia engaging with it by themselves. Of the participants who participated as dyads and used the website together, it was mainly the family caregivers who initiated the usage. This finding aligns with previous research showing the important role of family caregivers as primary sources of support and guidance for people with dementia (29,30). Research has shown that family caregivers often play a crucial role in making technology accessible and overcoming potential barriers to its use (29,30). According to Hirschman et al., prompts by family are important in beginning the ACP process (31). However, it is important that both the person with dementia and their family caregiver can engage with ACP support and that they are both empowered to better understand the potential of ACP and explore various options for future care and treatment (5,6).

Moreover, people with dementia scored the website a lower total System Usability Score than family caregivers, despite the fact that we developed the website together with people with dementia; people with dementia also indicated that they needed more support to use the website. These differences in experienced usability between people with dementia and family caregivers were also reported in other studies on technology-based interventions (32–35). This highlights the complexities of effectively supporting people with dementia using such a website, even when developed with their direct input through co-design.

Our study supports the importance of the early introduction of ACP in dementia care. Some family caregivers faced challenges initiating ACP conversations due to the moderate stage of dementia in the person they were caring for. The importance of commencing ACP early has also been emphasised by people with dementia themselves (7,8,13). This early start helps set expectations, understand values, and outline preferences for future care (5,6). As the website may offer valuable support to people with dementia and their families, introducing and adopting it early is important. Some family caregivers in the study expressed that although they found the website useful and informative, they wished they had accessed it earlier, as conversations on ACP were no longer possible because of the moderate stage of dementia. When introduced in a timely manner, the website can serve as an excellent introduction for those starting ACP. It provides a user-friendly entry point that facilitates

important conversations and exploration in the comfort of one's home, offering a supportive environment for people with dementia and families in this important process.

#### *Strengths, limitations, and future research*

This study is the first to explore the use of technology to support ACP within the family context and dementia. A notable strength lies in its mixed methodology, emphasising the active involvement of people with dementia and minimising recollection of specific website experiences by assessing these in-the-moment with ecological momentary assessment questions. Another strength is the study successfully achieved its predetermined sample size. Lastly, data was collected at two points before and after an eight-week intervention period to assess changes over time. This approach provided insights into participants' evolving perspectives regarding ACP when using the website during the eight weeks. However, this study also has some limitations. Our eight-week evaluation study found that participants had improved ACP knowledge, self-efficacy, and skills and reported fewer barriers to engaging in ACP. However, we must interpret our findings with nuance as they do not establish causal relationships, primarily due to the absence of a control group. While our study provides valuable insights into the changes observed before and after the intervention, the lack of a control group limits our ability to attribute these changes solely to the website, necessitating caution in drawing definitive causal conclusions. Second, while achieving some diversity in participant demographics, including age and educational background, the study could benefit from further diversity to comprehensively represent people with dementia and their family caregivers. Lastly, we may have potentially excluded individuals from lower socioeconomic backgrounds due to the implicit requirement for computer literacy and the explicit criterion of '*having a device*'.

To enhance website usage by people with dementia, further research is recommended, focusing on exploring additional measures or training needed to improve the website's accessibility. As the website's structure is innovative, moving away from the linear structure typically seen in other existing web-based ACP tools, there is a need for additional research to understand user behaviour on the website and user navigation patterns. Additionally, investigating how the website can effectively complement the role of healthcare professionals is essential for further exploration.

## **CONCLUSION**

This study revealed positive perceptions of the ACP support website among people with dementia and their family caregivers, indicating its usefulness in facilitating ACP within the family context. Over the 8-week study, participants showed enhanced ACP knowledge, self-efficacy, and skills. While users expressed a desire to continue using the website, family caregivers took the lead in its adoption, underscoring their essential role in embracing new technology. Despite active involvement in the website's development, lower usability scores from people with dementia highlight ongoing challenges in creating dementia-friendly technology. The website may be an ideal introduction for those embarking ACP, providing a unique and user-friendly platform for initiating and exploring ACP conversations from the comfort of one's home.

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## APPENDIX 1 – OVERVIEW OF THE WEBSITE

Note that the original language is Dutch. The English version is translated by the automatic translate function in Google Chrome.

The home page:

Vroegtijdige  
zorgplanning  
bij dementie

Home

Vroegtijdige  
zorgplanning:  
Wat is het?

Nadenken en  
praten over  
later

Opschrijven  
voor later

Hulpmiddelen

Woordenlijst

Veelgestelde  
vragen

Bronnen en  
contact

Over ons

Zoek

Home

Lees voor

# Vroegtijdige zorgplanning (VZP) & dementie

## Nu nadenken en praten over later



© Laurane Berkein - Vlaamse Ouderenaad

Deze website is bedoeld om mensen met dementie en hun naasten te helpen bij vroegtijdige of voorafgaande zorgplanning. De website is ontwikkeld voor iedereen die in aanraking komt met dementie.

Veel mensen die te maken krijgen met een ziekte, stellen zich wel eens vragen over hoe de toekomst zal zijn.

- Wat als ik niet langer voor mezelf kan zorgen?
- Waar zou ik wens te wonen?
- Wie zou er het best voor mij zorgen?
- Welke behandelingen zou ik nog willen krijgen, welke niet, en op welk moment?

Vroegtijdige zorgplanning is bedoeld om jou te helpen een antwoord te vinden op deze moeilijke vragen. Deze website richt zich in de eerste plaats naar mensen met dementie zelf, om hen te ondersteunen bij vroegtijdige zorgplanning. De website richt zich ook op mensen die iemand met dementie omringen, bijstaan, of ondersteunen.

Deze website is ontwikkeld voor en samen met mensen met dementie. Het project werd geleid door onderzoekers van de Vrije Universiteit Brussel, Universiteit Gent en KU Leuven, het expertisecentrum Dementie Vlaanderen, Alzheimer Liga Vlaanderen, en mensen met dementie en mantelzorgers verspreid overheen Vlaanderen.

Lees voor



**Daniel:**  
"Direct nadat ik de diagnose dementie kreeg, zijn wij gaan praten. Wat wil ik nog doen? Wat zou ik willen in de toekomst? Dat heeft ons geholpen om samen na te denken over mijn en onze toekomst"

Lees voor



### Vroegtijdige zorgplanning: wat is het

Wil je meer weten over wat vroegtijdige zorgplanning is en wat de meerwaarde is?

Lees meer



### Nadenken en praten over later

Wil je meer weten over hoe na te denken en/of te praten over vroegtijdige zorgplanning?

Lees meer



### Opschrijven voor later

Wil je meer weten hoe je opschrijft wat je wil voor toekomstige zorg en behandelingen?

Lees meer

Bronnen en contact

Over de website en ons

Privacy policy

 Vrije  
Universiteit  
Brussel

 Universiteit  
Gent

 KU LEUVEN

 Dementie  
Vlaanderen

 Alzheimer  
Liga Vlaanderen

 Mantelzorgers  
Vlaanderen

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# Advance care planning (VZP) & dementia

## Think now and talk about later



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This website is intended to help people with dementia and their loved ones with early or advance care planning. The website has been developed for everyone who comes into contact with dementia.

Many people who are faced with an illness sometimes ask themselves questions about what the future will be like.

- What if I can no longer take care of myself?
- Where would I wish to live?
- Who would take best care of me?
- Which treatments would I still like to receive, which ones not, and at what time?

Advance care planning is designed to help you find answers to these difficult questions. This website is primarily aimed at people with dementia themselves, to support them in advance care planning. The website also focuses on people who surround, assist or support someone with dementia.

This website has been developed for and together with people with dementia. The project was led by researchers from the Vrije Universiteit Brussel, Ghent University and KU Leuven, the Dementia Flanders expertise center, Alzheimer League Flanders, and people with dementia and informal caregivers throughout Flanders.



Daniel:

"We started talking immediately after I was diagnosed with dementia. What else do I want to do? What would I want in the future? That helped us to think together about my and our future"



Advance care planning:  
what is it

Would you like to know more about what advance care planning is and what the added value is?

read more



Think and talk about later

Would you like to know more about how to think and/or talk about advance care planning?

read more



Write it down for later

Would you like to know more about how to write down what you want for future care and treatments?

read more

## Example page: thinking and talking about advance care planning

Vroegtijdige  
zorgplanning  
bij dementie

- Home
- Vroegtijdige zorgplanning: Wat is het?
- Nadenken en praten over later
- Nadenken en praten over later
- Praten met zorgverleners
- Opschrijven voor later
- Hulpmiddelen
- Woordenlijst
- Veelgestelde vragen
- Bronnen en contact
- Over ons
- Zoek

Home » Nadenken en praten over later

aaa tekstgrootte contrast print

Lees voor

## Nadenken en praten over later



© Sien Verstraeten - Vlaamse Ouderenraad

Personen met dementie vinden het vaak moeilijk om na te denken over de toekomst omdat deze erg onzeker is. Sommigen hebben behoefte om erover te praten. Anderen denken er liever zelf over na. Iedereen is anders.

In het filmpje hieronder vertellen Daniel, Lucrece en Paul:

- hoe ze samen praten
- waarover ze praten
- en wat moeilijk is



F Nadenken en praten over vroegtijdige zorgplanning (Deel 1)

Bekijken op YouTube

### Hoe start je vroegtijdige zorgplanning?

Hieronder vind je tips en voorbeelden over hoe je vroegtijdige zorgplanning kan starten. Hoe kan je zelf nadenken en hoe je met anderen praten.

Lees voor

#### Ik heb dementie

Hoe start je met nadenken over wat belangrijk is voor jou en wat je zou willen voor je toekomstige zorg en behandelingen

Lees meer

#### Mijn naaste heeft dementie

Als naaste van iemand met dementie kan je met vragen zitten over vroegtijdige zorgplanning. Wat vindt hij of zij belangrijk voor de toekomst?

Lees meer

Bronnen en contact Over de website en ons Privacy policy

VUB VRIJE UNIVERSITEIT BRUSSEL UNIVERSITEIT GENT KU LEUVEN

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## Thinking and talking about later



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People with dementia often find it difficult to think about the future because it is very uncertain. Some people need to talk about it. Others prefer to think about it themselves. Everybody is different.

In the video below, Daniel, Lucrece and Paul explain:

- how they talk together
- what they talk about
- and what is difficult



### How do you start advance care planning?

Below you will find tips and examples on how to start advance care planning. How to think yourself and how to talk to others.

#### I have dementia

How do you start thinking about what is important to you and what you would like for your future care and treatments

[read more](#)

#### My loved one has dementia

As a loved one of someone with dementia, you may have questions about advance care planning. What does he or she consider important for the future?

[read more](#)

## Example page: frequently asked questions

Vroegtijdige  
zorgplanning  
bij dementie

Home

Vroegtijdige  
zorgplanning:  
Wat is het?

Nadenken en  
praten over  
later

Opschrijven  
voor later

Hulpmiddelen

Woordenlijst

Veelgestelde  
vragen

Bronnen en  
contact

Over ons

Zoek

Home » Veelgestelde vragen

aaa tekstgrootte contrast print

Lees voor

# Veelgestelde vragen



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Op deze pagina staan enkele veel gestelde vragen. Staat de vraag die je hebt er niet bij? Ga dan naar de [contactpagina](#). Op deze pagina staan contactgegevens van verschillende organisaties waar je ook terecht kan met je vragen over vroegtijdige zorgplanning en dementie.

Met wie moet ik best eerst praten?

Wat als niet iedereen het eens is in de familie over vroegtijdige zorgplanning?

Kan ik euthanasie krijgen als ik dementie heb?

Heeft vroegtijdige zorgplanning alleen betrekking op het einde van het leven?

Hoe begin ik aan vroegtijdige zorgplanning?

Hoe kies ik een vertegenwoordiger?

Lees voor

Een vertegenwoordiger neemt voor jou beslissingen wanneer je dat zelf niet meer kan. Bijvoorbeeld omdat je in coma ligt of gevorderde dementie hebt. Een vertegenwoordiger is:

- meerderjarig (iemand boven de 18 jaar)
- wilsbekwaam
- iemand die je vertrouwt;
- bij wie je je op je gemak voelt om over jouw wensen voor de toekomst te praten.

Via het [formulier 'Aanwijzing van een vertegenwoordiger'](#) kan je vastleggen wie je vertegenwoordiger is:

- Laat dat door je arts toevoegen aan je patiëntendossier.
- Zorg voor drie exemplaren van dit document: één voor jezelf, één voor je vertegenwoordiger en één voor je huisarts of behandelende arts.

**Ben je verplicht om een vertegenwoordiger te kiezen?**

Nee. Heb je geen vertegenwoordiger? Dan wordt een vertrouwenspersoon gekozen. Dit gaat volgens een [cascade of watevalstelsel](#).

Is vroegtijdige zorgplanning de taak van de arts?

Kan je van gedachten veranderen over eerdere beslissingen rondom toekomstige zorg en behandelingen?

Vervangt de zorgvolmacht de wilsverklaringen?

Voor wie is vroegtijdige zorgplanning?

Wanneer neemt een vertegenwoordiger mijn beslissingen?

Wat als ik niemand heb om vroegtijdige zorgplanning mee te bespreken?

Wat als de arts er niet over wil praten?

Wat is het verschil tussen een vertrouwenspersoon en een vertegenwoordiger?

Wat moet mijn arts weten rondom mijn vroegtijdige zorgplanning?

Bronnen en contact

Over de website en ons

Privacy policy

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## Frequently asked to ask



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This page contains some frequently asked questions. Is the question you have not listed? Then go to the [contact page](#). This page contains contact details of various organizations where you can also ask your questions about advance care planning and dementia.

|                                                                     |   |
|---------------------------------------------------------------------|---|
| Who should I talk to first?                                         | ▼ |
| What if not everyone in the family agrees on advance care planning? | ▼ |
| Can I get euthanasia if I have dementia?                            | ▼ |
| Does advance care planning only concern the end of life?            | ▼ |
| How do I start advance care planning?                               | ▼ |
| How do I choose a representative?                                   | ▲ |

A representative makes decisions for you when you are no longer able to do so yourself. For example, because you are in a coma or have advanced dementia. A representative is:

- adult (someone over 18 years old)
- competent
- someone you trust;
- with whom you feel comfortable talking about your wishes for the future.

You can use the ['Appointment of a representative' form](#) to determine who your representative is:

- Have your doctor add this to your patient file.
- Make sure you have three copies of this document: one for yourself, one for your representative and one for your GP or treating physician.

Are you obliged to choose a representative?

No. Don't have a representative? A confidential counselor is then chosen. This is done according to a [cascade or waterfall system](#).

|                                                                                         |   |
|-----------------------------------------------------------------------------------------|---|
| Is advance care planning the doctor's job?                                              | ▼ |
| Can you change your mind about previous decisions regarding future care and treatments? | ▼ |
| Does the health care proxy replace the advance directives?                              | ▼ |
| Who is advance care planning for?                                                       | ▼ |
| When does a representative make my decisions?                                           | ▼ |
| What if I don't have anyone to discuss advance care planning with?                      | ▼ |
| What if the doctor doesn't want to talk about it?                                       | ▼ |
| What is the difference between a confidential counselor and a representative?           | ▼ |
| What does my doctor need to know about my advance care planning?                        | ▼ |



## Appendix 2 – the interactive communication tools

### Preview of the Interactive Card Tool.

The interface is titled "JOUW KAART" and "AFLEGSTAPEL". It features a top navigation bar with a light green background. Below the bar, there are three main sections for card placement, each with a dashed border and a header:

- HEEL BELANGRIJK** (Green dashed border): Contains two small boxes with the text "Typ hier je gedachten of schrijf een extra kaart." and a large empty area below them.
- ENIGSZINS BELANGRIJK** (Orange dashed border): A large empty area.
- NIET BELANGRIJK** (Pink dashed border): A large empty area.

On the right side, there is a vertical column of green buttons:

- Toon instructies
- Lees alle kaarten
- Zoom (with a magnifying glass icon)
- Print op computer
- Print op tablet
- Opslaan
- Herstart

At the top left, there is a box labeled "Geen pijn hebben" and an empty box next to it.

## Example of the fill in tool ('Thinking Now About Later')

Vroegtijdige  
zorgplanning  
bij dementie

- Home
- Vroegtijdige zorgplanning: Wat is het?
- Nadenken en praten over later
- Opschrijven voor later
- Hulpmiddelen
- Overzicht
- Handvat
- Levenswensen kaarten
- Wilsverklaringen
- Woordenlijst
- Veelgestelde vragen
- Bronnen en contact
- Over ons
- Zoek

Home » Hulpmiddelen bij vroegtijdige zorgplanning » Handvat

Lees voor

## Handvat

### 'Nu nadenken over later'



© Bruno Nissen - Vlaamse Ouderraad

Dit handvat helpt jou nadenken over wat je belangrijk vindt rond toekomstige zorg en behandelingen. Het helpt je jezelf en anderen voorbereiden op moeilijke keuzes later.

- Je krijgt verschillende vragen over wat nu en in de toekomst belangrijk is voor jou.
- Je hoeft niet alle vragen te beantwoorden.
  - Wil je een vraag overslaan? Dan tik je op 'verder'.
- Je antwoorden zijn persoonlijk. Er zijn geen juiste of foute antwoorden.
- Je kan elk antwoord altijd nog aanpassen of aanvullen.
- Je moet niet alle vragen tegelijk antwoorden.
  - Je bewaart wat je al noteerde en je schrijft later verder.
- Je kan je antwoorden downloaden als PDF. Of je kan ze uitprinten.
- Je kan de vragen in je eentje invullen of samen met iemand uit je omgeving.
  - Misschien helpt dat jullie om een gesprek te starten over vroegtijdige zorgplanning.
- Vind je sommige vragen te moeilijk?
  - Bespreek ze met een arts of een zorgverlener die je vertrouwt.
- Dit handvat is volledig anoniem. Niemand kan jouw antwoorden zien.

[Lees meer info over je privacy](#)

Hieronder is een korte video met instructies:

Handvat instructies

Mijn keuzes Print Opslaan Herstart 2/9 Delen

**Wat is voor mij belangrijk, nu en in de toekomst?**

Dit is geen gemakkelijke vraag. Door deze vraag te beantwoorden kan je een idee krijgen wat voor jou belangrijk is en waar je waarde aan hecht. Dit kan gaan over het nu maar ook over de toekomst. Je kan hier aan verschillende dingen denken: je gezondheid, je onafhankelijkheid, welke activiteiten belangrijk zijn voor jou, wat je nog wil doen in de toekomst, waar je wil verblijven. Je kan ook denken aan je sociale contacten, je familie, vrienden, je collega's regelmatig zien, je geloof betuigen, de natuur of cultuur kunnen beleven. Het zijn maar enkele voorbeelden van wat belangrijk kan zijn voor iemand.

**WAT IS VOOR MIJ BELANGRIJK IN MIJN LEVEN?**

Bijkomende vragen ter inspiratie

Typ hier wat belangrijk is voor jou in jouw leven.

**WAT IS VOOR MIJ BELANGRIJK IN MIJN TOEKOMST?**

Bijkomende vragen ter inspiratie

Typ hier wat belangrijk is voor jou in jouw toekomst.

Bekijken op YouTube

**Start met het handvat**

Bronnen en contact Over de website en ons Privacy policy









## Handle

### 'Thinking now about later'



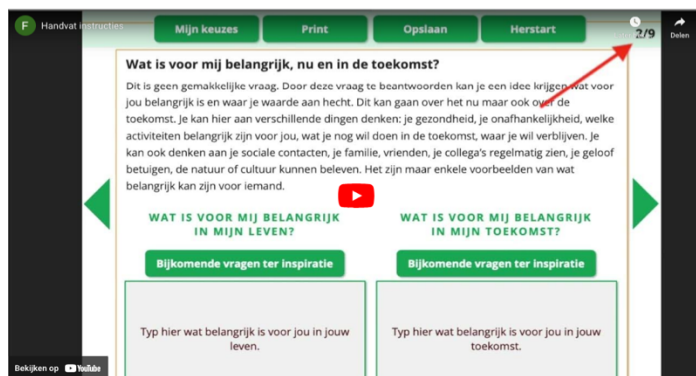
© Bruno Nissen - Flemish Council for the Elderly

This tool helps you think about what you find important regarding future care and treatments. It helps you prepare yourself and others for difficult choices later.

- You will be asked various questions about what is important to you now and in the future.
- You don't have to answer all the questions.  
Do you want to skip a question? Then tap 'continue'.
- Your answers are personal. There are no right or wrong answers.
- You can always adjust or supplement any answer.
- You should not answer all questions at once.  
You save what you already wrote down and continue writing later.
- You can download your answers as a PDF. Or you can print them out.
- You can complete the questions on your own or together with someone from your environment.  
Maybe that will help you start a conversation about advance care planning.
- Do you find some questions too difficult?  
Discuss them with a doctor or healthcare provider you trust.
- This handle is completely anonymous. No one can see your answers.

[Read more information about your privacy](#)

Below is a short video with instructions:



Start with the handle

**Wat is voor mij belangrijk, nu en in de toekomst?**

Dit is geen gemakkelijke vraag. Door deze vraag te beantwoorden kan je een idee krijgen wat voor jou belangrijk is en waar je waarde aan hecht. Dit kan gaan over het nu maar ook over de toekomst. Je kan hier aan verschillende dingen denken: je gezondheid, je onafhankelijkheid, welke activiteiten belangrijk zijn voor jou, wat je nog wil doen in de toekomst, waar je wil verblijven. Je kan ook denken aan je sociale contacten, je familie, vrienden, je collega's regelmatig zien, je geloof betuigen, de natuur of cultuur kunnen beleven. Het zijn maar enkele voorbeelden van wat belangrijk kan zijn voor iemand.

**WAT IS VOOR MIJ BELANGRIJK  
IN MIJN LEVEN?****Bijkomende vragen ter inspiratie**

Typ hier wat belangrijk is voor jou  
in jouw leven.

**WAT IS VOOR MIJ BELANGRIJK  
IN MIJN TOEKOMST?****Bijkomende vragen ter inspiratie**

Typ hier wat belangrijk is voor jou  
in jouw toekomst.

## **CHAPTER 6**

### **UNCOVERING USER PATHWAYS: EXPLORATION OF USER ENGAGEMENT WITH AN ADVANCE CARE PLANNING WEBSITE FOR PEOPLE WITH DEMENTIA AND FAMILY CAREGIVERS**

Charlèss Dupont, Tinne Smets, Courtney Potts, Fanny Monnet, Lara Pivodic, Aline De  
Vleminck, Chantal Van Audenhove, Maurice Mulvenna and Lieve Van den Block.

[Submitted]

## ABSTRACT

*Background:* To inform and support people to engage in advance care planning, web-based tools have gained popularity. We have developed an interactive website tailored to the unique needs of people with dementia and their families to support the advance care planning process beyond the professional context.

*Aim:* This study aims to assess the website's usage by people with dementia and their family caregivers, identify distinct user engagement patterns, and visualise how users navigate the website.

*Design:* We analysed the website's log data obtained from an eight-week evaluation study of the site. Interactions with the website were collected in the log data and included visited web pages or clicking on hyperlinks. Distinct user engagement patterns were identified using K-means clustering. AI-driven process mining was applied to visualise user pathways through the website.

*Participants:* Participants (n=52) were 21 people with dementia and their family caregivers as dyads and ten family caregivers alone.

*Results:* Throughout the eight-week study, users spent an average of 35.3 (SD = 82.9) minutes over 5.5 (SD = 3.4) unique days on the website. Mostly, family caregivers use the website (alone or with a person with dementia). Only three people with dementia used it on their own. Three distinct engagement patterns emerged: low, moderate, and high. Low-engagement participants spent less time on the website during the eight weeks, following a linear path from information to communication to documentation. In contrast, moderate and high-engagement users showed more dynamic patterns, frequently navigating between information pages, communication tips, and the interactive communication tools to facilitate exploration of aspects related to advance care planning and the question, '*what matters most to you?*'.

*Conclusions:* This study identified various user engagement patterns, with most navigating back and forth between pages. The diverse engagement patterns underscore the need for personalised support in advance care planning and challenge the conventional linear advance care planning representations found in other web-based tools.

## INTRODUCTION

Advance care planning is a communication process between patients, families, and healthcare professionals to “*define goals and preferences for future care and treatment*” (1). This process holds particular relevance in dementia (2). The cognitive decline in dementia highlights the need for early initiation of advance care planning, enabling people with dementia to reflect on and express their preferences for future care and treatments (3–5). While existing definitions of advance care planning often focus on medical care decisions (6), people with dementia and their families have emphasised that it should include exploring what matters now and, in the future,, including non-medical aspects of care (7–10). Moreover, people with dementia and their families have expressed a need to discuss future care together (7). This aligns with the recently introduced public health approach to advance care planning, emphasising a necessary shift towards a social focus on ‘*what matters most to people*’ rather than the current emphasis on end-of-life decision-making and underlining the need to support conversations in the family context (11).

To support advance care planning within the family context, interactive web-based tools like websites or apps have been promoted (12); however, despite their proven benefits in other populations, there is a noticeable absence of tools tailored to the specific needs of people with dementia and their families (13–15). To address this gap, we developed a website for and with people with dementia and their families (16). This website deviates from the structured linear pathways found in other tools to support advance care planning (15). Such tools adhere to a stepwise procedure, often commencing with information provision, prompting reflection, followed by communication, and concluding with documentation, commonly in the form of advance directives. Unlike these approaches, our website is more flexible, allowing usage without a predefined path.

Following the development of the website to support advance care planning, we performed an eight-week evaluation study involving people with mild to moderate dementia and their family caregivers (17). The primary focus of this evaluation was to assess the usability, acceptability, feasibility, experiences, and outcomes of using the website. Participants in the evaluation study found that the website supports ACP. After eight weeks, participants exhibited improved advance care planning knowledge, self-efficacy, and skills.

Beyond this evaluation, gaining insights into the website’s user engagement and usage patterns is crucial to enhance our understanding of how people with dementia and their families use a website to support ACP in the family context, how they engage with it and how

single users and dyadic users differ (i.e. people with dementia together with their family caregiver). Explore how people with dementia and their family caregivers used the ACP support website during an eight-week evaluation study;

- Explore whether and which user behaviour clusters can be typified based on the engagement of people with dementia and their family caregivers with the website;
- Explore and visualise user pathways of the identified user behaviour clusters, i.e. how the different user clusters of people with dementia and their family caregivers navigate through the website.

## **METHODS**

This study quantitatively analysed web log data from a convergent parallel mixed-methods evaluation study of a website designed to support people with dementia and their family caregivers in advance care planning. Web log data was collected during an 8-week evaluation study to capture participants' interactions with the website, e.g., time spent on the website and what pages were visited. This log data was used to explore the website's usage by people with dementia and their family caregivers, which user behaviour clusters can be typified and to visualise user pathways.

### *The development of the advance care planning support website*

The development of the website followed a user-centred, iterative design process, ensuring alignment with the needs of people with dementia and their families. The website was developed to provide information and support for people with dementia and their family caregivers in advance care planning (16). It includes advance care planning information, information about legal frameworks, communication tips, and documentation sections. Moreover, it provides accessibility features, such as text-to-speech and text enlargement and two interactive communication tools, an 'Interactive Card Tool' based on the recently developed paper-based version of the *Levenswensen (Life Wishes)* cards and the fill-in tool 'Thinking Now About Later', that guides users through a reflective process to support thinking and talking about and writing down their preferences for the present and future (appendix 1 and 2) (16,18).

### *Participants and setting*

People with mild to moderate dementia, including both early and late-onset, along with their family caregivers as dyads or the family caregiver alone, were recruited. To be eligible, participants needed to meet the following criteria:



Both people with dementia and their family caregivers:

- Express interest in and willingness to test the website to support advance care planning
- Provide consent for study participation
- Proficient in speaking and understanding Dutch
- Own a device (laptop, tablet, mobile phone, etc.)

People with dementia:

- Diagnosed with young- or late-onset dementia

Family caregivers:

- Actively involved in the care (physical, emotional, social, etc.) of the person with dementia.

For participants recruited as dyads, at least one had to be capable of navigating the website. For instance, the person with dementia and the family caregiver could not both have visual impairments or other disabilities hindering interaction with the ACP website. The study was conducted in Flanders, the Dutch-speaking region of Belgium.

#### *Data collection procedures*

Between October 2022 and May 2023, 52 people participated in the evaluation study: 21 dyads, i.e.,  $n=21$  people with dementia,  $n=21$  family caregivers, and  $n=10$  family caregivers alone. Information on sociodemographic data, including age, gender, computer literacy, type of diagnosis and date, was gathered through a survey assessed at the start of the eight weeks.

To capture the usage by the participants during the eight-week study, there was a continuous collection of log data. Usage refers to how people with dementia and family caregivers engage with the ACP website. The log data captured what pages were visited, time spent on each page, interaction with content or functions, frequency of visits to each page, and the search queries used. Upon accessing the website, participants were prompted to identify themselves through a pop-up question, requiring them to fill in their study ID and specify whether they were a person with dementia, a family caregiver, or engaging together as a dyad. A detailed study protocol of the evaluation study is published elsewhere (8).

### *Data analysis*

Log data of the ACP website were analysed using the programming language R (version 4.2.3) in RStudio. The log data was saved in three files: application and access logs and a file to save the interactions with the interactive communication tools. First, the three log datasets were cleaned by eliminating irrelevant data, such as admin and php requests. The application logs were further filtered to include only valid study IDs used by the participants. Study IDs were then added to the access logs based on cross-matching with IP addresses. The access and application logs were combined, and additional information from the third dataset regarding the completion of interactive communication tools was incorporated by matching IP addresses to study IDs.

- *Assessing the extent to which the website was used*

First, the interactions with the website were summarised by time spent on the website, pages visited, and who visited

- *Identifying distinct behavioural clusters*

After, the data underwent K-means clustering. Clustering the data aimed to identify behavioural or interaction patterns that typify user engagement. The six features derived from the summary data were used for clustering: total interactions, unique days, duration of use, total clicks on communication, information and documentation pages. The R package 'caret' was employed to normalise the data using min-max normalisation, converting variables to a range between 0 and 1 (19). The 'NbClust' package was then utilised to compare summary statistics, using 30 indices to determine the optimal number of clusters (k) between 2 and 10 based on these metrics (20). Subsequently, the k-means algorithm was applied to the data for k clusters. Principal component analysis (PCA) was used for data visualisation to reduce the multiple features to two dimensions. Finally, Kruskal-Wallis rank sum tests and chi-squared tests were conducted to evaluate the significant differences between features for each cluster, providing further insights into the characteristics of the identified user clusters.

- *Identification of user pathways*

To visualise the path users took on the website (e.g. how they navigated through the website), the R package BupaR was used (21). Log data were filtered to remove redundant information (taken out: change font size, contrast, privacy policy, read speaker, print, other). First, a process matrix, which is a two-dimensional matrix showing the flows between activities, was generated to visualise the entire log dataset (22). After, individual process maps were

produced per study ID to show the path taken by participants. Lastly, the individual paths were compared with the IDs per cluster to find similarities and differences between the participants' paths in each cluster.

## RESULTS

In total, 52 participants with 31 study IDs were included (21 dyads and ten family caregivers), consisting of 21 people with dementia and 31 family caregivers. Ten family caregivers participated alone, either because the person with dementia was unable to provide informed consent (n=6) or chose not to participate (n=4). The average age of people with dementia was  $62.8 \pm 10.4$  years, with 42.8% being female. Among family caregivers, 68% were female, with an average age of  $62.1 \pm 10.9$  years. Family caregivers reported an average computer literacy score of 7.5 (on a scale from 1 to 10, with higher scores indicating greater self-reported computer literacy), while people with dementia had an average score of four.

*Table 1 – Description of the study population*

| Variables          |                         | Person with dementia (n=21) | Family caregiver (n=31) |
|--------------------|-------------------------|-----------------------------|-------------------------|
| Gender             | Female                  | 9                           | 21                      |
| Age                | Mean $\pm$ SD           | 62.1 $\pm$ 10.9             | 62.8 $\pm$ 10.4         |
| Relationship       | Partners                | 18                          | 25                      |
|                    | Parent (in law)-child   | 3                           | 6                       |
| Profession         | Employed                | 1                           | 16                      |
|                    | Retired                 | 20                          | 15                      |
| Computer literacy  | Mean $\pm$ SD           | 62.1 $\pm$ 10.9             | 62.8 $\pm$ 10.4         |
| Date of diagnosis  |                         | 01/2013 – 12/2022           |                         |
| Dementia diagnosis | Alzheimer's disease     | 15                          | 20                      |
|                    | Vascular dementia       | 1                           | 3                       |
|                    | Frontotemporal dementia | 3                           | 3                       |
|                    | Lewy body dementia      | 1                           | 1                       |
|                    | Parkinson's dementia    | 0                           | 1                       |
|                    | I do not know           | 1                           | 3                       |

a: Married, living together or being in a romantic relationship. b: 6 of the retired persons with dementia were forced to take early retirement because of their diagnoses. c: One person with dementia moved to a nursing home during the study d: self-evaluation on a scale from 1 (no computer skills) to 10 (excellent computer skills).

### *Website usage*

Each study ID (n=31) was logged at least once in the log data, indicating at least one visit by one or both dyad members and by each family caregiver who participated alone. In 10 study IDs, both the family caregiver and dyad used the website. In 15 instances, only the caregiver accessed it and in 3 cases, solely the dyad engaged with the website. Additionally, 3 occurrences involved mixed usage, with indications of the family caregiver, dyad, or person with dementia using the website. The total number of unique interactions with the website was 1799, encompassing information searches, clicks, and utilisation of interactive elements.

On average, users had 58 (SD: 57) interactions over the eight weeks. The total duration spent on the website during the eight weeks was 35.3 (SD: 82.9) minutes, and, on average, people used the website on 5.5 (SD: 3.4) unique days of the eight-week study period.

User interactions revealed that family caregivers had the highest overall number of interactions (n=757), followed by dyads (n=235) and people with dementia alone (n=103). We faced difficulty attributing the information to specific user types for the other 701 interactions documented in the access log file. These unidentified usages per user type arose from difficulties linking interactions with corresponding user types when users left their browsers open for extended periods. Table 2 illustrates the total interactions per web page.

*Table 2 – overview visits of the main sections\* of the website per user*

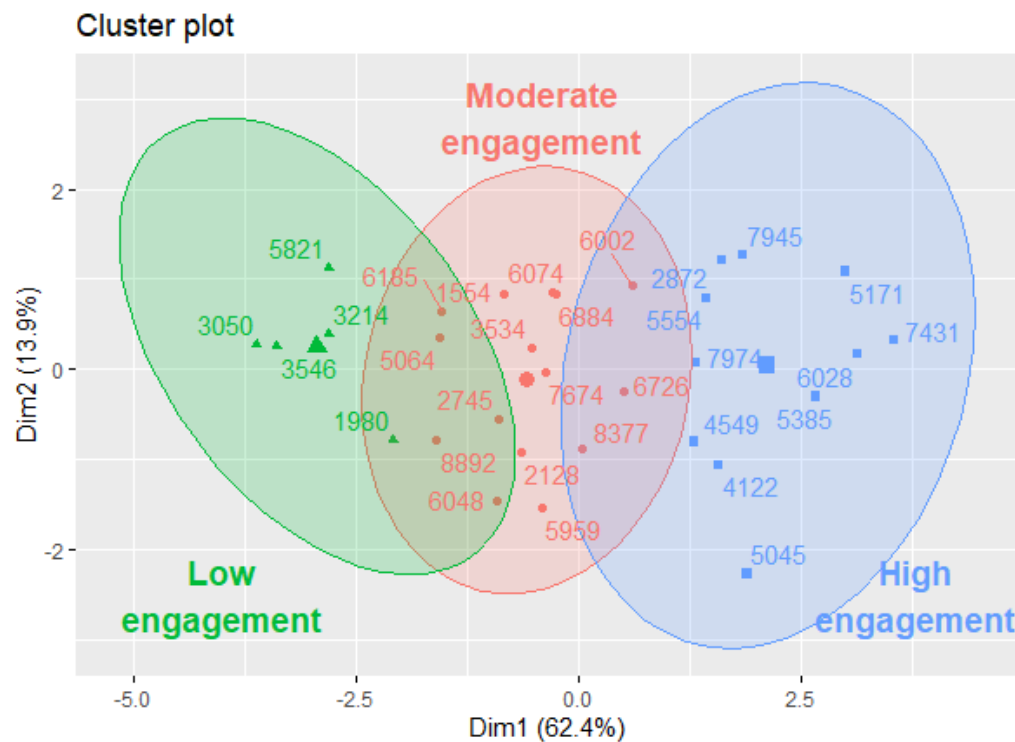
| Web pages of the ACP website                            | Total visits per page |
|---------------------------------------------------------|-----------------------|
| Advance Care Planning: What Is It?                      | 304                   |
| Glossary                                                | 209                   |
| Advance Care Planning: Thinking and Talking About Later | 277                   |
| Advance Care Planning: Writing It Down for Later        | 259                   |
| Interactive Writing Tool                                | 136                   |
| FAQ                                                     | 122                   |
| Interactive Card Tool                                   | 91                    |

*\* an overview of all sections is published elsewhere*

### *Identifying typical user behaviours by clustering*

To determine the optimal number of clusters, we applied NbClust with 30 indices, revealing that eight favoured two clusters and eight indicated three clusters. Following the majority rule, we opted for three clusters, each assigned to study IDs reflecting diverse user engagement patterns. Figure 1 visually depicts the three clusters, and Table 3 summarises each cluster's characteristics. To showcase the most-visited web pages by the clusters, we categorised all pages into ten categories, presented in Figure 2.

Figure 1 - Principal Component Analysis plot showing the identified clusters



This 2D image of a 3D representation of the three clusters represents the NbClust analysis. In the figure, each study ID ( $n=31$ ) is assigned to one of these clusters, indicating diverse user engagement patterns. Notably, 'accurately representing the original high-dimensional (3D) image in a two-dimensional space results in a partial depiction of the distinctive features within the clusters because of the limitation of paper-based printing. Therefore, Figure 1 can only partially capture these unique features of the clusters.

Cluster low engagement (5 participants) exhibited the fewest interactions (mean of 21), shorter duration (mean of 9.8 days), and accessed fewer pages. Cluster moderate engagement (15 participants) had a mean of 50 interactions, visited for 4.4 unique days, with a use duration of approximately 56.7 days. Cluster high engagement (11 participants) demonstrated the highest engagement, with the highest total interactions (mean of 86), longer duration (mean of 65.6 days), accessing more diverse pages and including the three people with dementia who used the website alone. Statistically significant p-values underscore distinct engagement patterns among the clusters.

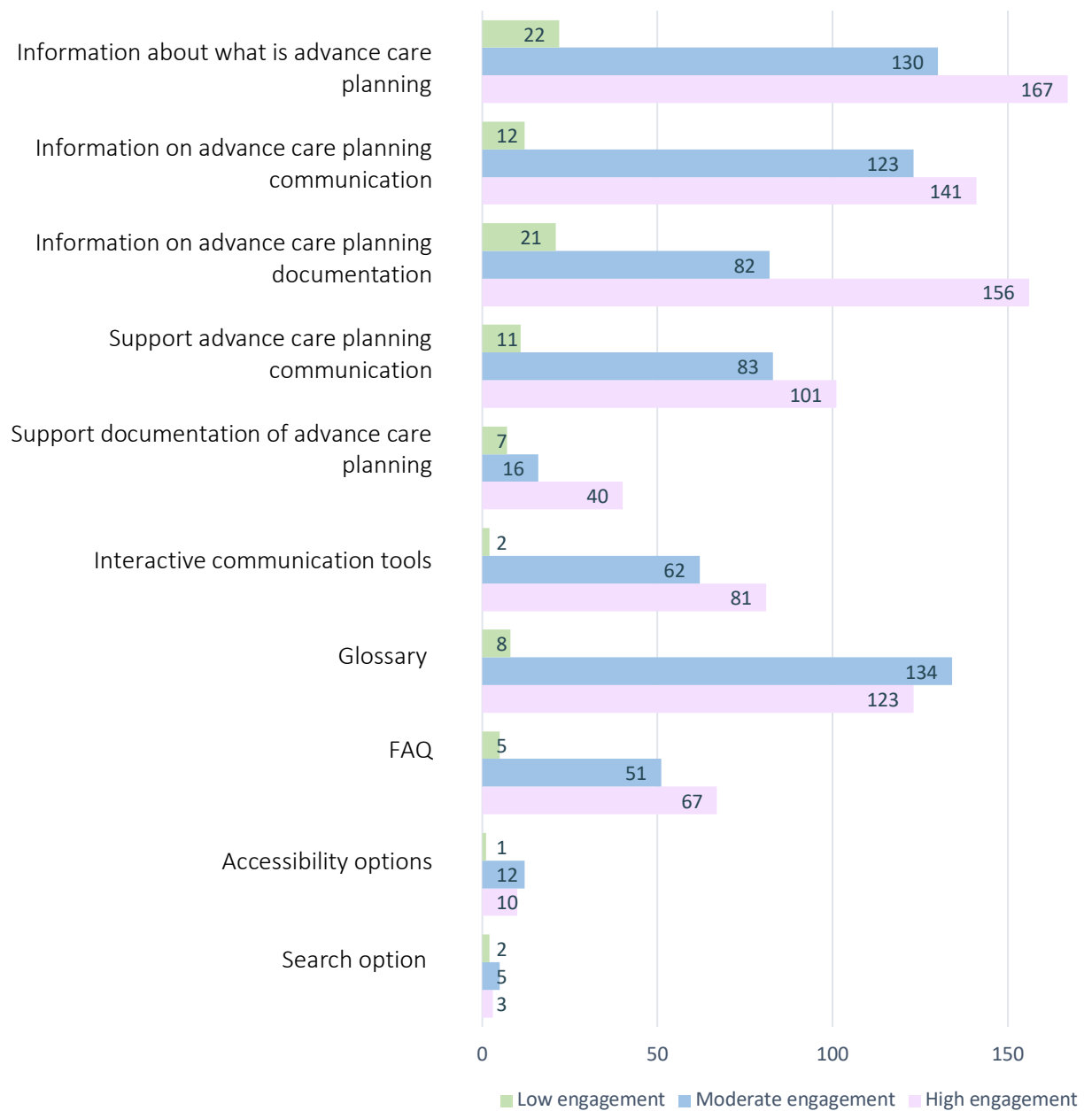
Table 3 - overview of the characteristics of use of the website of each cluster

|                                            |                                              | Low engagement level | Moderate engagement level | High engagement level | P-value          |
|--------------------------------------------|----------------------------------------------|----------------------|---------------------------|-----------------------|------------------|
| Size (study ID/n, %)                       |                                              | 5/10, (21)           | 15/21, (45)               | 11/16, (34)           |                  |
| Total interactions, mean (SD)              |                                              | 21 (9)               | 50 (13)                   | 86 (15)               | <b>&lt;0.001</b> |
| Unique days, mean (SD)                     |                                              | 1.6 (0.5)            | 4.4 (1.5)                 | 8.7 (3.3)             | <b>0.004</b>     |
| Range of use (days), mean (SD)             |                                              | 9.8 (19.2)           | 56.7 (19.3)               | 65.6 (16.9)           | <b>&lt;0.001</b> |
| Communication pages visited, mean (SD)     |                                              | 5 (3)                | 17 (7)                    | 28 (10)               | <b>&lt;0.001</b> |
| Documentation pages visited, mean (SD)     |                                              | 6 (4)                | 7 (4)                     | 18 (4)                | <b>&lt;0.001</b> |
| Information pages visited, mean (SD)       |                                              | 7 (5)                | 22 (10)                   | 34 (13)               | <b>&lt;0.001</b> |
| Total number of interactions per user type | Caregiver                                    | 420                  | 27                        | 310                   | <b>&lt;0.001</b> |
|                                            | Person with dementia                         | 0                    | 0                         | 103                   |                  |
|                                            | Dyad                                         | 124                  | 33                        | 88                    |                  |
|                                            | Family caregiver and/or person with dementia | 204                  | 54                        | 452                   |                  |

\* n is the number of users (the total is 46 because five people with dementia did not use the website/participate anymore). †: interaction is any movement of the user on the website. This can be clicking on a hyperlink, watching a video, opening a page, or printing the webpage. ‡: From the first day of use until the last day. For example, cluster moderate engagement started using the website, and on average, the last usage was 9.8 days later. §: when the IP address could not be matched with the date/time of the filled-in study ID. ¶: chi-squared test. #: Kruskal-Wallis rank sum test

Participants across all three clusters predominantly visited the ‘*what is advance care planning*’ webpage the most. Low-engagement participants mostly focused on the information pages, especially the documentation information and showed limited interest in interactive tools. Moderate engagement participants visited mostly the advance care planning information pages, frequently using the glossary and accessibility features like contrast and text-to-speech, distinguishing their usage from other clusters. In the high-engagement cluster, participants explored information, communication and documentation pages, actively using interactive communication tools.

Figure 2 – overview of the most-visited web pages by the three clusters

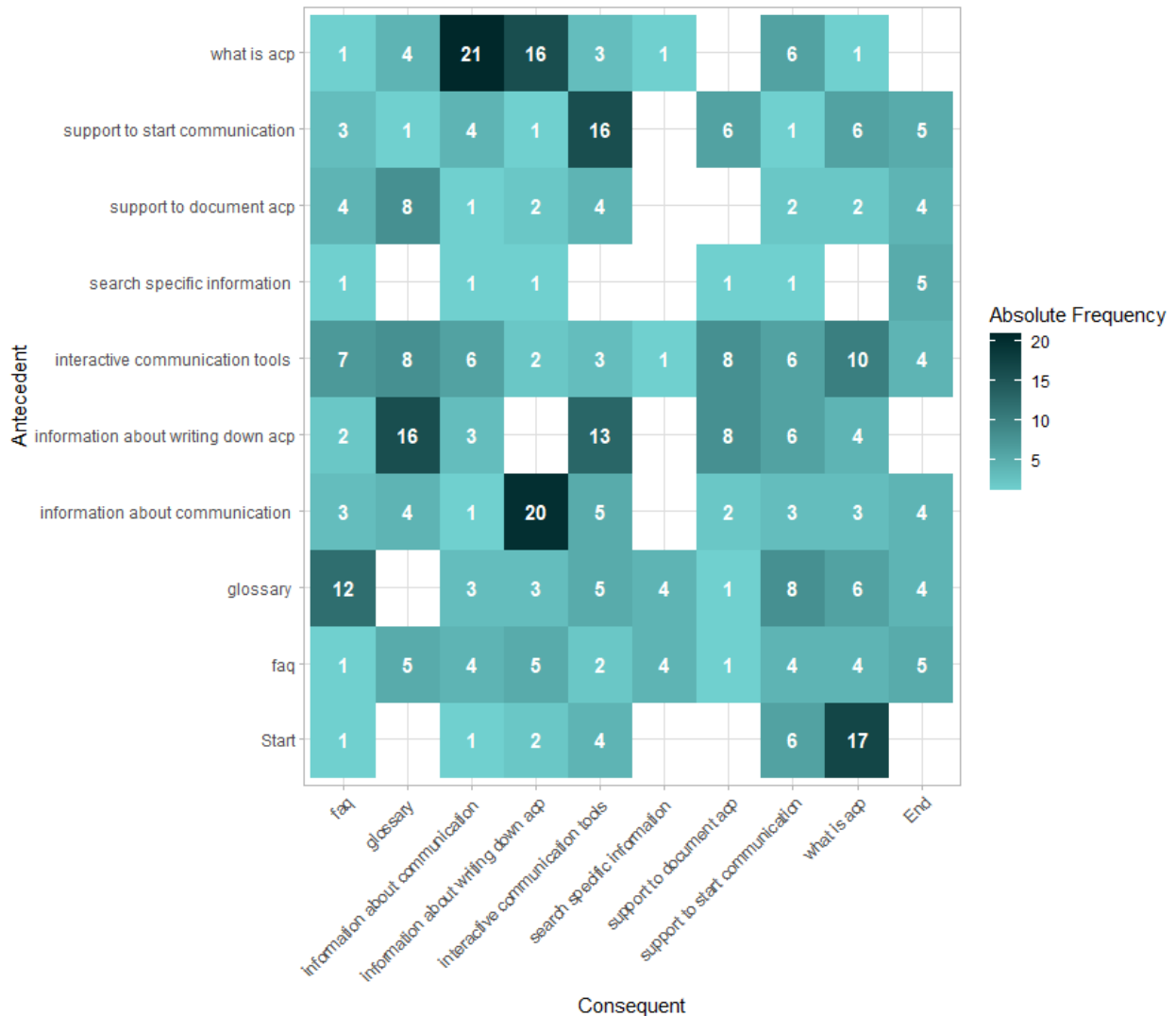


#### Identification of user pathways of the identified user behaviour

To identify the user pathways, we first look at the overall pathways of users using a process matrix (Figure 3). The primary pathway, observed in 21 instances, initiates with a visit to the ‘What is advance care planning’ page, followed by navigating to a subsequent page providing ‘information about communication.’ Significantly, users frequently started their pathway on informative pages such as ‘what is advance care planning,’ ‘information on communication,’ or ‘Information on documentation.’ Subsequently, they progress to explore additional information pages. Noteworthy is the observation that users typically visit pages providing

information about communication or documentation before engaging with the interactive communication tools.

Figure 3: identification of overall user pathways



The process matrix is a two-dimensional representation that illustrates the flow between the web pages that users have visited. The matrix is organised with antecedent events followed by the consequent events.

Then, the user pathways of the identified user behaviour clusters were identified (Figures 4, 5, and 6). Low-engagement participants (Figure 4) displayed a linear and direct browsing style, rarely revisiting previous pages during navigation. In contrast, the participants with moderate (Figure 3) and high engagement (Figure 6) explored the website by visiting pages sequentially, occasionally revisiting previously viewed pages. High engagement extensively explored various pages, moving between information and guidance pages. Participants with



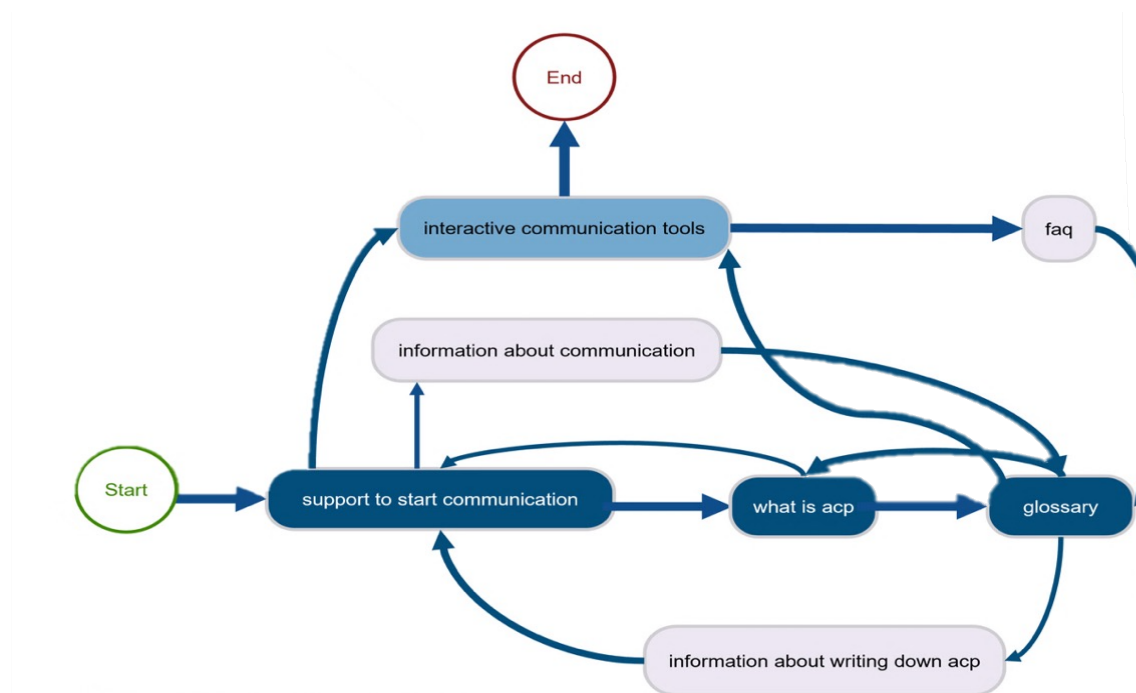
moderate engagement involved frequent transitions between pages but less often than those with high engagement.

*Figure 4 - example user path cluster 2 with low engagement*



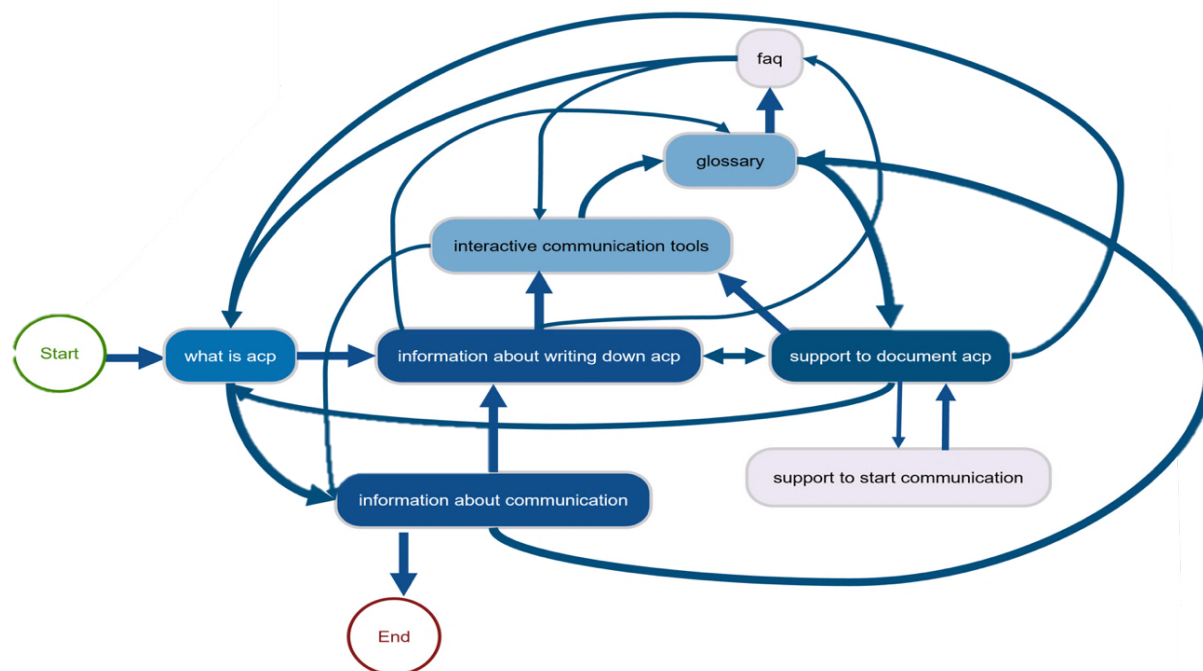
FAQ = frequently asked questions, ACP = advance care planning

*Figure 5 - example user path with moderate engagement*



FAQ = frequently asked questions, ACP = advance care planning

Figure 6 - example user path with high engagement



FAQ = frequently asked questions, ACP = advance care planning

## DISCUSSION

### *Main results of the study*

The analyses of the log data of an eight-week evaluation study of a website to support people with dementia and their families in advance care planning showed that family caregivers used the website most often, either alone or with a person with dementia, i.e. dyad. Three distinct engagement patterns emerged in this study: low, moderate, and high. Low-engagement users tended to follow a more linear path on the website, while moderate and high-engagement users displayed a more dynamic engagement, exploring the website in diverse ways.

### *What this study adds*

Flexible user navigation patterns were evident in our study, challenging the conventional linear advance care planning representations found in other web-based tools (15) in which users go through a stepwise process, typically starting with information provision, prompting reflection, moving on to communication, and concluding with documentation in the form of advance directives. While low-engagement users followed a linear pathway, those with moderate or high engagement displayed a more dynamic usage. Some users initiated their usage pathway by seeking information about advance care planning, while others focused on documentation or directly accessed the interactive communication tools. These results emphasise a need for a more flexible approach, indicating that users should have the freedom

to navigate tools that align best with their needs. These findings align with broader technological research indicating that family caregivers prefer flexible navigation in online tools (23,24). Additionally, the adaptation of advance care planning to the distinct needs of people with dementia and their families is highlighted, a statement also supported by other research (5,25,26). This also aligns with Belgian clinical guidelines (27), explicitly mentioning that healthcare professionals should tailor advance care planning in dementia, including style and content, to the “person’s level and rhythm”.

Despite the expressed interest in advance care planning of participants in the evaluation study, people with dementia rarely engaged with the website on their own. Family caregivers and the person with dementia did engage together, emphasising the family's importance. This finding is not necessarily surprising as much literature points at the importance of family in a dementia trajectory. A recently published consensus definition on advance care planning in dementia also highlighted family as highly important and specific in this population (6, 28). When it concerns the use or uptake of websites among people with dementia, involving family caregivers can play a facilitating role, however, it is essential to acknowledge that not all people with dementia have family caregivers or families directly engaged in their care (29). Additionally, overreliance on family caregivers may unintentionally hinder independent usage, undermining autonomy. Therefore, achieving an inclusive environment necessitates balancing involving family caregivers and promoting self-usage.

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

This study has several strengths that contribute to the robustness of our study's findings. Using log data, this study is the first to examine user engagement of people with dementia and their families with a website to support advance care planning. It offers a comprehensive understanding of their specific usage patterns. The elimination of recall bias is another key strength, as log data provided an accurate account of how users engaged with the website. The study also has limitations with regard to the data used. We encountered difficulty identifying the specific type of user for all log data because not all access logs could be matched with the date/time of the filled-in type of user in the application log. Additionally, due to a one-month retention period for log data, a small portion of data (7 days with interactions from 2 users, as indicated in Google Analytics) was lost as it was not downloaded before deletion from the server. Another limitation is the relatively small dataset for our log data analyses. With a smaller dataset, there may be constraints on the model's ability to generalise and uncover more nuanced insights. Finally, a limitation arises from self-selection

bias in user type; e.g., users might identify as ‘family caregivers’ while engaging together, and vice versa, introducing variability that could impact the accuracy of findings.

#### *Recommendations for practice, theory, and policy*

Ensuring everyone can engage in the process at their own pace is crucial to enhance advance care planning. By moving away from linear advance care planning seen in other support approaches and embracing flexibility to cater to individual preferences, web-based tools can support diverse advance care planning needs. Additionally, longitudinal studies that explore the impact of web-based tools on advance care planning within dementia and the evolving nature of engagement and needs over time, are desirable. Such research can provide valuable insights into optimising ACP support for people with dementia and their families throughout the dementia trajectory.

## **CONCLUSION**

This log data study reveals diverse user engagement patterns of people with dementia and their family caregivers when engaging with a website designed to support advance care planning. Particularly, moderate and high-engagement users displayed dynamic engagement, navigating diverse sections of the website – going back and forth between pages, while users with low engagement navigated the website in a more linear way. Our findings contribute to the emphasised need for personalised support in advance care planning and challenge the conventional linear advance care planning approaches seen in other web-based tools to support advance care planning.

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## APPENDIX 1 – OVERVIEW OF THE WEBSITE

*Note that the original language is Dutch. This presented English version is translated by the automatic translate function in Google Chrome.*

The home page:

Advance  
care planning  
in dementia

Home

Advance Care Planning: What is it?

Think and talk about later

Write it down for later

Tools

Word list

Frequently Asked Questions

Resources and contact

About us

Search

Home

read for

Advance care planning (VZP) & dementia

Think now and talk about later

  
© Laurane Berkein - Flemish Council for the Elderly

This website is intended to help people with dementia and their loved ones with early or advance care planning. The website has been developed for everyone who comes into contact with dementia.

Many people who are faced with an illness sometimes ask themselves questions about what the future will be like.

- What if I can no longer take care of myself?
- Where would I wish to live?
- Who would take best care of me?
- Which treatments would I still like to receive, which ones not, and at what time?

Advance care planning is designed to help you find answers to these difficult questions. This website is primarily aimed at people with dementia themselves, to support them in advance care planning. The website also focuses on people who surround, assist or support someone with dementia.

This website has been developed for and together with people with dementia. The project was led by researchers from the Vrije Universiteit Brussel, Ghent University and KU Leuven, the Dementia Flanders expertise center, Alzheimer League Flanders, and people with dementia and informal caregivers throughout Flanders.

read for



Daniel:

"We started talking immediately after I was diagnosed with dementia. What else do I want to do? What would I want in the future? That helped us to think together about my and our future"



Advance care planning: what is it

Would you like to know more about what advance care planning is and what the added value is?

read more



Think and talk about later

Would you like to know more about how to think and/or talk about advance care planning?

read more



Write it down for later

Would you like to know more about how to write down what you want for future care and treatments?

read more

Resources and contact

About the website and us

Privacy policy



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## Example page: thinking and talking about advance care planning

Advance  
care planning  
in dementia

[Home](#)

[Advance Care Planning:  
What is it?](#)

[Think and talk  
about later](#)

[Think and talk about  
later](#)

[Talking to healthcare  
providers](#)

[Write it down for  
later](#)

[Tools](#)

[Word list](#)

[Frequently Asked  
Questions](#)

[Resources and  
contact](#)

[About us](#)

[Search](#)

[Home](#) » Think and talk about later

aaa text size contrast print

read for

# Thinking and talking about later



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People with dementia often find it difficult to think about the future because it is very uncertain. Some people need to talk about it. Others prefer to think about it themselves. Everybody is different.

In the video below, Daniel, Lucrece and Paul explain:

- how they talk together
- what they talk about
- and what is difficult



How do you start advance care planning?

Below you will find tips and examples on how to start advance care planning. How to think yourself and how to talk to others.

read for

### I have dementia

How do you start thinking about what is important to you and what you would like for your future care and treatments

[read more](#)

### My loved one has dementia

As a loved one of someone with dementia, you may have questions about advance care planning. What does he or she consider important for the future?

[read more](#)

[Resources and contact](#) [About the website and us](#) [Privacy policy](#)

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Vrije Universiteit  
Brussel

 **UNIVERSITEIT  
GENT**

 **KU LEUVEN**







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## Example page: frequently asked questions

Advance  
care planning  
in dementia

Home

Advance Care Planning: What is it?

Think and talk about later

Write it down for later

Tools

Word list

Frequently Asked Questions

Resources and contact

About us

Search

Home » Frequently Asked Questions

text size contrast print

read for

# Frequently asked to ask



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This page contains some frequently asked questions. Is the question you have not listed? Then go to the [contact page](#). This page contains contact details of various organizations where you can also ask your questions about advance care planning and dementia.

Who should I talk to first?

What if not everyone in the family agrees on advance care planning?

Can I get euthanasia if I have dementia?

Does advance care planning only concern the end of life?

How do I start advance care planning?

How do I choose a representative?

read for

A representative makes decisions for you when you are no longer able to do so yourself. For example, because you are in a coma or have advanced dementia. A representative is:

- adult (someone over 18 years old)
- competent
- someone you trust;
- with whom you feel comfortable talking about your wishes for the future.

You can use the '[Appointment of a representative' form](#) to determine who your representative is:

- Have your doctor add this to your patient file.
- Make sure you have three copies of this document: one for yourself, one for your representative and one for your GP or treating physician.

Are you obliged to choose a representative?

No. Don't have a representative? A confidential counselor is then chosen. This is done according to a [cascade or waterfall system](#).

Is advance care planning the doctor's job?

Can you change your mind about previous decisions regarding future care and treatments?

Does the health care proxy replace the advance directives?

Who is advance care planning for?

When does a representative make my decisions?

What if I don't have anyone to discuss advance care planning with?

What if the doctor doesn't want to talk about it?

What is the difference between a confidential counselor and a representative?

What does my doctor need to know about my advance care planning?

Resources and contact

About the website and us

Privacy policy

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BRUSSEL

UNIVERSITEIT  
GENT

KU LEUVEN

dementia

AKR



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## APPENDIX 2 – THE INTERACTIVE COMMUNICATION TOOLS

### *Preview of the Interactive Card Tool (translated to English)*

#### Using the Life Wishes:

In total, there are 37 cards with short statements ( for example, “having no pain”, “keeping my sense of humor”). Some of these statements may be important to you, while others may be less so. **To assist your thoughts on “what is important to me or not”,** there are three piles where you can place the cards.

Read each card and consider: To me, does this card belong on:

- **Pile 1:** the cards that you find very important
- **Pile 2:** the cards that you find somewhat important
- **Pile 3:** the cards that you do not find important

If you’re unsure, place the card on the **discard pile**.

Questions you can ask yourself while using the cards:

- Do I think this is important?
- Would I want this in the future?
- Does my diagnosis influence how I think about this later?

**Do some of the things that are important to you not appear on the cards?** If so, you can use the ‘wild card’. Wild cards allow you to write down something that is important to you but is not on the other cards. Type in the ‘Wild card’ field what you still find important. For example: walking in nature or having someone take care of my pets. You can find the wild cards in the “very important” pile.

**You can use the cards to reflect on what is important to you.** The cards can also be used to talk together. Explain to the person you are using the cards with the reasons why you find a card important or not. They can also tell you their thoughts on the card. The piles you create are not fixed. The choices you make today may change later. Feel free to drag the card back or place it in one of the other piles. You can also print what you have laid out. For example, you can take this document be to the doctor or another healthcare provider to discuss with them.

**Start with the Life Wishes**

| YOUR CARD                                        |                                                  | DISCARD PILE                               |                                                                       |                                                                 |  |
|--------------------------------------------------|--------------------------------------------------|--------------------------------------------|-----------------------------------------------------------------------|-----------------------------------------------------------------|--|
| Being surrounded by good friends                 |                                                  | Keeping my sense of humor                  |                                                                       |                                                                 |  |
| <b>VERY IMPORTANT</b>                            |                                                  | <b>SOMEWHAT IMPORTANT</b>                  |                                                                       | <b>NOT IMPORTANT</b>                                            |  |
| Type here your thoughts or write and extra card. | Type here your thoughts or write and extra card. | Not being short of breath                  | Being neat and tidy                                                   | Being able to share my memories and accomplishments with others |  |
| Not being in pain                                | Not being afraid                                 | Dying at home                              | Being able to take care of unfinished business with family or friends | Type here your thoughts or write and extra card.                |  |
| Having physical contact                          | That my family is prepared for my death          | Being treated the way I wish to be treated | Keeping my dignity                                                    |                                                                 |  |
| Being able to say goodbye to my loved ones       |                                                  |                                            |                                                                       |                                                                 |  |

Show instructions

Read all cards

Zoom

Print on computer

Print on tablet

Save

Restart

## Example of the tool 'Thinking Now About Later'

Advance care planning in dementia

- Home
- Advance Care Planning: What is it?
- Think and talk about later
- Write it down for later
- Tools
- Overview
- Handle
- Life wishes cards
- advance directives
- Word list
- Frequently Asked Questions
- Resources and contact
- About us
- Search

Home » Tools for advance care planning » Handle

text size contrast print

read for

# Handle

## 'Thinking now about later'



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This tool helps you think about what you find important regarding future care and treatments. It helps you prepare yourself and others for difficult choices later.

- You will be asked various questions about what is important to you now and in the future.
- You don't have to answer all the questions.
  - Do you want to skip a question? Then tap 'continue'.
- Your answers are personal. There are no right or wrong answers.
- You can always adjust or supplement any answer.
- You should not answer all questions at once.
  - You save what you already wrote down and continue writing later.
- You can download your answers as a PDF. Or you can print them out.
- You can complete the questions on your own or together with someone from your environment.
  - Maybe that will help you start a conversation about advance care planning.
- Do you find some questions too difficult?
  - Discuss them with a doctor or healthcare provider you trust.
- This handle is completely anonymous. No one can see your answers.
  - [Read more information about your privacy](#)

Below is a short video with instructions:

Handvat instructies

Mijn keuzes Print Opslaan Herstart 2/9

Wat is voor mij belangrijk, nu en in de toekomst?

Dit is geen gemakkelijke vraag. Door deze vraag te beantwoorden kan je een idee krijgen wat voor jou belangrijk is en waar je waarde aan hecht. Dit kan gaan over het nu maar ook over de toekomst. Je kan hier aan verschillende dingen denken: je gezondheid, je onafhankelijkheid, welke activiteiten belangrijk zijn voor jou, wat je nog wil doen in de toekomst, waar je wil verblijven. Je kan ook denken aan je sociale contacten, je familie, vrienden, je collega's regelmatig zien, je geloof betuigen, de natuur of cultuur kunnen beleven. Het zijn maar enkele voorbeelden van wat belangrijk kan zijn voor iemand.

WAT IS VOOR MIJ BELANGRIJK IN MIJN LEVEN? WAT IS VOOR MIJ BELANGRIJK IN MIJN TOEKOMST?

Bijkomende vragen ter inspiratie Bijkomende vragen ter inspiratie

Typ hier wat belangrijk is voor jou in jouw leven. Typ hier wat belangrijk is voor jou in jouw toekomst.

Bekijken op YouTube

Start with the handle

Resources and contact About the website and us Privacy policy

VUB VRIJE UNIVERSITEIT BRUSSEL KU LEUVEN ZENITH Foundation KCM

My choicesPrintSaveRestart

## Overview

Below, you'll find the full contents of this tool. Don't want to view a particular section? Then click on the next arrow to skip that part.

1. Use and fill in the 'Thinking Now about Later' tool.
2. What is important to me now and in the future?
3. What do I want for my future care and treatments in the future or at the end of life?
4. Who is my trusted person and legal representative?
5. Do you want to document your preferences and choices in an advance directive?
6. Are there other things that are important to you?
7. Next steps: What now?
8. Still unsure about what you find important and want for your future care and treatments?
9. End

Click on the arrow to go to the next page

My choicesPrintSaveRestart1/9

## Using and filling in the 'Thinking Now about Later' tool

Below, you'll find some important questions to help you determine what is important to you and what you would like for your future care and treatments. Each question also includes some explanations and examples to get you started. These questions are meant as inspiration; you don't have to answer them all. There are no right or wrong answers to the questions in this tool. Your answers are likely never complete either. It's about what you find important and what you would or wouldn't prefer. You can and may always modify or supplement your answers. You also don't have to answer all the questions. By clicking on the next arrow, you can skip a question.

Click on the arrow to go to the previous page

My choices

Print

Save

Restart

2/9

### What is important to me now and in the future?

This is not an easy question. By answering this question, you can get an idea of what is important to you and what you value. This can be about the present but also about the future. You can think about different things: your health, your independence, what activities are important to you, what you still want to do in the future, and where you want to reside. You may also think about your social connections, seeing family, friends, and colleagues regularly, expressing your faith, and experiencing nature or culture. These are just a few examples of what could be important to someone.

#### WHAT IS IMPORTANT TO ME IN MY LIFE?

Additional questions for inspiration

Type here what is important to you in your life.

#### WHAT IS IMPORTANT TO ME IN MY FUTURE?

Additional questions for inspiration

Type here what is important to you in your future.

My choices

Print

Save

Restart

2/9

### WHAT IS IMPORTANT TO ME IN MY LIFE?

Additional questions for inspirations could be:

- Who is important to me?
- Which daily activities are important to me?
- What brings me happiness?
- Where do I derive my energy from?
- What makes my life meaningful?
- What do I value in my life?

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## **PART 4   GENERAL DISCUSSION**



## GENERAL DISCUSSION

*Summary of main findings, methodological considerations, discussion of the main findings, and recommendations.*

In this part of the dissertation, the main findings are summarised. After, the strengths and the limitations of the used methodologies are discussed. This part is followed by a general discussion of the most important findings of this dissertation. Finally, recommendations for practice, policy, and future research are formulated.

### 1. SUMMARY OF MAIN FINDINGS

**AIM 1: To inform the content and features of the website with people with dementia, family caregivers and healthcare professionals to support advance care planning in the family context**

In CHAPTER 1, the aim was to identify existing web-based advance care planning (ACP) support tools to describe their content characteristics, readability, and quality and explore whether and how they are evaluated. Initially, 436 web-based ACP tools were identified through the three search strategies, i.e. grey literature databases, Google, and App stores. After removing duplicates, a list of 96 potential web-based ACP support tools was obtained. This list was sent to 15 experts in ACP, who identified an additional 35 tools. Two researchers screened the 131 tools against eligibility criteria, excluding 91. The remaining 40 tools underwent full screening, resulting in the exclusion of ten more tools.

24 of the 30 tools mentioned a clear aim: to support reflection and/or communication, to support people in making decisions and/or to help document decisions, but only two (7%) aimed to achieve all three aims. Seven tools (23%) were developed in collaboration with healthcare professionals, but just three (10%) also involved end-users like patients in the development. **All tools except one encouraged users to follow steps in a predetermined order to support ACP.** This means people started, for example, by learning about what ACP is, leading them to the next step to reflect on what would be important to them, etc. Regarding the ACP elements, almost all tools stimulated the user to explore personal values, goals, and preferences regarding future care; 12 (40%) provided information on ACP and its legal frameworks. Twenty tools (66%) also encouraged the user to appoint a proxy decision-

maker. Most of the ACP tools had a good readability score, but the quality of the content varied between 11 and 28 on the QUEST scale (*score 0-28 – a higher score is a better quality*). Tools had a medium to low-quality score because they did not refer to any information sources or were not up to date, i.e. not updated in at least five years. Out of the 30 included tools, five have been evaluated in studies published in peer-reviewed literature.

Understanding the needs and preferences of people with dementia and their families is crucial in developing user-friendly web-based tools that are likely to be widely adopted. Therefore, the aims of CHAPTER 2 were to explore which content should be on the website, how that content should be delivered (i.e., functionalities), and the barriers and facilitators stakeholders perceive for finding and using the website. We conducted focus groups with family caregivers and healthcare professionals to meet these aims. The participants included 18 family caregivers, most caring for a partner with dementia, and 17 healthcare professionals from various backgrounds.

Participants highlighted three main content needs for the website to support ACP in the family context. Firstly, they emphasised the **importance of ACP information**, including explanations of what ACP is and why it may be important. Participants also suggested tailoring the information to different stages of dementia and addressing the declining cognitive capacities of people with dementia. Secondly, **guidance on how to initiate and conduct ACP conversations was identified as crucial**. Participants wanted practical advice and tools to facilitate conversations. They also emphasised the need to consider different types of family caregivers, as their roles and relationships vary. Lastly, while participants acknowledged the importance of information about dementia and care, they favoured hyperlinks to external websites for that specific information rather than including it directly on the website.

Regarding how the content should be delivered, **participants recommended presenting ACP as a process while allowing users to access the website at their own pace and offering flexibility**. They also suggested including a frequently asked questions section, a glossary of important terms, and peer testimonials to provide support and practical examples. Moreover, participants discussed functionalities that would enhance the website's accessibility. These included clear navigation, the option to print content, a text-to-speech option for those with reading difficulties, and the ability to adjust font sizes.

The study also explored barriers and facilitators to finding and using the website. To find the website, participants highlighted that health professionals and dementia organisations should introduce the website. Regarding using the website, we found a need for customisation based on individual ACP readiness and the ability to use the website at one's own pace. Other identified barriers to using the website were a **lack of computer skills and a negative perception of ACP**. Moreover, digital literacy in dementia and the impact of reduced ability for abstract thinking were also mentioned as barriers. A login system was suggested to facilitate returning to the website without losing progress. However, a login system would pose another barrier because users should remember their login codes.

Since providing practical guidance to facilitate conversations about preferences for future care and treatment was identified as important content for the website, we performed a cultural adaptation of an existing card game (Go Wish Cards) (CHAPTER 3). The cards were identified in Chapter 1 as **the only tool that did not use a predefined path to support ACP** and aims *'to help people easily start a comfortable conversation on the difficult topic of preferences including those at the end of life'* (1). The cultural adaptation was performed using an extensive, systematic, negotiated procedure of five steps with various community stakeholders and potential end-users (2).

First, the 36 cards of the original version of the United States were translated into Flemish (Step 1). This preliminary version of the cards was, in Step 2, evaluated by a reference group, including representatives of various organisations working around palliative care and patient and family caregiver support. Some cards were accepted without comments, while others underwent discussions and adaptations to ensure cultural appropriateness and clarity. Additional cards were added to address the legal frameworks for end-of-life care in Belgium (i.e. the right to choose one's end-of-life, including euthanasia). Although some members wanted to mention the word 'euthanasia' explicitly, others preferred a more general formulation. Consensus was reached to add two cards: 'A self-chosen end-of-life' (card 36) and 'being able to record my choices' (card 37), and the card game was named '*Levenswensen kaartspel*' (Life Wishes card game). Step 3 involved the evaluation of the translated cards by healthcare professionals, who provided feedback and suggestions for improvements. In Step 4, a content validity index (CVI) was calculated to assess the cards' content validity on linguistic equivalence, applicability, comprehensibility, and relevance. Most cards scored high on linguistic equivalence, applicability, comprehensibility, and relevance. Twelve cards needed adjustments because they scored lower than the minimum

recommended I-CVI score on linguistic equivalence, applicability, comprehensibility, and relevance of 0.78. Step 5 involved pre-testing the cards with a diverse group of participants. **They found the cards user-friendly and helpful in discussing end-of-life values.** Some cards were identified as unclear and were suggested to be rephrased. For example, several participants suggested changing the phrase on Card 35, '*not to be connected to machines*', to '*not being dependent on machines that keep me alive*' to clarify that it was about machines that keep you alive. Moreover, participants found the word game inappropriate and suggested using '*Levenswensen kaarten*' (*Life Wishes card*). Based on the feedback, the card deck was finalised, with adjustments to improve clarity and address specific concerns.

Afterwards, during the iterative development of the website (3), the paper-based version of the cards (available for purchase since 2022, appendix 1), we digitised the cards with input from people living with dementia, their families, healthcare professionals, representatives of dementia organisations and researchers. The digital interface is divided into three fields: 'not important,' 'somewhat important,' and 'very important,' mirroring the paper-based version. Users can drag and drop their digital cards into these designated fields, allowing an interactive sorting process. The cards are visually presented in a stack, reminiscent of a solitaire card game. Additionally, a small navigation column in the digital interface provides quick access to an overview of all cards, introductory information, and an option to print.

## **AIM 2: To evaluate the website to support advance care planning in the family context with people with dementia and family caregivers**

The findings presented in Chapters 1 to 3 have collectively informed the development of the website. The studies described in Chapters 4, 5 and 6 aimed to describe and evaluate the website with people with dementia and family caregivers. CHAPTER 4 provided a detailed overview of the website's content and functionalities as a result of a user-centred development process. The website contained sections covering advance care planning (ACP) definitions, legal frameworks, guidance on initiating ACP discussions, and options for documenting decisions. Additionally, the website featured two interactive tools to support: 1) the digital version of '*Levenswensen cards*' and 2) a fill-in tool ('*Thinking Now About Later*') with open-ended questions about '*what matters most to you*'. It has a glossary, an FAQ page, search functionality, a resource and contact page, and information about the developers and the website's purpose. Regarding accessibility functionalities, the website included an option for text size adjustments, colour contrast choices, speech-to-text, and printing options.

Additionally, Chapter 4 described the study's design to evaluate the website. The evaluation study design followed a convergent parallel mixed method pretest-post-test design, combining quantitative and qualitative data collection methods. The evaluation was conducted over eight weeks in Flanders, the Dutch-speaking part of Belgium, during which participants had access to the website. People with mild to moderate dementia and their family caregivers as dyads or the family caregiver alone were recruited. Eligibility criteria included having dementia, being an informal caregiver from a person with dementia, having an interest in testing the website, being able to consent to study participation, speaking and understanding Dutch, having a device to access the website, and not having participated in the cognitive testing of study materials. The Ethics Committee has approved the study protocol, and measures were taken to protect the participants and ensure ethical research practices. Data collection included interviews, surveys, log data registration, and in-the-moment questions or ecological momentary assessments. The baseline pre-test data collection (T0) was conducted at the start of the study, followed by a post-test data collection (T1) after the 8-week intervention period. Socio-demographic, clinical variables, quality of the relationship and ACP readiness were collected through questionnaires, and usage of the website was measured using log data. The website's usability, acceptability, and feasibility were assessed through surveys, interviews, and ecological momentary assessments. The effects of the website on ACP readiness, knowledge, attitudes, perceived barriers, self-efficacy, and skills were evaluated via the pre and post-interviews. The qualitative data from interviews were analysed using thematic framework analysis, while the quantitative data were analysed using descriptive statistics. The results from the qualitative and quantitative analyses were integrated at the point of interpretation to evaluate the website comprehensively and determine whether further adaptations were necessary.

In CHAPTER 5, we presented the results of the evaluation study, which aimed to assess the usability, acceptability, feasibility, and outcomes of using the website to support ACP. Fifty-two participants were included, consisting of 21 people with dementia and 31 family caregivers. Ten caregivers participated alone because the person with dementia could not consent or did not want to participate. Five participants with dementia were unable to complete the follow-up data collection (T1). The average age of people with dementia was 62.8 years, and 42.8% were female. Family caregivers had an average age of 62.1 years, and 68% were female. Family caregivers reported higher computer literacy scores than people with dementia.

Overall, **participants found the website useful and easy to use, with positive feedback on its accessibility features.** Via the System Usability Scale Survey, family caregivers agreed more on the website's ease of use than people with dementia. People with dementia indicated in the survey they needed support to use the website. In the interviews, participants mentioned they appreciated the website's structure, navigability, and accessibility features, while some younger participants mentioned that the design felt a bit outdated. Family caregivers of people with more moderate dementia considered the website too difficult for their family members with dementia. Family caregivers wanted more financial, progression, and care information, with suggestions for including videos of early-onset dementia cases.

The ACP readiness survey showed **an increased wish to discuss future care and treatment among people with dementia and their family caregivers** after the study period. In the interviews, people with dementia and their families (n=31) expressed improved ACP knowledge after the 8-week study period, with a better understanding of what ACP is and its potential benefits. Attitudes toward the website and ACP remained positive during the study, with participants mentioning a greater desire to discuss preferences and wishes for future care in post-study interviews (n=26 before the eight weeks and n=36 after). However, some family caregivers who used the website alone addressed in the interviews it was too late to discuss ACP with the person with dementia. Perceived barriers to engaging in ACP remained similar, with participants finding it challenging to start ACP due to the wish of the person with dementia to live in the present or the busyness of life. The website was seen as a valuable tool to overcome these barriers, especially by using interactive communication tools and watching testimonial videos. All participants recommended the website to others, and those who started thinking and talking about ACP during the eight-week study expressed a desire to continue using it. However, after considering the information provided, a small number of participants chose not to engage in ACP.

CHAPTER 6 aimed to explore to what extent the website was used by people with dementia and their family caregivers, to identify the type of users and visualise how these types of users navigated the website. On average, users had 58 interactions and spent 35.3 minutes on the website. The top five visited web pages were: [1] '*advance care planning: what is it?*' (n=409), [2] '*the glossary*' (n=361), [3] '*advance care planning: thinking and talking about later*' (n=277), [4] '*advance care planning: writing it down for later*' (n=259) and [5] '*faq*' (n=181).



In the study, three clusters of user engagement were identified. The low-engagement cluster (5 participants) had the fewest interactions (mean of 21), a shorter duration (mean of 9.8 days), and accessed fewer pages. The moderate-engagement cluster (15 participants) demonstrated a mean of 50 interactions, visited for 4.4 unique days, and had a use duration of approximately 56.7 days. The high-engagement cluster (11 participants) exhibited the highest engagement, with the highest total interactions (mean of 86), a longer duration (mean of 65.6 days), and access to more diverse pages. All clusters primarily visited the '*Advance Care Planning: What Is It?*' webpage. In the high-engagement cluster, participants actively explored information and communication pages using interactive tools. Moderate-engagement participants focused on information pages about ACP, frequently using the glossary and accessibility features. Low-engagement participants concentrated on information pages, particularly documentation information, with limited interest in interactive communication tools.

When examining the navigation patterns of individual users within the three identified clusters, we can discern three primary distinctions:

1. Low Engagement: Users in this cluster **followed a more linear path**, rarely returning to previous pages when navigating to new ones. They primarily focused on the 'What is ACP' page and ACP documentation, showing limited interest in utilising interactive communication tools or exploring a wide range of content.
2. Moderate Engagement: **Users in this group explored various pages on the website, transitioning frequently between them.** This demonstrated a more in-depth and comprehensive approach to understanding the available content.
3. High Engagement: Users in this cluster **exhibited broad exploration, actively moving back and forth** between informational and guidance pages for ACP conversations. This group showed a deep involvement with the content and a strong commitment to understanding and participating in ACP discussions.

The results of Chapters 5 and 6 were used to refine and adapt the website to support people with dementia and their families in ACP. Adjustments were made based on the feedback in the post-evaluation interview and discussed with representatives of the Flemish dementia organisations and a multidisciplinary group of researchers.

## 2. METHODOLOGICAL CONSIDERATIONS: STRENGTHS AND LIMITATIONS

### 2.1 OVERARCHING STRENGTHS AND LIMITATIONS

The research presented in this thesis was devoted to developing and evaluating a website for people with dementia and their families to support advance care planning (ACP) in the family context. To comprehensively explore this relatively new area in ACP and dementia, we employed diverse research methods. Integrating various data collection techniques contributed to the depth and richness of the findings presented in this thesis.

Our research approach was characterised by a strong commitment to actively involving people with dementia, their families, and other important stakeholders. Advocated by people with dementia, their families and dementia organisations (4,5), this ambition ensured that the valuable perspectives and experiences of people with dementia, their families and healthcare professionals working in dementia were integrated into this thesis. Another strength of this thesis may be that a nurse with ten years of experience in dementia care collected all qualitative data. This expertise may foster trust and possibly optimise participant collaboration, enhancing the data's richness and improving methodological quality.

Apart from these overarching methodological strengths of this thesis, there are also some overarching limitations. Due to practical constraints in participant recruitment, we opted for convenience sampling, which, while providing valuable insights, led to a homogenous sample of participants. Most participants were Caucasian, were above 60 years of age, had a partner, had Alzheimer's dementia, and lived in the countryside. This homogeneity warrants caution when extending our findings to people from different backgrounds. Purposive sampling of study participants with varying characteristics, such as cultural background, age, dementia diagnosis and family composition, may provide a more diverse and representative study population, ensuring a more comprehensive understanding of the complicated issues surrounding ACP in dementia.

### 2.2 SYSTEMATIC REVIEW

As recommended in the UK MRC framework for developing and evaluating complex interventions (28), we started with conducting a systematic review to identify existing web-based ACP support tools to describe content characteristics, readability, and quality and investigate whether and how they are evaluated before developing the website. This approach enabled us to review the already available knowledge, ensuring we could build

upon existing insights and developments, avoiding reinventing the wheel and accelerating the development process. Though other reviews searched peer-reviewed literature to identify web-based tools for ACP (6,7), our systematic review was the first to explore grey literature to identify existing ACP tools. This method's strength lies in its ability to uncover resources or information that might have gone unnoticed or overlooked. Technology is often developed outside academia, making it impossible to identify these developments in peer-reviewed databases. Grey literature, research not published in commercial publications, can help mitigate publication bias and contribute to a more balanced representation of available evidence (8). In our review, we searched a large amount of grey literature, including app stores and Google, to identify ACP tools.

However, our methodology does come with some limitations. We limited our search strategy to the first 150 search hits, potentially resulting in overlooking tools that might not have been included due to their position beyond this threshold. Since search engines often generate a substantial number of hits, we opted to screen only the first fifteen pages, or the initial 150 hits, for each search combination. This approach could inadvertently exclude relevant resources located further down in the search results. Another limitation of our review is that we may have omitted certain tools and resources since we only searched in two languages. Lastly, the exclusive use of Google as the search engine could have limited our search results. Expanding our search engines to include those prioritising user privacy, like DuckDuckGo, may have improved the comprehensiveness of our findings.

### 2.3 FOCUS GROUPS STUDY

We employed focus groups as our methodological approach to define the website's content and assess the barriers and facilitators to finding and using the website. One notable strength of using focus groups was that we could gather information from different perspectives about what to consider as content and functionalities for the website (9,10). In focus group discussions, people talked about each other's ideas, which made the information richer (9,10). We chose to use focus groups because how to support ACP via the website is a complex and abstract topic. In these group discussions, people shared their thoughts and got inspired by what others said, which may have helped us gather more ideas for the website.

Notably, we conducted these focus groups during the challenging period of the COVID-19 pandemic, necessitating online meetings. An online format may offer a unique advantage as it facilitates broader participation (11), particularly for busy family caregivers and healthcare professionals who might have found it challenging to attend in-person focus groups. A notable limitation of our focus group study was the exclusion of people living with dementia. Our primary aim of this study was to establish an initial understanding of the potential content of the website and strategies to address ACP before developing the prototype. In accordance with recommendations from the literature on technology for people with dementia, we chose not to involve people with dementia in the focus group study without being able to present a proper prototype (12). Therefore, people with dementia were not included in this phase. However, we aimed and managed to involve people with dementia in both the development and evaluation study, ensuring that we could comprehensively discuss and test the website with them and their families.

#### 2.4 CULTURAL ADAPTATION OF THE GO WISH CARD GAME

A cultural adaptation of tools to support thinking and discussing end-of-life preferences is essential as culture affects how people think about health, disease, death and dying (13,14). The five-step cultural adaptation process engaged a diverse participant group, ensuring a heterogeneous representation of stakeholders. Employing a bottom-up approach, this inclusive methodology enabled us to incorporate various cultural perspectives and preferences, enriching the cultural adaptation process. Another important strength of this study was its emphasis on community engagement in the adaptation process. We successfully developed a card set for discussing end-of-life values by involving various stakeholders, including community organisations and citizens. Engaging the community leads to more relevant interventions that can improve the uptake – which may enhance the community's ability to discuss end-of-life care (15–17). However, this study also has some limitations. While trying to include a diverse range of stakeholders through an open sampling strategy, inadvertent exclusions may have occurred. Lastly, it is crucial to note that this study did not assess the practical use of the cards.

#### 2.5 USER-CENTRED DEVELOPMENT OF THE WEBSITE TO SUPPORT ACP

The website development employed a robust, evidence- and theory-based, user-centred, and iterative process involving people with dementia, family caregivers, healthcare professionals, researchers, and representatives of Flemish dementia organisations (3). The development followed the recommendations from Alzheimer Europe and earlier research

emphasising the importance of actively involving people with dementia and their families (4,18,19). After being informed by theory and evidence of needs addressed by people with dementia and their families, the objectives of the website were identified and translated into a preliminary concept, i.e. outlining how it should look, selecting outcomes (corresponding with the website's objectives), selecting theoretical change methods, and choosing how to apply them on the website. This systematic approach of combining evidence and theory aligns with the recommendations of the MRC framework (20).

## 2.6 MIXED-METHOD EVALUATION STUDY

The overall strength of the evaluation of the website lies in our diverse data collection methods, which include interviews, surveys, log data and in-the-moment or ecological momentary assessment questions. This way, we were able to evaluate the website extensively.

To evaluate the usage, usability, acceptability, and feasibility (i.e. uptake) of the website, the experiences of people with dementia and their family caregivers in using the website and its effects, we used mixed methods. A notable strength of this study lies in the use of ecological momentary assessment questions. By employing ecological momentary assessments, data were collected in real-time, allowing participants to utilise the website as they saw fit and evaluate their user experience as they were using the website, reducing recall bias. Furthermore, our study reached its targeted sample size, while studies in dementia often struggle to reach the set sample sizes because of recruitment difficulties (21–24).

One notable limitation relates to the recruitment strategies, which primarily targeted people already involved in dementia organisations, engaged in peer-to-peer support, or receiving follow-up care at memory clinics. Consequently, the study's sample may be skewed towards individuals who are more proactive in seeking support or have access to specialized healthcare services, potentially overlooking those who are less engaged or have limited access to such resources. Another limitation is the implicit requirement for computer literacy and the explicit inclusion criterion of '*having a device*'. This may have unintentionally excluded people with dementia and family caregivers who were interested in ACP but lacked the confidence or means to participate due to technological barriers. These requirements could also affect those from lower socioeconomic backgrounds who may not have access to devices.

Moreover, this study did not have an active reassessment procedure for the consent and capacity of the person with dementia during the follow-up interview. Five of the 21 participants with dementia dropped out. In three cases, people with dementia themselves expressed their unwillingness or inability to participate in the follow-up interview. For the remaining two participants, their family caregivers communicated this decision. During the onboarding and follow-up call in the fourth week, we communicated to participants that they could discontinue participation at any time. However, we did not have a specific informed consent procedure for the follow-up data collection to reassess consent or capacity. Informed consent is a process that involves people with the capacity to understand the aim and procedures of the study and their rights as study participants and make voluntary decisions about their participation in a study (25,26). Capacity in informed consent is the ability to understand the information of the research protocol provided by the researchers, evaluate the implications of one's participation and communicate the decision to participate (26). However, in dementia, the capacity can fluctuate over time, and the required capacity level may vary depending on the specific decision (27). As recommended by the Alzheimer Society, we assumed that a person had the capacity to consent. Therefore, we used the double-consent method for people with dementia as recommended by the Alzheimer's Association National Board of Directors (28). In this procedure, the informed consent for participation by the person with dementia was signed by the person with dementia and their caregiver, who functions as a '*witness*' that the person with dementia fully understood the impact of their participation (29).

Lastly, it is crucial to acknowledge that selecting a mixed-method pre-post-test design has limitations. In this quasi-experimental research with a one-group pretest-posttest design, the absence of a control group poses a challenge in attributing outcomes solely to the use of the website, and temporal confounding introduces the possibility that external factors may influence observed changes in our outcomes (30). However, mixed-methods pre-post designs can provide valuable insights into user experiences, perceptions, and outcomes within a real-world setting (30). By letting people use the website as they wanted, we could better understand its practical utility, usability, and potential impact on participants' knowledge, attitudes, self-efficacy, and skills related to ACP.

### ***Exploration of user behaviour via log data analysis***

To explore to what extent the website was used by people with dementia and their family caregivers, identify the type of users and visualise how these types of users navigated the website, we used analysed log data collected during a mixed-method evaluation study. The primary strength of this study is the adoption of a methodology that is relatively uncommon within social health science. This approach provided an in-depth understanding of how people engaged with the website, which goes beyond the typical assessment of website usage metrics. By focusing on behavioural clusters, the study offered a comprehensive view of the interactions of individual participants and uncovered overarching patterns that transcend individual behaviours. Furthermore, the study's ability to interpret users' specific paths on the website gave insight into how people used the website.

However, the use of log data is not without its limitations. Due to a server error, some of the log data were lost. Though the amount of data lost is less than 30 interactions over five days, this exclusion may impact the completeness and accuracy of the study's findings. Another limitation is related to the relatively small dataset, as this can impact the accuracy of the predictions made by applying machine learning techniques. Moreover, despite the intention to link each user to their respective log data by collecting user identification upon entering the website, not all log data could be successfully associated with specific users. This discrepancy may have arisen when users left their browsers open. This limitation underscores the importance of careful consideration when designing the log structure for technological data collection systems.

### 3. DISCUSSION OF THE MAIN FINDINGS

The discussion of the main findings is organised into three overarching themes that summarise and interpret the results presented in this dissertation.

#### 3.1. NEW INSIGHTS TO IMPROVE ACP SUPPORT IN DEMENTIA

- *ACP as a flexible process: the need to address individual needs*
- *ACP beyond medical end-of-life planning: the importance of social aspects and ‘what matters most’*
- *ACP in the family context: complementary to ACP with the healthcare professional*
- *Importance of early initiation of ACP in dementia*
- *Personalised, accessible, and clear advance care planning information*

#### 3.2. THE POTENTIAL OF ONLINE TOOLS TO SUPPORT ACP IN DEMENTIA

- *The role of the website in ACP practice*
- *The potential of the website to support ACP in the medical context*
- *ICT, ACP, and dementia: balancing between potential and exclusion*
- *The primary usage and important contribution of family caregivers in using the website*

#### 3.3. THE NEED TO AND CHALLENGES OF INVOLVING PEOPLE WITH DEMENTIA AND THEIR FAMILY CAREGIVERS IN RESEARCH

- *Challenges in the recruitment of people with dementia*
- *Even over a relatively short period, fluctuating cognitive decline in dementia can influence study participation.*



### 3.1. NEW INSIGHTS TO IMPROVE ACP SUPPORT IN DEMENTIA

This thesis presents new insights into the support in advance care planning (ACP) for people with dementia and their family caregivers. It challenges the traditional linear approach of web-based ACP tools and highlights the importance of flexibility to cater individual needs. The research also emphasises the complementariness of ACP in the medical and family context, the value of the social aspects, and '*what matters most*' in ACP, and it argues for a complete ACP information provision.

#### ***ACP as a flexible process: the need to address individual needs***

Our systematic review (Chapter 1) identified a prevalent trend where most existing ACP tools (online or offline) adopt a linear, step-by-step approach. These tools commonly initiate with providing essential information and lead the user into moving on to stimulate reflection, supporting communication, and ending with the option to document the preferences and wishes formulated throughout the previous stages. This finding was also discussed in Fahner's 2019 systematic review of ACP interventions based on conversation guides, indicating that most ACP interventions adhere to a framework consisting of these four sequential steps: preparation, initiation, exploration, and action (31).

However, the perspectives shared by participants in our focus groups and the insights gathered from user interactions with our website during the evaluation study (Chapters 2, 5 and 6) suggest that ACP support should not always be confined to a linear model. The log data from the website (Chapter 6) offered valuable insights into how users engage with the website. While some users adhered to a linear path, progressing sequentially from one page to the next without revisiting previous sections, many others exhibited a more nonlinear pattern, navigating between pages as they explored various website sections. These findings indicate that a one-size-fits-all process may not suit everyone. This aligns with prior research emphasising the significance of acknowledging the distinctive needs of people with dementia and their families in ACP (32,33). The differences in ACP readiness, which can even manifest within dyads, significantly influence the ACP process (34–36). These insights were echoed by family caregivers and healthcare professionals in our focus group study (Chapter 2), with a call for the website's content to accommodate variations in ACP readiness within dyads. Moreover, participants in our evaluation study (Chapter 5) indicated that they occasionally broached specific topics within ACP, acknowledging their readiness to discuss certain aspects while being hesitant about others, such as end-of-life decisions. This highlights that ACP discussions can be initiated before people feel prepared to address all ACP-related

aspects. Lastly, in our evaluation study, a few participants opted not to engage in ACP after careful consideration. This decision should be respected if people believe it aligns with their preferences and values.

Hence, by adopting a more flexible and process-oriented approach, ACP can better cater to the diverse needs of people with dementia and their families. Such an approach is intended to empower people with dementia and their families to selectively engage with topics that align with their current readiness. It allows them to consciously postpone discussions on aspects they may not yet be prepared to address. It also allows them to start the ACP process how they want and feel comfortable with. Some people might be most interested in advance directives at the start and learn about the broader process afterwards. Others might want to explore what matters to them in their care now before going to the future. An adaptable approach has the potential to personalise the ACP experience, providing people with dementia and their families with a sense of control over when and which topics they wish to explore. As highlighted in various studies, the fear of discussing some topics like end-of-life decisions in ACP discussions has been a significant barrier for many people with dementia and their families (32,33,37,38). Providing people the opportunity to start ACP in a way that closely aligns with their needs and preferences at that time may be a crucial step in improving the ACP process and uptake in dementia. As dementia is a condition in which capacity varies and fluctuates, a flexible and process-oriented ACP support tool that considers these diverse needs allows people to access information at the time most suitable to them, revisit when wanted, and stop when needed.

***ACP beyond medical end-of-life planning: the importance of social aspects and ‘what matters most’***

There is a growing body of evidence that people with dementia and their families underline the importance of discussing ACP with their families and that the focus of ACP should be on non-medical aspects (32,39,40). These needs align with the public health approach to ACP that aims to normalise conversations about end-of-life preferences, death, and dying and underlines the need to support conversations in the family context (41–44). This is consistent with the broader community-focused perspective in palliative care, acknowledging the dynamic and situational nature of preferences and values in end-of-life care (45). Recent literature has raised questions about the efficacy of ACP, given the complexity of decisions as one approaches the end of life. These decisions are neither simple nor linear, often changing rapidly due to fluctuations in health (46–48). Furthermore, criticisms have been

directed at ACP's theoretical foundations for their perceived failure to align with the dynamic reality of healthcare practice and settings (46–48). This misalignment has led to scepticism regarding the necessity and effectiveness of ACP. The absence of clear outcome measures, coupled with clinicians' reluctance to initiate conversations about death and dying, contributes to the overall hesitancy towards embracing ACP (42).

In response to these challenges, the public health approach to ACP advocates for a shift in focus from purely medical to 'what matters most' and the social aspects of end-of-life care (42). Instead of concentrating solely on clinical needs and anticipating uncertainties, ACP conversations under this approach should prioritise understanding life priorities, identifying preferences during declining health, and accessing support from one's social network (42). This innovative approach in ACP aims to alter priorities, facilitating more relevant and accessible conversations, and acknowledges the unpredictability of life, emphasising that decisions may change over time (42). This aligns with the ACP definition supported by the European Association of Palliative Care, emphasising that decisions and wishes should be evaluated when needed (49).

This need to change how we define and conduct ACP is supported by the findings presented in this thesis. Also, in other studies, the importance of these social aspects and '*what matters most*' in ACP are emphasised by people with dementia and their families (41,50,51). In a recent qualitative study in early-onset dementia, people with dementia and their family caregivers argued that ACP should shift from a purely medicalised to a holistic approach in which ACP is a combination of medical, social, and mental health elements (52). The same message is echoed by the European Working Group of People with Dementia, as the Group stressed that ACP should focus on social aspects of care and '*what matters most in the future*' (39). In this qualitative study, the European Working Group of People With Dementia emphasised the under-addressed essential role of families or trust-based relationships in dementia discussions, recognising that family dynamics may vary but play a crucial role. Moreover, there was a shared concern that ACP tends to be overly centred on medical care, urging for a broader approach that incorporates discussions about what matters in the future, encompassing social care and daily life activities (53).

By providing interactive communication tools, the website aimed to meet these addressed needs and support people with dementia and their families in conversations beyond medical decisions to explore values and broader aspects of life that may impact their decisions for

future care and treatment. The utilisation of such tools has been validated as an effective strategy for involving individuals in emotionally sensitive health subjects, such as anxiety and end-of-life care and fostering positive changes in health-related behaviours and self-management (54). In the evaluation study (Chapter 5), participants indicated that these interactive communication tools supported them in starting with and engaging in conversations about ACP. Especially the digital ‘*Levenswensen*’ cards (Chapters 3 and 5) facilitated conversations about ACP and their end-of-life values and preferences. The same results have been found with the paper-based version of the original Go Wish card game (55–65), which was culturally adapted to the ‘*Levenswensen*’ cards. Similar effects were also found in other games that aim to facilitate conversations regarding end-of-life preferences (54). Van Scoy and colleagues (2017) found that that a comparable card game (Hello), designed to prompt participants to articulate their values, goals, and beliefs concerning end-of-life matters with questions like “*In order to provide you with the best care possible, what three non-medical facts should your doctor know about you?*”, led to satisfying, realistic, and clinically meaningful discussions. Furthermore, a substantial portion of participants (70%) initiated subsequent ACP behaviours following their engagement with the game (66).

Participants in our evaluation study (Chapter 5) underlined the comfort of the preformulated statements about social aspects in helping them to reflect, open up and start a conversation. This novel evidence shows that the online culturally adapted version of the original ‘*Go Wish*’ cards (1,67), can be valuable in fostering discussions about ACP and end-of-life values and preferences. Furthermore, the study observed that the *Levenswensen* cards, with the proactive involvement of certain family caregivers, served as an effective conversation initiator, even with people in a more moderate stage of dementia. These caregivers adeptly employed closed questions to assess the significance of the statements on the cards.

In prior studies, people with dementia encountered challenges when using the cards, especially with ranking their ‘top 10’ preferences from their ‘most important’ selections (55). As prioritising preferences demands considerable abstract reasoning, which can be difficult for dementia (68), people with dementia and their families recommended deleting this aspect in the online version. Previous studies have demonstrated that people with dementia can communicate preferences and wishes, even in advanced stages, when adjustments are made to meet their needs (69,70). Our research further emphasises that, when adapted to their specific needs, the ‘*Levenswensen*’ cards emerge as a valuable tool, facilitating people with dementia in expressing their wishes and needs.

### ***ACP in the family context: complementary to ACP with the healthcare professional***

The website to support people with dementia and their families in ACP in the family context aligns with the addressed needs of people with dementia and their families to discuss ACP together (39,52). However, the website to support ACP in the family context should be considered complementary to ACP with healthcare professionals. As emphasised in the ACP definition supported by the European Association for Palliative Care definition (49), and the findings from our focus group study (Chapter 2) and other relevant research in dementia (32,33,40), healthcare professionals are essential in the ACP process. Especially in medical decisions, e.g., avoiding unnecessary suffering and refusing invasive treatments, the input and involvement of healthcare professionals are essential. Moreover, healthcare professionals need to be aware of certain values, wishes and preferences in order to formulate care goals that align with the wishes of patients and their families (71).

However, the importance of conversations about values, wishes and preferences with regard to care between family and friends must also be underlined. Conversations people have at home and the knowledge of wishes and preferences from these conversations, which could guide the decision-making process, are underestimated facilitators in ACP (72). These conversations can empower people with dementia to express their preferences and values regarding potential future care and facilitate informed decision-making in dementia (73–75). This, in turn, can support family members, frequently tasked with making medical decisions for people with dementia, to make well-informed decisions that align with the expressed wishes of the person with dementia, potentially alleviating the burden on family caregivers (76,77).

Ensuring alignment between conversations within the family context and those with the healthcare professional is, therefore, fundamental. The family-initiated ACP conversations may complement the discussions about ACP with the healthcare professional. By having insights into these conversations in the family context, healthcare professionals could deliver more personalised care that aligns with the values of the person with dementia and their family. Healthcare professionals' expressed time constraints create a dual barrier in ACP, hindering the thorough preparation of patients and their families for the process and initiation of ACP discussions (48). By providing people with dementia and their families the opportunity to inform themselves about ACP and identify wishes and values that may impact decisions within ACP, the conversations with the healthcare professional could be focused on decisions for future care and treatment, considering the earlier identified values and wishes.

### ***Importance of early initiation of ACP in dementia***

Our evaluation study (Chapter 5) repeats the importance of early initiation of ACP in dementia. Some family caregivers noted that while they used the website themselves, they felt that due to the moderate stage of dementia, it was challenging to initiate discussions on ACP with the person with dementia. They felt that if they had started ACP earlier, the website could have helped them in the process. The importance of starting ACP early in dementia is often underlined (50,78), also by people with dementia themselves (39). Early initiation of ACP helps the person with dementia and the family caregiver set expectations and understand the values and preferences for future care (79,80). As dementia progresses to a more moderate stage, the importance of discussing ACP with family becomes even more evident, allowing for shared decision-making and ensuring the preservation of the preferences and values of the person with dementia, even when they may no longer have the capacity to make these decisions independently (76,77). It is worth considering that initiating ACP early may lay the groundwork for its reintroduction during the more moderate stages of dementia. Although substantiating this idea would require extensive longitudinal studies, early involvement in ACP may facilitate its continuation and adaptation as the disease progresses.

### ***Personalised, accessible, and clear advance care planning information***

Participants in the focus group study (Chapter 2) highlighted the need for comprehensive and clear information about ACP on the website. This implies that the information should clearly outline ACP's capabilities and limitations. Key topics included understanding ACP, its significance, and clear explanations of legal frameworks. They stressed the need for tailored information considering the evolving stages of dementia.

The lack of information perceived by people with dementia and their families has been described as an important barrier to ACP (33). Providing information on ACP is crucial in supporting people with dementia and their families in ACP, as it could support them in engaging in ACP (81,82). Currently, the content on ACP provided on Dementia Association websites in Europe strongly focuses on legal and medical topics, emphasising completing advance directives (83). To support people with dementia and their families, it is important to provide information about ACP and encourage communication with family and healthcare professionals, decision-sharing, and identifying personal values that align with the needs addressed by people with dementia and their families (39,52).

Another reason to provide accessible and clear information is the current taboo and misconceptions about ACP. This was mentioned in the focus group study (Chapter 2) and also in our evaluation study (Chapter 5); we noticed a certain reluctance when ACP was first introduced in, for example, the recruitment but also at the baseline interviews in the evaluation study. This taboo on ACP and end-of-life care has also been documented in other studies (33,52,78). Providing information that is adapted to the needs of people with dementia and their families, showing that ACP is more than death and dying, and emphasising the addressed needs of people with dementia and their families in how they think ACP should be introduced and discussed, may help to change the current idea about ACP and break the taboo.

Another noteworthy need expressed by people with dementia and their family caregivers with regard to ACP information involves incorporating peer testimonials on the website. Participants in the evaluation study (Chapter 5) highly valued this feature, emphasising a desire for personalised information that they can relate to. During the focus group discussions (Chapter 2), participants suggested using these testimonials to convey information about ACP in a more personalised manner. Peer-to-peer support is widely recognised for its informative value, for example, to support early diagnosis or a narrative on 'living well with dementia' (84–87). On platforms like YouTube, such testimonials are among the most viewed types of dementia-related content (88). However, it is important to acknowledge that the people with dementia and their family caregivers featured in the videos on the website may not resonate with everyone. In the evaluation study (Chapter 5), some participants expressed the need for videos featuring different dyad combinations, such as child and partner couples. Additionally, younger participants expressed a desire to see peers of their age group in the videos, as they may face distinct challenges, such as balancing the role of a family caregiver while caring for a person with dementia.

### 3.2 THE POTENTIAL OF ONLINE TOOLS TO SUPPORT ACP IN DEMENTIA

#### ***The role of the website in ACP practice***

In this dissertation, we found that the website could support people with dementia and their families in ACP. After using the website, participants in the evaluation study consistently expressed that it is a valuable resource for learning more about ACP, that it has added value in dementia to facilitate ACP, and that it has improved their willingness to engage in ACP (Chapter 5).

In recent years, there has been a growing use of websites and apps to promote ACP (89). Initially, the potential to guide ACP via the Internet focused on creating secure electronic databases for storing, retrieving, and transmitting advance directives (90). Later, web-based tools to offer educational resources on ACP, including legal frameworks and guidance on completing advance directives to assist people in making decisions about future care, treatment, and end-of-life preferences, were developed (7,91). The evolution towards web-based solutions to support ACP reflects the dynamic nature of healthcare practices to meet patients' changing needs and preferences. Currently, one in two people in Europe and 60% of older adults in the US search for online information, numbers which are likely to rise rapidly (92,93). Many patient populations, including people with dementia and their family caregivers, are receptive to utilising the Internet as a valuable resource for gaining knowledge about their condition and supporting them in (shared-) decision-making (94–97).

Websites and apps can support ACP in known barriers to ACP, like the lack of information provision on ACP and difficulties in initiating conversations (32,33). By offering comprehensible information about the legal aspects and the significance of ACP, such web-based tools can empower people to understand the potential relevance of ACP. Moreover, providing people with the means to prepare for ACP discussions when they want and within their own homes can make it easier to introduce this challenging topic and support people in navigating ACP. This may contribute to (future) shared and delegated decision-making, which is crucial for family caregivers of people with dementia (76).

In recent years, there has been a growing wave of initiatives promoting ACP in Flanders. For instance, specialised training programs have been developed for healthcare professionals working with people with dementia (82,98,99). Additionally, the websites of patient organisations provide valuable information regarding the legal frameworks and the significance of ACP (83). Collectively, these efforts reflect a heightened commitment to advancing ACP in Flanders. Despite these efforts, there remains a notable scarcity of comprehensive ACP information that is specifically tailored to the context of dementia. While several patient organisation websites offer information on ACP and dementia, and the Flemish app '*voor ik het vergeet*' strives to facilitate ACP conversations in dementia through a semi-structured questionnaire supported by photos, it is worth highlighting that this app primarily caters to healthcare professionals and lacks the provision of ACP-related information for a broader audience. In this regard, the website developed within the scope of



this dissertation is a pioneering effort, as it is the first that imparts not only essential ACP information but also aims to stimulate conversations through interactive communication tools.

Incorporating this website into the Flemish dementia context is necessary to increase awareness of its existence and emphasise its potential value. This integration enhances the website's potential and ensures seamless alignment with existing resources. To ensure the website's seamless integration into Flemish dementia care, we have undertaken collaborative efforts with '*Alzheimer Liga Vlaanderen*' (in English Flemish Alzheimer's League) and '*Expertisecentrum Dementie Vlaanderen*' (In English Flanders Centre of Expertise on Dementia), the two primary dementia organisations in Flanders. This transition will occur over several months to ensure a smooth launch and comprehensive consideration of integration, along with addressing technical aspects such as changing hosting. We have initiated this process to hand over the website, facilitating its inclusion within the operations of the organisations and making it easily accessible to people with dementia, family caregivers, and healthcare professionals.

Lastly, despite the measures taken to ensure the website's longevity through our collaborative efforts with '*Alzheimer Liga Vlaanderen*' and '*Expertisecentrum Dementie Vlaanderen*', it is essential to recognise that the ever-evolving landscape of healthcare advancements and potential alterations in legislation concerning ACP necessitate continuous updates and maintenance of the website (100). In our systematic review (Chapter 1), we observed that the quality of information provided by other web-based tools to support ACP, as assessed through the QUEST criteria, was relatively low. This was primarily because many of these tools had not undergone updates for a period exceeding five years. Hence, through collaborative decision-making with the '*Alzheimer Liga Vlaanderen*' and '*Expertisecentrum Dementie Vlaanderen*', we will ensure that the website undergoes regular assessments and that necessary adjustments are made in response to new research findings and legislative updates.

### ***The potential of the website to support ACP in the medical context***

As discussed before, the website is intended to complement ACP with healthcare professionals. To ensure the website is aligned with the ACP practice by healthcare professionals, we proactively involved healthcare professionals in our development process. This approach aligns with the guidance provided by the Medical Research Council for

developing and evaluating complex interventions (20), which underscores the importance of engaging relevant stakeholders. This collaborative effort was essential in tailoring the website to meet healthcare professionals' requirements, ensuring its usability in clinical practice.

Previous research on a similar interactive, web-based tool used by patients recruited in primary care clinics and outpatient cancer centres showed that such a tool can increase ACP engagement (101). Our evaluation study found that after using the website for eight weeks (Chapter 5), participants were more willing to engage in ACP discussions with their health professionals.

The website can support ACP in the medical context in several ways. First, the information on the website could help patients prepare for conversations about ACP with their healthcare professionals (73,75). By aiding people with dementia in thorough preparation, the website facilitates a clearer understanding of ACP and their values and potential preferences for future care and treatment (73–75). Secondly, the website can serve as a valuable conversation initiator for healthcare professionals, people with dementia, and their families. While recognising that some people with dementia and their family caregivers prefer healthcare professionals to initiate ACP discussions (102), the website emphasises the flexibility for the person with dementia and their family caregivers to introduce the topic during consultations. However, participants in the focus group study (Chapter 2) believed that people with dementia and their families would not actively search for the website themselves, and according to them, healthcare professionals should be the ones who introduced the website to people with dementia and their families.

### ***ICT, ACP, and dementia: balancing between potential and exclusion***

ICT and digital participation have been found to enhance the quality of life by providing valuable information, offering practical assistance, facilitating social connections, and supporting personal interests, such as relaxation and entertainment (103). However, it is essential to consider the possibility of digital exclusion, particularly among people with lower digital literacy. By developing a website, we may not have reached all people with dementia and their families who want(ed) to be supported in ACP, particularly those with lower digital literacy levels. Digital literacy is associated with age and cognitive abilities (104). The participants in our focus group study (Chapter 2) highlighted this potential limitation by emphasising the need for a certain level of computer literacy to use a website. Furthermore,

the results of our evaluation study (Chapter 5) further emphasised this challenge, as participants with more moderate dementia encountered difficulties using the website.

Digital exclusion can be defined as the inequity in skills, access and capability to use Information and Communication Technology (ICT), such as apps or the Internet (105). Digital exclusion can happen because of limited financial resources, lack of technical knowledge, or certain disabilities like cognitive impairment (105). Cognitive impairment caused by dementia can make it difficult to learn new digital skills and use ICT effectively (106,107). For example, people with dementia may have problems using difficult interfaces, remembering passwords, or following online instructions (108). Additionally, many people with dementia are older people who may not be accustomed to working with computers, further emphasising the inequities that can arise in accessing and providing ICT solutions (109).

To maximise the usage and interface accessibility of the ACP support website, we aimed to account for these difficulties as much as possible during the website's development phase. As advocated by Alzheimer Europe and the Alzheimer Society, we developed the website in co-creation with people with dementia and their families (110,111). Co-creation is designing with people, not just for them, to produce high-quality tools appropriate for the intended user (111). This so-called user-centred approach emphasises the importance of end-user needs during the development (112,113). During the development of the ACP support website, several prototypes were developed and revised in several iterations. In each iteration, the website's usability was evaluated by people with dementia and their family caregivers, and the website was adapted accordingly.

To support the accessibility and overcome the potential barriers to using the website mentioned during the focus groups (Chapter 2), functionalities like text-to-speech or contrast options were added. Implementing these functionalities is also recommended by DEEP (Dementia Engagement and Empowerment Project) and the Alzheimer Society, as they may support the inclusivity of ICT in dementia (114,115). By implementing such features, we aimed to ensure that the website would be more easily accessible. In the evaluation study (Chapter 5), some people with dementia used the website intensively, underscoring their positive experiences in the interviews after the eight-week study. They found the website easy to use and enjoyed using the interactive communication tools.

However, other participants with dementia in the evaluation study could and did not use the website because of cognitive difficulties (Chapter 5). Via the System Usability Scale Survey, people with dementia indicated they needed support to use the website. Family caregivers of people with dementia who did not use the website, while they did indicate they wanted to take part in the study, mentioned that the person with dementia enjoyed watching the videos, but independent usage was too challenging. A more extensive tailoring of technology to the specific needs of people with dementia may help mitigate this digital exclusion in dementia. A recent literature review by Kerkhof et al. (2021) showed that even people with dementia, including people with a more moderate stage of dementia, can (re)learn how to use new technologies (116). To support the adoption of new technology in dementia, delivering adjusted training, adapting interfaces, or providing personalised user guides is needed (114–116). Though the website was developed in co-creation with people with dementia to improve accessibility, and we provided an onboarding before the evaluation study, we did not include any training or personalised user guides. At present, concrete recommendations or guidelines for developing such training programs do, to our knowledge, not exist.

### ***The primary usage and important contribution of family caregivers in using the website***

Our evaluation study (Chapter 5) showed important insights into how family caregivers and people with dementia used the website. Most family caregivers of the dyads initially used the website alone, with some later involving the person with dementia. Notably, only a small fraction of people with dementia used the website on their own (Chapters 5 and 6). According to the family caregivers of the people with dementia who did use the website on their own, their reasons mostly revolved around either a lack of personal interest in ACP or their habits of doing most activities together.

The worries about a possible lower website uptake among people with dementia were not surprising; It had been anticipated and discussed in the focus group study (Chapter 2) and during the website's development. The systematic review of Bastoni et al. (2019), a comprehensive summary of the challenges associated with adopting new technology in dementia, identified several factors that can influence the uptake of ICT in dementia (117). The most dominant factors that positively affected the technology uptake by people with dementia were their involvement in the development and a gradual introduction during the disease trajectory (117). The largest group of factors that facilitate or hinder uptake were centred around the characteristics of the family caregiver, like motivation, training and digital literacy (117). Family caregivers are essential in adopting new technology in dementia, with

their knowledge of the person's needs and challenges. According to the review of Conway et al. (2023), exploring the factors influencing the adoption of digital health applications for people living with dementia, family caregivers can help overcome barriers preventing people from dementia using apps (118).

While embracing an adoption strategy that involves family caregivers may benefit the uptake of ICT in dementia, it is important to recognise that some people with dementia may not have family caregivers, or their families are not directly involved in their care (119). Moreover, relying too heavily on family caregivers may inadvertently discourage independent ICT use among people with dementia, potentially undermining their autonomy. To create an inclusive environment for people with dementia and promote the adoption of ICT, it is crucial to balance the often-necessary involvement of family caregivers and the encouragement of self-initiative. This approach may empower people with dementia to embrace the advantages of ICT at their own pace, leading to potential greater acceptance and use.

### 3.3 CHALLENGES OF DOING RESEARCH WITH PEOPLE LIVING WITH DEMENTIA

#### ***Challenges in the recruitment of people with dementia***

We experienced difficulties finding people with dementia and their families to participate in our research. For our evaluation study (Chapter 5), it took nine months to recruit 52 people. Also, in our development, we encountered considerable difficulties recruiting people with dementia and their family caregivers. Possible reasons for recruitment challenges could be attributed to several factors, such as the nature of the topic (ACP), the web-based format of the tool, and the tendency of people in the early stages of dementia to not frequently engage with specialised dementia care, which served as our primary recruitment channels.

Recruitment challenges in dementia research have been widely documented (21,120). While people with dementia and their families generally hold a positive attitude toward participating in research, one of the primary barriers to recruitment is their lack of awareness about available research opportunities (120). With the genuine intention to protect people with dementia, ethical committees and healthcare providers may inadvertently prevent them and their families from learning about ongoing research studies and participation (121,122). Moreover, because people with dementia are not in contact with the resources that can provide them with information about ongoing research opportunities, they do not have the opportunity to participate. The latter may have happened in our study. In Flanders, dementia

care is rather scattered. People with dementia usually see their neurologist or geriatrist every six months and their GP when needed. While in some regions, there is coaching or support by specified dementia consultants, these consultants work demand-driven. Many people in the early stages of dementia do not frequently engage with any form of specialised dementia care, which served as one of our primary recruitment channels.

Other recognised barriers in dementia recruitment are that the family caregivers frequently serve as gatekeepers, shielding people with dementia from potentially distressing situations and excessive burdens (120,123). In our evaluation study, people with dementia and their families initially showed interest in participating, expressing this interest to their physicians. However, some family caregivers indicated, after the initial expression of interest, that they could not participate due to time constraints. Lastly, a few family caregivers who initially expressed interest in participating in the evaluation study ultimately decided not to participate. Their decision was influenced by the reluctance of the person with dementia to engage in ACP discussions. This reluctance is a common theme observed in studies on ACP, palliative care and dementia (33,52,78) and was also mentioned in our focus group study (Chapter 2) as a barrier to finding the website.

These recruitment challenges may raise concerns about the potential limitations in generalising findings from dementia research and applying them to various social groups, such as women, ethnic minorities, and populations with rare forms of dementia (22,120,124,125). Building effective strategies, promoting research findings, and providing clear information about upcoming and ongoing studies to include people with dementia in research may mitigate the difficulties in recruiting people with dementia. Such initiatives already exist. For example, 'Alzheimer Nederland' (in English, the Dutch Alzheimer Association) provides information about various ongoing studies. Visitors of the '*Alzheimer Nederland*' website can read the information and fill in online forms or send an email to ask for more information (126). A step further, the Alzheimer's Society in the UK has a unique platform where people with dementia and their families can register if they want to participate in the research (127). Once the registration process is completed, people can review their study matches.

Lastly, an important observation from our study participants in Chapters 5 and 6, is the higher proportion of female family caregivers and a greater prevalence of men among people with dementia. This finding is noteworthy since, statistically, a dementia diagnosis is more

prevalent among women (128,129). This discrepancy in gender is in line with the concept known as the "double burden of dementia in women" wherein women not only face a higher risk of diagnosis but also disproportionately assume the caregiving role (128,129). This dual challenge places additional emotional, physical, and financial strain on women, who may already be balancing multiple responsibilities within their families and communities. Recognising this phenomenon is crucial, as differences in gender can significantly impact the caregiving experience and the specific needs of individuals living with dementia (128,129).

***Even over a relatively short period, fluctuating cognitive decline in dementia can influence study participation.***

In the evaluation study (Chapter 5), 21 people with dementia were included and participated in the baseline data collection. Eight weeks later, two people with dementia could not participate in the follow-up data collection because of their cognitive decline. In three other participants, the family caregiver indicated before the data collection started that the person with dementia because they did not want to talk about ACP, did not want to participate anymore.

Drawing from our insights gained throughout the evaluation study (Chapter 5), it seems crucial to acknowledge the potential effects of cognitive decline, which can manifest even within relatively short research periods. The concept of willingness to participate among people with dementia is inherently complex and subject to fluctuations. In previous research, the inclusion of people considered 'vulnerable,' including people with dementia, has raised significant ethical concerns, particularly in palliative care (130). Studies in dementia and palliative care have reported selection bias based on the need for participants to have the ability to provide consent based on research guidelines initially developed for people without cognitive impairment (130–132). The '*MORECare\_Capacity statement with 20 best practice solutions and implementation requirements to maximise study participation across the capacity spectrum*' guides how to include people with dementia in palliative care research (131).

However, even with adapted informed consent procedures, the problem of fluctuating capacity in longitudinal data collection remains. Adaptability in data collection may encompass strategies such as postponing data collection to a more suitable time, incorporating self-assessment tools, or exploring modified interview techniques (133–135).

This approach, oriented around the person and their evolving needs, can broaden the pool of research participants, advancing inclusivity while upholding ethical research standards.

#### **4. RECOMMENDATIONS FOR PRACTICE, POLICY, AND RESEARCH**

In this section, we discuss the implications and recommendations for practice, policy, and research drawn from the findings in this dissertation. Over the course of working on this dissertation, valuable input was gathered from people with dementia, their family caregivers, healthcare professionals, representatives of dementia organisations and researchers. Their feedback and insights have provided recommendations for the practical utilisation of the website and potential improvements for ACP. Additionally, the challenges encountered throughout the research process have served as a valuable source for formulating recommendations for policy and future research.

##### **A. RECOMMENDATIONS FOR PRACTICE**

**An ACP support website can optimally benefit people with dementia and their families if people are referred to it by healthcare professionals or dementia organisations.**

The evaluation study (Chapter 5) revealed that people with dementia and their families evaluated the website positively, with many crediting it for facilitating ACP. After the evaluation study, more people with dementia and family caregivers wanted to discuss ACP with their healthcare professionals. This underscores the valuable role that the website can play in empowering people with dementia and families to engage with ACP and the potential of the website to catalyse ACP with healthcare professionals.

Initiating ACP is reported as a major challenge (33). In response to this challenge, the website can function as a gentle introduction to ACP. Existing evidence has shown that tools to support ACP can indeed facilitate ACP or decision-making discussions (101,136–140). By offering information, enabling people to prepare, and providing the opportunity to discuss ACP from the comfort of their own homes, the website has the potential to support ACP.

However, as quoted by a family caregiver in the focus group study: *‘Healthcare professionals or organisations should recommend the website; otherwise nobody is going to find or use it’*. According to healthcare professionals and family caregivers in our focus group study (Chapter 2), a significant barrier to adopting the website is the likelihood that people may not



find it spontaneously, mainly due to the stigma around ACP, which is often associated solely with end-of-life matters, according to the participants. This resonates with the preferences of people with dementia and their family caregivers, who express a preference for healthcare professionals to initiate ACP (59). Consequently, the participants in our focus group study (Chapter 2) recommended promoting the website through dementia organisations, insurance agencies, and healthcare professionals.

Building upon the documented benefits of ACP support tools and the insights from this research, we recommend that healthcare professionals and dementia organisations proactively recommend the website. By leveraging the website's potential, healthcare professionals may effectively engage patients and their families in ACP discussions.

- *Introduce the website in consultations:* Present the website during consultations. To initiate discussions on ACP, consider introducing the website to people with dementia and their families during consultations. The website can function as an 'interactive, online brochure,' providing information about ACP and offering opportunities to delve into the topic before discussing ACP with the healthcare professional.
- *Reference to the website in training material:* Organisations working around dementia and palliative care should consider including references to the website in their training materials. This approach ensures that healthcare professionals across different levels of care and disciplines become aware of the website's existence and utility in ACP.
- *Reference to the website on websites or online platforms:* Dementia organisations and healthcare professionals can further promote the website by referencing it on their websites or online platforms. Providing direct links or resources highlighting the website's importance can increase its visibility and accessibility.
- *Integrate into materials for peer-to-peer support:* to reach a broader audience, dementia organisations working with volunteers may consider integrating the website into materials designed for peer-to-peer support. These materials can include conversation guides, brochures, or informational packets shared within support groups or community gatherings.

**ACP should be introduced early in the dementia process and be tailored to the readiness of the person with dementia and the family caregiver.**

Our evaluation study (Chapter 5) highlighted the importance of introducing ACP early in the trajectory of dementia. The importance of initiating ACP early in the dementia journey has been highlighted previously, as it facilitates the involvement of people with dementia in decisions regarding their future care and treatment (141). In dementia, people's ability to imagine abstract topics such as future care needs makes it increasingly challenging to envision scenarios and make proactive decisions (142). Beginning discussions about healthcare preferences early is also crucial as families sometimes struggle to differentiate between their preferences and those of the person with dementia (72,108,143). Additionally, early initiation of ACP is necessary due to the inherent difficulty in accurately predicting the prognosis of dementia (144).

Several studies have shown the possibility of introducing ACP early in the dementia trajectory (145–147). These studies suggest that introducing ACP should be done soon after the diagnosis – after patients had time to process the diagnosis but early enough so people with dementia still have the capacity to make decisions about future care (78). Though early introduction is widely stressed, it remains limited. Possible ways to introduce ACP early are:

- *Introduce ACP with 'what matters to you' as argued in the ACP public health approach:* Following the principles of the ACP public health approach, discussions on ACP can be initiated by asking people with dementia and their families, 'what matters to you?' and how will this affect your future and possible decisions you have to make. This patient-centered approach can lead to ACP conversations by addressing individual preferences, values, and goals.
- *Integrate ACP discussions into broader life planning conversations:* As people with dementia and their families seem to discuss topics like funeral arrangements and financial planning, ACP could be presented as part of these broader discussions about future planning. By emphasising that ACP is a natural component of life planning, people with dementia and their families may be more inclined to actively participate in these conversations. Normalising ACP in this way not only reduces associated stigma but also transforms it into a routine and essential aspect of healthcare discussions.
- *Introduce topics related to ACP gradually:* Participants in our study demonstrated a commendable willingness to initiate conversations about specific aspects of ACP while being hesitant about others. This insight underscores the importance of

recognising that ACP discussions can be initiated before people feel fully prepared to address all facets of ACP. We may enhance ACP conversations by fostering an environment that supports gradual exploration and discussion.

- *Use the website to introduce ACP:* The website can serve as a gradual introduction to ACP, providing users with information, resources, and interactive tools that help them understand the concept and importance of ACP. This incremental approach can help people with dementia and their families ease into the process. As observed during the evaluation study, participants engaged with the website content by discussing and exploring topics of immediate interest while setting aside those that felt too early for consideration at that particular time.

**The healthcare professional should provide information about dementia itself to facilitate the ACP process.**

In the focus group study (Chapter 2), family caregivers expressed the importance of having access to information about dementia, its prognosis, and future care options. Healthcare professionals echoed this sentiment, emphasising the importance of understanding the trajectory of dementia when engaging in ACP. Also, during the cultural adaptation of the Levenswensen kaarten (Chapter 3), some participants who used the cards expressed the need for more information about possibilities for care and treatment. As the website aimed to support ACP, we chose not to incorporate this information but include references or hyperlinks to other reputable websites dedicated to dementia-related information.

However, during the evaluation study (Chapter 5), family caregivers mentioned in interviews that they felt the website lacked some information about the progression of dementia and possibilities for future care. This need for access information about ACP, dementia, and disease progression was also highlighted in previous research (32,33,40). Providing tailored information on ACP and dementia is crucial in aiding people with dementia and their families in navigating the ACP process (148). This information can catalyse the initiation of ACP discussions (82).

We, therefore, recommend that healthcare professionals should prioritise providing comprehensive and tailored information about dementia itself before and during ACP. This information should encompass the nature of the disease, its likely progression and available treatment options. By addressing the informational needs of people with dementia, healthcare professionals can empower them to make informed decisions about their

healthcare journey, reducing uncertainties and fostering a sense of readiness. Important to note is that sharing of prognosis is difficult in itself, and several training courses are available for serious illness communication, including discussions about prognosis (149). In the case of dementia, it seems important to follow patients' informational preferences and balance between being realistic about the progressive nature of the disease and, at the same time, highlighting the positive elements in the trajectory (150).

**Because of the important role of the family caregiver in supporting the person with dementia, she or he should receive support in using the website, taking into account the autonomy of the person with dementia**

Based on the results of our evaluation study (Chapter 5), it is evident that family caregivers play a crucial role in using the website to support ACP. While people with dementia occasionally engaged with the website independently, family caregivers within the included dyads predominantly used the platform alone or together with the person with dementia. These family caregivers employed personalised strategies to involve the person with dementia in using the website. For instance, they formulated closed questions using interactive communication tools to determine the wishes of the person with dementia. However, relying excessively on family caregivers might unintentionally overlook people with dementia who lack a family caregiver or those whose family caregiver is not interested in ACP. Therefore, we advocate for a nuanced strategy that acknowledges and supports the essential role of family caregivers while simultaneously fostering the autonomy of people with dementia.

Recognising and utilising the expertise of family caregivers is crucial. Family caregivers often have a good understanding of the capabilities and limitations of the person with dementia. This intimate knowledge extends to recognising the specific tasks that the person can still perform and those that may present challenges. Supporting family caregivers using the website could enhance their ability to assist people with dementia. Simultaneously, encouraging autonomy among people with dementia is essential—tailoring interventions to their unique interests, preferences, and capabilities to foster empowerment. Acknowledging the diversity of caregiving situations is vital, requiring exploring alternative support systems for those without family caregivers or with less involved families to ensure equitable access to technology resources. While the healthcare professional may do the initial initiation, patient or family caregiver organisations could offer valuable support to both the family caregiver and the person with dementia in using the website.

## B. RECOMMENDATIONS FOR POLICY

### **Develop a comprehensive, accessible online overview of evidence-based support tools for people with dementia, their family carers, and healthcare professionals.**

It is important to acknowledge that the mere existence of evidence-based support tools does not always guarantee widespread awareness or utilisation. In an age where people, especially the younger generation, frequently search for information on the internet, offering a thorough and accessible overview of these supportive tools to both patients, their families, and healthcare professionals can be a game-changer. This approach has the potential to empower patients, their families and healthcare professionals to identify and access the most suitable support resources effectively. For example, in the United Kingdom, the NHS (National Health Service) website provides overviews of tools to support decision-making and self-management guides and gives examples of their use in case studies to inform the public (151). By bridging the gap between existing tools and their practical use in patient care, such guidance can enhance the uptake of available tools to improve care support and overall patient experience.

### **Create a platform collaboratively with dementia organisations, healthcare professionals and researchers to facilitate research participation, enhancing research accessibility for people with dementia and their families.**

To address the challenges related to recruiting participants for research studies, a proactive approach inspired by specific patient organisations abroad can be instrumental in making research more accessible for people with dementia and their families (126,127). Some patient organisations have successfully implemented strategies designed to connect interested people with dementia and their families with scientific researchers seeking participants, offering a solution that can significantly benefit people with dementia and their families and the progression of research. Creating such strategies in the form of a platform would streamline the recruitment process for research studies and serve as an invaluable resource for patients and patient organisations. It can offer a user-friendly interface for people with dementia and their families to explore and engage with current research projects that align with their interests. People with dementia and their families can express their willingness to participate in specific research projects, making research more accessible and tailored.

This recommendation should be a collaborative effort between dementia organisations, researchers, and healthcare professionals. By uniting their expertise and resources, these stakeholders can collectively work towards creating a platform that truly serves the best interests of people with dementia, their families, and the advancement of dementia research. This collaborative approach ensures that the platform's design and functionality align with the specific needs and preferences of people with dementia and their family caregivers while adhering to ethical and scientific standards.

The participation of healthcare professionals is crucial in this collaboration because of their key role as trusted sources of medical advice and information for people with dementia (152). They can provide valuable insights on effectively engaging patients in research and making informed decisions about participating in research studies. Additionally, their involvement can help ensure the platform aligns with clinical standards. For patient organisations, supporting the establishment of a platform aligns with their mission to empower and assist people with dementia. By actively promoting and facilitating research initiatives, patient organisations can strengthen their advocacy for patient-centred research and enhance their members' access to meaningful research opportunities. This proactive approach bridges the gap between researchers and people with dementia, creating a mutually beneficial scenario where patients can contribute to advancing dementia research while gaining more accessible access to research studies that matter to them.

**When providing information about ACP, make sure it covers all aspects of ACP.**

To enhance support for people with dementia in information provision, policymakers are advised to develop complete and accessible ACP information, emphasising key topics and tailoring content to accommodate the evolving stages of dementia. Currently, ACP content is often focused on advance directives, what care people do not want, and financial aspects (83). ACP content should go beyond legal and restrictive medical aspects and include complete information about ACP, identification of personal values and wishes and strategies for communication with family and healthcare professionals. By incorporating peer testimonials, ACP information can become more personalised and relatable.

### C. RECOMMENDATIONS FOR RESEARCH

**Adopt a flexible, person-centred approach in research protocols that recognises the evolving nature of cognitive capacity and changes in informed consent.**

Based on our experiences from the evaluation study (Chapter 5), we strongly recommend that researchers conducting studies involving people with dementia consider the evolving nature of informed consent. Informed consent is a critical process involving study participants comprehending the study's objectives, procedures, and rights as participants and making voluntary decisions about their participation. In the context of dementia, where cognitive capacity can vary over time and may differ based on the specific decision, it is crucial to recognise these fluctuations.

To address this challenge, we recommend that researchers adopt a flexible research approach that accommodates the individual needs of participants with dementia. Researchers should embrace a person-centred approach that acknowledges the diversity in cognitive abilities among people with dementia and adapts research protocols accordingly. This approach can facilitate the inclusion of more participants in research and ensure that participants are sufficiently informed about the study, upholding ethical research standards.

**Prioritise diversity among study participants by actively seeking participants from various cultural backgrounds, living environments (urban and rural), and different types of dementia.**

To enhance the comprehensiveness and applicability of research findings related to ACP and dementia, it is essential to prioritise diversity among study participants. When developing the Levenswensen cards (Chapter 3), we successfully incorporated a broad spectrum of participants, including representatives from organisations serving individuals affected by structural vulnerabilities, such as ethnic minorities, immigrants, and those facing economic challenges. Our inclusion extended to representatives from Christianity, Judaism, and Islam. Moreover, the cards underwent testing with diverse individuals, encompassing those affected by structural vulnerabilities and nursing home residents with mild or moderate dementia. While our sample in the focus group and evaluation study exhibited some diversity in age, diagnosis, education, and caregiver relationships, we acknowledge the need for

increased diversity, particularly concerning cultural backgrounds and living environments (urban or rural).

Differences in dementia symptoms and the unique experiences of people with dementia underline the importance of diversity in study participants (153). To gain a comprehensive understanding of the possibilities and implications of the website, it is essential to include participants with varying backgrounds and experiences. Our sample in Chapters 2, 3 and 5 exhibited some diversity in age, diagnosis, education, and the relationship between family caregivers and people with dementia. However, we recognised the need for additional diversity, particularly regarding cultural backgrounds, gender, and living environments (urban or rural).

Dementia research faces a critical challenge concerning diversity and inclusivity (153). Despite risk factors like ethnicity, air pollution, and poor diet playing a role in dementia, people with these risk factors are often underrepresented in research (124,153). In the Blueprint for Dementia Research published by the WHO, increasing diversity in dementia research is one of the issues addressed (154). To ensure the generalisability of dementia research findings, participants in dementia research must, according to the Blueprint, '*be diverse in terms of sex, gender, race, ethnicity, religion, disability, socioeconomic status, and marginalised status (e.g., Indigenous populations)*' (154).

However, including diverse participants in dementia research is still limited. A recent systematic review on characterising demographic, racial, and geographic diversity in dementia research by Mooldijk (2022) found that participants in 302 studies with populations bigger than 50 participants were predominantly white and relatively young (155). In a systematic review and meta-analysis conducted by Vyas et al. (2019) on 96 randomised controlled trials with the goal of enhancing cognitive function in dementia, it was discovered that only 39.4% of these trials included information about participants' ethnicity. Furthermore, 11.4% of these trials had non-white individuals as part of their participant pool (125). Hence, efforts must be made to incorporate people from diverse backgrounds and regions, marginalised communities, and those with different types of dementia into all facets of dementia research.



Efforts must be made to ensure the representation of people from diverse backgrounds, regions, marginalised communities, gender, and those with varying types of dementia across all facets of dementia research. This commitment to inclusivity will promote a more comprehensive and equitable understanding of dementia and facilitate the development of interventions like the website.

**Starting at the beginning of their research activities, researchers should proactively consider longevity, sustainability, and implementation of developments and engage relevant stakeholders to maximise real-world impact.**

Throughout the studies presented in this dissertation, a dominant consideration was ensuring the website's longevity beyond the scope of the research activities. To achieve this, we recognised the importance of engaging with key stakeholders in the dementia field, e.g. two major dementia organisations in Flanders. Their involvement was integral to the development process, as we sought their expertise as consultants and maintained an open line of communication through regular meetings to keep them updated on our progress.

The significance of anticipating the real-world implementation of research findings has gained importance in recent years. It signifies the transition from research to practical utility, acknowledging that new interventions or developments should ultimately benefit those they are designed to support. A potential successful handover of developments or interventions that arise from academic research requires clearly defined roles and responsibilities and active involvement from the potential organisation(s) that could take responsibility and, ultimately, ownership for its continuation (156,157).

With our commitment to ensuring the longevity of the website, we have made concrete arrangements to transfer the Website to Alzheimer Liga Vlaanderen and Expertisecentrum Dementie Vlaanderen. By defining clear responsibilities and collaborative efforts, we aimed to ensure that the Website reaches and benefits as many people with dementia and their families as possible.

Based on our experiences and the website handover, we strongly recommend other researchers proactively consider the aspects of future implementation and sustainability from the beginning of their research activities. Given the increasingly competitive landscape of research funding and the pressing need for research to translate into practical applications,

early consideration of implementation strategies and engaging relevant stakeholders are essential. Adopting a comprehensive approach that integrates implementation planning throughout the research process may maximise the real-world impact of research, ultimately benefiting patients, their families and healthcare professionals.

**Robust longitudinal studies should rigorously explore ACP within dementia and assess the impact of web-based support tools in family contexts.**

The study showed the potential of the website to support ACP in dementia. Participants were more willing to engage in ACP after the evaluation study (Chapter 5). However, because of the study's design, we did not establish causal relationships. Moreover, given that people with dementia and their families have shown interest in continuing to use the website, it might be worthwhile to investigate this in a long-term study, aligning with the emphasis of ACP on continuous conversations. In-depth longitudinal research, enriched by innovative approaches like tailored interviews, more straightforward and flexible survey methods, or adding observational strategies to ensure ongoing inclusion of people with dementia, even amidst cognitive decline, could offer an understanding of how people with dementia and their families engage in ACP over a longer time. Such thorough investigation is crucial for deepening our understanding of the complex dynamics surrounding ACP in dementia and the potential of web-based tools used by people with dementia and their families in, for example, continuous conversations with healthcare professionals.

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## **ENGLISH AND DUTCH SUMMARY**

## ENGLISH SUMMARY

### SUPPORTING PEOPLE WITH DEMENTIA AND THEIR FAMILY IN ADVANCE CARE PLANNING: THE INNOVATIVE USE OF TECHNOLOGY

#### INTRODUCTION

Dementia is a syndrome marked by progressive cognitive decline, affecting memory, thinking, and social abilities. It is expected to be a major health concern, with a projected increase in cases and societal costs. While Alzheimer's is the most known type of dementia, there are also other types of dementia, e.g. vascular dementia or Lewy body dementia. Factors contributing to the risk of developing dementia include age, genetics, and lifestyle choices. Currently, there is no cure, but treatments can help to manage and slow down symptoms. While dementia is a progressive and life-limiting disease, not every person with dementia dies from dementia care. Predicting the course of dementia proves challenging, with a median survival period post-diagnosis varying, spanning from one to twelve years. Recognising the unpredictable but progressive nature of dementia, palliative care emerges as a crucial aspect of dementia. Palliative care focuses on enhancing comfort, managing symptoms, and addressing the diverse needs of people with dementia and their families. Timely and adequate palliative care can positively influence the quality of life for those with dementia, alleviate symptom burden, promote comfort, and provide crucial support to families. To facilitate timely access to palliative care, advance care planning emerges as a crucial tool.

#### *Advance care planning in dementia*

Advance care planning (ACP), as defined in 2017 by the European Association for Palliative Care, is a communication process that “*empowers individuals to identify their values, reflect on the consequences of serious illness scenarios, establish goals and preferences for future medical treatment, and engage in discussions with family and healthcare professionals*”. ACP was first mentioned around 1969 and mainly focussed on regulating end-of-life treatments via advance directives. However, the limited impact of these directives on end-of-life decision-making and the quality of care prompted a shift towards ACP as an ongoing communication process. This perspective, emphasised since the 1990s, underscores the importance of continuous conversations between the patient, family, and healthcare professional. However, a systematic review of public knowledge on ACP revealed widespread misunderstandings and misconceptions about the purpose of ACP. Despite the



limited knowledge, individuals often engage in ACP conversations with family and friends. This emphasises that ACP goes beyond the medical context, an idea also recognised by the public health or health-promoting approaches to palliative care and ACP.

Advocates for a public health approach to ACP stress the need for normalising conversations about end-of-life preferences, death, and dying. Within this new approach, ACP conversations can start within the family context, and there should be a bigger focus on social aspects rather than solely emphasising end-of-life decision-making. This advocated shift aligns with the needs of people with dementia and their families, emphasising the importance of discussions around '*what matters now and in the future*' and non-medical aspects of care. It is crucial to emphasise that, in our perspective, the public health approach to ACP is not a matter of choosing between 'ACP within the medical context' and 'ACP in the family context' but rather recognises their complementarity.

In dementia, the variable pace of cognitive decline underscores the imperative for early discussions about future care, treatment, and end-of-life preferences. As dementia progresses, people with dementia may lose decision-making capacity, placing family caregivers in crucial decision-making roles. However, despite the recognised importance of ACP, the uptake in dementia remains low. Numerous barriers to ACP in dementia have been identified, including limited knowledge about ACP and difficulties in addressing end-of-life considerations. Conversations at home and knowledge from lifelong conversations emerge as underestimated yet valuable facilitators in ACP.

#### *The use of web-based tools to support advance care planning in dementia*

Interactive web-based tools, such as websites or apps, have been proposed to support ACP within the family context. These tools offer flexibility, allowing access at any time and location, and can provide tailored content to meet the specific needs of users. Various websites and applications have been developed to support ACP. However, none of the existing tools were developed for people with dementia patients and their families. Recent research showed that using web-based tools in dementia can improve people's health through disease progression monitoring, personalised medicine, and support for social and leisure activities. Moreover, it can support communication and prompt conversations by serving as '*ice breakers*'. However, the use of web-based tools by people with dementia is challenging because of low digital literacy or late introduction. To support usage, such tools should be personalised and tailored to the needs of people with dementia and their families. Involving people with

dementia and their family caregivers through a user-centred approach and patient and public involvement can lead to a better understanding of the target group, supporting the development of more meaningful and appropriate tools. However, this is still relatively rare.

#### *Research gaps in ACP support tools for people with dementia and their family caregivers*

People with dementia and their families face unique challenges in ACP due to cognitive decline and the transition of decision-making responsibility to family caregivers in later stages. Despite the expressed wishes of people with dementia to discuss ACP within the family context, research on their specific needs and support within this context is limited. Web-based tools can address barriers to ACP, yet there is a notable gap in specific tools for people with dementia and their families. A comprehensive user-centred development approach is crucial to bridge this gap. Furthermore, the current landscape of web-based ACP support tools lacks comprehensive evaluation, hindering a deeper understanding of how people use them, their potential benefits, and their shortcomings. Traditional evaluation methods like interviews and surveys may have limitations in the evaluation of web-based tools. Leveraging web log data or digital traces for real-time assessment can provide more accurate insights into user behaviour and guide improvements, an approach underutilised in medical social sciences.

## **RESEARCH AIMS**

The primary objective of this dissertation was to develop and evaluate a website designed to support people with dementia and their family caregivers in advance care planning (ACP). This overarching aim is delineated into two principal aims, each incorporating three specific objectives.

The first aim revolved around informing the development of a website to support ACP in the family context in dementia. This included identifying existing web-based ACP support tools, assessing their content characteristics, readability, and quality, and studying if and how they were evaluated. Additionally, it includes defining the website's content and assessing the barriers and facilitators in using and finding such a website. The third objective was to develop a card tool that initiates and supports ACP conversations. The results of these first three objectives were crucial inputs in the subsequent development of the website using a user-centred approach.

The second aim focussed on evaluating the ACP support website with people with dementia and their family caregivers. This involved describing the study protocol and second, evaluating the usability, acceptability, and feasibility of the website, the experiences of people with dementia and their family caregivers with the website and assessing the impact of the website on ACP readiness, knowledge, self-efficacy, skills, and perceived barriers to initiating ACP. The third objective of the second aim was to explore to what extent and how the website was used by people with dementia and their family caregivers in the evaluation study, identifying user behaviour clusters and visualising the navigation patterns of these clusters.

## **METHODS**

To address aim 1, we employed multiple methodologies. Firstly, we conducted a systematic review of grey literature to identify and evaluate existing web-based ACP support tools. This involved four search strategies, including exploration of online grey literature databases, app stores, search engines, and expert consultations. The content, functionalities and accessibility of the identified ACP support tools were evaluated. Moreover, the readability assessment utilised the Flesch-Kincaid Grade Level and Common European Framework of Reference for Languages (CEFR) levels. The Quality Evaluation Scoring Tool (QUEST) was employed to gauge the quality of identified ACP tools. In addition, we explored how ACP tools had been evaluated in both grey literature databases and primary studies. Second, we conducted a focus group study involving family caregivers and healthcare professionals to define the website's content and functionalities and assess the barriers and facilitators to finding and using such a website. Due to COVID-19 restrictions, focus groups were conducted online, with separate sessions for family caregivers and healthcare professionals of people with dementia. We used a semi-structured topic guide to direct the discussions. Data analysis in Nvivo followed a framework analysis approach, which included data familiarisation, thematic framework development, indexing of study data based on this framework, data summarisation through charting, and final mapping and interpretation. Third, we performed a thorough, systematic, and collaborative cultural adaptation of a card game to initiate and support ACP discussions to identify values and preferences regarding end-of-life issues, which involved diverse community stakeholders and potential end-users to develop. The original English Go-Wish card game served as the basis for the cultural adaptation, and subsequently, the cards were digitised for integration into the ACP website. After, the website was developed using an evidence- and theory-based, iterative, user-centred approach involving people with dementia, family caregivers, healthcare professionals, researchers, and representatives of Flemish dementia organisations.

To achieve the second aim, which focused on assessing the website's usage, usability, acceptability, and feasibility (uptake) and understanding the experiences of people with dementia and their family caregivers using the website and its effects, we conducted an eight-week evaluation study. This study employed a convergent parallel mixed methods pretest-post-test design. Web log data or digital traces of in-the-moment usage were collected throughout the eight-week study period. Participants were shown in-the-moment pop-up questions while using the website, enabling real-time evaluations. The study involved people with mild to moderate dementia (both early and late onset) and their family caregivers, either as dyads or the family caregiver alone. Interviews and surveys were conducted at the beginning of the 8-week intervention period (baseline at T0) and after the intervention period (follow-up at T1). All interviews were transcribed and analysed in Nvivo using thematic framework analysis. Descriptive statistics were applied to quantitative data (surveys) and analysed using SPSS. The responses to pop-up questions were examined using RStudio. Second, during the evaluation study, log data was collected to analyse the usage patterns on the ACP support website. The log data was analysed in RStudio. Usage patterns, including time spent and pages visited, were summarised. K-means clustering was applied to identify user behavioural clusters. Afterwards, AI-driven process mining was used to explore user pathways.

## **FINDINGS**

In Chapter 1, the primary focus was identifying existing web-based advance care planning (ACP) support tools to describe content characteristics, readability, and quality and explore whether and how they are evaluated. This review initially identified 436 tools, narrowed to 30 for in-depth analysis after a thorough screening process. Most tools aimed to support reflection, communication, or decision-making, with only a tiny percentage aiming to achieve all three. All tools, except for one, followed predetermined steps in the tool to support ACP, meaning that users first had to go through the pages of information before going to reflection and communication, followed by documentation. The involvement of healthcare professionals and end-users in the development varied. Only five out of the 30 tools had undergone evaluation in peer-reviewed literature, highlighting a gap in systematic assessment.

Recognising the importance of addressing the needs and preferences of people with dementia and their families, Chapter 2 explored the content, functionalities, and perceived

barriers and facilitators of the website to support ACP in dementia. This involved conducting focus groups with 18 family caregivers of people with dementia and 17 healthcare professionals from diverse backgrounds. Two primary content needs for the website emerged: comprehensive and realistic ACP information and practical guidance for initiating conversations about ACP. Participants recommended presenting ACP as a flexible process as people may have different needs and readiness. Moreover, participants expressed the need for features like FAQs, a glossary of important terms, and peer testimonials. They also discussed enhancing usability with clear navigation, print option, text-to-speech option, and adjustable font sizes.

In Chapter 3, we culturally adapted the Go Wish Cards, previously identified in Chapter 1 as the only tool to support ACP without a predefined path. These cards aim to facilitate conversations on values and preferences regarding end-of-life matters. The adaptation process involved a systematic five-step approach with input from various stakeholders. Beginning with translating 36 cards (Step 1) from the original U.S. version into Flemish, a reference group, including palliative care and patient support representatives, provided feedback in Step 2, leading to cultural adjustments. Additional cards addressing the legal framework in Belgium were introduced, and in consensus with the reference group, the cards were named ‘Levenswensen kaarten’ (Life Wishes cards). Step 3 involved evaluation by healthcare professionals, followed by a content validity index assessment in Step 4. In Step 5, various possible end-users used the cards and found them user-friendly and helpful in discussing end-of-life wishes. During the iterative development of the website, the paper-based cards were digitised with the input from people living with dementia, their families, healthcare professionals, and dementia organisations. The digital interface mirrors the paper-based version, featuring distinct fields for users to drag and drop cards, creating an interactive sorting process.

The results of these first three chapters informed the development of the website to support ACP. Chapter 4 provided a comprehensive overview of the website's content and functionalities. The website included sections on ACP information, legal frameworks, and guidance for initiating ACP discussions. It featured two interactive communication tools: 1) the digital version of Levenswensen cards and 2) a fill-in tool with open-ended questions about “*what matters most to you*”. Accessibility features included text size adjustments, colour contrast choices, speech-to-text, and printing options. Moreover, Chapter 4 described the study protocol for the evaluation study. The evaluation study employed a convergent

parallel mixed-method pretest-post-test design over 8 weeks, combining quantitative and qualitative data collection methods. The evaluation study involved people with mild to moderate dementia and their family caregivers. Data collection methods included interviews, surveys, log data registration, and ecological momentary assessments. Baseline pre-test data (T0) and post-test data (T1) were collected, assessing usability, acceptability, feasibility, and outcomes related to ACP readiness, knowledge, attitudes, perceived barriers, self-efficacy, and skills.

In Chapter 5, the evaluation study results were presented. Fifty-two participants, including 21 people with dementia and 31 family caregivers, participated. Overall, participants found the website helpful to support ACP and user-friendly, praising its accessibility features. In a usability survey, family caregivers rated the website's ease of use higher than people with dementia, who expressed a need for support. While participants appreciated the website's structure, navigability, and accessibility, some suggested modernising its design in the post evaluation interviews.

Participants in the evaluation study indicated an increased preference to discuss future care in the ACP readiness survey after the study. In interviews, people with dementia and their families demonstrated improved ACP knowledge after the 8-week study period. Attitudes toward the website and ACP remained positive during the study, with participants expressing a greater desire to discuss preferences for future care (n=26 before, n=36 after). However, certain family caregivers who used the website alone expressed the sentiment that it was too late for them to initiate ACP conversations with the person with dementia, indicating the importance of early access. All participants indicated that they would recommend the website, and those who initiated ACP during the study period expressed a desire to continue.

Chapter 6 aimed to assess the website's usage by people with dementia and family caregivers who participated in the evaluation study, identify user behaviour clusters, and visualise the navigation. On average, users had 58 interactions and spent 35.3 minutes on the site. The top three visited pages included 'Advance Care Planning: What Is It?' (n=409), 'The Glossary' (n=361) and 'Advance Care Planning: Thinking and Talking About Later' (n=277). Three user engagement clusters were identified: low engagement (5 users), moderate engagement (with 15 users), and high engagement (11 users). In general, users typically started one of the informative pages and then explored additional information pages or used the interactive communication tools afterwards. The behaviour clusters illustrated

that participants with moderate engagement frequently transitioned between pages, although less frequently than those with high engagement. High-engagement participants explored various pages, navigating extensively between pages. Conversely, low-engagement participants demonstrated a more linear and direct browsing style, rarely revisiting prior web pages during navigation.

The findings from Chapters 5 and 6 informed refinements to the website. Adjustments were discussed with representatives from Flemish dementia organisations and a multidisciplinary group of researchers.

## **GENERAL DISCUSSION**

Our research found that existing advance care planning (ACP) web-based tools favour a linear, step-by-step approach. However, insights from the focus group study and user interactions with the website suggest that a one-size-fits-all model may only suit some. Most people with dementia and their families who used the website to support ACP had nonlinear usage patterns, navigating back and forth between pages of the website. Hence, to better support the diverse needs of people with dementia and their families, adopting a flexible and process-oriented approach to ACP is recommended. This approach empowers them to selectively engage with topics aligned with their current readiness, postponing discussions on aspects they may not be prepared to address. It allows for a personalised ACP experience, where people with dementia and their families can start the ACP process as they wish and explore topics at their own pace. Some may prioritise advance directives initially, while others may focus on current care preferences before addressing future considerations. This adaptable approach aims to overcome significant barriers, such as the fear of discussing end-of-life decisions.

Moreover, given the growing body of evidence indicating that people with dementia and their families want to discuss ACP in the family context and think ACP should focus more on non-medical aspects, the website to support ACP was developed to address these needs. These expressed needs align with the public health approach to ACP, emphasising the importance of normalising conversations about death and dying and a need for focussing on social aspects and ‘what matters most’ in ACP. The website includes interactive communication tools, comprising digital Levenswensen cards and an interactive writing tool, to support these conversations. In the evaluation study, participants noted that these tools facilitated discussions about ACP and end-of-life values. Particularly, the Levenswensen cards,

adapted from the Go Wish card game, were mentioned by people with dementia and their families to support the initiation of conversations. The preformulated statements on social aspects provided comfort and aided reflection, emphasising the value of these tools in fostering discussions about ACP.

Further, while the website supports ACP in the family context, it is crucial to recognise its complementary role to ACP with healthcare professionals. Healthcare professionals play a crucial role in ACP, but family conversations about values and preferences are underestimated facilitators in ACP. These conversations between family and friends may empower people with dementia to express their wishes, aiding informed (shared) decision-making. Aligning ACP conversations in the family context and ACP with the healthcare professional can support personalised care, as care and treatment decisions are based on considerations about values. Additionally, family caregivers stressed the importance of initiating ACP early in the disease trajectory, as some family caregivers expressed challenges in initiating ACP discussions due to the moderate stage of dementia.

Additionally, family caregivers of people with dementia and healthcare professionals in the focus groups considered the website as an additional asset to the existing ACP landscape in Flanders. After using the website, people with dementia and their families in the evaluation study expressed that it was a valuable source to learn more about ACP. To increase awareness of its existence and emphasise its potential value, collaborative efforts with dementia organisations in Flanders have been made throughout the studies to facilitate integration into the Flemish dementia landscape. Proactively involving healthcare professionals in the development process was crucial to align the website with ACP practices. Following the guidance of the Medical Research Council for complex interventions, this collaborative effort tailored the website to meet healthcare professionals' practice, ensuring its usability and clinical relevance. For example, the website can support ACP in the medical context by aiding patients in preparing for ACP conversations with healthcare professionals. This preparation can help people with dementia and their families better understand ACP, their values, and potential preferences for future care and treatment.

Nevertheless, while the website could be valuable in supporting ACP, digital exclusion is an important consideration. Technology and digital participation have been shown to enhance social connection and quality of life, but addressing potential barriers related to age, cognitive abilities, and familiarity with technology is crucial. The evaluation study highlighted these



challenges faced by participants with lower digital literacy levels, especially in people with more moderate dementia. To maximise the website's accessibility, a user-centered approach was adopted during development, involving people with dementia and their families in co-creation. Iterative evaluations, adaptations, and adding features like text-to-speech and contrast options to enhance accessibility and usability. Despite these efforts, our evaluation study revealed that family caregivers of the dyads mostly used the website alone, and sometimes, later involving the person with dementia. Notably, a small fraction of people with dementia used the website independently, with reasons attributed to a lack of interest in ACP or established habits of shared activities with the family caregiver.

Literature on factors influencing technology adoption in dementia highlights that family caregivers' characteristics, such as motivation, training, and digital literacy, notably facilitated or hindered technology uptake in dementia. While involving family caregivers in the adoption strategy proves beneficial, it is crucial to recognise the diversity of support structures for people with dementia. Some lack family caregivers, and overreliance on family caregivers may inadvertently discourage independent usage, potentially compromising the autonomy of the person with dementia. Striking a balance between family caregiver involvement and encouraging self-initiative is essential to creating an inclusive environment and empowering people with dementia to embrace – if they want – technology at their own pace.

Lastly, we perceived challenges in recruiting and involving people with dementia. Our evaluation study faced difficulties in recruiting people with dementia and their families, taking nine months to recruit 52 participants and similar difficulties were experienced in the development phase. Factors that may contributed to the recruitment challenges included the topic, e.g. ACP, the online nature of the support, and the limited engagement of people in early-stage dementia with specialised care, our primary recruitment channel. Though literature highlights a positive attitude among people with dementia and their families to be participants in research, it is hindered by a lack of awareness of these opportunities. These recruitment challenges raise concerns about generalising and applying findings to diverse social groups. Finally, in our evaluation study, cognitive decline impacted participation, with two people with dementia unable to participate in follow-up due to decline and others withdrawing based on their reluctance to discuss ACP. Fluctuations of willingness to participate among people with dementia, even over short periods, poses inherent complexities. Ethical concerns around including 'vulnerable' populations in research, particularly palliative care, have been acknowledged. Despite adapted informed consent

procedures, fluctuating capacity remains a challenge. A person-oriented approach involving adaptable data collection strategies, such as self-assessment tools or modified interview techniques, can enhance inclusivity while upholding ethical standards.

## **RECOMMENDATIONS FOR PRACTICE, POLICY AND RESEARCH**

Drawing insights from people with dementia, caregivers, healthcare professionals, and researchers, the recommendations aim to enhance the practical use of the advance care planning (ACP) support website and improve ACP.

### **A. Recommendations for Practice:**

- An ACP support website can optimally benefit people with dementia and their families if people are referred to it by healthcare professionals or dementia organisations.
- ACP should be introduced early in the dementia process and be tailored to the readiness of the person with dementia and their family caregivers.
- The healthcare professional should provide information about dementia to facilitate the ACP process.
- Because of the important role of the family caregiver in supporting the person with dementia, she or he should receive support in using the website, taking into account the autonomy of the person with dementia.

### **B. Recommendations for Policy:**

- Develop a comprehensive accessible online overview of evidence-based supportive tools for people with dementia, their family carers, and healthcare professionals.
- Create a platform collaboratively with dementia organisations, healthcare professionals and researchers to facilitate research participation, enhancing accessibility for people with dementia and their families.
- When providing information about ACP make sure it covers all aspects of ACP.

### **C. Recommendations for Research:**

- Adopt a flexible, person-centred approach in research protocols that recognises the evolving nature of cognitive capacity and changes in informed consent.
- Prioritise diversity among study participants by actively seeking participants from various cultural backgrounds, gender, living environments (urban and rural), and different types of dementia.

- Starting at the beginning of their research activities, researchers should proactively consider longevity, sustainability, and implementation of developments and engage relevant stakeholders to maximise real-world impact.
- Robust longitudinal studies should rigorously explore ACP within dementia and assess the impact of web-based support tools in family contexts.

## NEDERLANDSE SAMENVATTING

### ONDERSTEUNING VAN MENSEN MET DEMENTIE EN HUN FAMILIE BIJ VROEGTIJDIGE OF VOORAFGAANDE ZORGPLANNING: INNOVATIEF GEBRUIK VAN TECHNOLOGIE

#### INLEIDING

Dementie is een syndroom gekenmerkt door progressieve cognitieve achteruitgang en heeft impact op het geheugen, oriëntatie in tijd, concentratie en sociale vaardigheden. Naar verwachting zal dementie uitgroeien tot de grootste volksziekte, met een verwachte toename van het aantal gevallen en maatschappelijke kosten. De ziekte van Alzheimer is de meest bekende vorm van dementie, maar er zijn ook andere vormen, zoals vasculaire dementie of Lewy body dementie. Factoren die bijdragen aan het risico op dementie zijn leeftijd, genetica en keuzes in levensstijl. Op dit moment is er geen genezing mogelijk, maar er zijn wel behandelingen die kunnen helpen om de symptomen te beheersen en te vertragen. Hoewel dementie een progressieve en levensverkortende ziekte is, sterft niet elk persoon met dementie aan de gevolgen van de ziekte. Het voorspellen van het verloop van dementie is moeilijk. De mediane overlevingsperiode na de diagnose varieert van één tot twaalf jaar. Vanwege de onvoorspelbare maar progressieve aard van dementie is palliatieve zorg aangewezen voor personen met dementie. Palliatieve zorg is multidimensionale zorg die zich richt op kwaliteit van leven, het verbeteren van het comfort, het omgaan met symptomen en tegemoet komt aan de uiteenlopende behoeften van mensen met dementie en hun familie. Tijdige en adequate palliatieve zorg kan de levenskwaliteit van mensen met dementie positief beïnvloeden, de last van symptomen verlichten, het comfort bevorderen en cruciale steun bieden aan familieleden. Om tijdige toegang tot palliatieve zorg mogelijk te maken, komt vroegtijdige of voorafgaande zorgplanning naar voren als een cruciaal hulpmiddel.

#### *Vroegtijdige of voorafgaande zorgplanning bij dementie*

Vroegtijdige of voorafgaande zorgplanning (VZP), zoals gedefinieerd in 2017 door de European Association for Palliative Care, is een communicatieproces dat *“individuen in staat stelt om hun waarden te identificeren, na te denken over de gevolgen van ernstige ziektescenario's, doelen en voorkeuren vast te stellen voor toekomstige medische behandeling, en in gesprek te gaan met familie en zorgprofessionals”*.

VZP werd voor het eerst genoemd rond 1969 en richtte zich voornamelijk op het reguleren van behandelingen aan het einde van het leven via ‘advance directives’ of wilsverklaringen.

Echter, de beperkte impact van wilsverklaringen op de besluitvorming aan het einde van het leven en de kwaliteit van de zorg leidde tot een verschuiving naar VZP als een continu communicatieproces. Deze benadering onderstreept het belang van voortdurende gesprekken tussen de patiënt, familie en zorgprofessional. Een systematische review van publieke kennis over VZP onthulde echter wijdverbreide misvattingen over het doel en de mogelijke voordelen van VZP. Ondanks deze beperkte kennis, zien we dat patiënten en hun familie onderwerpen gerelateerd aan VZP, zoals mogelijke toekomstige zorg, samen, thuis, bespreken. Dit benadrukt dat VZP verder gaat dan de medische context, een idee dat ook wordt erkend door de volksgezondheid of gezondheidsbevorderende benaderingen van palliatieve zorg en VZP.

Voorstanders van een VZP-volksgezondheidsbenadering benadrukken de noodzaak om gesprekken over voorkeuren aan het einde van het leven, de dood, en sterven te normaliseren. Binnen deze nieuwe benadering kunnen VZP-gesprekken beginnen in de familiecontext, en zou er meer nadruk moeten liggen op sociale aspecten in plaats van enkel op de besluitvorming aan het einde van het leven. Deze bepleite verschuiving komt overeen met de behoeften van mensen met dementie en hun families. Zij geven aan dat de nadruk van VZP zou moeten liggen op *‘wat nu en in de toekomst belangrijk is’* en niet-medische aspecten van zorg. Het is cruciaal om te benadrukken dat, vanuit ons perspectief, de volksgezondheidsbenadering van VZP geen kwestie is van het kiezen tussen *‘VZP binnen de medische context’* en *‘VZP in de familiecontext’*, maar eerder hun complementariteit erkent.

Bij dementie onderstreept het variabele tempo van cognitieve achteruitgang de noodzaak van vroegtijdige discussies over toekomstige zorg, behandeling en voorkeuren voor het levenseinde. Naarmate dementie vordert, kunnen mensen met dementie de capaciteit om besluiten te nemen verliezen, waardoor hun familie cruciale besluitvormende rollen op zich zal nemen. Ondanks het erkende belang van VZP in dementie, blijft het aantal mensen waarbij VZP wordt opgestart laag. Talrijke barrières voor VZP bij dementie zijn geïdentificeerd, waaronder beperkte kennis over VZP en moeilijkheden van het bespreekbaar maken van het levenseinde. Gesprekken thuis en kennis uit levenslange conversaties komen naar voren als onderschatte maar waardevolle facilitatoren in VZP.

*Het gebruik van online tools ter ondersteuning van VZP bij dementie*

Interactieve online tools, zoals websites of apps, worden aangedragen om VZP binnen de familiecontext te ondersteunen. Deze tools bieden flexibiliteit omdat ze op elk moment en op elke locatie gebruikt kunnen worden, en hun inhoud kan worden aangepast aan de specifieke behoeften van gebruikers. Er zijn verschillende websites en applicaties ontwikkeld om VZP te ondersteunen. Echter, geen van de bestaande hulpmiddelen is ontwikkeld voor mensen met dementie en hun familie.

Recent onderzoek toonde aan dat het gebruik van online tools bij dementie de gezondheid kan verbeteren door het ziekteverloop te monitoren, medicijnen op maat aan te bieden en sociale en vrijetijdsactiviteiten te ondersteunen. Bovendien kunnen ze communicatief ondersteunen en gesprekken op gang brengen door te dienen als ‘ijsbrekers’. Het gebruik van online tools door mensen met dementie is echter een uitdaging vanwege de lage digitale geletterdheid binnen deze groep of door een te late introductie in het ziekteproces. Om het gebruik van online tools te bevorderen, dienen dergelijke tools afgestemd te worden op de behoeften van mensen met dementie en hun familie. Het betrekken van mensen met dementie en hun naasten bij de ontwikkeling van deze tools kan leiden tot een betere afstemming van de tools op hun behoeften en voorkeuren, wat op zijn beurt de ontwikkeling van zinvolle en geschikte tools kan ondersteunen. Niettemin wordt deze benadering nog maar weinig toegepast.

#### *Hiaten in onderzoek naar VZP-ondersteunende tools in dementie*

Mensen met dementie en hun familie worden geconfronteerd met unieke uitdagingen in VZP als gevolg van cognitieve achteruitgang en de graduele verschuiving van de besluitvormingsverantwoordelijkheid naar familieleden van personen met dementie. Ondanks de uitgesproken wens van mensen met dementie om VZP binnen de familiecontext te bespreken, is onderzoek naar hun specifieke behoeften en ondersteuning binnen deze context beperkt. Online tools lijken ondersteuning te bieden in VZP, maar er is een opvallend gebrek aan specifieke hulpmiddelen voor mensen met dementie en hun familie. Een uitgebreide gebruikersgerichte ontwikkeling is cruciaal om deze kloof te overbruggen. Daarnaast ontbreekt grondige evaluatie in het huidige landschap van online tools ter ondersteuning van VZP, wat een dieper inzicht in het gebruik van deze tools, de mogelijke voordelen en tekortkomingen ervan belemmert. Traditionele evaluatiemethoden zoals interviews en vragenlijsten kunnen beperkingen hebben bij deze evaluatie van online tools. Het gebruik van weblog data of digitale sporen van gebruik van online tools voor real-time evaluatie kan preciezere inzichten bieden in het gedrag van gebruikers en gerichte

verbeteringen aansturen, een aanpak die in de medische sociale wetenschappen onderbenut blijft.

## **ONDERZOEKSDOELEN**

Het hoofddoel van dit proefschrift was de ontwikkeling en evaluatie van een website die bedoeld is ter ondersteuning van mensen met dementie en hun familie bij vroegtijdige of voorafgaande zorgplanning (VZP). Dit hoofddoel is opgesplitst in twee doelen, elk met drie specifieke doelstellingen.

Het eerste doel is gericht op het identificeren van de content en het ontwikkelen van een website ter ondersteuning van VZP bij dementie. Eerst werden bestaande online tools voor VZP geïdentificeerd en geëvalueerd op hun informatie over VZP, leesbaarheid en kwaliteit. De tweede doelstelling was het definiëren van de content van de website en het identificeren van de barrières en facilitators voor het gebruik en vinden ervan. De derde doelstelling omvatte de ontwikkeling van een kaartenspel dat VZP-gesprekken kan ondersteunen. De resultaten van deze eerste drie doelstellingen dienden als cruciale input voor de verdere ontwikkeling van de website, waarbij nauw werd samengewerkt met personen met dementie en hun familie.

Het tweede doel was gericht op het evalueren van de website met personen met dementie en hun familie. Het opstellen van een studieprotocol, als eerste doelstelling van het tweede doel, omvatte het beoordelen van de bruikbaarheid, acceptabiliteit en haalbaarheid van de website. Het betrof tevens het verkrijgen van inzichten in de ervaringen van mensen met dementie en hun familie met de website, en het beoordelen van de impact van de website op VZP-bereidheid (in het Engels *readiness*), kennis, zelfeffectiviteit, vaardigheden en waargenomen barrières voor het initiëren van VZP. De derde doelstelling van het eerste doel betrof het onderzoeken van het gebruik van de website door mensen met dementie en hun familie in de evaluatiestudie. Hierbij stond het identificeren van gedragsclusters en het visualiseren van gebruikerspaden in deze gedragsclusters centraal.

## **METHODEN**

Om doel één te adresseren, hebben we verschillende methodologieën toegepast. Als eerste hebben we een systematische review van grijze literatuur uitgevoerd om bestaande online vroegtijdige of voorafgaande zorgplanning (VZP) support tools te identificeren en te evalueren. Hierbij werden vier zoekstrategieën toegepast, waaronder het verkennen van

online grijze literatuurdatabases, app stores, zoekmachines en consulteren van experts. De inhoud, functionaliteiten en toegankelijkheid van de geïdentificeerde tools werden geëvalueerd. Voor het evalueren van de leesbaarheid maakten we gebruik van de Flesch-Kincaid Grade Level en het Common European Framework of Reference for Languages (CEFR) niveaus. De Quality Evaluation Scoring Tool (QUEST) werd ingezet om de kwaliteit van geïdentificeerde tools te evalueren. Daarnaast hebben we mogelijke evaluaties van de tools geïdentificeerd in zowel grijze literatuurdatabases als peer-reviewed studies. Tevens, hebben we een focusgroepstudie uitgevoerd met mantelzorgers en zorgprofessionals om de inhoud en functionaliteiten van de website te definiëren en de barrières en faciliterende factoren voor het vinden en gebruiken van de website te beoordelen. Vanwege beperkingen door COVID-19 werden de focusgroepen online gehouden, met afzonderlijke sessies voor mantelzorgers en zorgprofessionals. De focusgroepen maakten gebruik van een semigestructureerd topic guide om de discussies te ondersteunen. De data-analyse volgde een thematic framework analysis, bestaande uit data familiarisatie, ontwikkeling van thematisch kader, indexering van studiegegevens op basis van dit kader, data samenvatting via overzichtstabellen, en uiteindelijke mapping en interpretatie. Ten derde hebben we, om het kaartenspel te ontwikkelen dat VZP-gesprekken kan ondersteunen, een grondige en systematische culturele aanpassing uitgevoerd met diverse stakeholders en potentiële eindgebruikers. Het oorspronkelijke Engelstalige Go-Wish kaartenspel diende als basis voor de culturele aanpassing. Na de culturele aanpassing, werden de kaarten gedigitaliseerd voor integratie in de website.

Om doel twee te bereiken (evalueren van de bruikbaarheid, acceptatie en haalbaarheid van de website en evalueren van de ervaringen van personen met dementie en hun mantelzorgers met het gebruik van de website en de effecten), hebben we een evaluatiestudie van acht weken uitgevoerd. Deze studie maakte gebruik van een convergent parallel design met zowel kwantitatieve en kwalitatieve onderzoeksmethoden. Gedurende de acht weken werden web log data of digitale sporen van het gebruik van de website verzameld. Deelnemers kregen in-the-moment pop-up vragen te zien tijdens het gebruik van de website, waardoor real-time evaluatie mogelijk was. De studie omvatte mensen met milde tot matige dementie en hun mantelzorgers, als dyaden of alleen de mantelzorger. Interviews en enquêtes werden uitgevoerd aan het begin van de 8 weken (baseline op T0) en na de interventieperiode (follow-up op T1). Alle interviews werden getranscribeerd en geanalyseerd met behulp van thematische framework-analyse. Beschrijvende statistieken werden toegepast op kwantitatieve gegevens (enquêtes) en geanalyseerd met behulp van SPSS. De antwoorden



op pop-up vragen werden geanalyseerd met behulp van RStudio. Ten tweede werd tijdens de evaluatiestudie log data verzameld om de gebruikspatronen op de website te analyseren. De log data werden geanalyseerd in RStudio. Gebruikspatronen, inclusief de tijd besteed op de website en bezochte pagina's, werden samengevat. K-means clustering werd toegepast om gedragsclusters te identificeren. Vervolgens werd AI-gestuurde proces mining gebruikt om gebruikerspaden te verkennen.

## **BELANGRIJKSTE BEVINDINGEN**

In hoofdstuk 1 was de primaire focus het identificeren van bestaande online tools hun om informatie, leesbaarheid en kwaliteit te evalueren en te onderzoeken of en hoe ze worden geëvalueerd. In eerste instantie werden 436 tools geïdentificeerd, die na een grondige screening werden teruggebracht tot 30 tools voor diepgaande analyse. De meeste tools waren gericht op het ondersteunen van reflectie, communicatie of besluitvorming, waarbij slechts een klein percentage alle drie de doelstellingen nastreefde. Alle hulpmiddelen, op één na, volgden vooraf bepaalde stappen om vroegtijdige of voorafgaande zorgplanning (VZP) te ondersteunen, wat betekende dat gebruikers eerst de pagina's met informatie moesten doorlopen voordat ze naar reflectie en communicatie gingen, gevolgd door documentatie. De betrokkenheid van zorgverleners en eindgebruikers in de ontwikkeling varieerde. Slechts vijf van de 30 tools waren geëvalueerd in peer-reviewed literatuur, wat wijst op een leemte in systematische beoordeling.

In hoofdstuk 2 werd onderzocht hoe belangrijk het is om tegemoet te komen aan de VZP behoeften en voorkeuren van mensen met dementie en hun naasten, en werden de inhoud, functionaliteiten, barrières en faciliterende factoren van de website ter ondersteuning van VZP onderzocht. Hiervoor werden focusgroepen gehouden met 18 familieleden van mensen met dementie en 17 zorgprofessionals met verschillende achtergronden. Er kwamen twee primaire inhoudelijke behoeften voor de website naar voren: uitgebreide en realistische informatie over VZP en praktische ondersteuning voor het starten van gesprekken over VZP. Deelnemers raadden aan om VZP te presenteren als een flexibel proces omdat mensen verschillende behoeften kunnen hebben. Bovendien gaven deelnemers aan behoefte te hebben aan secties met veel gestelde vragen, een verklarende woordenlijst en getuigenissen van lotgenoten. De deelnemers bespraken ook het verbeteren van de gebruiksvriendelijkheid met duidelijke navigatie, print en tekst-naar-spraak opties en aanpasbare lettergroottes.

In hoofdstuk 3 hebben we de Go Wish Cards, die eerder in hoofdstuk 1 werden geïdentificeerd als de enige tool zonder een vooraf gedefinieerd pad, cultureel aangepast. Deze kaarten zijn bedoeld om discussies over waarden en voorkeuren met betrekking tot het levenseinde te vergemakkelijken. Het aanpassingsproces omvatte een systematische aanpak in vijf stappen met input van verschillende belanghebbenden. Na het vertalen van 36 kaarten van de originele Amerikaanse versie naar het Nederlands voor gebruik in Vlaanderen (Stap 1), gaf een referentiegroep, bestaande uit vertegenwoordigers van palliatieve zorg, verschillende patiënten populaties, afgevaardigden het Christendom, Islam, Jodendom en mensen met structurele moeilijkheden, feedback in Stap 2, wat leidde tot culturele aanpassingen. Er werden extra kaarten geïntroduceerd die betrekking hadden op het wettelijke kader in België en in consensus met de referentiegroep kregen de kaarten de naam 'Levenswensen'. Stap 3 bestond uit evaluatie door zorgverleners, gevolgd door een beoordeling van de inhoudsvaliditeitsindex in Stap 4. In Stap 5 werden verschillende mogelijke eindgebruikers geëvalueerd. In stap 5, gebruikten mogelijke eindgebruikers de kaarten. Zij vonden de kaarten gebruiksvriendelijk en behulpzaam bij het bespreken van wensen rond het levenseinde. Tijdens de iteratieve ontwikkeling van de website werden de papieren kaarten gedigitaliseerd in samenwerking met mensen met dementie, hun familie, zorgverleners en vertegenwoordigers van dementieorganisaties. De digitale interface is een afspiegeling van de papieren versie, met verschillende velden waarin gebruikers kaarten kunnen slepen en neerzetten, waardoor een interactief sorteerproces ontstaat.

De resultaten van deze eerste drie hoofdstukken vormden de basis voor de ontwikkeling van de website ter ondersteuning van VZP. Hoofdstuk 4 geeft een uitgebreid overzicht van de inhoud en functionaliteiten van de website. De website bevat secties met VZP informatie, wettelijke kaders en richtlijnen voor het starten van VZP-gesprekken. Er zijn twee interactieve communicatiemiddelen: 1) de digitale versie van Levenswensenkaarten en 2) een invultool met open vragen over 'wat voor jou het belangrijkst is'. Daarnaast zijn er toegankelijkheidsfuncties waarbij de tekstgrootte en het contrast kunnen worden aangepast, maar ook een spraak-naar-tekst- en printoptie. Hoofdstuk 4 beschrijft bovendien het studieprotocol voor het evaluatieonderzoek. Het evaluatieonderzoek van 8 weken maakte gebruik van een convergent parallel mixed-method pretest-post-test design, waarbij kwantitatieve en kwalitatieve gegevensverzamelingsmethoden werden gecombineerd. De evaluatiestudie includeerde mensen met lichte tot matige dementie en hun mantelzorgers. De methoden voor gegevensverzameling bestonden uit interviews, enquêtes, registratie van loggegevens en in-het-moment vragen. Er werden baseline pre-testgegevens (T0) en post-

testgegevens (T1) verzameld, waarbij de bruikbaarheid, aanvaardbaarheid, haalbaarheid en uitkomsten met betrekking tot de bereidheid tot VZP, kennis, attitudes, waargenomen barrières, zelfeffectiviteit en vaardigheden werden geëvalueerd.

In hoofdstuk 5 werden de resultaten van het evaluatieonderzoek gepresenteerd. 52 deelnemers, waaronder 21 mensen met dementie en 31 mantelzorgers, namen deel. Over het algemeen vonden de deelnemers de website nuttig om VZP te ondersteunen, gebruiksvriendelijk, en ze prezen de toegankelijkheidsfuncties. In een bruikbaarheidsonderzoek beoordeelden mantelzorgers het gebruiksgemak van de website hoger dan mensen met dementie, die aangaven behoefte te hebben aan ondersteuning bij het gebruik van de website. Hoewel de deelnemers de structuur, navigeerbaarheid en toegankelijkheid van de website waardeerden, stelden sommige jongere deelnemers in de interviews na de evaluatie voor om het ontwerp te moderniseren.

Deelnemers van het evaluatieonderzoek gaven na de evaluatie studie in de VZP bereidheid vragenlijst aan dat ze een grotere voorkeur hadden om toekomstige zorg te bespreken. In interviews post evaluatie gaven mensen met dementie en hun familie aan een verbeterde VZP kennis te hebben. De houding ten opzichte van de website en VZP bleef positief tijdens het onderzoek, en deelnemers hadden een grotere wens om voorkeuren voor toekomstige zorg te bespreken (n=26 voor, n=36 na). Sommige mantelzorgers die de website alleen gebruikten, hadden echter het gevoel dat het starten van VZP-gesprekken met de persoon met dementie te laat kwam, wat wijst op het belang van vroegtijdige toegang tot de website. Alle deelnemers raadden de website aan, en degenen die VZP begonnen tijdens het onderzoek gaven aan hiermee door te willen gaan.

Hoofdstuk 6 had als doel het gebruik van de website door mensen met dementie en mantelzorgers die deelnamen aan het evaluatieonderzoek te beoordelen, clusters van gebruikersgedrag te identificeren en de navigatie te visualiseren. Gemiddeld hadden gebruikers 58 interacties met de website en brachten ze 35,3 minuten door op de site. De drie best bezochte pagina's waren 'VZP: Wat is het?' (n=409), 'woordenlijst' (n=361) en 'VZP: denken en praten over later' (n=277). Er werden drie clusters van gebruikersbetrokkenheid geïdentificeerd: lage betrokkenheid (5 gebruikers), gemiddelde betrokkenheid (met 15 gebruikers) en hoge betrokkenheid (11 gebruikers). Over het algemeen begonnen gebruikers met een van de informatieve pagina's en verkenden daarna aanvullende informatiepagina's of gebruikten de interactieve communicatiemiddelen. De gedragsclusters lieten zien dat

deelnemers met matige betrokkenheid vaak wisselden tussen pagina's, hoewel minder vaak dan degenen met hoge betrokkenheid. Deelnemers met een hoge betrokkenheid verkenden verschillende pagina's en navigeerden uitgebreid tussen pagina's. Omgekeerd vertoonden deelnemers met een lage betrokkenheid een meer lineaire en directe manier van browsen, waarbij ze tijdens het navigeren zelden eerdere webpagina's opnieuw bezochten.

De bevindingen uit hoofdstuk 5 en 6 vormden de basis voor aanpassingen aan de website. Aanpassingen werden besproken met vertegenwoordigers van Vlaamse dementieorganisaties en een multidisciplinaire groep onderzoekers.

## **ALGEMENE DISCUSSIE**

Uit ons onderzoek bleek dat bestaande online tools voor vroegtijdige of voorafgaande zorgplanning (VZP) de voorkeur geven aan een lineaire, stapsgewijze aanpak. Inzichten uit de focusgroepstudie en gebruikersinteracties met de website suggereren echter dat dit *one-size-fits-all* model alleen geschikt is voor sommigen. De meeste mensen met dementie en hun familie die de website gebruikten, hadden niet-lineaire gebruikspatronen, waarbij ze heen en weer navigeerden tussen pagina's van de website. Om beter tegemoet te komen aan de uiteenlopende behoeften van mensen met dementie en hun familie, wordt daarom een flexibele en procesgerichte benadering van VZP aanbevolen. Deze aanpak stelt hen in staat om zich selectief bezig te houden met onderwerpen die aansluiten bij hun huidige bereidheid, waarbij discussies over aspecten waar ze misschien niet klaar voor zijn, worden uitgesteld. Het maakt een gepersonaliseerde VZP-ervaring mogelijk, waarbij mensen met dementie en hun familie het VZP-proces kunnen starten zoals ze willen en onderwerpen in hun eigen tempo kunnen verkennen. Sommigen kunnen in eerste instantie prioriteit geven aan wilsverklaringen (in het Engels advance directives), terwijl anderen zich kunnen richten op de huidige zorgvoorkeuren voordat toekomstige overwegingen aan bod komen. Deze flexibele aanpak is erop gericht om belangrijke barrières te overwinnen, zoals de angst om beslissingen rond het levenseinde te bespreken.

Omdat er steeds meer bewijs is dat mensen met dementie en hun familie VZP willen bespreken in de familiale context en vinden dat VZP zich meer moet richten op niet-medische aspecten, werd de website ter ondersteuning van VZP ontwikkeld om aan deze behoeften tegemoet te komen. Deze geuite behoeften komen overeen met de volksgezondheidsbenadering (public health) van VZP, waarbij de nadruk ligt op het belang van het normaliseren van gesprekken over dood en sterven en de noodzaak om zich te

richten op sociale aspecten en ‘*wat belangrijk is, nu en in de toekomst*’ in VZP. De website bevat interactieve communicatiemiddelen, waaronder de digitale Levenswensenkaarten en een interactieve, invultool met open vragen, om deze gesprekken te ondersteunen. In het evaluatieonderzoek merkten deelnemers op dat deze hulpmiddelen gesprekken over VZP en waarden rond het levenseinde vergemakkelijkten. Met name de *Levenswensen* kaarten, aangepast van het Go Wish kaartspel, werden door mensen met dementie en hun familie genoemd als ondersteuning om gesprekken op gang te brengen. De vooraf geformuleerde uitspraken over sociale aspecten boden troost en hielpen reflectie, wat de waarde van deze hulpmiddelen voor het stimuleren van discussies over VZP benadrukt.

Hoewel de website VZP in de familiale context ondersteunt, is het van cruciaal belang om de onmiskenbare rol van zorgverleners in VZP te erkennen. Zorgprofessionals spelen een cruciale rol in VZP, maar gesprekken met familie over waarden en voorkeuren worden onderschat als facilitators in VZP. Deze gesprekken tussen familie en vrienden kunnen mensen met dementie in staat stellen om hun wensen kenbaar te maken, wat geïnformeerde (gedeelde) besluitvorming bevordert. Het afstemmen van VZP-gesprekken in de familiecontext en VZP met de zorgprofessional kan gepersonaliseerde zorg ondersteunen, doordat zorg- en behandelingsbeslissingen gebaseerd zijn op overwegingen over waarden. Daarnaast benadrukten mantelzorgers het belang van het vroeg in het ziekteverloop starten met VZP, aangezien sommige mantelzorgers aangaven problemen te hebben met het starten vanwege het matige stadium van dementie.

Bovendien beschouwden mantelzorgers van mensen met dementie en zorgverleners in de focusgroepen de website als een extra troef voor het bestaande VZP-landschap in Vlaanderen. Na het gebruik van de website gaven mensen met dementie en hun familie in het evaluatieonderzoek aan dat de website een waardevolle bron was om meer te weten te komen over VZP. Om meer bekendheid te geven aan het bestaan van de website en om de potentiële waarde ervan te benadrukken, werd tijdens de studies samengewerkt met dementieorganisaties in Vlaanderen om de website te integreren in het Vlaamse dementielandschap. Het proactief betrekken van zorgprofessionals bij het ontwikkelingsproces was cruciaal om de website af te stemmen op de huidige VZP praktijk. In navolging van de richtlijnen van de Medical Research Council voor complexe interventies, werd de website door deze samenwerking afgestemd op de praktijk van zorgverleners, waarbij de bruikbaarheid en klinische relevantie werden gegarandeerd. De website kan bijvoorbeeld VZP in de medische context ondersteunen door patiënten te helpen zich voor

te bereiden op gesprekken met zorgverleners. Deze voorbereiding kan mensen met dementie en hun familie helpen om VZP, hun waarden en mogelijke voorkeuren voor toekomstige zorg en behandeling beter te begrijpen.

Hoewel de website waardevol kan zijn voor de ondersteuning van VZP, is digitale uitsluiting toch een belangrijke overweging. Het is aangetoond dat technologie en digitale participatie de sociale verbondenheid en levenskwaliteit van personen met dementie verbeteren, maar het is van cruciaal belang om mogelijke barrières met betrekking tot leeftijd, cognitieve vaardigheden en vertrouwdheid met technologie te onderschrijven. Het evaluatieonderzoek benadrukte deze uitdagingen waarmee deelnemers met een lager niveau van digitale geletterdheid worden geconfronteerd, vooral bij mensen met een meer gevorderde vorm van dementie. Om de toegankelijkheid van de website te maximaliseren, werd tijdens de ontwikkeling gekozen voor een gebruikersgerichte aanpak, waarbij mensen met dementie en hun familie werden betrokken bij de co-creatie. Iteratieve evaluaties, aanpassingen en het toevoegen van functies zoals tekst-naar-spraak en contrastopties om de toegankelijkheid en bruikbaarheid te verbeteren. Ondanks deze inspanningen om cognitieve moeilijkheden te ondersteunen, toonde ons evaluatieonderzoek aan dat de mantelzorgers van de dyades de website meestal alleen gebruikten, en soms pas later met de persoon met dementie. Slechts een klein deel van de mensen met dementie gebruikte de website zelfstandig, met redenen die werden toegeschreven aan een gebrek aan interesse in VZP of gevestigde gewoonten dit soort activiteiten samen met de mantelzorger te doen.

In de literatuur over factoren die van invloed zijn op het gebruik van technologie bij dementie wordt benadrukt dat kenmerken van mantelzorgers, zoals motivatie, opleiding en digitale geletterdheid, het gebruik van technologie bij dementie vergemakkelijken of belemmeren. Hoewel het gunstig is om mantelzorgers te betrekken bij de adoptie van de technologie, is het cruciaal om de diversiteit aan ondersteuningsstructuren voor mensen met dementie te erkennen. Sommigen hebben geen mantelzorgers, en te veel vertrouwen op mantelzorgers kan onbedoeld zelfstandig gebruik ontmoedigen, waardoor de autonomie van de persoon met dementie in het gedrang kan komen. Het vinden van een balans tussen de betrokkenheid van mantelzorgers en het aanmoedigen van zelfinitiatief is essentieel om een inclusieve omgeving te creëren en mensen met dementie in staat te stellen om - als ze dat willen - technologie in hun eigen tempo te omarmen.

Tot slot, tijdens de studies werden uitdagingen bij het werven en betrekken van mensen met dementie geïdentificeerd. Onze evaluatiestudie ondervond moeilijkheden bij het rekruteren van mensen met dementie en hun familie. Het duurde negen maanden om 52 deelnemers te rekruteren en tijdens de ontwikkelingsfase van de website ondervonden we gelijkaardige moeilijkheden. Factoren die bijdroegen aan de wervingsproblemen waren onder andere het onderwerp VZP en het online karakter en de beperkte aanwezigheid van mensen met beginnende dementie bij gespecialiseerde dementie zorg, ons primaire wervingskanaal. Hoewel de literatuur wijst op een positieve houding onder mensen met dementie en hun familie om deel te nemen aan onderzoek, wordt dit belemmerd door een gebrek aan bewustzijn van deze mogelijkheden. Deze wervingsuitdagingen geven aanleiding tot bezorgdheid over het generaliseren en toepassen van bevindingen op diverse sociale groepen. Tot slot had cognitieve achteruitgang in onze evaluatiestudie invloed op de deelname, waarbij twee mensen met dementie niet konden deelnemen aan de follow-up als gevolg van achteruitgang en anderen zich terugtrokken op basis van hun terughoudendheid om VZP te bespreken. De fluctuerende aard van de bereidheid om deel te nemen onder mensen met dementie, zelfs over korte perioden, brengt inherente complicaties met zich mee. Ethische bezwaren rond het betrekken van 'kwetsbare' populaties in onderzoek, in het bijzonder palliatieve zorg, worden erkend. Ondanks aangepaste geïnformeerde toestemmingsprocedures blijft fluctuerende capaciteit een uitdaging. Een persoonsgerichte aanpak met aanpasbare strategieën voor gegevensverzameling, zoals zelfbeoordelingsinstrumenten of aangepaste interviewtechnieken, kan de inclusiviteit verbeteren en tegelijkertijd de ethische normen respecteren.

## **AANBEVELINGEN VOOR PRAKTIJK, BELEID EN ONDERZOEK**

De aanbevelingen in dit proefschrift zijn gebaseerd op inzichten van mensen met dementie, verzorgers, zorgverleners en onderzoekers en zijn bedoeld om het praktische gebruik van de website en vroegtijdige of voorafgaande zorgplanning (VZP) te verbeteren.

### **A. Aanbevelingen voor de praktijk:**

- Mensen met dementie en hun familie kunnen optimaal profiteren van een website ter ondersteuning van VZP als zij hiernaar worden verwezen door zorgverleners of dementieorganisaties.
- VZP moet vroeg in het dementieproces worden geïntroduceerd en moet worden afgestemd op de bereidheid van de persoon met dementie en de betrokken mantelzorgers.

- De zorgverlener moet informatie geven over dementie zelf om het VZP proces te ondersteunen.
- Door de belangrijke rol van de mantelzorger in het ondersteunen van de persoon met dementie, zou zij of hij ondersteuning bij het gebruik van de website moeten krijgen, rekening houdend met de autonomie van de persoon met dementie.

#### **B. Aanbevelingen voor beleid:**

- Ontwikkel een uitgebreid toegankelijk online overzicht van evidence-based ondersteunende hulpmiddelen voor mensen met dementie, hun mantelzorgers en zorgverleners.
- Dementieorganisaties, zorgverleners en onderzoekers zouden samen een platform moeten creëren om participatie aan onderzoek te vergemakkelijken, waardoor onderzoek toegankelijker wordt voor mensen met dementie en hun familieleden.
- Zorg ervoor dat bij het geven van informatie over VZP, alle aspecten van VZP aan bod komen.

#### **C. Aanbevelingen voor onderzoek:**

- Gebruik een flexibele, persoonsgerichte benadering in onderzoeksprotocollen die de veranderende aard van cognitieve capaciteit en veranderingen in geïnformeerde toestemming erkent.
- Geef prioriteit aan diversiteit onder studiedeelnemers door actief te zoeken naar vertegenwoordiging van verschillende culturele achtergronden, leefomgevingen (stedelijk en landelijk) en verschillende soorten dementie.
- Onderzoekers zouden vanaf het begin van hun onderzoeksactiviteiten proactief rekening houden met de levensduur, duurzaamheid en implementatie van ontwikkelingen en relevante belanghebbenden betrekken om de werkelijke impact te maximaliseren.
- Toekomstig onderzoek moet grondig het VZP concept binnen dementie verkennen en de impact van op online ondersteuningstools in familiale contexten beoordelen door middel van robuuste longitudinale studies.





## APPENDIX 1 –THE PAPER-BASED VERSION OF THE LEVENSWENSEN CARDS







# CURRICULUM VITAE

Charlèss Dupont is a registered nurse with a Master's degree in Healthcare Management and Policy from Vrije Universiteit Brussel. In October 2017, she started working as a research assistant at the End-of-Life Care research group to implement quality indicators into the Flemish palliative care services. In 2019, she started her doctoral research on the CAPACITY project, developing an online advance care planning tool for people with dementia and their family caregivers supervised by Prof. Dr. Lieve Van den Block, Prof. Dr. Tinne Smets. During her doctoral research, she was granted a research fellowship by INTERDEM, a pan-European network of researchers collaborating in research on and dissemination of early, timely, and quality psychosocial interventions in dementia. During her research fellowship, she was a visiting researcher at Ulster University (Belfast, UK) for four months to learn how web log data could be collected and the ethical considerations involved.

## EDUCATION

| Institution                                                                                       | Degree | Year           | Field of study                      |
|---------------------------------------------------------------------------------------------------|--------|----------------|-------------------------------------|
| Vrije Universiteit Brussel (VUB)<br>Faculty of Medicine and Pharmacy                              | Ph.D.  | 2019 – current | Medical Sciences                    |
| Vrije Universiteit Brussel (VUB)<br>Faculty of Medicine and Pharmacy                              | MSc    | 2017-2019      | Management and Policy in Healthcare |
| Karel de Grote University of Applied Sciences and Arts, Antwerp<br>Faculty of Healthcare          | RN     | 2014-2017      | Nursing                             |
| Windesheim University of Applied Sciences, Zwolle (NL)<br>Faculty of Journalism and Communication | BSc    | 2009 – 2014    | Communication                       |

## PROFESSIONAL CAREER

|              |                                                                                                                                                         |
|--------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2019-Current | <b>PhD Researcher</b><br><i>End-of-Life Care Research Group, Department of Family Medicine &amp; Chronic Care, Vrije Universiteit Brussel (VUB)</i>     |
| 2017-2019    | <b>Research assistant</b><br><i>End-of-Life Care Research Group, Department of Family Medicine &amp; Chronic Care, Vrije Universiteit Brussel (VUB)</i> |
| 2017- 2019   | <b>Registered Nurse</b><br><i>Nursing home in Antwerp, Belgium</i>                                                                                      |
| 2009- 2017   | <b>Care assistant</b><br><i>Nursing homes in both the Netherlands and Belgium</i>                                                                       |

## PEER-REVIEWED PUBLICATION

1. **Dupont C**, Smets T, Monnet F, Pivodic L, De Vleminck A, Van Audenhove C, Van Den Block L. Defining the content of a website on advance care planning in dementia: a focus group study with family and health professionals. *BMC Med Inform Decis Mak* 2023 Nov 8;23(1):254. <https://doi.org/10.1186/s12911-023-02359-1>
2. Aguzzoli Peres F, Haas AN, Martha AD, .. **C. Dupont** ... Agustin Ibanez. Walking the talk for dementia: A unique immersive, embodied, and multi-experiential initiative. *Alzheimer's Dement*. 2024; 1-14. <https://doi.org/10.1002/alz.13644>
3. Monnet F, Diaz A, Gove D, **Dupont C**, Pivodic L, Van den Block L. The perspectives of people with dementia and their supporters on advance care planning: A qualitative study with the European Working Group of People with Dementia. *Palliat Med*. 2024 Jan 31:2692163231219915. doi: 10.1177/02692163231219915. Epub ahead of print. PMID: 38293945.
4. **Dupont C**, Gilissen J, Dassen FCM, Branco RM, Heins P, Heffernan E, Bartels SL. Supporting early-career dementia researchers: Identifying support needs and ways forward via a European study. *Alzheimer's & Dementia* 2023 Nov 20;alz.13530.. <https://doi.org/10.1002/alz.13530>
5. **Dupont C**, Monnet F, Pivodic L, Vleminck AD, Audenhove CV, Van Den Block L, Smets, T. Evaluating an advance care planning website for people with dementia and their caregivers: Protocol for a mixed method study. *DIGITAL HEALTH*. 2023 Jan;9:20552076231197021
6. **Dupont, C.**, De Vleminck, A., Deliens, L., & Gilissen, J. (2023). Advance Care Planning in Belgium. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, 180, 121-126. <https://doi.org/10.1016/j.zefq.2023.05.003>
7. Monnet, F., **Dupont, C.**, Smets, T., De Vleminck, A., Van Audenhove, C., Van den Block, L., & Pivodic, L. (2023). Advance Care Planning Website for People With Dementia and Their Family Caregivers: Protocol for a Development and Usability Study. *JMIR Research Protocols*, 12, [e46935]. <https://doi.org/10.2196/46935>
8. **Dupont, C.**, Monnet, F., Pivodic, L., Vleminck, A. D., Audenhove, C. V., Van den Block, L., & Smets, T. (2023). Evaluating an advance care planning website for people with dementia and their caregivers: Protocol for a mixed method study. *Digital health*, 9. <https://doi.org/10.1177/20552076231197021>
9. Monnet, F., Pivodic, L., **Dupont, C.**, Dröes, R-M., & Van den Block, L. (2023). Information on advance care planning on websites of dementia

- associations in Europe: A content analysis. *Aging & Mental Health*, 27(9), 1821-1831. <https://doi.org/10.1080/13607863.2022.2146051>
10. Monnet, F., **Dupont, C.**, & Pivodic, L. (2023). In global approaches to dementia research, do not forget care. *Nature Medicine*, 29(7), 1595-1595. <https://doi.org/10.1038/s41591-023-02356-x>
  11. **Dupont, C.**, Smets, T., Monnet, F., Pivodic, L., De Vleminck, A., Van Audenhove, C., & Van den Block, L. (2022). Publicly Available, Interactive Web-Based Tools to Support Advance Care Planning: Systematic Review. *Journal of Medical Internet Research*, 24(4), 1-15. [e33320]. <https://doi.org/10.2196/33320>
  12. **Dupont, C.**, Smets, T., Monnet, F., Eneslätt, M., Tishelman, C., & Van den Block, L. (2022). The cultural adaptation of the go wish card game for use in Flanders, Belgium: a public health tool to identify and discuss end-of-life preferences. *BMC Public Health*, 22(1), 1-14. [2110]. <https://doi.org/10.1186/s12889-022-14523-9>
  13. Cohen, J., Hermans, K., **Dupont, C.**, Van den Block, L., Deliens, L., & Leemans, K. (2021). Nationwide evaluation of palliative care (Q-PAC study) provided by specialized palliative care teams using quality indicators: Large variations in quality of care. *Palliative Medicine*, 35(8), 1525-1541. <https://doi.org/10.1177/02692163211019881>
  14. **Dupont, C.**, De Schreye, R., Cohen, J., De Ridder, M., Van den Block, L., Deliens, L., & Leemans, K. (2021). Pilot Study to Develop and Test Palliative Care Quality Indicators for Nursing Homes. *International Journal of Environmental Research and Public Health*, 18(2), 1-15. [829]. <https://doi.org/10.3390/ijerph18020829>

## RESEARCH PRESENTATIONS (AT CONFERENCES)

### 2024

1. Invited Speaker. Masterclass Neurology – Lewy Body Dementia 2024 (Sheffield). Palliative care for people with Lewy Body Dementia: from diagnosis until the end-of-life.

### 2023

2. Invited Speaker Brain Innovation Days 2023. Documentary Preview & In Discussion With: Innovative Model of a Multidisciplinary Immersive Experience.
3. 33rd Alzheimer Europe 2023. An advance care planning website for people with dementia and their caregivers: Results of an evaluation study. [oral presentation]
4. 33nd Alzheimer Europe 2023. Supporting early career dementia researchers: Identifying needs for support and ways forward via an international mixed-methods study. [poster presentation]

5. 8th International Advance Care Planning (ACP-i) Conference. Supporting Advance Care Planning Conversations: using web-based tools for people living with dementia and their family. [invited speaker]
6. 8th International Advance Care Planning (ACP-i) Conference. Developing an advance care planning website for people with dementia and their family: developing the content using an iterative, user-centered approach. [poster presentation].

## 2022

7. 32nd Alzheimer Europe Conference. INTERDEM: Early career researcher seminar by INTERDEM Academy and ISTAART PEERs: Sharing best practices to support early career dementia researchers: A World Café. [invited workshop moderator]
8. 7th Public Health Palliative Care International Conference (2022). The cultural adaptation of the GoWish cards for use in Flanders, Belgium: a game to identify and discuss end-of-life preferences. [oral presentation]
9. Nederland-Vlaams Wetenschapsdagen Palliatieve zorg (Dutch-Flemish Science Days Palliative Care). Levenswensen: Vertaling en culturele aanpassing van het Go Wish kaartspel over vroegtijdige zorgplanning en levenseinde voorkeuren voor Vlaanderen. [oral presentation]

## 2021

10. 17th World Congress of the European Association for Palliative Care. A systematic review of interactive web-based tools to support the general population in advance care planning. [poster presentation - **nominated as 1 of the 3 best poster abstracts in its category**]

## GRANTS AND AWARDS

### 2023

- Koninklijke Vlaamse Academie van België voor Wetenschappen en Kunsten (KVAB)/ Royal Flemish Academy of Belgium for Sciences and Arts **jaarprijs wetenschapscommunicatie/ annual science communication award** for the *Levenswensen* cards
- Grant from Landsbond der Christelijke Mutualiteiten for development *Levenswensen* cards to develop a guide for social workers to use a public health tool to identify and discuss end-of-life preferences - €18.000

### 2021

- FWO travel grant for a long stay abroad to visit Ulster university, Belfast UK - €5.346
- INTERDEM academy fellowship to visit Ulster university, Belfast UK - €2,810



## 2020

- Grant from Landsbond der Christelijke Mutualiteiten for development *Levenswensen* cards to the cultural adaptat the American card game Go Wish for the use in Belgium (Dutch/French/German) - €20.000



